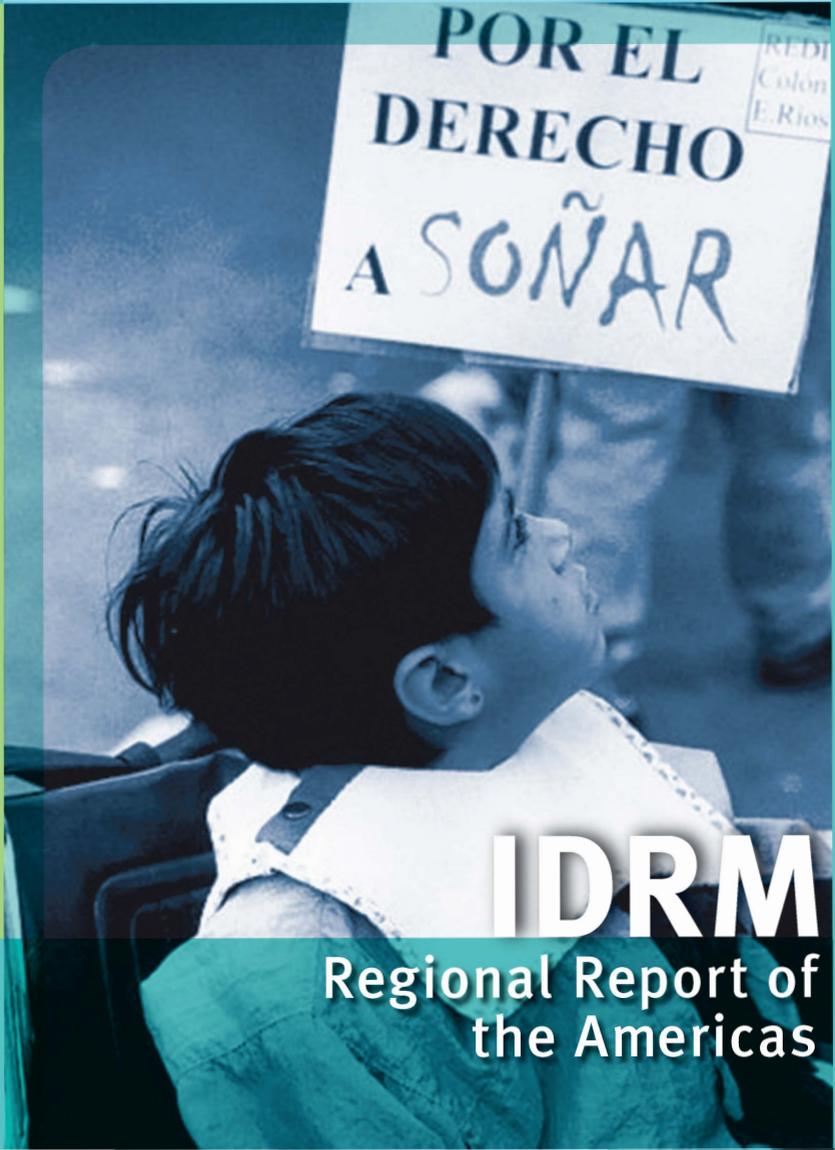




International Disability
Rights Monitor 2004



IDRM

Regional Report of
the Americas

**International Disability Rights
Monitor (IDRM)
Regional Report of the Americas
2004**



The mission of the International Disability Network is to assist people with disabilities worldwide in achieving their full potential.

The mission of the International Disability Rights Monitor project is to promote the full inclusion and participation of people with disabilities in society and to advance the use of international law to ensure that their human rights are respected and enforced.

International Disability Rights Monitor

Regional Report of the Americas 2004

Copyright © July 2004 by Center for International Rehabilitation
All rights reserved. Published 2004
Printed in the United States of America

International Disability Rights Monitor™

For more information visit: www.disability.ws
Reports available online: www.disability.ws/idrm
For inquiries email: idrm@cirnetwork.org

International Disability Network/Center for International Rehabilitation

Washington, DC:
1900 L Street, NW
Suite 500
WDC, 20036
Tel/TTY: 202.223.3559
Fax 202.223.3581

Chicago
211 E. Ontario St.
Suite 300
PO Box 11011
Chicago, IL 60611-3004
Tel/TTY: 312.229-1359
Fax 312 229-1370

El Salvador:
CERPROFA
6a 10a Calle Poniente y 31
AV Sur, NO. 1629, Col. Flor Blanca,
San Salvador, El Salvador
Tel/TTY: 503-222-0206
Fax: 503-259-0623

Nicaragua
Km. 5 1/2 carretera Sur
Detrás del Hospital de
Rehabilitación Aldo
Chavarría CENAPRORTO
Managua, Nicaragua
Tel/TTY: 505-268-7988

Bosnia
Donje BRDO 37
Tuzla, Bosnia & Herz 75000
Tel/TTY: 387.35.273.154
Fax 387-35-231-154

Cover image designed by Rachel Dow of Dao Design
Report Card designed by Jason Simmons of Gradient Labs
Back cover image featuring Eleanor Roosevelt courtesy of UN Photo # UN 23783

Preface

About the International Disability Rights Monitor

This is the second publication and the first regional report of the International Disability Rights Monitor (IDRM) project. The project represents an ongoing collaboration between the International Disability Network (IDN), Disabled Peoples International (DPI), and many other international and national disability groups. The goals of the IDRM project are to promote the full inclusion and participation of persons with disabilities in society and to advance the use of international humanitarian law to ensure that the human rights of persons with disabilities are respected and enforced.

The impetus for the project grew from the reality that policy makers, the human rights community, treaty monitoring bodies, and global leaders have access to very little information about the extent or the nature of the challenges faced by persons with disabilities. The IDRM project addresses this gap by documenting the problems, progress and barriers experienced by people with disabilities in a coordinated, systematic and sustained way.

In 2003, the IDRM published a disability rights compendium that covered a broad range of topics. It included articles examining issues of concern to the disability community, a comparative analysis of disability law in 52 countries around the world, and the results of field trials of the IDRM methodology in El Salvador and Nicaragua. This book marks the first of a series of regional reports that document and assess the condition and treatment of people with disabilities internationally. This Regional Report of the Americas contains reports from 24 countries and a regional report card summarizing the degree to which basic protections for the rights of people with disabilities are in place. The next Regional Report will focus on the Asia Pacific Region and is due to be released in December 2004.

The IDRM research network that is responsible for these reports consists of local and regional researchers drawn primarily from the disability community. The researchers come together for regional training on IDRM data collection methodology then engage in extensive research in their home countries. Researchers consult with both government officials and leaders of civil society in preparing their reports. The research for this report was conducted during the second half of 2003, and each researcher submitted a preliminary report in early 2004. Reports were then edited during April, May, and June before being returned to the researchers for their approval.

While the IDRM strives to be as comprehensive and accurate as possible, disability is a complex issue and presents inherent data collection challenges. Thus, the IDRM welcomes feedback from all sources. Through a cooperative effort, the project aims to create resources that will be of use to all those who wish to promote and protect the human rights of all persons with disabilities.

IDRM Research Network 2004 - 2005

International Coordinating Team:

William Kennedy Smith, M.D.

Project Founder

Maria Verónica Reina

International Coordinator

Katherine J. Dorsey, Ph.D.

Director of Publications

Ines M. Basaen, Ph.D.

Asia Pacific Regional Coordinator

Researchers: Americas

Elena Dal Bo, *Argentina*

Peter Anthony August, *Belize*

Demetrio Marca Marca, *Bolivia*

Ana Beatriz Silva Thé Praxedes, *Brazil*

Rachael Ross, *Canada*

Paulina Victoria Cavada Molina, *Chile*

Hernan Perilla Prieto, *Colombia*

Luis Fernando Astorga Gatjens, *Costa Rica*

Cristina A. Francisco Reyes, *Dominican Republic*

Ligia Pilar Samaniego Santillán, *Ecuador*

Eileen Giron, *El Salvador*

Silvia Judith Quan Chan, *Guatemala*

Dayana Gisell Martínez Burke, *Honduras*

Monica Nettie Bartley, *Jamaica*

Marcos Antonio Hernández Hernández, *Mexico*

Freddy Trejos Jarquín, *Nicaragua*

Fanny Hermelinda Wong Chen, *Panama*

Zulma Myriam Ferreira Servin, *Paraguay*

Jane Margarita Cosar Camacho, *Peru*

Vincent Kok Sey Tiong, *Suriname*

Peter Blanck, *United States of America*

Marta Susana Barera Rodríguez, *Uruguay*

Victor Alexander Bauté Sánchez, *Venezuela*

Researchers: Asia Pacific

Yi Veasna, *Cambodia*

Ritu Kumar, *India*

Miyamoto Taisuke, *Japan*

Dominga Quejado, *Philippines*

Prayat Punong – ong, *Thailand*

Duong Thi Van, *Vietnam*

Table of Contents

Acknowledgements	xiii
Researcher Biographies	xiv
Foreword	xix
Executive Summary	1
Regional Reports of the Americas	19
Argentina	20
Belize	59
Bolivia	67
Brazil	85
Canada	99
Chile	119
Colombia	141
Costa Rica	158
Dominican Republic	175
Ecuador	186
El Salvador	203
Guatemala	215
Guyana	229
Honduras	240
Jamaica	250
Mexico	260

Nicaragua	290
Panama	300
Paraguay	312
Peru	326
Suriname	341
United States	349
Uruguay	372
Venezuela	391

Appendix A	408
-------------------	-----

Appendix B	437
-------------------	-----

Appendix C	444
-------------------	-----

Acknowledgements

The disability rights movement, like all movements, encompasses a broad array of individuals and organizations working together toward a common goal. Those who have made, and continue to make, important contributions to the field of disability rights are too numerous to mention. This inaugural report of the IDRM project focuses on disability rights in the Americas, so we feel it is appropriate to acknowledge some of those in the hemisphere who have made particularly important contributions to the IDRM project and to disability rights in general. First and foremost the IDRM staff would like to thank Senator Tom Harkin, author of the Americans with Disabilities Act and champion of disability rights. No one has made greater contributions over the years to the field in general and to this project in particular than he has. We would also like to thank Senator Dick Durbin, Secretary of Health & Human Services Tommy Thompson and Congressman Tom Lantos for their important assistance in making this project a reality.

More broadly, the IDRM wishes to acknowledge the global leadership of Disabled Peoples International and, in particular, its visionary President Venus Ilagan and Executive Director Moira Horgan-Jones. They remain outstanding champions of disability rights, and this project. Finally, we would like to thank Mary Chamie, Don Lollar, and Charles O'Byrne, who have provided excellent guidance and support to the project at critical moments. We are most grateful.

The IDRM reports result from the efforts of the local researchers in each country whose hard work and insights produced this volume. Their commitment to the field and ability to secure the most accurate and timely information on the rights of people with disabilities in their countries are remarkable. Given the dearth of information on disabilities in general, completing their task required a large measure of resourcefulness and perseverance. The quality of this report is a testament to their dedication and abilities. Special thanks go to Elena Dal Bo for her assistance in fact-checking. Thanks also to all those who generously allowed their photographs to be included in this volume and especially to Ana Maria Martinez for kindly allowing the use of her daughter's photo on the report cover.

Finally, a number of IDRM staff members worked tirelessly to make this report a reality. Many thanks to International Coordinator and project leader Maria Veronica Reina, and to Research Coordinator Katherine Dorsey, Ph.D for their outstanding work and good humor. Thanks also to Kelly Hamel and Maggie Coleman for their assistance in the areas of research coordination and publication. Thanks to Marta Isabel Trejo for her excellent translations and to Katie Cleland, Sara Zweig, and Andrew Shiveley for providing valuable assistance in the production of this volume.

2004 IDRM Researchers: Americas

Argentina, Elena Dal Bó

Elena Dal Bó is an agronomist engineer in Argentina. She completed her degree in agronomic engineering at the National University of La Plata and holds a certificate in learning disabilities from the School of Education at the University of Birmingham. She is currently working as a professor at the National University of La Plata, Argentina, where she holds the position of disability representative at the Commission of the Faculty of Agronomy and Forest Sciences. Elena is the President of the Sub-Commission for Community Inclusion of the La Plata Institute for the Assistance of Blind and Visually Impaired People.

Belize, Peter A. August

Peter A. August is a finance officer and office manager at the Enhancement of Technical, Vocational Education & Training Project in Belize. He has a level III accounting certificate from the Association of Accounting Technicians in London, England, and belongs to the Belizean Assembly of and for Persons with Disabilities (BAPD).

Bolivia, Demetrio Marca Marca

Demetrio Marca Marca holds a Sociology and Anthropology degree from the Universidad Santo Tomás de Aquino. He is former president of the Bolivian Confederation of People with Disabilities and is a member of the Ibero American Network of Organizations of People with Disabilities and their Families. A wheelchair user, he is also an Aymara translator.

Brazil, Ana Beatriz Silva The Praxedes

Ana Beatriz Silva The Praxedes holds a bachelor's degree in psychology from the Universidade de Fortaleza in Brazil. A practicing psychologist, Ana is a representative for disabled people to the Health Council of the state of Ceara, a position for which she trains others on health and disability issues in Brazil. She is vice president of ROOT, an institution for the integration of development. Ana is wheelchair user and a member of the Life Movement promoting independent living.

Canada, Rachael Ross

Rachael Ross is a social research consultant with expertise in disability related issues like social policy, national disability rights movements, labor market trends as they relate to the disability population, human rights, and post-secondary education. Rachael lives in Victoria, British Columbia. From this location she works across the country and internationally. Some current international projects she is involved in are as the Canadian Researcher for the International Disability Rights Monitor, Phase II, and as a co-chair for the Disabled People's International World Summit to be held in September 2004.

2004 IDRM Researchers: Americas

Chile, Paulina Cavada Molina

Paulina Cavada Molina is a Chilean architect specializing in housing accessibility. She is a member of Disabled People International and the advisor to several universities on accessibility for people with disabilities. A wheelchair user, she is a trainer on universal design and a panelist in many seminars on accessibility throughout Brazil, Chile, and Uruguay, and has also been an advisor to the National Fund for Disabilities in Chile.

Colombia, Hernan Perilla

Hernan Perilla is a high school teacher at the Institucion Educativa Empresarial in Dosquebradas Risaralda, Colombia. He holds a bachelor's degree in mathematics and computer science, and is an official representative on his county's Disability Planning Board. Hernan, who has a physical disability, founded the first business run by persons with disability in Colombia and is the founder of the Association of Persons with Disability of Risaralda, an association which works for rehabilitation and disability rights protection. He lives in Risaralda with his wife and children.

Costa Rica, Luis Fernando Astorga

Luis Fernando Astorga is a journalist and a human rights advocate from Costa Rica. He is the president of the Forum for Disability Rights, and a member of the Directory of the National Committee on Disability of Costa Rica and the Directory of the Ibero-American Network of Non Governmental Organizations of People with Disabilities and their Families. Luis Fernando was the Latin American NGO representative in the Working Group that drafted the Disability Convention, and is the Executive Director of the Inter-American Institute on Disability. Luis is a wheelchair user and lives with his wife and three children in San José, Costa Rica.

Dominican Republic, Cristina A. Francisco Reyes

Cristina A. Francisco Reyes obtained a degree in administration and human resources from the Ibero-American University. She is a co-founder and the coordinator of the Circle of Women with Disabilities in the Dominican Republic. Cristina also founded the National Association on Physically Impaired Persons and the Wheelchair Sportive Club. Cristina, who has a motor disability, has participated in many international sporting and advocacy activities in her country.

Ecuador, Ligia Pilar Samaniego Santillán

Ligia Pilar Samaniego Santillán is the general secretary of the Ibero-American Network of Non Governmental Organizations of People with Disabilities and their Families. A native of Ecuador, she is the executive secretary of the Pro Human Rights and Fundamental Freedoms of People with Mental Disabilities of Ecuador organization. Ligia is the president of the AVILUZ Foundation for people with borderline, mild, and moderate mental disabilities and has represented Ecuador in several international conventions and congresses. She is a recognized author of books on Mathematics Didactics and Disability, is a trainer and currently works as a curriculum administrator at Liceo Bilingüe Montanar

2004 IDRM Researchers: Americas

El Salvador, Eileen Giron

Eileen Giron is a founding member and executive director of ACOGIPRI, an organization of persons with disabilities working on human rights, independent living, training and employment in El Salvador. Eileen's various posts at Disabled Peoples International include regional development officer for Central America, world council member, and chairperson for the Latin America Women's committee. She was also a consultant for the Landmine Survivors Network operations in San Salvador and the national coordinator of the 2003 Elections Monitoring Project. Eileen is currently the secretary of the Board of Directors of the Inter American Institute on Disability, and coordinator of the Municipal Commission of Citizens with Disability working in San Salvador.

Guatemala, Silvia Quan

Silvia Quan of Guatemala holds a degree in chemical sciences and a diploma in social management. She is currently pursuing her graduate degree in gender issues at the UNAM/AECI. She has participated as a representative in many international activities on disability, including the negotiations of the Inter-American Convention. She has served as an advisor on the drafting of the National Disability Policy of Guatemala, and is a recognized trainer on disability issues. Silvia is blind and is currently working as a free-lance consultant at the Ombudsman Office, heading the defense of people with disabilities.

Honduras, Dayana Gisell Martinez Burke

From Honduras, **Dayana Gisell Martinez Burke** has a degree in foreign languages. She is the founder and current executive director of the National Association of Disabled of Honduras. Dayana, who is blind, is also the founder and president of the Federation of Disability Organizations of Honduras, Coordinator of the Committee of Inclusion (Mexico, Canada, and Central America), president of the Association of Japan Fellows, and a member of the Honduras chapter of GLARP.

Jamaica, Monica Bartley

From Jamaica, **Monica Bartley** is the vice chairperson excelsior of the High School Past Students Association, the vice chairperson for the Jamaica Coalition on Disability Committee, the vice chairperson of the Combined Disabilities Association, and a member of the National Advisory Council on Disability and the Caribbean Association for Feminist Research and Action (CAFRA). A wheelchair user, Monica is the director of administrative statistics at the Statistical Institute of Jamaica (STATIN). She has a degree from the University of the West Indies; certificates from the U S Census Bureau International Statistical Program and the Center of Economic Statistics; and a master's degree in economics and statistics from the George Washington University in Washington D. C.

2004 IDRM Researchers: Americas

Nicaragua, Freddy Trejos Jarquin

Freddy Trejos Jarquin holds a degree in Science & Letters and a Diploma in project design, monitoring, and evaluation from the National Engineering University in Nicaragua. Freddy was a project advisor to SOLIDEZ, and the regional director of an investigative project by Stockholm's Institute of International Education, on the special educational needs of children with disability. He is a project official of the Danish Association of the Disabled; a member of the National Rehabilitation Council (CONARE), and a founding member and director of the Collective 3 H Home Habitat Habilitation. He was a project management advisor on the Directive Council of the Center for the Promotion of Integral Rehabilitation (CEPRI) and is currently president of the center.

Mexico, Marcos Antonio Hernandez Hernandez

Marcos Antonio Hernandez Hernandez owns a major distribution company for Corona, and is president of Free Access, one of the most well known associations on disability awareness in Mexico. He is the founder and treasurer of Generation in Movement, holds a technical degree in industrial engineering, and is a member of the National Council on Disability of Mexico. A quadriplegic, Marcos was a key promoter for the national stadium in Mexico, is an international wheelchair table tennis champion, and won a gold medal in the 1998 Paralympics.

Panama, Fanny H. Wong Chen

Fanny H. Wong Chen is a participant in the drafting of the National Plan on Disabilities in Panama. Fanny is the continental coordinator of the Christian Fraternity of People with Disabilities; a member of the International Commission of Technology and Accessibility Latin America; an advisor of the National Direction of the Childhood, Youth, Women, and Family of Panama; and a member of the Municipal Technical Committee on Accessibility for People with Physical Impairments. A wheelchair user, she is a certified public accountant and works as the administrative manager of Continental, S. A. Travel Agency.

Peru, Jane Cosar

Jane Cosar is an attorney and a mediator registered with the Ministry of Justice. She is president of the Peruvian Association of Lawyers with Visual Disabilities, and a legal advisor to the private business, Inversiones ACH S.A.C. Jane is a member of the special Commission on Disability Studies of Peru's National Congress as well as the 2004 consultative and executive committees on Human Rights at the Law School of Lima. A blind person, she has a master's degree in civil and commercial law and is currently working on her Ph.D. in law and political science at the National University of San Marcos. In addition, Jane holds diplomas in human rights and in regional and municipal law. She lives in Lima with her husband and three children.

2004 IDRM Researchers: Americas

Suriname, Vincent Kok Sey Tjong

Vincent Kok Sey Tjong is a member of the Federation of Private Social Institutions in Suriname. Mr. Kok Sey Tjong is responsible for coordinating all implementation contact with the Ministry of Social Affairs, and has guided several local researchers in gathering data and describing findings related to target groups.

United States of America

Peter David Blanck, PhD/JD is the Charles M. and Marion Kierscht Professor of Law, and Professor of Psychology, and of Public Health at the University of Iowa. He received his Ph.D. in psychology from Harvard University and his J.D. from Stanford Law School. Blanck is the Director of the Law, Health Policy & Disability Center at the Iowa College of Law. Blanck has written over 100 articles in law reviews and peer-reviewed journals as well as books on the Americans with Disabilities Act (ADA) and related laws, received grants to study disability law and policy, represented clients before the United States Supreme Court in ADA cases, and testified before Congress. Blanck is a former member of the President's Committee on Employment of People with Disabilities, and has been a Senior Fellow of the Annenberg Washington Program. He has been a Commissioner on the American Bar Association Commission on Mental and Physical Disability Law, chair of the American Psychological Association's Committee on Standards in Research, and President of the American Association on Mental Retardation's Legal Process and Advocacy Division. He has been a Fellow at Princeton University's Woodrow Wilson School, and a Mary Switzer Scholar.

Uruguay, Marta Susana Barera Rodriguez

Marta Susana Barera Rodriguez holds a Ph.D. in law and social sciences and is a free-lance lawyer in Uruguay. Marta is the attorney for the Cooperative of Able and Disabled Workers (COTHAIN) and the President of the Uruguayan Chapter of GLARP-IIPO. She has participated in several national and international panels as a disability expert, and has a motor disability.

Venezuela, Victor Alexander Baute Sánchez

Victor Alexander Baute Sánchez studies accounting and administration at the Central University of Venezuela. A native of Venezuela and a deaf person, he is the president of the Deaf Youth Federation of Venezuela, general secretary of APROSIMIR (Sport Association of Deaf People of Miranda) and a peer trainer on deaf youth leadership. Victor works as a cook.

Foreword

“Let no-one be discouraged by the belief that there is nothing that one man or one woman can do against the enormous array of the worlds ills. Each time a man stands up for an ideal or acts to improve the lot of others or strikes out against an injustice, he sends forth a tiny ripple of hope and crossing each other from a million centers of energy and daring those ripples build a current that can sweep down the mightiest walls of oppression and resistance.”

Robert F. Kennedy

June 1966

University of Cape Town, South Africa

It has been said that civilization advances when what had been perceived as misfortune is recognized as injustice. The International Disability Rights Monitor finds its roots in the struggles for liberty, equality and freedom that over the last several centuries have ignited the imaginations and passions of people around the globe. Human beings have struggled to expand the human franchise to people of color, to women and to indigenous people. Now, persons from the disability community are standing up for their rights. As one very capable individual with a disability has said, “I do not wish to be a kept citizen, humbled and dulled by having the State look after me. I want to take the calculated risk, to dream and to build, to fail and to succeed. I want to enjoy the benefits of my creations and face the world boldly and say, this is what I have done.”

The injustice of disability lies in the fact that, all too often, people with disabilities are not fully recognized as human beings. They suffer neglect and mistreatment in housing, in education, and in healthcare. They have been the focus of eugenic policies and sterilization practiced in the United States and other countries. Today, even in the most inclusive group of countries, many voting booths remain inaccessible denying the right to vote to thousands of people with disability. The list goes on and on.

The human rights of 500 million people with disabilities around the world should be protected by an umbrella of human rights principles such as the Universal Declaration of Human Rights and the Covenant on Economic, Social and Cultural Rights. The International Disability Rights Monitor (IDRM), however, is the first global mechanism of its kind created by civil society to systematically monitor and promote the human rights of people with disabilities under national and international law. The IDRM is part of an encouraging trend in recent years toward the creation of international laws and policies that commit governments to promoting access, ensuring inclusion and providing necessary services for people with disabilities. This trend has culminated in current efforts by the United Nations to craft a treaty, or Convention, on the Rights of People with Disabilities. For the first time in UN history, non-governmental organizations have been permitted to sit at the table with States Parties during these important negotiations. It is a new high water mark for inclusion under international law. It should be noted that these UN negotiations would not have been possible without the leadership of two nations from the hemisphere: Mexico and Ecuador. Credit is due to President Vincente Fox of Mexico, who proposed the elaboration of a disability convention in the UN

General Assembly in 2001, and to Mexico's Ambassador to the United Nations, Luis Alfonso De Alba, whose visionary leadership and strategic sense were largely responsible for the inception of negotiations. President Gustavo Noboa of the Republic of Ecuador, winner of sixth annual Franklin Delano Roosevelt International Disability Award, also deserves credit. Ecuador's Permanent Representative, Ambassador Luis Gallegos, chairs the Ad Hoc Committee currently negotiating the proposed Convention and does so with extraordinary intelligence, patience and skill. But despite these important and exciting developments at the United Nations, much remains to be done.

The sad fact is that, as this report documents, few countries show signs of thinking about or planning to include people with disabilities in national life. People with disabilities are often invisible. Ignored by policy makers and planners, warehoused in institutions, forgotten, neglected and frequently abused. If you are blind in the Americas you will not find a Braille copy of the constitution in more than 60% of the countries surveyed, and only one in three have national news that is captioned. Imagine what it must feel like to be almost entirely cut off from the political life of your country, unable to access even the most basic information about your government and the world around you, unaware of what your rights are, let alone how to protect them.

Only one in five of the countries covered in this report have a wheelchair accessible bus system in the capital city. Without access to reliable public transportation, how can people with disabilities reach schools, jobs, polling places, recreational facilities or even critical health care services? All the elements of a full life are held just beyond their grasp, and it is not simply a lack of resources. Most often it is a question of attitudes and awareness. A story from the United States makes the point. A postmaster in a town was told to make his post office accessible. The building had 20 steep steps leading up to a revolving door at the only entrance. The postmaster questioned the need to make such repairs. He said, "I've been here for thirty-five years, and in all that time, I've yet to see a single customer come in here in a wheelchair." Unfortunately, as you will discover in this report, fewer than half of the countries in the region have an accessible post office in their capital city. Even at this basic level, planning for, and awareness of the disability community is found to be lacking.

In other social sectors the picture is not much brighter. Of the largest employers in each of the countries covered by this report only 29%, less than one in three, have policies forbidding discrimination against people with disabilities. Only half the countries surveyed have training available to their physicians on the provision of care to people with disabilities. Only 60% of countries have training available for teachers on educating children with disabilities. Thus, nearly 40% percent of those countries that signed the Salamanca Statement and Framework for Action on Special Needs Education still have not implemented such training more than a decade after the signing. Although peer counseling and referral services have proven to be an effective way to increase the integration and inclusion of people with disabilities, only about a third of countries have such Independent Living Centers.

There is a saying; a hole makes the entire fabric weaker. It lacks richness, texture, and the strength of diversity. People with disabilities have been left out of the fabric of international human rights. The result is a hole that makes all our rights weaker. The framework of universal human rights will be stronger when people with disabilities are no longer left out and left behind. We all benefit when people with disabilities stand up for our ideals. That is what the IDRM initiative is all about, and that is exactly what you find inside the cover of this report.

Dr. William Kennedy Smith M.D.
Founder & Chairman of the Board
International Disability Network
Center for International Rehabilitation
July 2004

Executive Summary



Argentina 2003

The Role of International Law in Disability Rights

The rights of people with disabilities are included under the umbrella of universal non-discrimination principles such as the Universal Declaration of Human Rights and the Covenant on Economic, Social and Cultural Rights, but many countries and regions of the world have failed to develop laws that reflect the principles and standards set forth in these and other covenants and agreements. Cultural and social perceptions also hinder the development and implementation of such policies, especially when it comes to the place of the disabled person in society. Existing disability-specific instruments include the United Nations Declaration on the Rights of Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, but these documents are only guidelines that lack the force of law. In recent years, there has been an encouraging trend at the international, regional, and national level to develop disability laws and policies that commit governments to including people with disabilities in society and providing access to necessary services. The Organization of American States' 1999 Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities is a notable example of a supranational agreement regarding disability rights. The Americans with Disabilities Act of 1990 provides a model for national and regional efforts and has served as an inspiration for reform, particularly in Europe. The persistent lack of legally enforceable global standards, however, remains a challenge.

In December 2001, the General Assembly of the United Nations passed a resolution to establish an Ad Hoc Committee of member-states to consider a proposal for a treaty, or convention, on the rights of people with disabilities. The first meeting of that committee was held in July-August 2002. The second and third meetings were held in June 2003 and May-June 2004, respectively. Disability advocates have long viewed a United Nations Convention as an essential step in ensuring that basic human rights are fully extended to people with disabilities. Even though the process of adopting a convention will take years, there is an immediate need for disability, health, and human rights advocacy groups worldwide to monitor and promote the rights of people with disabilities and the Ad Hoc Committee process in a collaborative, systematic way.

IDRM Overview

The International Disability Rights Monitor (IDRM) documents and assesses the rights and treatment of people with disabilities internationally. The genesis of the project lies in the dearth of available data concerning the actual, every day conditions in which people with disabilities around the world live. The IDRM research network is designed to seek out, analyze, and organize information that has never before been collected on this scale. This year's report provides a baseline assessment from which to track annual changes in the level of human rights protections afforded to persons with disabilities on a country-by-country basis.

This project is the first of its kind to address issues surrounding disability but takes as its structural model the Landmine Monitor project. The IDRM, like the Landmine Monitor, is a civil-society based initiative that relies on data collected by an international network of researchers. The IDRM was conceived

as a shadow reporting system, paralleling shadow reports that bolster adherence to norms of behavior enshrined in international instruments. Examples of such reports include those produced by International Women's Rights Action Watch to monitor the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW, 1979) or the International Human Rights Law Group shadow reports relating to the Convention on the Rights of the Child (1989).

Unlike the Landmine Monitor, which assesses the implementation of a United Nations Convention (the Ottawa Convention Banning Anti-Personnel Landmines, 1997), and the other shadow reporting mechanisms, the IDRM does not assess member-country adherence to an existing United Nations instrument.

United Nations member states do, however, have a monitoring system that is associated with the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules), which were adopted by the General Assembly in 1993. Member states self-monitor their compliance with the Standard Rules under the guidance of a Special Rapporteur who reports to the Commission for Social Development. The monitoring system in place relies on governmental self-reporting; whereas, the International Disability Rights Monitor is based on reporting conducted by organizations and individuals in civil society, with members of the disability community reporting on their own countries. Thus, not only does the IDRM complement the current monitoring system, but with efforts to establish a United Nations Convention on the Rights of Persons Disabilities underway, the IDRM will also be a useful instrument in assessing compliance should the convention be established.

Methodology

The methodology employed in IDRM research is primarily of an exploratory nature, with the guiding question being, "what rights and conditions are experienced by persons with disability in each country?" The items contained in the research guide include closed-ended (yes/no) questions and open-ended questions. This methodology consciously combines a quantitative approach, eliciting data that is comparable across countries, and a qualitative approach to obtain textured responses that will support a narrative description of the situation in each country. Researchers are not limited to questions included in the guide but rather are encouraged to document situations and circumstances in their locale.

Items in the research guide were largely designed with the recommendations of the Standard Rules in mind. The questions were then refined via consultation with members of the international disability community and experts on disability law in a variety of jurisdictions. Once the IDRM project was operationalized, the questions were again evaluated by international disability experts as well as by disability advocates, including IDRM local researchers. All English to Spanish translations were checked independently, and a selection of questions were back-translated for accuracy.

The research guide (also known as the questionnaire) is comprised of 101 distinct questions. A total of 85 items were included in the main body of the guide. Nineteen items were included in the panel discussion section. Of these, three were also included in the main body. The questions in the main body of the research guide were distributed among four sections focusing on different topic

areas. Ten items were concerned with identifying the population of people with disabilities in the country. Researchers obtained statistical materials and interviewed national governmental officials to gauge the accuracy of the existing data.

The second section of the research guide, entitled “Disability Rights,” is comprised of 24 items, with several questions asking researchers to follow up certain responses with further questions. This section deals primarily with the nature of national laws and policies protecting the rights of persons with disability, including anti-discrimination laws, and protections of civil, political and social rights. It also addresses questions on the institutionalization of persons with disabilities.

The third section of the guide addresses issues of inclusion and accessibility. This part is divided into six segments, comprising a total of 43 items. The segments include: communication, education, employment, health services, housing, and accessibility of the built environment. The fourth section addresses the activities of disability organizations at the national and local levels. This section includes items related to governmental entities as well as non-governmental organizations. It was comprised of eight items.

In order to complete these questions, researchers collect epidemiologic and census data as well as materials related to laws and statutes regarding disability. They also conduct interviews with a variety of officials and disability leaders to obtain additional information and verification of policies. Interviewees are selected based on positions within governmental ministries and agencies, and for their reputation as having expertise in the issue-area.

In addition, the researchers gathered attitudinal/opinion data from focus groups comprised of disability leaders. The methodology for the panel sessions differed from the methodology used to obtain responses and data for the main questionnaire items. Focus panels were conducted with experts on disability—i.e. persons with personal experience of disability and/or long-standing work in the field of disability. The researchers then conduct an open-ended discussion around the 17 panel questions. Panel sessions generally do not produce data that can be easily analyzed, statistically or otherwise. Instead, panel sessions produce a great deal of verbal data, which must be summarized before justifiable conclusions can be drawn. The purpose of these panel discussions was to gain understanding and insight into the issues of disability in the countries in question, not to quantify an opinion of a larger population.

A field test of the IDRM research methodology was conducted during 2003 in two countries in the Americas, El Salvador and Nicaragua. Over a six-week period, the researchers collected data regarding the legal regime surrounding disability rights, issues of inclusion, and the activities of disability organizations in their respective countries. The results of that field test were published in the 2003 International Disability Rights Compendium.

Once the methodology was tested, local researchers were trained in standard data gathering techniques during in-person, online and distance-learning training sessions conducted by IDRM staff from the International Disability Network. Researchers were also brought together for two major training workshops in order to develop their research and advocacy skills. The first of these workshops was regional in focus and took place in parallel to the Americas regional consultation of the United Nations Ad Hoc Committee Established to

Consider Proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities (the Ad Hoc Committee) in Quito, Ecuador in April of 2003. The second workshop, staged in collaboration with Disabled Peoples International, took place in parallel to the meeting of the Ad Hoc Committee in June of 2003 at the United Nations in New York. Primary data was then collected in each country during the second half of 2003. Reports submitted to the IDRM were translated into English, where necessary, and edited by IDRM staff. While the edited reports were translated back into the language of the researcher for approval whenever possible, the translation process may have inadvertently introduced some errors.

There are a few important challenges and limitations to this research that need to be acknowledged. Most importantly, there is not yet an international consensus on how to define disability. Although the World Health Organization's International Classification of Functioning, Disability and Health (ICF) has been accepted as an international standard, it is not yet employed around the world or around the region. Because collecting independent population-based data is outside the scope of this report, the statistical data presented in the reports are based upon surveys conducted in each country. Without a standard definition, however, these numbers are not strictly comparable.

A second challenge was presented by the overall low priority that is generally given to disability issues in most countries. Consequently, official records are often scarcely kept or even completely lacking, and previous research from which to draw was minimal. The IDRM researchers had to compile their information from a variety of sources. Information was cross-checked as thoroughly as possible, but the lack of documented sources presented challenges.

Report Card Methodology

The IDRM report card at the front of this book is a critical part of the IDRM monitoring system. The report card displays at a glance the extent to which fundamental human rights protections are currently in place in each country. Moreover, it does so by means of a methodology that allows this piece of the IDRM to make direct comparison between countries. The report card is based on a series of 11 closed-ended questions covering six issues: convention support; legal protections; education and employment; accessibility; health services and housing; and communication. The exact items used are included in Appendix C of this report.

Based on the answers to these questions, each country is assigned to one of three categories indicating the overall level of inclusion of people with disabilities: Most Inclusive, Moderately Inclusive, and Least Inclusive. Countries where basic human rights protections are available in all or almost all sectors, are identified as the Most Inclusive nations. Those countries with some basic protections in some sectors are identified as Moderately Inclusive nations. Finally, countries with few or no protections in the majority of sectors are the Least Inclusive nations.

Inclusiveness was determined based upon the total number of items where actions have been taken that can help promote the inclusion of persons with disabilities. Resources are not evenly distributed in the region, however,

which could result in a direct relationship between wealth and inclusiveness. Thus, in calculating inclusiveness, national resources were taken into account. First, items were correlated with GDP per capita to identify those that were more often associated with countries that have more resources.¹ These items were then given additional weight for those countries with a GDP per capita below the regional median.² The logic behind this weighting is one of commitment to inclusion. When countries with limited resources undertake projects that are expensive and usually only implemented in wealthier countries, this is considered to indicate a level of commitment to disability rights and social inclusion.

Because it is intended to identify only the most basic level of rights protections on a variety of issues, the report card is not intended to rank order countries. Some countries may provide protections that have an important impact on the integration of persons with disabilities, which go beyond those measured for the report card. Additionally, there may be tremendous variation experienced within a single country. For these reasons, the report card cannot be used to draw conclusions beyond the basic inclusiveness category.

Terminology

The issue of language choice is an important one within any study of disability issues. There is still no consensus on how to talk about people with disabilities. Each term stresses a different relationship. Some terms, like “persons with disabilities”, focus on the individual, preferring to acknowledge that a disability is simply a condition of living and not inherent in any person. Others, like “disabled person”, stress membership in a disability community. In the era of identity politics, membership in a minority group can be an important and defining piece of self-identity that can be expressed through language. Finally, some terms may stress the responsibility of communities to support people with disabilities.³ Preferred terminology varies by language, by group, and by individual. It remains a widely debated issue.

In the absence of an internationally agreed upon disability nomenclature, two primary choices confront the editors of a report of this kind: update all language to a chosen standard or retain local language even if it might be considered problematic or discriminatory. In general, the IDRM has chosen to update language except when it occurs in a legal context. Because the codification of discriminatory language in law may adversely affect the rights of people with disabilities, it is important to identify and preserve such terminology in context.

¹ Correlations were run both with and without the United States. There was some concern that the U.S., with the largest GDP per capita in the region, might skew the correlations in favor of its disability actions. While its inclusion did influence the strength of the correlation somewhat, the items most associated with GDP per capita remained relatively unchanged.

² GDP per capita was chosen because it is the measure used by the UN Human Development Report.

³ Gary L. Albrecht, Katherine D. Seelman, and Michael Bury, “Introduction: The Formation of Disability Studies” in *Handbook of Disability Studies* (Thousand Oaks: Sage Publications, 2001), 1-8.

In those country reports where problematic language remains, there is a "Terminology" section at the beginning of the report identifying the problematic terms. To the greatest extent possible, the remainder of this report utilizes person-first language. As preferred language shifts, the IDRM will work to update its style in order to respect this important issue.

Findings

Report Card Findings

Only five countries in the Americas region have attained Most Inclusive Nation status: Brazil, Canada, Costa Rica, Jamaica, and the United States. Ten countries have been classified as Moderately Inclusive including: Argentina, Chile, Colombia, the Dominican Republic, Ecuador, Mexico, Panama, Peru, Uruguay, and Venezuela. Finally, a full nine countries have been identified as the Least Inclusive, indicating that they lack the most basic elements necessary for the social inclusion of people with disabilities. These countries include: Belize, Bolivia, El Salvador, Guatemala, Guyana, Honduras, Nicaragua, Paraguay and Suriname.

Among the most telling patterns identified by the report card is the lack of support for a UN Disability Convention among the Least Inclusive Nations. Only two of these countries, Bolivia and El Salvador, have expressed support for a convention. Out of the remaining 15 countries, only the United States and Argentina do not support the creation of a convention.⁴

The report card also shows that legal protections are widely available throughout the region. Only Belize provides no legal protections specifically for people with disabilities. Despite the existence of legal protections throughout the region, the report card shows that implementation of legal standards across the various sectors is inconsistent, and enforcement of the rights of people with disabilities is frequently lacking.

Definitions of Disability

The majority of the countries in the Americas region continue to use older definitions of disability in at least some of their legislation. The most common definition is that included in the WHO's 1980 International Classification of Impairment, Disability and Handicap (ICIDH-1) which defines disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." At least half of the countries in the region continue to use definitions that are based on the ICIDH-1, despite the release of the International Classification of Functioning Disability and Health (ICF), a more recent classification from the WHO.

⁴ Information regarding government positions on the UN Convention is based on statements available as of December 2003 when data collection for this report was completed. Some countries may have issued new statements at the May-June 2004 Ad Hoc Committee meeting, changing their position. Any such changes will be reflected in the 2005 IDRM report.

Some countries in the region are moving toward the use of a definition based on the ICF. Guatemala bases their definitions on an interpretation of the ICF, and Colombia has begun using an updated definition in recent disability policy. Canada has not officially adopted the ICF, but it is intermittently used within certain government agencies. In addition, Costa Rica and Mexico are both in the process of reviewing the ICF for potential use in updating their definitions.

As a result of shifts in the concept of disability over time, many countries are left with conflicting definitions within their national legislation. Among the countries reporting multiple definitions of disability are Canada, Chile, Colombia, the Dominican Republic, Jamaica, Panama, and Venezuela. A number of other countries report the existence of multiple definitions although one is predominant. In a few cases, remaining definitions promote discriminatory concepts of disability. For example, one program of the Guatemalan Social Security Institute defines disability in terms of the “lost” economic value of an impairment. In many other cases, definitions focused on impairments continue to be used in population-based data collection. Two countries, Belize and Guyana, have no official definition of disability.

Disability Population

Scholars have noted that population-based data is often inadequate and/or lacking in developing countries.⁵ This situation is largely the case in the Americas region. Although all countries with the exception of Colombia and Peru have recently undertaken surveys to enumerate the disability population, the state of disability statistics in the region is still problematic. Few countries included disability in surveys before 1990, and frequent changes in methodology have led to a situation where the number of persons with disabilities is currently impossible to track over time based on national survey instruments. Additionally, despite the frequency with which the concept of “activity limitations” occurs in national legislative definitions of disability, survey questionnaires widely retain the language of “impairments.” Table One compiles the results of all available studies as well as noting wherever possible whether the survey items were based upon the concept of “impairments” or “activity limitations.”

⁵ Glenn T. Fujiura and Violet Rutkowski-Kmitta, “Counting Disability,” in *Handbook of Disability Studies* (Thousand Oaks: Sage Publications, 2001), 69-96.

Table 1: Disability Statistics in the Americas

	Disability as % of total population	Definition of disability
Argentina		
2001 Census	No results	
Belize		
1991 Census	6.5%	Impairment-based
2000 Census	5.7%	Activity limitations
Bolivia		
1998 Demographic and Health Survey	1%	Impairment-based ⁶
2001 Census	.9-1e2%	Impairment-based
Brazil		
1991 Census	1.41%	Impairment-based
2000 Census	14.5%	Activity limitations
Canada		
1991 HALS	14.7%	
2000 PALS	12.4%	
Chile		
2000 Social & Economic Survey	5.3%	Impairment-based
2000 Quality of Life and Health	21.7%	Activity limitations
2002 Census	2.2%	Impairment-based
Colombia		
1993 Census	1.85%	Impairment-based
Costa Rica		
1998 Multipurpose Household Survey	8%	Impairment-based
2000 Census	5%	Impairment-based
Dominican Republic		
2002 Census	No results	

⁶. This survey did not include mental disabilities among the types of disabilities listed in the question.

Guatemala		
1994 Census	.72%	
2002 Census	6.2%	
Guyana		
1991 Census	9%	
2003 Census	No results	
Honduras		
2002 Multipurpose Household Survey	2.6%	
Jamaica		
1991 Census	4.7%	
2001 Census	6.2%	
Mexico		
2000 Census (basic)	1.84%	
2000 Census (extended)	2.31%	
Nicaragua		
Census	12.5%	
Panama		
1990 Census	1.33%	Impairment-based
2000 Census	1.8%	Impairment-based
Paraguay		
2002 Census	No results	
Peru		
1993 Census	1.3%	
1993 Specialized Rehabilitation Institute	13%	
Suriname		
1980 Census	2.7%	
2003 Census	No results	
Uruguay		
2003-2004 National Disability Survey	In progress	
United States		
2000 Census	19.3%	Activity limitations
Venezuela		
2001 Census	4.4%	Impairment-based

Most countries report disability rates well under 10% but these results are suspect for a variety of reasons. First, the lack of reliable data from the region is striking. In the case of Chile, the percentage of the population comprised of persons with disabilities varies from 2.2% to 5.3% to 21.7% depending on the survey and the methodology used. Second, the continued focus on impairments is also problematic. In the vast majority of cases, when questions ask about activity limitations rather than impairments, more persons with disabilities are identified. In Bolivia, for example, over 1/2 of the persons identified by the impairment-based question have a serious or very serious disability, suggesting that persons with mild or moderate disabilities are being undercounted. Consequently, the likelihood that the disability population is underreported in many countries throughout the region is very high.

Legislation & Disability Rights

Overall legal protections in the region are good. One significant factor is the existence of the Organization of American States' (OAS) Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With Disabilities, which compelled the creation of at least some disability legislation through the ratification process. Moreover, by protecting people with disabilities under international law, the convention is an important regional instrument for the protection of disability rights. All countries in this report have signed the treaty except for six. Non-signatories include: Belize, Canada, Guyana, Honduras, Suriname, and the United States.

In addition to international law, the national constitutions of half of the countries in the region specifically identify people with disabilities as the subjects of rights. Fourteen countries have passed additional laws that deal solely with protections for people with disabilities, and most others include disability issues within other types of legislation. Particularly important is the number of countries that have passed laws prohibiting discrimination against persons with disabilities. These include: Canada, Chile, Costa Rica, Dominican Republic, Ecuador, Panama, Uruguay, and the United States.

Despite these encouraging trends, however, people with disabilities are most often seen as being in need charity rather than full human rights. Much recent regional legislation lacks regulatory enforceability. Penalties for noncompliance are often lacking, and when they do exist, are frequently not imposed. The overall status of legal protections in the region may be summarized as having reached a state where the creation of legal protections has outstripped the willingness and/or ability of nations to implement and enforce them.

Voting rights, for example, are universally recognized throughout the region although only a handful of countries make any significant effort to ensure their full enactment for persons with disabilities. Instead, many persons with disabilities face inaccessible polling places, a lack of information regarding the political process, and occasionally, disdain from election officials. Moreover, some countries have provisions allowing people to be deemed legally incapable solely on the basis of their disability. Some people with disabilities are stripped of the right to vote, as well as a host of other rights, in this manner. People with multiple disabilities or “mental disabilities” are most frequently singled out for this treatment. Argentina, Bolivia, Peru, and Uruguay classify people who are deaf and cannot speak as legally incapable. People with mental disabilities can have their rights taken away in Brazil, El Salvador, Guyana, Jamaica, and Peru. People with a sensory disability, such as the blind, may face such treatment in El Salvador, Guatemala, and Guyana. Finally, Canada reports that persons with disabilities whose health represents a potential financial burden to the state may not be allowed to immigrate.

Communication

Governments in the region communicate very little information in alternative formats for those with sensory impairments. Only 40% countries have an alternative format version of their Constitution, and of those, even fewer translate other documents of national importance into such formats.

Few countries have systems allowing people with disabilities to communicate with authorities in the case of complex emergencies. Emergency communication services for people with disabilities are available in Canada and the United States. Among the countries reporting efforts to make national communications systems for complex emergencies more inclusive are Chile, Costa Rica, and Panama. Brazil reports that 70% of the country is currently covered by a telephone system that is accessible by persons who are deaf. Some localities also include people with disabilities in city planning. The city of Buenos Aires, for example, requires signage designed for use by persons with disabilities.

The majority of resources dedicated to translating materials into alternative formats are focused on producing educational texts. The translation of other materials, and even that of educational materials in some countries, is often a paid service. In many libraries, Talking Books are becoming more readily accessible than Braille books. Because talking books are less expensive to produce, they can be updated more frequently, thus providing a broader range of materials. El Salvador’s national library, for example, last purchased Braille books in 1992.

Education

As with the disability population as a whole, there is very little reliable statistical information about the number of children with disabilities who are attending school. Based on the data that is available however, it can be safely stated that children with disabilities are frequently excluded from educational systems. In Colombia, only 0.32% of students have a disability. Similar figures are reported for Argentina (.69%) and Mexico (.52%), while slightly higher figures are reported in Uruguay (2.76% of students) and Nicaragua (3.5%). When the estimated number of children with disabilities is compared to the number enrolled, only 20% to 30% percent of children with disabilities are likely to be attending school. Only Canada and Costa Rica reported significantly higher levels of participation in the educational system, while some countries reported lower participation. In Bolivia, for example, somewhere in the range 74% to 97% of children with disabilities are currently being excluded from education. The breadth of this estimate reflects uncertainty about the total number of children with disabilities in that country. It should also be noted that although Costa Rica reports high levels of participation, it also reports a large number of formal complaints regarding the education of persons with disabilities.

Exclusion from school may result from the actions of teachers, school administrators, and parents as well as from inaccessible facilities, or absent services. Although most countries have some sort of special education training available, it is often not mandatory for those intending to become mainstream teachers, and not all teachers are properly trained to educate students with disabilities. Among those countries requiring special education training are Belize, which recently made such training mandatory, and Bolivia.

Access to education varies according to type and degree of disability. In particular, children with severe disabilities are often not admitted to schools. Moreover, students with many types of disabilities are largely restricted to elementary education. Throughout most of the region, there are few special secondary schools and integration at the secondary level is uncommon. Consequently, even those persons with disabilities who do receive an education typically receive less education than persons without disabilities. In Chile, persons with disabilities only complete 6.4 years of schools on average. In Brazil, only 10% complete 8th grade. A similar number complete high school in Ecuador, while only 5% complete high school in El Salvador.

Although many countries are working toward inclusive education, progress toward this goal varies. Some countries such as Canada and Costa Rica include most students with disabilities in inclusive educational situations. On the other hand, 70% of children with disabilities attend special schools in Mexico, as do 90% of children with disabilities in Suriname. In Chile, only 19% of students with disabilities receive inclusive education at the elementary level despite the stated goal of including these children in the mainstream educational systems.

Employment

Unemployment and exclusion from the workforce is a significant problem for persons with disabilities in the region. On average, close to 70% of persons with disabilities in the region are reported to be either unemployed or outside of the workforce. High unemployment results from a variety of factors including lack of training, inaccessible workplaces, lack of accessible transportation, and ongoing regional economic problems. Even among those persons with disabilities who are "occupied" (employed), many receive little to no monetary remuneration. Mexico reports that 14% of those who are working receive no pay and another 22.6% receive less than a minimum wage. Similarly, in Brazil, 30% of persons with disabilities receive less than a minimum wage.

The type of work available to people with disabilities further illustrates the lack of employment opportunities available. In Chile, only 1/3 of persons with disabilities who are employed have full time work. Many people work informally, are self-employed, or are underemployed. In Bolivia, almost 40% are self-employed or work informally, and in Honduras, 73% are reported to be self-employed or work for no pay. Additionally, once employed, persons with disabilities in Canada report being subject to harassment at a rate of 36%.

In light of the lack of employment for persons with disabilities, a number of countries in the region have instituted laws and/or policies aimed at integrating persons with disabilities into the workplace. Several including Argentina, El Salvador, Nicaragua, Panama, Uruguay, and Venezuela have quotas for the number of persons with disabilities that should be hired by the government or companies of a certain size. While some private companies are reported to have either formal or informal non-discrimination policies, most do not.

Some form of occupational training is available in most countries, however, poor job placement rates in most countries mean that very few persons with disabilities ultimately reap benefits from these programs. Private initiatives by NGOs in Argentina and Venezuela show some promise in this regard.

Health Services

Throughout much of the region, access to health insurance is based upon employment status, so high rates of unemployment may deprive people with disabilities of insurance. For example, 84% of people with disabilities have no insurance benefits in Ecuador. In Chile, only 7% of persons with disabilities have private health insurance; while anywhere from 60 to 80% receive care through the public health system. People with disabilities are also more likely to be rejected by health insurers. There have been a number of complaints in Uruguay about this type of discrimination. When people with disabilities lack access to health insurance, governments are left to assume the responsibility of providing health care and rehabilitation. Unfortunately, although governments may accept this responsibility, many countries lack the necessary resources and, consequently, services are inadequate. Frequently, important services or the provision of assistive devices, such as wheelchairs, are not considered necessities and are not provided. Non-governmental organizations often play a vital role in attempting to fill these needs.

Medical professionals with proper training are also often unavailable. While many countries have some training on the provision of health and rehabilitation care to persons with disabilities, most is aimed at producing rehabilitation specialists. General physicians and medical specialists in areas unrelated to disability often receive little training in how to care for people with disabilities, which results in a generally low quality of medical care. This situation is especially prevalent in small towns and rural areas. While large cities may have a supply of trained specialists, they rarely can provide services outside the larger urban areas.

Housing

Throughout the region, persons with disabilities most often live with their families and not independently. The Independent Living philosophy is not yet well established. Approximately 2/3 of all countries in the region report no Independent Living center. Moreover, the infrastructure for independent living is often missing. One positive exception is a project in “sustainable housing” for persons with disabilities in San Salvador.

Subsidized housing is sometimes available for persons with disabilities as are funds for purchasing, adapting, or improving a home. In several countries, disability related eligibility criteria are used to give people with disabilities extra consideration in housing programs. For example, persons with disabilities receive priority in subsidized housing in Uruguay due to their designation as a vulnerable population. In Jamaica a percentage of all affordable houses are reserved for people with disabilities and adapted for their use. The majority of countries, however, do not provide subsidies. In the cases of Chile and El Salvador, even when persons with disabilities are eligible for subsidies or public housing, the available housing stock is not accessible.

The housing situation of people with disabilities is currently the focus of substantial work in many countries. Proposed or recently adopted housing initiatives are reported by Argentina, Bolivia, Colombia, the Dominican Republic, Guyana, Honduras, and Mexico. The impact of these initiatives, however, is still uncertain. In the Dominican Republic, for example, no adapted housing units have been constructed despite requirements. Similarly, in Guatemala, an agreement on the allocation of 5% of affordable homes to persons with sensory disabilities resulted in housing for only 18 people.

Institutionalization

Many people with disabilities face involuntary institutionalization in countries throughout the region resulting in some of the most blatant and abusive human rights violations. A June 2003 report from Argentina detailed the horrific conditions under which persons with disabilities were institutionalized. Some people were kept in rooms soiled with their feces, while others were denied clothing or forced to eat off the floor. In the past, Canadian and U.S. institutions often sterilized persons with disabilities, and people with disabilities are still many times more likely to be abused than those without disabilities. In Jamaica, investigations have identified persons with disabilities who were kept in jail for years and even decades without being brought to trial because they were considered “unable” to go to court.

Although many countries allow the refusal of medical or psychiatric treatment in theory, such refusal is often elusive in practice. In Bolivia, for example, people with disabilities are often unaware of their right to refuse treatment and so cannot exercise that right. Refusal of treatment is especially problematic for those who have lost legal capacity or who have been abandoned by their families. Many countries report that abandonment is common among people with disabilities who end up in institutions. Some countries such as Costa Rica and Canada report the existence of deinstitutionalization efforts.

Accessibility

Most countries have legislation requiring that public buildings be accessible to people with disabilities. In many cases, these standards only apply to new buildings or renovations of existing buildings. Nevertheless, enforcement of these laws is reported to be rare. In Peru, for example, the law mandates that accessibility adaptations were to have been completed by June of 2003, but as of this writing no penalties for noncompliance have been issued. Partial and inadequate adaptation is also frequently reported. Examples include ramps that are too steep and bathrooms that are not accessible. Among those countries with no accessibility legislation are Belize, Honduras, and Suriname.

The lack of accessibility often extends into public spaces as well. Lack of curb cuts or blockage of existing curb cuts is common as is a lack of sound signals or other accessible signage at intersections. A lack of level surfaces and the ubiquitous presence of street merchants present other barriers in many countries.

Accessible transportation is also lacking throughout the region. Only Brazil, Canada, Jamaica and the United States report having accessible bus systems in some cities. In many cases, like those of Argentina, Chile, Colombia, Ecuador, Mexico, and Venezuela, transportation is partially accessible with a small percentage of adapted buses or train stations. The transportation system as a whole remains functionally inaccessible due to inconsistent adaptations. An initiative to make 8% of buses accessible is currently underway in Costa Rica. For many persons with disabilities, private transportation or taxis, both of which tend to be very expensive, are the only reliable choices.

Disability Action & Awareness

The majority of countries in the region have an agency that is responsible for the creation and coordination of disability policy. In some cases, such as Brazil, Canada, Colombia, Ecuador, Mexico, and Panama, these organizations have helped create a disability action plan. Argentina, Costa Rica, Guatemala, Nicaragua, and Uruguay on the other hand, report that the coordinating agency has not yet been able to take effective action. Chile and Guyana have developed national disability action plans without the guidance of a coordinating agency. Moreover, in most instances the inclusion and input of persons with disabilities in the coordinating organization is minimal. Exceptions include Ecuador, where people with disabilities have had an important impact on the laws and policies

advocated by the National Disability Council, and Mexico where participation by disability NGOs is currently encouraged, among others.

The focus of NGO activity varies widely around the region. Some countries, such as Canada, have a well-developed disability movement. In others, such as Argentina and Costa Rica, activities by non-governmental organizations are more restricted to the area of disability service provision. Groups in those countries may be unable or unwilling to become involved in extensive advocacy around human rights issues. Many countries report a lack of coordination between disabilities groups and the need for cooperation before effective action will be possible. Among the strategies for the promotion of disability rights that are generally recommended by disability advocates are the initiation of legal proceedings, where laws currently exist, or the creation of a legal regime where they do not. In addition, groups feel it is extremely important to increase the media's coverage of important disability issues. Generally, the level of awareness and the amount of information pertaining to the human rights of people with disabilities in the region is inadequate. There is general consensus that this must be addressed if any sustained progress is to be made.

Regional Report of the Americas: Country Reports



Argentina

Key Factors: The struggle for disability rights is being waged against a backdrop of deep social and economic deterioration that gave way to a profound crisis in 2001. The change of government in 2003 has created expectations for positive change.

Terminology

In general, existing laws use appropriate terminology except in a few circumstances. The laws on retirement and pensions use the terms “minusvalía” and “minusválidos.” When directly quoting such documents within this report, these phrases have been translated as “handicap” and “handicapped”, respectively.

The Civil Code does not refer to disability, but to “demencia,” “demente,” and “insano,” translated as “dementia,” “demented,” and “insanity,” respectively. It also uses the term “sordomudos,” translated as “deaf mute.” Even though this language is currently regarded as offensive by the disability community, its redrafting has not been formally proposed. Additionally, in the field of education, the term “disability” is not used. Rather, reference is made to “necesidades educativas especiales” which has been translated as “special educational needs.”

Definition of Disability

The definition of disability used in most official papers and legal documents is derived from Law 22431, also known as the Comprehensive System of Protection for Persons with Disabilities Act. Pursuant to Section 2, “a disabled person is an individual suffering from a permanent or long-term functional disorder, either physical or mental, which, in relation to his or her age and social environment, implies a considerable disadvantage for his or her family, social, educational or labor integration.”²

¹. Alicia Bustos Fierro (lawyer, social worker, former Director of Legal and International Affairs of the Presidential National Advisory Committee for the Integration of Persons with Disabilities, former representative of the Southern Cone to the Executive Committee of the Ibero-American Network of Disability Policies, former Head of the Litigation Office of the Ministry of Labor), interviewed by author, Buenos Aires, 22 September 2003; Daniel Sarmiento (lawyer, Assistant Secretary, Office of Public Guardians for the Mentally Ill, Federal District of La Plata), interviewed by author, Province of Buenos Aires, 19 September 2003.

² Law 22431, 16 March 1981, www.cndisc.gov.ar.

There are two deviations from this general definition. First, the law concerning pension and retirement benefits states that “a handicapped person is an individual whose working capacity is reduced by more than 33% as a result of physical or intellectual impairments duly certified by an official health authority.”³

Second, the Framework Agreement for Special Education, issued by the Ministry of Education to provide guidance to the provinces on dealing with students with disabilities within the framework of the Federal Education Act, states that “special educational needs are those experienced by individuals who require aids or resources that are not usually available in an educational environment, and which enable them to participate in the learning process established in the Curriculum Design.”⁴

Except in these two instances, the definitions and terminology used in official documents consistently refer to Law 22431 and to the World Health Organization ICDH-I classification.⁵ The International Classification of Functions, Disability and Health (ICF) has not yet been officially used.⁶

Disability Population

Through the middle of the twentieth century, Argentina collected information on persons with disabilities. After 1960, however, no consistent data on the disability population was collected for forty years. In response to the demands of people concerned with disability issues and the requirements of the United Nations, the topic was again included in the 2001 Census.⁷ According to that census, the total population of the Argentine Republic was 36,260,130 people.⁸

³ Argentine Federation of Institutions for Persons with Intellectual Disabilities (FENDIM), *Legislación aplicable al Sector de las personas con discapacidad*. [Legislation Applicable to the Disability Sector] Siglo XXI Collection, (Argentina 1999) Law 20475, sec 1, 1973.

⁴ Ley Federal de Educación [Federal Education Act], 1993, www.me.gov.ar/leyfederal.

⁵ Federal Council for Culture and Education, Ministry of Culture and Education, *Acuerdo Marco para la Educación Especial, Documentos para la Concertación* [Framework Agreement for Special Education, Documents for Concerted Action], series A, no. 19, (December 1998).

⁶ *International Classification of Impairment, Disability and Handicap*, <http://www.who.int/icidh/>.

⁷ *International Classification of Functioning, Disability and Health*.

⁸ The 2000 census was postponed until 2001 due to financial constraints.

⁹ <http://www.indec.mecon.ar>.

The census form included a question intended to identify whether at least one person with a disability lived in a household. The disability related portion of the census was designed based on lessons learned from Latin America, Canada, the United States and some European countries,¹⁰ taken together with information provided through various United Nations publications.¹¹

Three supplementary surveys were designed to follow the census: one on the disability population, one on the indigenous population, and one on the population of immigrants from neighboring countries.¹² The survey on disability—the first of the three supplementary surveys—was conducted between December 2002 and March 2003. Data collected during the Census was used to design the sampling frame for the survey. Interviewers conductive the disability survey received specific training.¹³ Findings will be released in the second half of 2004. There will likely be significant discrepancies between the census results and the survey findings.¹⁴

Leaders of the disability community report skepticism about the quality of the data coming from both the 2001 Census and the supplementary survey. They cite difficulties in defining who has a disability and regard this challenge as one of the main factors resulting in the overall lack of information and the poor quality of existing data.

Since the 1990 census, several other attempts have been made to quantify the disability community. Several provinces initiated projects to address the issue, but all of them were eventually discontinued due to budgetary constraints. Unfortunately, the lack of coordinated methodologies makes it impossible to cross-check data from these projects for reliability.¹⁵

Another avenue for examining the size of the disability community is provided by Law 25504. This law, also known as the Unique Disability Certificate Act, allows persons with disabilities to obtain certificates from the Ministry of Health or from the provincial agencies.¹⁶ The certificates act as identifying documents used for obtaining services. Data supplied by the recipient of the certificate is to be

10. National Office of Social and Population Statistics, INDEC *Censo Nacional de Población Hogares y Viviendas* [National Population, Household and Housing Census], 2001, <http://www.indec.mecon.ar/webcenso/>.

11. *United Nations Antecedentes de la Medición de la Discapacidad en Censos de Población* [Background of Disability Measurement in Population Censuses], Disability, Working Paper No. 1 May 1999 and Updating Annex, May 2001; United Nations, *Principles and Recommendations for Population and Housing Censuses*, 1996.

12. INDEC, *First National Disability Survey*.

13. Gladys Massé (head of the Statistics Office, National Institute of Statistics and Census), interviewed by author, Buenos Aires, 22 September 2003; Carlota Callman, (lecture given at the 4th Latin American Congress of the International Society for Prosthetics and Orthotics, ISPO, Buenos Aires, 22 October 2003).

14. Jorge Mascheroni (lawyer and President of the Presidential National Advisory Committee for the Integration of Persons with Disabilities), interviewed by author, Buenos Aires, 7 January 2004.

15. Gladys Massé.

16. Law 25504 was enacted in 2001 within the framework of 1997 Law 24901 on the System of Basic Services for Habilitation and Comprehensive Rehabilitation of Persons with Disabilities.

entered into a national database that could provide reliable figures on this sector of the population. However, only 14 provinces have approved this law to date, and they still lack accurate data because not all people with disabilities have applied for certificates.¹⁷ Although Buenos Aires—the most densely populated province of the country—has not signed Law 24901, it has adopted a similar registration system.¹⁸

At present, government agencies and social organizations use the estimates of the World Health Organization, which suggest that approximately 10% of the population has some kind of disability. According to this estimate, there would be over 3,000,000 people with disabilities in Argentina. Most people interviewed for this report dispute this figure. Government officials generally believe that the disability community accounts for 7 to 8% of the country's total population,¹⁹ while members of social organizations estimate that disability affects 15% of the population.²⁰

Officials generally agree that there are regional variations in the disability population due to a number of causes. For example, in the northeastern part of Argentina (NEA), particularly in the provinces of Misiones and Corrientes, there is a high incidence of myelomeningocele. The condition is thought to be associated with use of agrochemicals on crops although there are no studies to confirm this assumption and the specific cause of it is unknown.²¹

In the northwestern part of the country (NOA), the province of Salta is known to have very good physical rehabilitation services for persons with mobility impairments. Consequently, many immigrants from neighboring countries—primarily from Bolivia and Paraguay—are believed to travel to Salta for treatment, which may result in an increased rate of disability in that area.²²

Since there are no statistics prior to the 2001 census, it is impossible to know whether the number of people with disabilities has changed in the past 5 years. However, many interviewed for this report are inclined to think that it has increased. Manuel Maza, a physician from the Latin American Association of Pediatrics (ALAPE), explained that a number of causes could potentially result in increased numbers of people with disabilities.²³

¹⁷. Jorge Badaracco.

¹⁸. Soledad Schilling, (lecture given at the 4th Latin American Congress of the International Society for Prosthetics and Orthotics, ISPO, Buenos Aires, 22 October 2003).

¹⁹. Jorge Badaracco; Susana Sequeiros, Gladys Masse; Letter to the President of Argentina, Mr. Néstor Kirchner, with reference to the Request of People with Disabilities, August 2003, signed by Eduardo Joly (REDI) Victor Abramovich (CELS) and Elizabeth Aimar (Assistance Network for Rights and Social Integration); Liliana Díaz, "Discapacidad y pobreza" [Disability and Poverty] in *La Discapacidad: una cuestión de derechos humanos* [Disability: A Human Rights Issue], (C. Eroles and C. Ferreres, CTA - Espacio Editorial, Buenos Aires, 2002), 158.

²⁰. Manuel Maza (pediatrician, Secretary of the Disability Committee of the Latin American Association of Pediatrics (ALAPE), former secretary of the Disability Committee of the Argentine Pediatric Society), interviewed by author, Province of Buenos Aires, 16 December 2003.

²¹. *Ibid.*

²². *Ibid.*

He divided these causes into two groups: positive and negative. Positive causes include: increasing longevity and scientific and technological advances enabling the survival of people who, under the same circumstances, previously would have died and who now, in many cases, become disabled. Modern pediatric intensive care and neonatology technology, for example, save the lives of 8% of babies born between 20 and 22 weeks gestation. At the same time, children may develop neurological damage and a chronic pulmonary condition that renders them permanently dependent on oxygen supply. Similarly, inadequate control of O₂ administration in some neonatal care units has resulted in a growing population of visually-impaired children.²⁴

Negative causes include two major factors. The first is accidents. Despite the lack of official figures, officials estimate that 1 person dies every hour and that between 4 and 8 become disabled in the same period of time.²⁵ The second factor is progressive impoverishment and its impact on health and other basic living conditions of the population.²⁶ Although the spending on health care in Argentina is two times the percentage of the GDP spent on health care in Chile and 5 times the amount spent in Cuba, the health care and education systems are poor.

A large number of children are stricken by extreme poverty throughout the country.²⁷ An outbreak of severe iron deficiency has been reported, causing tiredness, sleepiness, and weakness in children and affecting their neural development. An increasing number of children will likely be affected by disabilities resulting from such nutritional deficiencies experienced during the most important period of neural development.²⁸

Some disability advocates suggested that the actual number of people with disabilities may not have increased, but reported numbers may increase, as more disabilities are being recognized. As a result of information campaigns on various conditions, such as autism, many parents now recognize the symptoms and consult a physician.²⁹

²⁷ E. Alda, "Los neonatólogos entre dos epidemias" [Neonatologists between Two Epidemics], *Argentine Archives of Pediatrics*, 101(4): 24, (1 August 2003). There has also been an increase in the enrollments of schools for blind and visually impaired children.

²⁸ Jorge Badaracco.

²⁹ Liliana Bastons (lawyer, Chairwoman of the Disability Committee of the Bar Association of the Federal District of La Plata), interviewed by author 21 August 2003; Jorge Badaracco; Susana Sequeiros; Manuel Maza.

³⁰ The INDEC defines poverty as a monthly family income less than the estimated cost of basic needs including food, clothing, transportation, education, and health, among others. Extreme poverty is a monthly family income less than the estimated cost of the food necessary for subsistence, <http://www.indec.mecon.ar>.

³¹ Manuel Maza.

³² *Ibid.*

³³ Panel discussion with leaders of disability organizations.

Legislation & Disability Rights

Legal Protections

The National Constitution of the Argentine Republic was enacted in 1853.³⁰ During the 20th century the country's history was marked by alternating democratically-elected administrations and military governments imposed by coups d'etat that ruled the country outside the National Constitution. The last coup took place in 1976, and democracy was restored in 1983.

The Constitution was last amended in 1994, when a number of human rights provisions were introduced. Section 75 empowers Congress "to approve or reject treaties concluded with other nations and international organizations, and concordats with the Holy See. Treaties and concordats have a higher standing than laws."

International Protections

Argentina is party to the following international human rights instruments: the American Declaration of the Rights and Duties of Man; the Universal Declaration of Human Rights; the American Convention on Human Rights; the International Covenant on Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights and its optional Protocol; the Convention on the Prevention and Punishment of Genocide; the International Convention on the Elimination of all Forms of Racial Discrimination; the Convention on the Elimination of all Forms of Discrimination against Women; the Convention against Torture and other Cruel, Inhuman or Degrading Treatments or Punishments; and the Convention on the Rights of the Child. The potential for incorporating other treaties and conventions is provided for in the Constitution.

Argentina ratified the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities with the passage of Law 25280 on 6 July 2000. The ratification document was deposited on 10 January 2001. In April 2002, Resolution 192 of the Ministry of Justice and Human Rights established a Working Committee to draw up draft regulations for Law 25280. Both government institutions and civil organizations participated, including the CTA, the AMIA, and the Archbishop of Buenos Aires. On 3 December 2002, the Working Committee concluded its task and submitted the draft regulations. The Committee later became the Follow-up Committee on the Convention.

³⁰ Soledad Figueroa (Office of Human Rights, Ministry of Foreign Affairs), interviewed by author 20 August 2003.

³¹ *Ibid.*

Although the Argentine delegation to the United Nations has not made a formal declaration with regard to an International Convention on the Rights of Persons with Disabilities, at the Ad-Hoc Committee meeting in June 2003 in New York, it did express its support for such an initiative.³¹

The Argentine government does not support supplementing the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Although it recognizes that the Standard Rules have made a substantial contribution to the formulation of policies for improving the rights of individuals with disabilities, the possibility of an international convention on disability rights preclude further work on the Standard Rules as discussions of any supplement would overlap with the start of the negotiations of the Comprehensive and Integral International Convention. However, the government feels that any comments by the Special Rapporteur should be taken into account during the negotiation process of the international convention.³²

A section on disability rights was included in the latest report to be submitted to the Committee for the Elimination of Racial Discrimination.

National Protections

With regard to national legislation, people with disabilities are provided with legal protection under the National Constitution, some provincial constitutions, and national and provincial laws. In general, Argentinean law acknowledges and formally protects most aspects of disability rights, but since Argentina is organized as a federal system of government and all the provinces have not adopted many national laws, rights protections may be uneven.

Subsection 23 empowers Congress “to legislate and promote positive measures guaranteeing true equal opportunities and treatment, the full enjoyment and exercise of the rights recognized by this Constitution and by the international treaties on human rights in force, particularly referring to children, women, the aged, and people with disabilities.”

³². *Constitución de la Nación Argentina* [National Constitution of Argentina], <http://www.senado.gov.ar/principal.php>.

³³. Liliana Bastons; Alicia Bustos Fierro.

The following national laws on disability have been enacted in Argentina:

Accessibility

Law 24314. Amendment to sections 20, 21 and 22 of Law 22431 Accessibility, Elimination of Architectural, Urban, Environmental, Transportation and Communication Barriers

Law 24204. Public Telephony for Hard-of-Hearing Individuals

Law 24421. Residential Telephony for Hard-of-Hearing Individuals

Law 25634. Amendment to the third paragraph of subsection a) of Section 22, Chapter IV "Accessibility to the Physical Environment" of Law 22431. Frequency of Bus Service

Law 25635. Amendment to the third paragraph of subsection a) of Section 22, Chapter IV "Access to the Physical Environment" of Law 22431. Free Passes on Public Transportation

Motor Vehicles

Law 19279. Exemption System for the Acquisition of Vehicles for Persons with Disabilities

Law 24183. Modification of Law 19279

Discrimination

Law 23592. Discrimination

Law 25280 Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities

Education

Law 24195. Federal Education Act

Law 25573. Higher Education Act

Funding

Law 24452. Check Act

Law 25730. Penalties for Drawers of Rejected Checks

³⁴. FENDIM, *Legislación aplicable al Sector de las personas con discapacidad*.

Government Agencies

- Law 22431. Comprehensive System of Protection for Persons with Disabilities
- Law 24657. Federal Disability Council
- Law 25346. National Day of Persons with Disabilities

Pension and Retirement

- Law 13478 and amendments thereto. Non-contributory Disability Pension Scheme
- Law 18910. Old Age and Disability Benefits
- Law 20475. Granting of Retirement Benefits to the Disabled
- Law 20888. Granting of Retirement Benefits to the Blind
- Law 24241. Integrated Retirement and Pension System
- Law 25364. Disability Benefits Scheme.
- Law 25615. National Institute of Social Services for Retirees and Pensioners

Health

- Law 23413. Early Detection of Phenylketonuria
- Law 23660. Social Health Care Organizations
- Law 23661. National Health Insurance System
- Law 23874. Early Detection of Hypothyroidism and Phenylketonuria
- Law 24754. Private Medical Insurance
- Law 24901. System of Basic Services for Habilitation and Comprehensive Rehabilitation of Persons with Disabilities
- Law 25404. Adoption of Protective Measures for Epileptics
- Law 25415. Program for the Early Detection of Hearing Impairments
- Law 25421. Primary Mental Health Care Program
- Law 25504. Unique Disability Certificate

Labor

- Law 23462. Vocational Rehabilitation and Employment of Persons with Disabilities
- Law 24013 National Employment Act
- Law 24147. Sheltered Workshops and Work Groups
- Law 24308. Licenses to Operate Small Stores and Shops
- Law 24714. Family Allowances Scheme
- Law 24716. Special leave of absence for working mothers who give birth to a child with Down Syndrome
- Law 25212. Federal Labor Pact
- Law 25689. Amendment to Law 22431 regarding the percentage of persons with disabilities to be employed by the national government.

Of this list, the Comprehensive System of Protection for Persons with Disabilities Act (Law 22431), mentioned earlier in this report, represents a particularly important milestone in the history of disability action in Argentina.³³ It was enacted in 1981, and accompanying regulations were issued in 1983. The Argentine Federation of Organizations for Persons with Intellectual Disabilities (FENDIM), a member of Inclusion International, played a key role in this process. The law covers a number of areas including assistance, prevention, health care, social welfare, labor, education, security, transportation, and architecture. Section 27 states that "... the National Executive Power shall propose that provinces adopt, in their own jurisdictions, regulatory systems establishing similar principles to those provided for under this law." Accordingly, many provinces have gradually enacted their own laws.³⁴

Although it may appear that legislation related to disability in Argentina is broad ranging and advanced, there are two major problems. First, there is a general lack of awareness about the legal framework for protecting disability rights.³⁵ Second, most laws lack penalties for non-compliance, and some of them are not enforced.³⁶ In a 10 August 2003 editorial, *La Nación*, a newspaper in Buenos Aires, stated:

....it is a mistake to assume that this country lacks legislation aimed at eliminating all forms of discrimination and at addressing the needs of people suffering from some physical disability. This legislation exists. What is lacking in Argentina is a clear moral awareness of the need to defend the principle of social inclusion in all specific situations and to adopt... an appropriate behavior so that no individual is excluded from the community.³⁷

Two reports produced by civil society organizations in 2003 raised the issue of non-compliance by the state, social health care organizations, and private actors.³⁸ One of these reports contained the following statement:

³⁵ Panel discussion.

³⁶ Alicia. Bustos Fierro; Soledad Figueroa, information provided with the endorsement of Alicia Olivera, head of the Office of Human Rights; Alberto Rantucho (member representing NGOs of visually impaired people in the Provincial Council for People with Different Abilities, Member of the Municipal Committee on Disability of Bahía Blanca,) interviewed by author, Province of Buenos Aires; Conference on Legislation and Disability, (Montessori Association, La Plata 16 October 2003).

³⁸ REDI, CELS and Assistance Network for Rights and Social Integration, August 2003.

³⁷ "Editorial II", *La Nación*, (City of Buenos Aires, 10 August 2003).

³⁹ Follow-up Committee on the *Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disability*, Informe preliminar sobre la situación de las personas con discapacidad en la Argentina [Preliminary Report on the Situation of Persons with Disabilities in Argentina], September 2003.

⁴⁰ *Ibid.*

⁴¹ Jorge Mascheroni.

We wish to express our deep concern for the critical situation faced by people with disabilities in Argentina and for the indifference shown by many government agencies and even by civil society itself to non-compliance with current legislation, the ineffectiveness or non-enforcement of many public policies and to the occurrence of discrimination.³⁹

According to Jorge Mascheroni, President of the National Advisory Committee for the Integration of Persons with Disabilities (CONADIS), the laws on disability are not enforced because they do not rest on a solid foundation of social awareness. They are broad statements of principles, rather than laws.⁴⁰ They do not incorporate any mechanisms for monitoring compliance and, as a result, infractions must be dealt with on an ad hoc basis. Additionally, most laws lack specific proscribed punishment for offenders. Some sections of the Argentine Criminal Code have occasionally been used to fill the gap.⁴¹ In particular, Law 13944, Sections 1 and 2, defines the crime of “failure to comply with the duties of family support” and establish the penalties for the divorced father or mother who does not provide alimony as decreed to children who are minors or disabled children of any age. Sections 148 to 153 allow that violations of law may be the responsibility of government officials who have failed to exercise due control or take required action. These particular sections of the code may be used to define and punish the crime of “abuse of authority and breach of duties by a government official” in regard to a person with a disability. Sections 106 to 108 define and proscribe punishment for the crime of “abandonment and neglect of a person”, placed special emphasis on people who cannot take care of themselves or who have a disability.

Failure to comply with these laws has led to a large number of “amparo” proceedings (summary proceedings which serve to guarantee constitutional rights and seek their enforcement). Some disability advocates reported having used these proceedings to assert their own rights or having advised others to do so. The use of these proceedings along with the presentation of particular cases to the media, are widely considered the most effective ways of challenging rights violations.⁴²

Reporting violations to monitoring agencies and filing ordinary lawsuits are other strategies for asserting disability rights. Both are generally considered ponderous and ineffective. Some NGOs provide counsel on the proper procedures for reporting disability rights violations, including: the Center for Legal and Social Studies, the Bar Association, the Argentine Workers Trade Union Center (CTA), the Israelite Mutual Benefit Association of Argentina (AMIA), the Assistance Network for Rights and Social Integration (REDI), among others. Lawyers are not always conversant with disability laws, although in recent years interest in disability issues appears to have increased slightly.

⁴¹. Daniel Sarmiento.

Disability rights violations may be reported to the National (Human Rights) Ombudsman's Office, the provincial Ombudsman's Offices, or the municipal Ombudsman's Offices in jurisdictions where they operate. There is also a National Institute against Discrimination, Racism and Xenophobia (INADI) created under Law 24515, whose role it is to take appropriate steps in both addressing and preventing discrimination. Provincial human rights offices may also receive reports for INADI.⁴³ Between January 2002 and January 2003, 31% of the reports addressed by INADI concerned disability and health issues. Monitoring agencies, Ombudsman's Offices, and the branch offices of INADI are not well known by people with disabilities in most cities in the interior of the country.⁴⁴

Legal Barriers

People with disabilities who are declared legally incapable by a court are excepted from many general human rights protections. The Civil Code establishes that: "a person who, by reason of mental illness, lacks the ability to care for himself or herself or his or her property, shall be declared incapable due to dementia."⁴⁵ It also states that "deaf mutes shall be declared incapable for acts in civil life when they cannot make themselves understood in writing." The law establishes identical legal procedures and provisions for these two groups of people.⁴⁶

A person with a disability may be found entirely incapable under the law. This occurs, for example, when someone is declared "insane" by a court. Persons may also be found "partially incapacitated" pursuant to the recently amended Civil Code. Among those who may be declared partially incapacitated are "those with diminished abilities, when they do not meet the conditions established under section 141 of the Civil Code and a court considers that they may presumably harm themselves or cannot make responsible decisions about their property when exercising their full legal capacity. A partially incapacitated person may perform administration acts on his or her own behalf, except for those restricted by the court order, taking into account the circumstances of the case."⁴⁷

⁴². Law 24515, <http://infoleg.mecon.gov.ar>.

⁴³. Código Civil, book 1, part 1, title 11, sec. 153-154.

⁴⁴. Código Civil, book 1, part 1, title 11, sec. 152.

The Civil Code also establishes who shall exercise guardianship or act as the representative of a person declared legally incapable. Guardians are appointed to any adult who has been declared “incapable of administering his or her property,” including “the insane, even if they have periods of lucidity, and the deaf mutes who do not know how to read or write are incapable of administering their property.” Section 482 establishes other criteria by which people may be legally institutionalized. It states that “the insane shall not be deprived of their personal freedom except in cases where it is feared that, by exercising such freedom, they may harm themselves or others. Nor shall they be taken to an asylum without an authorization issued by a court. The police authorities may give instructions for placing individuals suffering from mental illness, or chronic alcoholics or drug addicts, who may harm themselves or others or affect the public peace, in a residential care facility, immediately reporting this to the competent court. Such placement may only be ordered upon prior advice from the official medical doctor.”⁴⁸ In the Province of Buenos Aires, hospitalization for “dementia” is regulated under Law 7967. There are no similar protections at the national level. In all other instances, admission to private institutions is regulated only by the policies and procedures of health care providers.

Procedures to declare a person with disabilities legally incapable may be initiated by his or her relatives or a public defender of minors.⁴⁹ During the proceedings, the judge in charge completes a number of steps before appointing the guardian. These may include a hearing involving the person with a disability. After an individual is declared legally incapable, his or her guardian is entrusted to safeguard his or her rights. When a person is declared partially incapacitated, he or she may exercise all his or her rights as a citizen except those relating to the buying or selling property or the handling of money in excess of a predetermined amount. Legal provisions associated with partial incapacity are seldom used.

⁴⁵. Código Civil, book 1, part 2, title 13, sec. 468-469, 482.

⁴⁶. Código Civil, book 1, part 2, title 13, sec. 470.

Civic Participation

People with disabilities have the same rights and duties as other members of society including: the right to vote, the right to stand for elective office, the right to hold public office, the right to free association, the right to get married, and the right to exercise parental authority over their children.

With reference to the right to vote, disability leaders identified the major obstacle to voting as the roads leading to the ballot box: specifically, the cost of transportation to reach voting centers coupled with the inevitable wait at the voting desk while the necessary arrangements are made.

All voting centers are mandated to have an accessible voting room available for person with disabilities. Such accommodations when present, however, are only designed for persons with mobility impairments. In reality, disability advocates have identified very few fully accessible voting centers. Most voting centers are located in schools that are only partially accessible. The rooms used for voting may be situated on higher, inaccessible floors of the buildings, and there are no ballot boxes designed for people who are blind, although they may be accompanied into the voting booth by the presiding election authority or by a member of their family.

Disability advocates have furnished numerous examples of individuals being denied the right to vote. In one instance, election authorities at a voting center refused to accompany a young person with multiple disabilities into the voting booth. In another, voters waiting in line demanded that the vote of a young man with a disability be invalidated because he was accompanied into the voting booth by his mother. In a third case, people waiting to cast their vote complained when the ballot boxes had to be taken to a wheelchair accessible room. In practice, the elections officials at individual polling stations play an extremely important role in determining whether or not people with disabilities are able to vote.⁵⁰

Inclusion

Communication

Laws 24204 and 24421 mandate that telephone companies provide public telephone services that are accessible to people who are deaf and people with speech impairments.⁵¹ People who are deaf, however, must buy a special device in order to be able to use these services, and these devices are prohibitively expensive for most of the Argentine population.⁵²

A review of television programming revealed that use of closed captioning is extremely limited. Only one news show, broadcast by the state-owned TV station, provides for simultaneous sign language translation. At the national level, an Optional Captioning Bill—Bill CD 132/02—has already been adopted by the Lower House and is currently under review by the Senate.⁵³

People with disabilities are generally left out of emergency planning. There is no centrally devised contingency plan for communicating with people who are deaf in case of a complex emergency. Even the many government buildings where people who are deaf work have no capacity or plans for inclusive communication in such instances.⁵⁴ By contrast, the headquarters building of the Israelite Mutual Benefit Association of Argentina (AMIA), which fell victim to a terrorist attack in 1996, has strict security measures that include a system to identify the location of personnel, including those with disabilities, inside the building.⁵⁵ Generally, planning for emergency exits is somewhat better. The Building Code of the Buenos Aires City Government establishes that all required emergency exits should be clearly identified with large-sized directional signage in contrasting colors to help guide people out of the building. These signs must be placed in visible places on each floor.⁵⁶

Braille texts are published in Argentina. There is a government-owned Braille publishing house called Editora Nacional Braille that produces Braille and talking format materials. It published a Braille version of the National Constitution and translates all documents provided by government officials into an alternative format. It sends material to The National Library as well as Braille libraries in

⁴⁷. INDEC *National Population, Household and Housing Census, Antecedentes de la Medición de la Discapacidad en Censos de Población*.

⁴⁸. Adrián Reynoso (President of the Sign Language Teaching Institute of La Plata), email response.

⁴⁹. Argentine Association for the Deaf, www.aso.org.ar.

⁵⁰. Susana Sequeiros; Cecilia Pazos (lawyer, Presidential National Advisory Committee for the Integration of Persons with Disabilities), interviewed by author, City of Buenos Aires, 7 August 2003.

⁵¹. Abraham Felperin (journalist, Director of the Disability Office of the Israelite Mutual Benefit Association of Argentina – AMIA, former president of REDI and former president of the Provincial Disability Council, Province of Buenos Aires), interviewed by author, City of Buenos Aires, 21 July 2003.

⁵². Nélide Galloni Balmaceda (architect, CIBAUT researcher, Professor at the UB School of Architecture and Urban Planning, Member of IRAM committees), interviewed by author, Buenos Aires, 7 August 2003.

⁵³. Secretary Office, Publishing House Editora Nacional Braille y Libro Parlante, telephone conversation, 29 September 2003.

the interior of the country and abroad.⁵⁷ Editora Nacional Braille also publishes two periodic magazines: *Correo del Sur*, a general information magazine, and *Nosotras ahora*, a women's magazine. Both are distributed to subscribers across the country. Other Braille libraries produce a variety of texts, but due to financial constraints they give priority to school textbooks. The libraries also produce recorded tapes of university books upon request.

Books in other alternative formats are also available. The Argentine Library for the Blind (BAC) is a non-profit, non-governmental organization based in the city of Buenos Aires. It has both Braille and Talking Book sections. The cost of updating Braille materials is very high, so the materials are rather limited. The Talking Book Section, in contrast, is updated on a regular basis and literary works in this format are updated yearly based on feedback obtained from user surveys. Recordings of educational texts may be obtained if those requesting the service are willing to provide a printed version.⁵⁸ The BAC claims that these services are available both to members who pay fees, as well as any individual who is blind and who needs them.

The BAC publishes three Braille magazines that have an international readership of over 1,400. An agreement with Correo Argentino, the postal company, enables free distribution to the interior of the country via certified mail. The BAC also exchanges titles with Braille publishers in other Spanish-speaking countries, enabling access to such titles as *Hacia la luz* and *La Rosa Blanca*. Unfortunately, the frequency of such publications and exchanges has recently declined due to the economic crisis.⁵⁹

There are eight other Braille libraries throughout the country. They are run by the provincial governments and occasionally funded, as in the case of La Plata's Braille library, through donations and voluntary work because the resources provided by the provincial government are not enough to support their full operation.⁶⁰ Argentina is also home to a digital library called Tifolibras that offers persons who are blind free access to over 6,000 digital books.⁶¹

Information technology and the Internet are not widely used by Argentina's blind community. One reason is that accessible telecommunications technology is very expensive and is not regarded as a basic need by organizations providing funds for technical aids.⁶²

For persons with multiple disabilities, the barriers to communication are even greater. Social health care organizations will not provide the necessary

⁵⁴. María Angélica and Graciela Urbano (librarians at the Argentine Library for the Blind), interviewed by author.

⁵⁵. *Ibid.*

⁵⁶. Marcelo Calvo (library technician, Director of the Braille Library of the Provincial Institute for Culture of the Province of Buenos Aires), interviewed by author, 25 July 2003.

⁵⁷. Tifolibras, <http://www.tifolibras.com.ar>.

⁵⁸. Liliana Bastons; Marcelo Calvo.

technical aids or trained interpreters. There is generally limited experience in the use of alternative forms of communication with this population, and it is difficult to find professional expertise. Individuals with significant communication impairments are, by and large, excluded from educational life and social participation.⁵⁹

Education

Education in Argentina is regulated by the Federal Education Act, which requires ten years of compulsory schooling from the ages of 5 to 15. However, not all students with “special educational needs” are bound by these requirements.

Although there are statistics on the number of children with disabilities who are enrolled in the school system, there are no statistics available on the total number of children with disabilities in the country. Thus, the number of children who are not receiving any education cannot be determined. Of a total student population of 10,442,350, the percentage of students, aged 6 to 16, with some kind of disability is 0.69%.⁶⁰ That this is substantially less than all estimates of Argentina’s disability population, including the 10% estimated by the World Health Organization, suggests that many children with disabilities are excluded from the educational system.

Educational settings vary depending on the type and degree of the student’s disability and whether he or she lives in an urban or rural area. Generally, for children with disabilities who are enrolled in the school system, there are two primary types of educational settings: special schools and mainstream schools. Teachers, headmasters, and administrators generally decide the types and degree of disabilities that make a child eligible for integration, but parents may play a strong role in determining an individual child’s setting. Approximately 70% of all students with some kind of disability in the school system attend a special school.⁶¹ The remaining 30% are integrated into mainstream schools, where they are supported by an “integration teacher” from a special school or specialized center.⁶² The percentage of children and young students integrated into mainstream schools in the province of Buenos Aires is 19%.⁶³

⁵⁹. Hebe Campaña (biologist, member of the Scientific Research Council of the province of Buenos Aires, Coordinator of ECLAMC (Colaborative Study on Congenital Malformations, vice president of María Montessori Association, cofounder of the Profound and Multiple Learning Disabilities Committee of FENDIM), interviewed by author.

⁶⁰. Law 24901, para. 2.1.3, <http://www.infoleg.mecon.gov.ar>.

⁶¹. Interview with parents and headmasters of Schools and Day Care Centers of La Plata.

⁶². FENDIM, *Legislación aplicable al Sector de las personas con discapacidad* [Legislation Applicable to the Disability Sector]; Collective of NGOs working in the area of Childhood and Adolescence, *Informe de Organizaciones no gubernamentales argentinas sobre la aplicación de la Convención sobre los Derechos del Niño, 2003* [Report on the Implementation of the Convention on the Rights of the Child Prepared by Argentine Non-governmental Organizations], (2003), 49.

⁶³. Panel Discussion.; Colectivo de ONGs de Infancia y Adolescencia, 2003,

In December 1998, the Federal Council for Culture and Education of the Ministry of Culture and Education released a paper titled "Framework Agreement for Special Education"⁶⁸ that provides guidance on the enforcement of the Federal Act to schools in the provinces. Some Argentine provinces have interdisciplinary traveling teams that provide support to students with disabilities enrolled in mainstream schools. The effectiveness of such teams is linked to their ability to travel, which unfortunately has been reduced due to the 2001 economic crisis.⁶⁹

Overall, education officials admit that inclusive education is not a reality in Argentina.⁷⁰ The requisite policy planning, teacher training and educational resources are simply non-existent.⁷¹ The lack of specialized teacher training often serves as an excuse for the failure to integrate children with disabilities into mainstream educational settings.⁷² Some isolated initiatives have been undertaken by inclusion-oriented private schools, such as the General San Martín School from Bahía Blanca in the province of Buenos Aires, but the headmaster at the school readily admits the school is only able to accommodate certain types of disabilities. A request for a list of these disabilities has gone unanswered as of this printing.⁷³

Special schools are located in most large and small cities throughout the country and may be state-run or privately-managed. Most private special education schools are owned by non-profit organizations founded by groups of parents. State-run special schools are designed to provide services in a multidisciplinary framework, but they are often inadequately staffed due to the shortage of qualified professionals and teachers trained in special education.

Overall, the system suffers from a lack of expertise in providing education to those with sensory impairments and multiple disabilities. Therefore, many children with multiple disabilities or significant intellectual or emotional impairments are not admitted to special schools.⁷⁴ Some children who are enrolled in special schools may spend a minimum of time, as little as one to two hours per week, in school.⁷⁵ The curriculum for children with "minor" mental or physical impairments is similar to the one used in mainstream schools, while children with more significant disabilities do not receive a standard education.⁷⁶

Law 24901 establishes that children, young people, or adults with severe and profound disabilities can attend Day Care Centers instead of schools. Resolution 428/99 of the Ministry of Health and Social Welfare, known as the "List of Basic Benefits for Persons with Disabilities" describes the program at these centers as "outpatient treatment aimed at providing therapeutic assistance to enable an individual with disabilities to develop to the maximum extent possible

⁶⁴. Bureau of Educational Quality Research and Evaluation, Ministry of Education, *Anuario 2000* [Yearly Report 2000], <http://diniece.me.gov.ar>.

⁶⁵. *Informe de Organizaciones no gubernamentales argentinas sobre la aplicación de la Convención sobre los Derechos del Niño*.

⁶⁶. Bureau of Educational Quality Research and Evaluation, *Anuario 2000*.

⁶⁷. *Ibid.*

⁶⁸. Alicia Di Meglio (Special Education Teacher, Director of Special Education of the General School Office of the Province of Buenos Aires), interviewed by author, La Plata, 20 October 2003.

⁶⁹. *Ibid.*

⁷⁰. César Ambrogetti (teacher of Education, Head of the Special Teacher Training Office of the Ministry of Education), interviewed by author, city of Buenos Aires, 29 September 2003.

his or her self-reliance and independence.” It goes on to describe the target beneficiaries of these Centers as “children, young persons and/or adults with severe and/or profound disabilities who cannot access schooling, training and/or sheltered employment.”⁷⁷ Although Day Care Centers do not provide formal education, they offer a broader, more flexible timetable than schools, which may appeal to parents. Some parents see these Centers as an attractive option that meets their child’s particular needs; others view them as the only possible alternative for a child they believe is unable to attend school.⁷⁸

In small towns where there are not enough students or resources to open a special school, some mainstream schools create special classes for children with disabilities. These classes are not part of an intentional integration strategy, but they may serve as a starting point.⁷⁹

The number of children with disabilities receiving education in boarding schools or at home is very small. Argentina used to have a number of boarding schools for students who are blind, but they have been closed. A few boarding schools for deaf students still remain. There are also a few residential institutions that provide education. The country also have a small number of private tutors available who will travel to homes or hospitals in order to provide education to children who have an illness or a health-related disability that prevents them from going to school.⁸⁰

The type of disability a particular student has clearly influences the setting through which he or she will likely receive an education and the level of education he or she will attain. In the elementary school system, within both special and integrated school settings, children with intellectual or cognitive disabilities constitute the majority. Approximately 70% of the elementary school students with disabilities who are integrated into mainstream schools are classified as having mild mental or intellectual disabilities. The population of students with disabilities within the education system shifts over time, however, so that in the secondary school system, students with physical impairments predominate.⁸¹



Children singing in sign language, Green Classroom- Afternoon section. Kindergarten N 501. San Fernando. Buenos Aires Argentina

⁷¹. *Ibid.*

⁷². Federal Education Council, <http://www.me.gov.ar>.

⁷³. Bureau of Educational Quality Research and Evaluation, *Anuario 2000*.

⁷⁴. Panel Discussion.

⁷⁵. Alicia Di Meglio; César Ambrogetti.

⁷⁶. Interviews with parents and teachers of regular and special schools from different parts of the country.

More often than not, children with multiple disabilities and severe communication difficulties do not attend school or attend only during the first years of schooling. For children and adolescents who are deaf, there is a marked tendency towards segregated education and issues surrounding communication are often controversial. For example, in order to promote integration, some schools for the deaf still ban the use of sign language, and some parents insist that their children who are deaf learn lip reading and speech rather than sign language.⁸²

Although there are no exact statistics available, the percentage of young people with disabilities studying at the university is thought to be very low. Despite the fact that Law 25573 on Higher Education requires “accessibility to the physical environment, interpretation services, and the necessary and sufficient technical aids for people with disabilities”, universities are not universally accessible.⁸³ Some university buildings are fully accessible, while others are completely inaccessible. Inaccessible bathrooms, for instance, are common. People with sensory disabilities must typically try to obtain auxiliary aids by themselves. There is some evidence that the number of people with disabilities studying at Universities is increasing due to the increase in rights granted to them as a result of Law 25573.⁸⁴

There is no specific program for identifying disabilities within the educational system.⁸⁵ Teachers often try to fulfill this role, although they are not specifically trained to do so. A teacher who identifies a child with a disability must seek help for the child, who may then be examined and, if necessary, referred to a special school. Students identified in this manner have the option of continuing to attend the mainstream school as integrated students—that is, with the support of a special school—or be transferred to special schools. In the province of Buenos Aires, more than half of mainstream elementary schools have a team of psychologists who evaluate children with disabilities and determine a prescribed course of action.⁸⁶

Although the delivery of education to people with disabilities in Argentina appears hampered by a lack of expertise, training programs for teachers on disability related topics appear to be generally available. Under Argentina's federal system, each province regulates teacher training. All the provinces but two have special education training programs. Teachers from provinces without training programs may obtain training from a neighboring province.⁸⁷ Student teachers can attend training programs geared toward standard education or a number of special education programs that focus on specific disabilities. Students in the standard education program may also choose special education-related topics as optional subjects.⁸⁸ After graduating, teachers may choose from a wide range of continuing education courses, some of which cover special education. Enrollment in these courses depends on the personal decisions of individual teachers.⁸⁹

⁷⁷. Panel discussion.

⁷⁸. Raúl Ayude (Headmaster of the General San Martín School).

⁷⁹. Jorge Badaracco.

⁸⁰. Alicia Di Meglio.

⁸¹. César Ambrogetti.

⁸². *Ibid.*

⁸³. *Ibid.*

⁸⁴. Office of Infrastructure, Ministry of Education, <http://www.me.gov.ar>.

Argentina does have laws to promote the accessibility of school facilities. All new schools must be built in accordance with the accessibility provisions of Law 24314, which amends Sections 20, 21 and 22 of Law 22431, and Decrees 914/97 and 476/98, which govern the construction of public buildings. The Office of Architecture and Infrastructure of the Ministry of Education has also drafted a set of standards that has been approved by the Federal Education Council.⁸⁰ For the most part, accessibility has been taken into account in the construction of new schools and in the refurbishing of existing special schools. Existing regular schools have generally not been adapted. There are no figures on the percentage of schools complying with accessibility standards, although all interviewees agreed it is somewhere between 0 and 20%

Employment

In recent years, Argentina has undergone a gradual process of impoverishment as a result of the economic recession that reached its peak in 2001-2002. Some estimates classify 53% of the country's population as poor. Unemployment, which reached a peak of 22% in May 2002, was 15.3% in May 2003.⁸¹ Additionally, a greater percentage of the job market belongs to what may be characterized as temporary work or informal, unprotected employment, while flexible and increasingly longer work schedules are being combined with hazardous or injurious assignments.

Although the Ministry of Labor reported an increase in the number of people employed in 2003,⁸² unemployment in the disability community remains high. Trade union organizations have estimated the unemployment rate for people with disabilities at 91%⁸³ although it is important to note that this figure is not based upon independent data collection.⁸³ An article by Dr. Pablo Rosales reports a World Health Organization estimate that the unemployment rate for people with disabilities is four times greater than that for people without disabilities.⁹⁴ Using this estimate, the unemployment rate for people with disabilities in Argentina in May 2003 would have been approximately 61%. Although without reliable population data it is impossible to calculate the exact percentage of persons with disabilities who are willing and able to work but unable to find a job, the unemployment rate among people with disabilities is, by all accounts, unacceptable.

⁸⁵. Law 25573 sec. 2, April 2002

⁸⁶. This information is based on meetings and workshops held by the National University of La Plata Committee on Disability prior to March 2003.

⁸⁷. INDEC, *Permanent Household Survey*, <http://www.indec.mecon.ar>.

⁸⁸. Ignacio Rizzi

⁸⁹. Carlos Ferreres, "El rol de la CTA en la lucha por el reconocimiento de los derechos de las personas con discapacidad" [The Role of CTA in the Struggle for Disability Rights Recognition] in *La Discapacidad: una cuestión de derechos humanos* [Disability: A Human Rights Issue], (C. Eroles y C. Ferreres CTA- Espacio Editorial, Buenos Aires, 2002) 158.

⁹⁰. Pablo Rosales, "La Discapacidad En El Sistema De Obras Sociales Nacionales: Los derechos de los beneficiarios con discapacidad," [Disability in the System of National Social Works: The rights of the beneficiaries with disabilities], *Jurisprudencia Argentina* [Jurisprudence Argentina], Buenos Aires, (4 April 2002).

The legal framework for providing equal employment opportunities for persons with disabilities is formed by a number of laws. Law 22431, for example, creates a 4% quota in the hiring of persons with disabilities for state jobs. Private companies are encouraged to follow suit and are offered economic incentives, detailed on the Ministry of Labor's website.⁹⁵ Law 25689 augmented the 4% requirement to hire workers, and the the Auditor's General Office led by Leandro Despouy is charged with enforcing this provision.⁹⁶ The IDRM has been unable to ascertain the degree of compliance.⁹⁷

A review of the private sector reveals a somewhat mixed picture. Techint-owned Siderar—one of the most important private companies in Argentina—has no policies ensuring non-discrimination in employment for persons with disabilities, although they do make accommodations, including relocation, for those employees who have become disabled. The company also has a Training and Employment program for persons with disabilities that has led to employment, on an indefinite-term contract basis, for approximately ten persons with different disabilities, some of whom have disabilities that would greatly disadvantage them in or eliminate them from the competitive job market.⁹⁸ The employment terms they received are equivalent to those offered to other employees who have joined the company within the past few years. The program includes an in-house team providing specialized support as well as agreements with NGOs, such as the Par Foundation, that are focused on the training and employment of persons with disabilities.

Some Non-Governmental Organizations (NGOs) are also trying to develop their own employment ventures. The Sanisidrense Foundation, for example, has created its own fast food chain, Cadena Laboral, where it employs persons with disabilities and has also placed newspaper ads to recruit employees with mobility impairments to work in a retail telecommunications center. The Millennium Foundation, of San Martín de los Andes, which is run by people with disabilities, makes and sells home-made chocolate, a typical product of the region.⁹⁹

The Ministry of Labor has a Disability and Vulnerable Groups Unit that centralizes all disability programs and provides an Employment Service. This unit acts as a focal point for disability programs, keeps a register of people with disabilities (PWDs) who are seeking employment, receives requests from companies for job applicants, and conducts on-site surveys of workplaces. The service also screens applicants for job interviews, promotes the hiring of PWDs in the private sector, and consults on relevant procedures and documentation.¹⁰⁰

⁹¹. Ministry of Labor, <http://www.trabajo.gov.ar>.

⁹². Despouy was rapporteur on disability at the United Nations Commission on Human Rights.

⁹³. The information was requested from the National Auditor General's Office, but no response was given.

⁹⁴. Marian Diego (teacher of Special Education, Human Resources Management, Southern Area, SIDERAR), interviewed by author, Ensenada, Province of Buenos Aires 30, September 2003.

⁹⁵. Horacio Espinoza (member of Millenium), interviewed by author, San Martín de los Andes, 30 October 2003.

Vocational training workshops are also available for people with disabilities over the age of 18. The province of Buenos Aires, for example, offers occupational integration support to working persons with disabilities.¹⁰¹ Various NGOs have similar initiatives, some of which offer training and advice on how to improve the applicant's profile and apply for a job, while others offer training in specific industries. The Par Foundation, founded in 1988, "is a non-profit non-governmental organization devoted to the occupational advancement of workers who have mobility or sensory disabilities and no mental impairments for their incorporation into the production spheres of society on a competitive basis."¹⁰² Since its inception, the Par Foundation has helped place over 1,500 workers with disabilities in jobs and has partnered with a private company to offer wine tasting courses for people who are blind and training in product testing of perfumes, soaps, jellies, and cleaners, which require the senses of taste, smell, and touch.¹⁰³ The National Farming Technology Institute (INTA) is one of the government agencies offering jobs to people trained in such skills.

The DISCAR organization, which supports "a Program for the Occupational Integration of Persons with Mental Disabilities, also provides occupational training. Since 1994, DISCAR has integrated 100 young persons into companies throughout the country.¹⁰⁴ Adardicha, a non-governmental organization from Entre Ríos, financed by the Abilis Foundation from Finland, carrying out a project that "identifies people with disabilities living in rural areas, checks whether their parents are willing to offer them a job within their own farms and adapts the tasks or the production to the individual's type of disability."¹⁰⁵ The CONADIS is organizing a network of sheltered workshops, vocational training workshops, and companies looking for the products manufactured in the workshops.¹⁰⁶ In 2001, the city of Buenos Aires issued regulations for the city government's purchase of goods produced in Sheltered Workshops.¹⁰⁷ As of May 2003, the Sheltered Workshop Support Program was the only such government program still in place after the economic emergency.

⁹⁶ Ignacio Rizzi.

⁹⁷ Alicia Di Meglio.

⁹⁸ Par Foundation, <http://www.fundacionpar.org.ar>.

⁹⁹ Pedro Lipcovich, "Capacidades diferentes, Ciegos que se forman como catadores para lograr una inserción laboral" [Different Abilities, Blind Persons Trained in Wine Tasting to Enter the Labor Market], *Página 12* newspaper, <http://www.pagina12web.com.ar/>.

¹⁰⁰ Discar Foundation, <http://www.fundaciondiscar.org.ar>.

¹⁰¹ Enrique Sarfatti (Member of ENCIDIS), e-mail response, November 2003.

¹⁰² Macelo Calvo.

In general, it is still difficult to obtain employment upon completion of training, which is due, in part, to the economic crisis. For example, the Once Foundation for Latin America (FOAL) and the World Bank, which together contributed 1,800,000 dollars to a job training program in Argentina, but the subsequent placement efforts were not successful. Despite computer training courses, participants lacked access to computer technology and thus could not utilize what they learned.¹⁰⁸ In addition to the economic crisis, there appear to be three major barriers to the employment of persons with disabilities. First, employers may have a generalized fear of absenteeism or poor performance, or a fear that hiring PWDs will embroil them in complex legal or health issues. Companies may also perceive government incentives as not worth the efforts involved in obtaining the accompanying bureaucratic approvals.¹⁰⁹

Second, some disability leaders expressed the view that people with disabilities must find a better way to demonstrate their skills and qualifications. Because of their exclusion from higher education, people with disabilities often underestimate themselves. Improved opportunities for occupational advancement will require that both employers and PWDs better understand the capabilities of persons with disabilities.

Third, disability advocates note that transportation is often the decisive determinant of access to employment. Without adapted public transportation, people who cannot afford private transportation cannot accept a job offer, since they will be unable to travel to work.

Health Services

According to the National Institute of Statistics, between 1991 and 2001, the percentage of those without health care coverage increased from 36.9% to 49%.¹¹⁰ This change was primarily due to a corresponding higher unemployment rate.¹¹⁰ Under Argentina's federal system, responsibility for the rehabilitation and health care of persons with disabilities falls to the national Ministry of Health and Social Welfare and the provincial Ministries of Health.¹¹¹ There are three primary forms of health care coverage available: social health care organizations for those who are employed, health care provided by the state, and private health insurance plans for those who can afford to pay the premiums. Sections 2 and 4 of Law 24901 guarantee full health care coverage for all persons with disabilities and specify that social health care organizations cannot exclude people with disabilities who

^{103.} Jorge Mascheroni.

^{104.} Ana Sequeiro.

^{105.} Panel discussion.

^{106.} INDEC Tables, <http://www.indec.mecon.gov.ar>.

^{107.} Law 24901, *System of Basic Services for Habilitation and Comprehensive Rehabilitation of Persons with Disabilities*.

are entitled to health benefits from the organization.¹¹² The law also mandates that the State assume responsibility for those people with disabilities without medical insurance. Services may be provided by either state-run institutions or at private centers authorized by the Ministry of Health and Social Welfare. To date, only 14 out of the 23 Argentine provinces and the city of Buenos Aires have adopted Law 24901. In the remaining provinces, health care coverage is not guaranteed by law.

Social health care organizations in Argentina provide health and rehabilitation services to those who are employed. Many of these organizations are owned and operated by labor unions, while others, such as the National Institute of Social Services for Retirees and Pensioners (PAMI), are jointly managed with the state. The creation of PAMI by Law 19032 in May 1971 was intended to increase the availability of services for the elderly, who suffered from a lack of social and health care services from their original social health care organizations. Those receiving national non-contributory pensions, including some people with disabilities, are eligible for health care services through PAMI.¹¹³

The Ministry for Social Development's Federal Health Program (PROFE), allocates public funds to those suffering from extreme poverty. The PROFE is responsible for providing health care to over 430,000 families who receive non-contributory pensions from provincial institutions, including persons with disabilities, mothers of more than seven children, and the elderly. Over 85% of beneficiaries cannot meet their basic needs. The National Revenue Office provides the resources, while the Ministry of Social Welfare, or its provincial equivalent, distributes the funds.¹¹⁴ Only services deemed to be of the utmost necessity are provided, and requests for important services may be rejected as unnecessary.¹¹⁵ Some disability advocates have reported that the opposite also occurs, as physicians may occasionally diagnose a greater degree of disability than is actually detected in order to help individuals access greater benefits. The same system covers the provision of technical and mobility aids, although most are provided by social health care organizations, since few public funds are allotted to such aids. Rehabilitation services and assistive devices are scarce and access to them varies from region to region. Some public health facilities have shops that manufacture the auxiliary aids if the user supplies the necessary materials.¹¹⁶

¹⁰⁸. Government jurisdiction is determined by Law 22431, sec. 4 to 7, and by Regulatory Decree 498/83.

¹⁰⁹. National Institute of Social Services for Retirees and Pensioners, <http://www.pami.org.ar>.

¹¹⁰. Press release of ATE – PROFE – CTA Workers, 31 July 2003.

¹¹¹. Liliana Bastons.

¹¹². Jorge Badaracco.

Technical aids for people who are blind are expensive, and are therefore seldom covered by either public funds or social health care organizations. Foreign donations are received from organizations like Hilton Perkins, Spain's ONCE, and Sweden's SHIA, as well as from private companies like Techpetrol of the Techint Group, and other oil companies.¹¹⁷ In oil-producing provinces, companies provide special schools with technical, IT, and teacher training materials, as well as necessary infrastructure. This kind of assistance is less common in other regions of the country.

Many individuals with disabilities experience seizures and require anticonvulsants. Although Law 25404, known as the Epilepsy Act, provides that medication is to be furnished free of charge to all who need it, the accompanying regulations were not issued within the required timeframe. Social health care organizations are non-compliant and the requisite paperwork is onerous. Therefore, the law has not significantly benefited people with disabilities.

Availability and Distribution of Rehabilitation and Allied Services

Rehabilitation services are provided in major cities by both public and private institutions, though currently there are not enough physiatrists (rehabilitation specialists) to meet the needs of people with disabilities in Argentina. Medical specialties such as physiatry, neurology, orthopedic neurology, and nutrition are available with a focus on disability issues at the major health care centers in large cities, as are nurses specializing in physical therapy. Programs in occupational therapy and kinesiology are similarly limited to the major cities, although speech therapy is more widely available.¹¹⁸ The government has very few rehabilitation centers for those with visual impairments, with only three centers in the province of Buenos Aires and none in other provinces.¹¹⁹

Early childhood services are coordinated between health care and education providers, while primary and other health care centers focus on early detection. Children who exhibit a disability or impairment are referred to Early Stimulation Centers that have the appropriate resources for babies and children aged 0 to 3. In the province of Buenos Aires, 8,490 children were receiving early stimulation in April 2003.¹²⁰

¹¹³ Hilton Perkins, <http://www.sordoceguera.org/Programas%20y%20Organizaciones/Argentina.htm>; Marcelo Calvo; "Experiences of teachers and company employees from Comodoro Rivadavia, Chubut", compiled in September 2003.

¹¹⁴ Marcelo Calvo.

¹¹⁵ Alicia Di Meglio.

¹¹⁶ Jorge Badaracco.

¹¹⁷ Eudeba Guide.

¹¹⁸ Twenty private universities and five state-run universities offer a degree in Kinesiology. Four private universities and six state-run universities offer a degree in Occupational Therapy. Five private universities and institutes and six state-run institutions offer a degree in Speech Therapy.

Rural Areas

In contrast to the excellent care for children and adults with disabilities which may be found at public hospitals in major cities, members of the disability community living outside major metropolitan areas may expect to confront a serious shortage of trained health professionals. In these areas especially, the period immediately following the diagnosis or acquisition of a disability is especially trying, since the person with a disability and their family often do not receive adequate guidance. Furthermore, children with multiple disabilities or other complex needs often receive inadequate treatment in the emergency wards of hospitals and private institutions, and practitioners may not know how to deal with basic problems affecting them, including simple colds or a mild trauma.¹²¹ It may also be difficult to find practitioners who can manage common diseases in patients with epilepsy, for example. For these reasons, the provinces will sometimes pay to transport patients to major referral centers.

Also in response to these and other issues, a Community-Based Rehabilitation (CBR) strategy has been integrated into the primary health care delivery systems of the provinces of Neuquén, La Rioja, Jujuy, and Mendoza and in one district of the Greater Buenos Aires area.¹²² In Neuquén, the strategy was introduced four years ago after several earlier failed attempts. The first assessment, carried out in three different towns within the province, revealed that in rural towns, access to health care improved, while in urban areas, better networking developed among available resources. In all cases, those responsible for its implementation felt that CBR was useful in making the community aware of disabilities and improving both the situation of persons with disabilities and that of the community in general.¹²³

In contrast to these reports, there have been some indications that CBR is still not strongly established. One experienced health care professional told IDRM that CBR strategies have yet to be effectively implemented in Argentina. He attributed the implementation failure to the difficulty in convincing second-level practitioners to train parents and people in the community in rehabilitation practices. Some leaders of disability NGOs also report that some physicians working at public hospitals in Neuquén are still not aware of the CBR program, while other physicians of the province's health care system believe that the CBR strategy does not work in the cities because users prefer to use traditional health services.

¹¹⁹ Inter-American Open University, <http://www.uai.edu.ar>.

¹²⁰ Manuel Maza. A new version of Module 4 was in press at the time of this writing.

¹²¹ Interviews of parents of children with disabilities.

Training

None of the medical schools of national public universities offer training in rehabilitation and/or disability as part of their regular curriculum. Training on the provision of care to people with disabilities is only included in medical specialties in disability-related fields.¹²⁴ No training is available to general practitioners or to medical doctors who are not disability specialists and instead choose to specialize in fields such as gynecology or internal medicine. One public university, the University of San Martín, has recently begun offering a technical bachelor's degree in Prosthetics and Orthotics.¹²⁵ As of this writing, there has been only one graduate, although there are currently about 70 students from different Latin American countries pursuing the degree. The Inter-American Open University has recently opened a similar program that offers on location courses and distance learning courses. The distance learning program lasts two years and is designed for orthotists and prosthetists with over ten years' experience who wish to obtain a university degree.¹²⁶ The University of San Martín and the National Rehabilitation Service are planning to create a joint post-graduate course for all university graduates who wish to study disability topics.

The Argentine Pediatric Society has been conducting a monthly forum on disabilities in the city of Buenos Aires since 1990. For 10 years, it has been running a national, distance-learning Refresher Training Program that includes a module on disabilities, in which 5,000 of Argentina's 13,000 pediatricians have participated.¹²⁷ In June 2001 the Society organized the 1st Latin American Congress on Pediatric Disabilities in Buenos Aires, which was attended by 400 pediatricians and other health and education professionals.

Housing

In Argentina, few people can afford to choose where to live. The official web page of the Government of the City of Buenos Aires states that:

The City of Buenos Aires has a housing shortage that affects 100,000 families. It is characterized by precarious conditions and overcrowding; slums, rooming houses and lodgings are the most acute evidence of the problem. There are also families that have no access to utilities due to the lack of infrastructure, as is the case in the 15 slums and two temporary settlements.¹²³

If choosing where and how to live is a remote possibility for the ordinary Argentine citizen, people with disabilities face exceptional difficulties. A lack of financial resources is a major obstacle, as is the generally poor accessibility of the built environment.

¹²² Cristina Basavilbaso, (Physiatrist, Rehabilitation Service of the Province of Buenos Aires, (lecture given at the 4th Congress of the International Society for Prosthetics and Orthotics, ISPO, Buenos Aires, 22 October 2003).

¹²³ Official Web page on housing of the Government of the City of Buenos Aires, http://www.buenosaires.gov.ar/areas/com_social/vivienda.

People with disabilities live under varying conditions, with their families, by themselves, or in institutions. As defined in Law 24901, institutions include: residences, where people can live relatively independently—small homes, managed by adults with no disabilities; and homes, which are usually run by non-profit organizations or the Catholic Church.¹²⁴ In practice, group homes are the most common type of housing, while no operating residences have been identified.

Individuals with sensory or mobility disabilities typically enjoy the same opportunities to purchase a house and live independently as do people with no disabilities. Persons with multiple disabilities, intellectual disabilities, or mental disabilities are very likely to live in institutions for some portion of their lives. In large cities, it is especially common for them to live in large hospitals or in small homes. By contrast, there are no group homes in small cities in the interior of the country. If a person from these areas requires housing, he or she must be transferred to Buenos Aires.

People with disabilities may be assigned to integrated public accommodations if they are self-reliant. There are only two facilities that admit elderly people with physical impairments.¹²⁵ It is very difficult to obtain permission to adapt integrated accommodations. Disabilities thought to negatively influence an individual's behavior or self-reliance generally lead to segregated accommodation in an institution. In the city of Buenos Aires, the only institutions for persons who are not self-reliant persons are homes for the elderly, so many younger people with disabilities are homeless.

The National Housing Council is responsible for coordinating national low-cost housing policies. Construction of affordable housing was resumed during 2003 after a hiatus during the 2001-2002 economic crisis, and the new national administration has proposed that all newly constructed affordable houses be accessible, for persons with reduced mobility. The percentage of houses currently accessible for persons with disabilities could not be determined.¹²⁶

The criteria for allocating public accommodations are determined by the provinces and municipalities. In many locations, the City Council allocates a specific number of accessibility-compliant houses to people with disabilities. For example, in Alberti, a town in the province of Buenos Aires, the allocated quota is 5%.¹²⁷ People with disabilities may be assigned to integrated public accommodations if they are "self-reliant," but may end up in segregated accommodations in an institution if they have a disability that is deemed to negatively impact behavior or self-reliance. In the city of Buenos Aires, the only institutions for persons who are not "self-reliant" are homes for the elderly, of which only two admit people with

¹²⁴. *Aumentó un 47% la inversión del Ministerio de Salud para la atención de discapacitados* [47% Increase in the Ministry of Health's Investment in Disability Services], (Press release of the Ministry of Health, 15 September 2003), http://www.msal.gov.ar/hm/site/noticias_a342.asp.

¹²⁵. María Isabel Ferreira, (lawyer, Ombudsman's Office of the City of Buenos Aires), email response, 9 November 2003.

¹²⁶. Jorge Mascheroni.

¹²⁷. Honorable City Council of Alberti, Ordinance 933, 28 April 2003.

¹²⁸. Huarpe Foundation, <http://www.fuarpe.org.ar>.

physical impairments.¹²⁵ It is very difficult to obtain permission to adapt integrated accommodations, so many younger people with disabilities are homeless.

The Independent Living philosophy is not widespread in Argentina. The Fuarpe Foundation champions the principles of Independent Living, but at present its programs only include courses on independent wheelchair handling to teach people with myelomeningocele how to overcome architectural barriers.¹²⁸

Public and private healthcare organizations currently do not support independent living programs. For the most part, the special housing services available are provided through institutions. For example, a government or social healthcare organization may pay for a person with disabilities to live in a nursing home, but not in an ordinary home.

Institutionalization

There are 275 residential care facilities and 43 psychiatric hospitals in Argentina. The number of people residing in each of these varies. Some facilities are very small and care for fewer than 10 people, while large psychiatric hospitals in the metropolitan area house between 1,000 and 1,600 people. These institutions are managed by private non-profit organizations, private corporations, and the State. Expenses incurred at the non-profit or for-profit facilities are borne by social healthcare providers or, in a minority of cases, by the patients' families, and people without medical insurance can be placed in psychiatric hospitals through a court ruling. The decision to place an individual in residential care may be made by the family, a physician, or the court. By law, individuals or their guardians must authorize all treatments or procedures provided in these institutions. When individuals act violently, they may be restrained or tied down but the use of strait jackets is prohibited at all times. Only certain prescribed interventions are approved without consent, and then only in the event of an emergency.

Reports of actual conditions in some facilities, however, suggest that legal guidelines are not always followed. A report by the National Ombudsman states that in pavilion 6 of Colonia Cabred, which is located in Open Door, in the Province of Buenos Aires, the filth of the rooms, kitchen, and bathrooms comparable to the that of the worst prisons, and the emergency room has two beds with belts to immobilize patients.¹²⁹

On 18 October 2002, the Clarin newspaper reported on the of a 38-year-old woman confined at the Braulio Moyano Neuropsychiatric Hospital in the city of Buenos Aires, which was the second suicide reported in a period of four days. The hospital employees alleged that there was a staff shortage, making it impossible for them to keep control over such a large number of patients.¹³⁰

¹²⁹. Eduardo Mondino, "Punishments and bad treatments of persons who are mentally ill should be abolished," National Ombudsmans Office, Buenos Aires, Argentina, 23 June 2003, <http://www.defensor.gov.ar/articulos/arti03-en.htm>.

¹³⁰. Clarin, 18 October 2002, http://www.clarin.com/diario/2002/10/18/index_diario.html.

In addition, unsolved crimes have occurred in some of these institutions. One such case is the 1985 disappearance of Dr. Cecilia Giubileo from Colonia Montes de Oca, located in Torres, in the Province of Buenos Aires. Dr. Giubileo disappeared while working at this psychiatric hospital that occupies 250 hectares in the Pampas, and houses over 1,000 residents with different disabilities.¹³¹ The police never discovered what happened to her or who was responsible for her disappearance, although there are two widely reported versions of the reason for her disappearance. One states that Dr. Giubileo was about to report illegal human organ trafficking at the Colonia. Another version claims that her two brothers, who had disappeared during the military dictatorship, had been kidnapped and taken to the Colonia and she was killed while investigating the use of this hospital as a concentration camp during the 1970's.¹³²

Journalistic investigations into the Colonia throughout the last decade have revealed evidence of cruelty and extreme mistreatment. There is evidence that patients have been tied up, naked, lying in their feces, or forced to eat off the floor.¹³³ There have also been reports of discoveries of human bones in neighboring marshland and drains on the property, suspected to be the remains of dead patients buried, unidentified, in a nearby cemetery. Judges that have committed residents to this hospital have also commented on the dreadful conditions they later discovered.¹³⁴ Whatever abuses have taken place cannot be ascribed to a lack of resources. Payments made by the National Institute of Social Services for Retirees and Pensioners (PAMI) are more than sufficient to adequately provide for the needs of the residents.¹³⁵

The National Rehabilitation Service (NRS) is responsible for financial and programmatic oversight of centers caring for people with disabilities throughout the country. The NRS has developed basic guidelines that outline physical and human resources appropriate for each type of facility, which are enshrined in the regulatory decree to Law 24901.¹³⁶ Enforcement of these guidelines suffers, however, because public health and judicial offices do not have the staff necessary to conduct audits, and only intervene in response to reports by families, guardians, institution staff, or any other interested person. In view of the prevailing conditions in these institutions, both the safety and well-being of the residents depends to an inordinate degree on the ability and willingness of their guardians to properly represent them.

¹³¹. <http://www.fcen.uba.ar/prensa/micro/1992/ms50.htm>.

¹³². <http://www.comite.bioetica.org/mesa4.htm> <http://www.revistaestrategas.com.ar/tel49.htm>.

¹³³. *Telenoche Investiga*, 1996, www.telenoche.com.ar;

Microsemanario (publication), University of Buenos Aires, year 2 Issue 50, 18 to 24 February 1992. <http://www.fcen.uba.ar/prensa/micro/1992/ms50.htm>.

¹³⁴. <http://www.oscurosol.com.ar/MontesdeOca.htm>.

¹³⁵. *Telenoche Investiga*.

¹³⁶. Decree 762/97.

Accessibility

Regulations concerning accessibility are typically implemented only when there is pressure exerted by nongovernmental organizations or the media, or through the use of court proceeding, or when government agencies take action in response to the demands of disability stakeholders.¹³⁷ In Argentina, Law 224341 and its amendment, Law 24314, on Accessibility for Persons with Reduced Mobility regulate the accessibility of public buildings, public pathways, open spaces, parking areas, public buildings and private buildings used by the public, common areas in apartment houses, and all manners of transportation.¹³⁸ Technical specifications for each type of space may be found in Decree 914/97. Law 24314 mandates accessibility compliance for all buildings constructed after its enactment and any existing buildings undergoing entrance repairs or additions. Under the federal system local implementation depends on the legislation of each province. The province of Buenos Aires did not adopt the national law but passed its own accessibility law, while the city of Buenos Aires enacted Law 962/2003, a Building Code with very strict accessibility requirements, which is currently being challenged by some professional associations and public agencies.¹³⁹

All government offices are obliged to observe accessibility laws, as are private offices that are open to the public. Owners of apartment houses may not reject a request for accommodation from a tenant if there is no proper access to the building.



Entry to the main post office, Buenos Aires.

¹³⁷ National Ombudsman's Office, Proceedings Reports, Resolution 73/03; Ombudsman's Recommendation to Telefónica de Argentina, *Acceso para discapacitados en Telefónica de Lomas de Zamora* [Access for the Disabled in Telefónica in Lomas de Zamora], 2003, <http://www.defensor.gov.ar/presentacion/quejas-sp.htm>.

¹³⁸ Law 24314, <http://www.trabajo.gov.ar/legislacion/ley/>. The modified law replaced sections 20, 21 and 22 of Chapter IV of Law 22431e

¹³⁹ Law 962, Urban Building Code of the City of Buenos Aires, Law 962, http://www.buenosaires.gov.ar/areas/leg_tecnica/; Information provided by employees of the Secretary for Housing, Letter made public by the Rumbos Foundation and REDI (through FENDIM) on 7 August 2003.

The accessibility laws do not contain provisions for enforcement, making lawsuits the only redress available. Accessibility have the most impact on new public constructions and on private constructions, such as gas stations, that are intended for public use.¹⁴⁰

The laws are only partially observed in regard to existing buildings which means that presently there are very few accessible public buildings in the city of Buenos Aires.¹⁴¹ Some buildings, such as banks or restaurants, have only been partially adapted. For example, the entrance of a fast food restaurant may be accessible, while its restrooms are inaccessible. An informal survey of 40 restaurants and cafés in La Plata and Buenos Aires identified few that were in compliance with the accessibility laws.

The oldest National Universities, such as the University of Buenos Aires and the University of La Plata, are partially accessible, but some schools within the universities are completely inaccessible. The Teatro Colón Opera House is partially accessible, and there are public buildings where only a few areas are accessible, such as the building of the Ministry of Education.



An inaccessible entry to the building of the Ministry of Education.

¹⁴⁰: Nélica Galloni Balmaceda (architect, CIBAUT Researcher, Professor at the UB School of Architecture and Urban Planning, Member of IRAM committees), interviewed by author, Buenos Aires, 7 August 2003.

¹⁴¹: Jorge Mascheroni.

Disability leaders note that there are very few ramps in place to help people cross streets, and parked vehicles often block existing ramps. Sidewalks are often broken, and rubble from construction may impede movement, appropriate signage for people who are blind is rare, and there are no intersections with sound signals. These conditions seriously inhibit the free movement of people with disabilities.

All other forms of public transportation present barriers to access. The subway system recently constructed in the city of Buenos Aires has a very small number of accessible train stations, making the system as a whole of limited use to people with disabilities.¹⁴² Trains are also inaccessible,¹⁴³ and although individual lawsuits have forced the train companies to adapt stations, the trains themselves are still not wheelchair accessible.¹⁴⁴

Buses are currently being adapted in the City of Buenos Aires and in some major cities in the interior of the country. Approximately 12% of buses in the city of Buenos Aires have low or semi-low floors, although the procedure is slow and does not comply with the timelines stipulated by Law 24301. Non-governmental organizations in the city of Buenos Aires have been working to enforce the timelines, but delays have been blamed on the Economic Emergency Act of 2002 and all attempts to expedite the process have proved unsuccessful.¹⁴⁵ A study conducted by the Auditor General's Office on "Accessibility to Automotive Public Transportation for People with Reduced Mobility and/or Communication Abilities" has taken note of the situation.¹⁴⁶ The lack of accessible buses is compounded by the fact that the frequency of the buses in route is also unpredictable, further limiting the usefulness of those buses that are accessible.¹⁴⁷

¹⁴². "De Villa Ortúzar al centro en 25 minutos, con la Línea B del subte" [From Villa Ortúzar to downtown in 25 minutes with the B subway line], *Página 12* newspaper, 12 September 2003, <http://www.pagina12web.com.ar>.

¹⁴³. Leandro Despouy (President of the National Auditor General's Office), (speech Senate based on a report issued by that Office in commemoration of the Disability Day, City of Buenos Aires, 3 December 2003).

¹⁴⁴. Abraham Felperin.

¹⁴⁵. *Argentine Workers Labor Center, CTA, www.cta.org.ar; Follow-Up Committee on the Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities*; REDI, CELS and Assistance Network for Rights and Social Integration.

¹⁴⁶. Leandro Despouy, www.agn.gov.ar. The report on automotive public transportation was not yet published at the time of this writing.

¹⁴⁷. "El Drama Diario de los Discapacitados que Viajan en Colectivo" [The Daily Struggle of Persons with Disabilities who Travel by Bus], *Clarín*, 7 April 2003, <http://old.clarin.com/diario/2003/04/07/s-02904.htm>.

Accessibility and universal design are taught at the School of Architecture and Urban Planning of the University of Buenos Aires. Before 2001, universal design was an optional subject in the undergraduate course on Architecture, but is now a compulsory subject. A post-graduate course on Amendments to the Building Code of the city of Buenos Aires is also available,¹⁴⁸ and the Central Society of Architects has a universal design center that conducts a post-graduate course on “Architecture for the Elderly from Housing for the Elderly to Universal Design” that is taught by architects Norma Sharovsky and Eduardo Frank.¹⁴⁹

Regulations concerning accessibility are typically implemented only when there is pressure from civil society. Such pressure may be exerted through nongovernmental organizations, the media, summary proceedings before the courts, or government agencies that are driven by stakeholders from the civil society.¹⁴⁹

Culture, Sports, and Recreation

The Argentine national government is not active in promoting culture, sports, and recreation for any segment of the population. However, municipalities in the city of Buenos Aires and in a number of cities in the provinces often organize activities for people with disabilities in coordination with Non-governmental organizations. These activities include swimming, summer day camps, dancing parties for young persons with disabilities, and crafts workshops, among others. People with multiple disabilities find it especially difficult to participate.¹⁵⁰

The city of Buenos Aires furnishes a wider range of options than do other regions, although many of these are public shows rather than participatory events. Arts activities are frequently organized by disability NGOs. Some of these NGOs include the Disabled Artists Foundation, which organizes activities in the city of Buenos Aires; the Candilejitas group; and the integrated theater troupe of the Teatro Argentino de La Plata theater.¹⁵¹

There are also sports federations, such as the Argentine Blind Sports Federation (FADEC), whose soccer team, called “Los Murciélagos” (The Bats), won the 2003 World Blind Championship.

¹⁴⁸ School of Architecture, Design and Urban Planning, University of Buenos Aires, <http://www.fadu.uba.ar/posgrados/oferta>; Central Society of Architects, <http://www.socearq.org>.

¹⁴⁹ Eduardo Frank, *Vejez, arquitectura y sociedad* [Old Age, Architecture and Society], (Paradiso Ediciones, Buenos Aires, 1998). Mr. Frank is the author of a book on universal design that addresses the built environment needs of individuals with reduced mobility.

¹⁵⁰ Panel discussion.

¹⁵¹ Disabled Artists Foundation, <http://www.fundacion.artistas.org.ar>.

Disability Action & Awareness

In 1987, following the guidelines of the 1982 UN World Program of Action Concerning Disabled Persons, Argentina issued Decree 1101 creating the National Advisory Committee for the Integration of Persons with Disabilities (CONADIS). CONADIS, which is part of the Presidential National Council for Social Policies, is made up of a president, a Board of Directors, an Advisory Committee and a Technical Committee. The Advisory Committee consists of representatives of organizations of and for persons with different disabilities.¹⁵² The duties of CONADIS were established by Law 22431. Decree 984/92 makes the committee responsible for coordinating between the offices of the national government, provincial governments, and disability organizations. CONADIS is empowered to define disability policies advocate for their ratification by the relevant authorities.

Officials of CONADIS reported that the committee is not currently fulfilling its coordinating role. One of the goals of the current administration led by President Jorge Mascheroni, who took office in August 2003, is to begin to build multi-sectoral policies.¹⁵³ He has given directives to ministries and government offices to facilitate this work.¹⁵⁴

Law 24657 established the Federal Disability Council in 1996, thus creating a stronger link between CONADIS and the provinces. The Federal Council is "made up of officials exercising the maximum authority in this field at the highest level in each of the provinces and in the Municipality of the City of Buenos Aires, and by representatives of non-governmental organizations of and working for persons with disabilities.....elected by their peers in each of the regions of the country." The president of CONADIS acts as president of the Federal Council as well. The goal of the Federal Council is "to preserve the key role of provinces and the above-mentioned municipality in the implementation of national policies regarding prevention and comprehensive rehabilitation and equalization of opportunities for persons with disabilities, as well as in the planning, coordination and execution of tasks involving the concerted action of the various areas."¹⁵⁵

The provinces are also required to have Councils of Persons with Disabilities. For instance, the province of Buenos Aires has the Provincial Council for Persons with Different Abilities. This council, created by Provincial Law 10592, is to be composed of persons representing various disabilities, however, there are no provisions ensuring adequate representation of different types of disabilities. Representatives must act on behalf of a disability organization, but they do not have to be a person with a disability or a relative of a person with a disability. Some civil society organizations have raised objections to this type of representation and the Sign Language Teaching Institute of La Plata has proposed a new plan, approved by the Argentine Confederation of Deaf Persons for electing members to the Disability Council.¹⁵⁶

¹⁵². Susana Sequeiros.

¹⁵³. *Ibid.*

¹⁵⁴. Jorge Mascheroni.

¹⁵⁵. CONADIS, Responsibilities and Functions section, <http://www.cndisc.gov.ar>.

The lack of political will presents a major obstacle to the implementation of disability programs. There is no national disability policy, although the current administration has expressed its intention of creating one. Other barriers are presented by the way such policies are implemented within the Argentine political system.¹⁵⁷ Specific disability policies are invariably associated with individual administrations and are not part of national policy. Because they are not "state" policies, they are subject to change as administrations and office holders change.¹⁵⁸ A succession of policies results in shifting priorities and programmatic instability that interrupts disability action and makes efforts to coordinate disability groups more difficult. Economic challenges and political patronage have led disability organizations to largely abandon cross disability advocacy and thwarted efforts to build unity among organizations working in the field.¹⁵⁹

Social health care organizations constitute the largest source of funds for disability organizations that provide services. Non-governmental organizations working in the field of disability have traditionally been non-profit associations of parents of children and adolescents with disabilities. They provide a patchwork of services not furnished by government agencies including services in the areas of: education, rehabilitation, sheltered employment, assistance (Day Care Centers), and lodging for people with disabilities. These groups receive funds from a variety of sources, but the most importantly from the social health care organizations to which their beneficiaries belong. A physician prescribes authorized services, and the Non-governmental organization is reimbursed for services on a monthly basis. Other funding sources of disability organizations include contributions from members, as well as contributions and donations from companies, individuals, government agencies, and national or foreign civil organizations. For example, organizations for people who are blind are financially supported by ONCE from Spain and are provided with publications and blank tapes by SHIA from Sweden.¹⁶⁰

Because so much funding comes from social health care organizations, most disability groups are more eager to advocate for health care or rehabilitation services than disability rights in general. Moreover, concern over jeopardizing funding may deter them from strong advocacy stands. By contrast, only rarely are people with disabilities furnished with assistance in the defense or exercise of their rights. Few lawyers work in the field, and those who are, typically receive little financial remuneration for their work.¹⁶¹

¹⁵⁶ Adrián Reynoso, (President of IPLESA), email response, <http://www.amc.com.ar/iplesa/>.

¹⁵⁷ Jorge Mascheroni.

¹⁵⁸ Alicia Bustos Fierro.

¹⁵⁹ Jorge Mascheroni.

¹⁶⁰ Marcedlo Calvo.

¹⁶¹ Liliana Bastons.

With regard to state funding, the first significant budget allocation for disability was a result of the enforcement of the first Check Act, enacted in 1995. This law established that fines collected by the Central Bank of Argentina for overdrawn checks should be transferred to the National Social Security Institute for Retirees and Pensioners for the exclusive use by comprehensive assistance programs for people with disabilities.¹⁶²

The funds were used to support sheltered workshops, physical infrastructure construction projects, and the purchase of vehicles for people with disabilities. During the 2001 crisis the transfer of funds to the disability sector stopped. The administration that took office in May 2003 reinstated the transfer of funds, and all money collected after January 15, 2004 will be allocated to the "National Fund for the Integration of Persons with Disabilities."¹⁶³ The newly created Committee for the Coordination of Programs for Persons with Disabilities will oversee the use of those resources.¹⁶⁴ Some governmental and civil society organizations have suggested that money collected during 2003 also be transferred to this fund.¹⁶⁵

In addition to those issues related to funding, other challenges to the disability rights movement come from within the disability community itself. Some of these are a product of success. In some instances, as people with disabilities begin to receive more integrated services they lose touch or leave disability organizations, damaging their advocacy capabilities.¹⁶⁶ In addition, there is frequently a lack of cooperation or open competition between disability organizations.¹⁶⁷ For example, some organizations of deaf people have had notable disagreements that have impaired their ability to work together.

Argentina is home to a few cross-disability organizations including AMIA, REDI, the Foro Pro, and ECIDIS. Government committees and councils at the national, provincial, and municipal levels also integrate people with different disabilities. The disability community as a whole however, suffers from an overall lack of coordination. This may be due to the country's serious economic and financial problems, a lack of interest in coordination by the members of these organizations, or concerns about the survival of organizations providing services.¹⁶⁸ This lack of coordination is most prominent in large cities. In smaller cities near the interior of the country, cooperation is

¹⁶². Law 24452, <http://infoleg.mecon.gov.ar>.

¹⁶³. Decree 1277/2003, *Official Gazette*, 26 May 2003.

¹⁶⁴. The committee is composed of the president of CONADIS, a member of the CONADIS Advisory Committee, representatives from government ministries, and a representative from the Federal Council.

¹⁶⁵. Jorge Mascheroni.

¹⁶⁶. Marcelo Calvo.

¹⁶⁷. Susana Sequeiro

¹⁶⁸. Hebe Campaña (President of the Maria Montessori Association), interviewed by author, La Plata, 25 September 2003.

more common. The municipal level is perceived as most responsive to individual complaints and therefore, the level where disability action can be most effective.

The leaders of disability organizations all stressed the importance of bringing disability rights to the forefront of public attention. Two strategies are considered to be the most effective: initiating "amparo" proceedings, and presenting issues to the mass media. Unfortunately media coverage of disability issues is relatively scarce, although when it does occur it is generally positive. La Nación newspaper published supplements on disability in 2001 and in early 2004. In the interior of the country, newspapers will accept articles submitted on disability issues, but generally there are no particular staff who are designated to cover disability issues.

Belize



Key Factors: In 2000, the government of Belize began dismantling the Disability Services Division of the Ministry of Human Development.¹ The Disability Services Division was responsible for developing and monitoring programs and services for people with disabilities. After disbanding the division in 2001, the government transferred responsibility for disability service provision to private companies and nongovernmental organizations. Many of these organizations, however, do not have the financial or technical resources necessary to implement and sustain programs for people with disabilities.

Definition of Disability

There is no official definition, government document or national policy relating to disability in Belize.²

Disability Population

The population of Belize is approximately 248,916, according to the 2000 census conducted by the Central Statistical Office.³ The last two censuses, in 1991 and 2000, both included a question on disability. The censuses identified a total of 12,431 (6.5%) persons with disabilities in 1991, and 13,774 (5.7%) persons with disabilities in 2000. The 1991 three-part question asked:

Does suffer from any long-standing illness, disability or infirmity?
(yes/no)

What type of disability or impairment does have? (Sight/Hearing/
Speech/Upper limb/Lower limb/Neck and spine/Slowness at learning or
understanding/Mental retardation/Other)

¹ Government of Belize, *The Convention on the Rights of the Child: Periodic Report 2002, Belize, 2002.*
² Evan Dakers (Social Planner of the Ministry of Human Development), interviewed by author, Belize City, July-August 2003.
³ Central Statistical Office, *Abstract of Statistics, 2001.* The population actually enumerated by the census comprised 240,204 persons. Based upon a follow-up survey to the 1991 census, the undercount was estimated at 3.5%. The 248,916 figure represents the final adjusted population.

In which of the following ways are’s activities limited compared with most people your/his/her age?
(self-care/mobility/communication/schooling/employment/other/none)⁴

In 2000, the question consisted of two parts, but was more specific in its approach.⁵

“Do you/Does have problems with any of the following?”
(sight difficulties (even with glasses, if worn)/hearing difficulties (even with hearing aid, if used)/speaking difficulties (talking)/moving [or] mobility difficulties (walking, climbing stairs, standing)/body movement difficulties (reaching, crouching, kneeling)/gripping [or] holding difficulties (using fingers to grip or handle objects)/learning difficulties (intellectual difficulties, retardation)/behavioural difficulties (psychological, emotional problems)/personal care difficulties (bathing, dressing, feeding self)/ other)

“In which of the following ways are your/.....’s activities limited compared with most people your/his/her age? (self-care/mobility/communication/schooling/employment/other/none)⁶

The change in question wording and subsequent decrease in the measured size of the disability population suggest a lack of reliability. In addition, surveys by the Special Education Unit of the Ministry of Education have found that the percentage of children and adolescents (between the ages of 3 and 18) who are diagnosed with some form of disability is closer to 15%.⁷ The differences may be due to the fact that the census is carried out by persons who may not be adept at recognizing all types of disabilities and may only identify people with significant disabilities.

Legislation & Disability Rights

Legal Protections

Belize signed the International Labor Organization Convention on Employment and Occupation Discrimination (No. 111) and ratified it on 22 June 1999.⁸ However, Belize has not signed the Organization of American States Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities.

⁴ Central Statistical Office, *Census Form*, 1991, photocopy provided by the Central Statistical Office.

⁵ The 2000 census reports impairments by type: 27.3% sight; 10.3% hearing; 6.7% speech; 16.6% moving; 13.2% body movement; 6.6% grip/hold; 5.8% slow learning; 3.9% behavior; 5.8% personal care; 3.8% other.

⁶ Central Statistical Office, 2000.

⁷ Sharon August (Director of the Special Education Unit of the Ministry of Education, former Principal of the Stella Maris School for the Disabled), interviewed by author, Belize City, 25 June 2003.

⁸ International Labor Organization, *Discrimination (Employment and Occupation) Convention*, (1958), <http://www.ilo.org/ilolex/english/convdisp1.htm>.

The government of Belize has not issued any statements regarding adoption of the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities. In addition, no statement has been issued in support of the creation of a United Nations Convention on the Rights of Persons with Disabilities.

Currently, Belize has no national laws that specifically protect the rights of people with disabilities. The Constitution of Belize makes reference to the equal rights of all Belizeans. It recognizes "the principles of social justice...that there should be adequate means of livelihood for all,...and that a just system should be ensured to provide for education and health on the basis of equality," but it does not specifically mention people with disabilities.⁹

While both the Ombudsman's office and the Human Rights Organization of Belize are charged with the responsibility of protecting the human and civil rights of all citizens of Belize, there is no official body in place to protect persons with disabilities.

Civic Participation

People with disabilities theoretically have the right to vote, but some may need special assistance to exercise it. Braille is not used to facilitate the voting process. An escort must accompany a person who is blind into the voting booth and mark the ballot in accordance with the voter's instructions. Representatives from the contesting parties must witness the voting. The Department of Elections and Boundaries states that they are currently evaluating the confidentiality in the voting process and would like to improve the process for people with disabilities.¹⁰

People with disabilities also have the right to be elected or appointed to public office. The late Honorable Philip S. W. Goldson, who was blind, recently served as Minister of Human Development. The right to form associations is also protected. There are several associations that address issues faced by people with disabilities. The most active of these groups include the Belize Council for the Visually Impaired (BCVI) and the Belize Institute of the Deaf.

⁹ Belize Constitution, ch 4b, <http://www.belize.gov.bz/lawadmin/index2.html>.

¹⁰ Myrtle Palacio (Chief Elections Officer), (presentation at a workshop organized by the Elections and Boundaries Department, broadcast on Love FM radio, Belize City, April 2004.)

Inclusion

Communication

The Belizean government does not provide a Braille version of the Constitution. The National Library Service in Belize City provides materials in alternative formats such as video and audio cassettes, for people with visual and hearing disabilities. Local television stations are owned and operated solely by private entities and do not regularly provide captioning of their programming.

There is no established strategy for authorities to communicate with people with disabilities in the case of a complex emergency. In such an instance, most individuals with disabilities would be forced to rely on family members or caregivers.

Education

According to the former Director of the Special Education Unit, up to 15% of school aged students in the public school system are diagnosed with some degree of disability. Ministry of Education estimates refer primarily to those with learning disabilities and not necessarily those with physical or other types of disability.¹¹ No other data on the number of students with disabilities is currently available in Belize.

All schools nationwide are obliged to enroll children with disabilities. However, in many cases schools require that parents or other family members provide special assistance to such students, as the school itself is unable to provide it. Regular schools are normally equipped with a special classroom for students who require special attention. Otherwise, students are included in the regular classrooms. In most urban areas there are special schools with limited capacity to accommodate students with profound disabilities.¹²

Of all elementary students with disabilities: 50% receive inclusive education in which all students of the same grade are in the same classroom; 15% are taught in special classes; 3% attend special day schools; 17% are taught at home; and 15% have no education available to them. With regard to high school students with disabilities: 65% receive inclusive education; 5% of students are taught at home; and 30% have no education available to them.¹³

The Special Education Unit of the Ministry of Education has drafted a policy document mandating that schools be made accessible to students with disabilities. This policy, however, has not been ratified. In the meantime, new school buildings are being erected without the proper physical infrastructure in place.¹⁴

¹¹. Sharon August.

¹². *Ibid.*

¹³. *Ibid.*

¹⁴. *Ibid.*

All national teacher training programmes include courses on special education. Until recently, these courses were optional. This has changed and the teacher training Bachelors programme includes two mandatory courses on the topic.¹⁵ In urban schools, there will normally be at least one teacher with some training in special education who will assist other teachers on a rotating basis as the need arises. In some cases, parents may provide some assistance to their children at school.

The Disability Services Division (DSD) of the Ministry of Human Development developed a national program for the early detection of disabilities in children.¹⁶ In 2001, however, the division was closed and the government stated its intention to transition the activity to the private sector. According to the transition plan, the government would assist with the creation of a private sector organisation that would develop a national detection program. The organization, CARE Belize has been commissioned but, to date, has not developed the capacity to assume all the functions of the former Division.¹⁷ In the meantime, hospitals have conducted some early detection screening. However, the capacity for disability screening has been greatly diminished by the disbandment of the DSD.¹⁸

With its limited staff, the Special Education Unit of the Ministry of Education attempts to carry out a country-wide programme to assess students in schools for learning disabilities. All schools are expected to participate in the program. Travelling teachers do the assessment.

Employment

There is no national policy to encourage the employment of people with disabilities by the private sector, and there is no policy requiring the national government to employ people with disabilities itself.¹⁹ The Belize Sugar Industries, one of the largest employers in Belize, reported that it has no written policy regarding the employment of persons with disabilities. Moreover, no one with a disability is currently employed by the organization.²⁰ All employers are expected to observe the provisions of the Labour Ordinance and ILO Convention No. 111 dealing with non-discrimination.²¹ Nevertheless, the employment of people with disabilities in the private sector and by the government is mainly determined by the skills they possess and by the perceptions of employers as to how well they might compete with persons without disabilities.²²

¹⁵ *Ibid.*

¹⁶ *Ibid.*

¹⁷ Dolores Godfrey (Director of CARE Belize), Joan Musa (Coordinator), Joan Samuels (Head of Belize Council for the Visually Impaired), and Roxanne Jones (Office Support), interviewed by author, Belize City, 5 August, 2003.

¹⁸ *The Convention on the Rights of the Child: Periodic Report 2002, Belize.*

¹⁹ Godfrey Young (Acting Labour Commissioner), interviewed by author, Belmopan, 6 August 2003.

²⁰ Narciso Avila (Manager Corporate Administration, Belize Sugar Industries Limited), emailed response, 23 May 2004.

²¹ Godfrey Young.

²² *Ibid.*

There are limited training and placement programs for people with disabilities in Belize. The Stella Maris School for the Disabled offers some skills training in areas such as home economics and wood working for school aged children and youth.²³ In addition, a few regular schools have begun "inclusive" programmes whereby students with mild mental or other disabilities are taught life skills. These students may eventually be placed as apprentices or even employees.²⁴

Health Services

Currently, the Ministry of Health does not allocate funding specifically for promoting the health or rehabilitation of persons with disabilities. This function was assigned to the former Disability Services Division. UNICEF is currently assisting in the delivery of health services by providing technical and financial support to various agencies, including certain departments within the Ministries of Education, Health and Human Development.²⁵

While the National Health Service has not implemented a strategy of Community Based Rehabilitation (CBR), the Ministry of Human Development and the Belize Council for the Visually Impaired are promoting CBR activities in the rural areas where the services of professionals are not available.²⁶ The former Disability Services Division of the Ministry of Human Development used to provide training in rehabilitation and physical therapy for parents of children with severe, profound, or multiple disabilities. Very little training or support is now available to such parents. Parent associations and support groups have been encouraging parents to organise themselves and provide mutual support. These efforts have not been very effective, but in many rural areas, CBR is seen as the only available option.

Private organizations and nongovernmental organizations, such as the Red Cross Society and Rotary International, provide some assistive devices to people with disabilities.²⁷

Housing

Depending on their financial resources, people with disabilities may be eligible for public housing. There are no centers that provide counselling and referral services to people with disabilities in need of housing, and facilities for people with disabilities are almost non-existent. Leaders of disability organizations

²³. Sharon August.

²⁴. *Ibid.*

²⁵. Dr. Michael Pitts (Consultant for the Health Reform Project and former Director of Health Services, Entomology Unit, Ministry of Health), interviewed by author, Belmopan, August 2003.

²⁶. *Ibid.*

²⁷. *Ibid.*

estimate that approximately 85% of people with disabilities are living with family. Of the remainder, most are thought to be living in institutions, while some are homeless.²⁸

Institutionalization

To date, there are no known cases of death by questionable circumstances within Belize institutions; however, there are no organizations in Belize keeping records of abuse or violence against people with disabilities. The Department of Labor investigates any reported cases of abuse. In addition, all institutions are subject to periodic inspection by the members of the Ministry of Human Development and the Human Rights Organization.

Most families or parents house and raise their children with disabilities with little or no subsidies or supports. There are a few institutions that offer help and then only to a limited number of individuals. The Dorothy Menzies Child Care Centre operated by the Ministry of Human Development will provide temporary care to a limited number of children with disabilities under special circumstances, as space permits. A similar institution, Marla's House of Hope, was established in Belmopan a few years ago. This home can accommodate up to sixteen children and receives some financial support from the government and the community. The elderly are often institutionalized when they are too old to look after themselves and have no family member who may be willing or able to look after them.²⁹

Accessibility

In Belize only 25% of public buildings are estimated to be accessible to people with mobility disabilities. The capital city's post office is located on the ground floor, however, the building sits approximately 6 inches above the ground making it difficult for wheelchair users to enter without assistance.

There are no regulations stating that private buildings and facilities must be accessible to people with disabilities. The Ministry of Housing is only now developing regulations for the construction industry regarding accessibility and ramps for new buildings.

Belize does not have a national system of transportation that is wheelchair accessible. The only institution that operates an adapted system of transportation is the Stella Maris School for the Disabled. People with mobility impairments normally have to travel by taxi or are transported by family members in private vehicles.³⁰

²⁸. Panel discussion with leaders of disability organizations, discussion conducted by author, Lions' Training Center, Belize City, 30 August, 2003.

²⁹. Ava Pennill (Head of Family Services Division and formerly of the Disability Services Division), interviewed by author, Belize City, 12 August, 2003.

³⁰. *Ibid.*

Disability Action & Awareness

Belize lacks a national coordinating agency to develop disability policy, and there is no national disability action plan. Bureaucracy, lack of political will, and financial constraints are significant barriers to achieving more effective disability action.³¹

Existing disability organizations tend to operate independently of each other, and there are no cross-disability organizations in Belize. In general, disability organizations have few financial resources and rely on the support of international agencies to fund activities. Disability advocates report that the sector is not effectively prepared to lobby the government or other agencies in demand of disability rights.³²

³¹. Panel discussion.

³². *Ibid.*



Bolivia

Key Factors: Disability rights are established by the 1995 Persons with Disabilities Act. Because enforcement agencies are still being created, implementation of the existing legislation is lacking. However, various ministries, departmental governments, and municipalities are beginning to develop policies and regulations, which is hoped will improve the situation.

Terminology

Before core disability instruments were adopted by the United Nations, Bolivian legislation was based on stigmatizing and discriminatory language. Although this trend gradually shifted, amendments and supplementary laws continued to use such language well after it had lost acceptance among the disability community. For example, the Political Constitution of the State of Bolivia, which was amended in February 1995, refers to people with disabilities as “*personas inutilizadas*,” translated here as “invalids.”¹

The Criminal Code refers to “*enajenada mental*,” translated as “mentally deranged.”² The 1956 law on social security uses “*lesions*,” translated as “handicap,” and “*invalides*,” translated as “invalid.” Additionally, the word “*incapacidad*” (incapacity) is used instead of “*discapacidad*” (disability).³ Such usage continues in later laws like the Pension Act, the Municipalities Act, and the 2001 Electoral Code.⁴ The term “*impedimento*,” translated as “impediment,” is also used in some legal documents.

More recently, some ministries have adopted terminology preferred by the disability community. The Ministry of Health adopted the term “*personas con discapacidad*” (persons with disabilities) in its 1995 national policies.⁵

¹ *Constitución Política del Estado* [Political Constitution], (UPS Publishing House, La Paz, 2002), 48.

² Justice and Criminal Matters of the Andean Jurist Committee, *Código Penal y Código Procesal Penal, 2003* [Criminal Code and Criminal Procedural Code, 2003].

³ *Código de Seguridad Social* [Social Security Code], *La Tarjeta Jurídica*, (Provin Servicios de Comunicación CD, La Paz, 2002).

⁴ *Ley de Pensiones* [Pension Act], *La Tarjeta Jurídica* (Provin Servicios de Comunicación CD, La Paz, 2002); *Ley de Municipalidades* [Municipalities Act], *La Tarjeta Jurídica*, (Provin Servicios de Comunicación CD, La Paz, 2002); *Código Electoral* [Electoral Code], *La Tarjeta Jurídica*, (Provin Servicios de Comunicación CD, La Paz, 2002).

⁵ Ministry of Human Development, National Secretary of Health, Health Services Organization Bureau, World Health Organization, *Política Nacional de Prevención de Discapacidades y Rehabilitación en Salud* [National Policy for Disability Prevention and Health Rehabilitation], (Bolivia Nueva Sociedad, La Paz, 1996).

Likewise, the Ministry of Education now uses “discapacidad” and the expression “necesidades educativas especiales” (special education needs).⁶

Definition of Disability

The definitions of disability used in Bolivian legislation resulted from changes in approaches to disability over time. Because early concepts of disability were based on “impediment” and “incapacity,” definitions tended to focus on impairments. The act dated 22 January 1957 that created the Bolivian Institute for Blindness stated that “a blind person is an individual with a visual ability of 20/200 or lower or a visual field of 20 degrees or lower, considering the best eye and the best correction.”⁷

With the international development of new frames of reference, Bolivia’s concept of disability began to reflect those shifts taking place elsewhere. For example, the International Classification of Impairment, Disability and Handicap (ICIDH) definition of disability is included in the People with Disabilities Act, Law 1678. According to the text, a disability is “any restriction or lack, resulting from an impairment, of ability to perform an activity in the manner or within the range considered normal for a human being.”⁸ The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the United Nations in 1993, also served as important guidelines for the drafting of legislation and official documents.

However, population measurement instruments in Bolivia continue to rely on ideas about disability based on individual impairments. All survey questions about disability present respondents with a short list of impairments that implicitly define disability. This impairment-based approach is common among the general population making such questions easy for interviewers to ask and respondents to understand. However, this narrow definition of disability does not conform to the newer legislative framework and likely resulted in a deflated estimate of the number of persons with disabilities.

⁶ Ministry of Education, *Políticas de Integración para los Alumnos con Necesidades Educativas Especiales a la Modalidad Regular* [Integración de Niños con Discapacidad a la Modalidad Regular [Integration of Children with Disabilities into Regular Schools], (Documento Trabajo, La Paz, 2002), 13.

⁷ *Ley del 22 de enero de 1957* [Act passed on 12 January 1957], (certified copy provided by Norberto Vargas (Director of the General Archive of Bolivia’s Presidency)), La Paz, 1986.

⁸ Ombudsman, *Ley de la Persona con Discapacidad*, 2nd ed. [People With Disabilities Act, Second Edition Chapter I, Definitions; sec. 1. B] (D.P., La Paz, 2002), 5.

Disability Population

In the last decade, three national surveys have attempted to measure the number of people with disabilities. There are concerns about the accuracy of the data resulting from all three.⁹

The first attempt by the National Institute of Statistics (INE) to quantify the number of people with disabilities in Bolivia took place in 1998. A question on disability was included in the National Demographics and Health Survey (ENDSA). The survey asked “do you have any severe physical impairments?”¹⁰ with answers including “deaf-mute, mental retardation, deaf, mute, blind, paralytic, crippled/one-armed.”¹¹ In the 13,136 households sampled, 461 persons with “severe physical impairments” were identified. Persons with disabilities were estimated to account for approximately 1% of the Bolivian population.¹¹

As the result of advocacy efforts by disability organizations, the INE included an item on disability in the 2001 census. The census asked “In this household, how many people are blind?/deaf-mute?/paralytic/and/or have had an arm or leg amputated?”¹³ There was no question designed to identify people with mental disabilities. Out of 1,977,665 households nationwide, 61,145 households reported persons with disabilities. The disability population identified by the census ranged from 0.9 to 1.2% of the total population.¹²

Most recently, the INE fielded a survey for the Improvement of Living Conditions Program (2001 MECOVI) in October and November 2001. A total of 5,744 households were sampled. The survey asked “Do you have (...) any kind of permanent disability?”¹⁴ Based on the results, the projected population of people with disabilities in Bolivia is 87,293.¹⁵

⁹ Interview with the person in charge of the Program on Human Rights of People with Disabilities of the Ombudsman’s Office, La Paz, 14 November 2003; interview with the Head of the Social Security Unit of the Disability Area of the Ministry of Health and Sports, La Paz, 12 September 2003.

¹⁰ National Institute of Statistics, *Encuesta Nacional de Demografía y Salud* [National Demographics and Health Survey], INE/ENDSA, La Paz, 1998, Household Questionnaire Appendix.

¹¹ National Institute of Statistics, *Encuesta Nacional de Demografía y Salud*, 216-217.

¹² National Institute of Statistics, *Censo Nacional de Población y Vivienda de 2001* [National Population and Housing Census, 2001] INE, La Paz, 2002, 94-95.

¹³ National Institute of Statistics, *Manual del Empadronador/a* [Census Taker Manual] INE, La Paz, 2001, 56.

¹⁴ National Institute of Statistics, *Encuesta de Hogares, Programa de Mejoramiento de Condiciones de Vida MECOVI-2001* [Household Survey, Improvement of Living Conditions Program, 2001 MECOVI], INE, La Paz, 2001.

¹⁵ *Ibid.*

According to Clarita Franco de Machado and Rodrigo De Urioste, all INE surveys underestimate the rate of persons with moderate and mild disabilities. In the above surveys, only 11% of respondents with disabilities reported a mild disability, while slightly over half reported a serious or very serious degree of disability. Rates of moderate and mild disabilities are likely much higher than has yet been detected by the INE.¹⁶ Even though the last household survey moved away from a specific focus on severe disabilities, the continued focus on “permanent” disabilities and the overly vague question wording suggest serious validity problems for the current figures.

With no accurate source of national disability data, the population estimates used in this report have been taken from the World Health Organization (WHO), which estimates that an average of 10% of the world’s population is comprised of people with disabilities. At that rate, and with a total population in Bolivia of 8,274,325 people, there would be approximately 827,432 people with disabilities in the country.¹⁷

Legislation & Disability Rights

Legal Protections

The Bolivian government ratified the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities on 26 April 2002 and deposited the relevant instrument with the Secretary General of the Organization of American States (OAS) on 30 May 2003.¹⁸ Bolivia has also signed the Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159) of the International Labor Organization. It was ratified by means of Law 1658, enacted on 2 August 1995.¹⁹

Additionally, the Bolivian government supports the creation of a United Nations Convention on the Rights of the People with Disabilities. The Ministry of Foreign Affairs endorsed the creation of a national Committee to Promote the International Convention. At a working meeting held on 12 November 2003, a ministry representative announced that the government supported the position and proposed convention submitted by Mexico.²⁰

¹⁶. Clarita Franco de Machado and Rodrigo De Urioste, *Estudio sobre la Incorporación de Personas con Capacidades Diferentes al Sistema de Formación Técnica y Tecnológica* [Research on the Inclusion of People with Different Abilities into Technical and Technological Training], (Corporación Calidad, La Paz, 2003), 94.

¹⁷. National Institute of Statistics, *Censo Nacional de Población y Vivienda de 2001*.

¹⁸. Law 2344 of 26 April 2002, (certified copy provided by Norberto Vargas).

¹⁹. Law 1658, National Committee of People with Disabilities, www.conalpedis.org.

²⁰. Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman’s Office.

With regard to national legislation, the protection of individual rights in Bolivia is based on the Political Constitution. Although implicitly included, the Constitution does not specifically refer to the rights of people with disabilities. Section 6 states that “any human being has a legal personality and capacity according to law. Any human being enjoys the rights, freedoms and guarantees recognized by this Constitution, regardless of race, sex, language, religion, political or other opinion, origin, economic or social status or otherwise.”²¹ The only direct reference to people with disabilities is in section 158 of Title 2, which mandates that “the State shall assure continuing means of living and rehabilitation for invalids.”²²

Bolivia also has a disability-specific law. Law 1678 explicitly identifies people with disabilities as subjects of the rights set forth in the Political Constitution. Among the rights and benefits described by the act are education, employment, health care, rehabilitation, vocational training, and access to public spaces. All relevant public, private, and semi-public agencies must comply with the act. According to an official from the Ombudsman’s office, this legislation “must be accompanied by the political and budgetary will and by a change in social behavior in society at large.”²³

Other laws also specifically mention people with disabilities. Children and youth with “physical, mental, psychiatric or sensory disabilities” are covered by the Child and Adolescent Code.²⁴ People who are blind or visually impaired comprise one of the most well-established, active sectors of the disability community, with the largest organizational culture. Their advocacy efforts resulted in the creation of the Bolivian Institute for Blindness and established its goals and responsibilities.²⁵

Sections of the Criminal Code create punitive consequences for crimes committed against people with disabilities or those that concern injuries resulting in disabilities. Thus, “individuals who commit a crime against a person with disabilities [such as] rape, etc., may be sentenced... to a longer [imprisonment] period due to the aggravating circumstances.”²⁶ The Act Against Family or Domestic Violence sets out similar aggravated penalties when “the victim is disabled, older than sixty years of age or is pregnant.”²⁷

²¹. *Constitución Política del Estado*, 3-4.

²³. *Ibid.*, 48

²³. Ombudsman, *Ley de la Persona con Discapacidad*, 22-38.

²⁴. *Código del Niño, Niña y Adolescente* [Child and Adolescent Code], La Tarjeta Jurídica, (Provin Servicios de Comunicación CD, La Paz, 2003), www.conalpedis.org.

²⁵. *Ley del 22 de enero 1957*, (certified copy provided by Norberto Vargas).

²⁶. Interview with the Executive Director of the National Committee of People with Disabilities, La Paz, 19 September 2003; *Criminal Code La Tarjeta Jurídica*, (Communication Services, La Paz, 2002).

²⁷. *Ley Contra la Violencia en la Familia o Domestica* [Act Against Family or Domestic Violence], *La Tarjeta Jurídica*, (Provin Servicios de Comunicación CD, La Paz, 2002).

This penal framework is the primary mechanism for enforcement of disability rights. Law 1678 does not contain provisions for noncompliance. Thus, there has been little progress in the enforcement of rights granted by the Political Constitution and by Law 1678.²⁸

The Ombudsman's Office is the most active entity that keeps records about death, abuse, violence, or discrimination against people with disabilities.²⁹ However, several offices work to resolve specific violations. The Ombudsman safeguards the rights guaranteed by the Political Constitution and other laws. The head of the Ombudsman's Program on Human Rights of People with Disabilities is in charge of handling all disability cases.³⁰ The National Committee of People with Disabilities (CONALPEDIS) works to enforce Law 1678. Its Board of Directors includes a National Secretariat specifically appointed to defend the rights of people with disabilities, pursuant to Section 3 of Regulatory Decree 24807 of Law 1678.³¹

In some cases CONALPEDIS tries to clarify alleged violations of disability rights with those who are involved. When that process fails to remedy an abuse, CONALPEDIS may resort to the Ombudsman, the Ministry of Labor, or other appropriate authorities.³² In one case, CONALPEDIS intervened when "a woman with disabilities was raped,...[and] the criminals tried to be released on parole."³³ In response, CONALPEDIS worked to ensure that appropriate penalties were applied. The CONALPEDIS has also defended people with disabilities from guardians who have tried to violate their rights.

Overall, the Executive Director of CONALPEDIS reports that compliance with current regulations is low. This situation is in part because of the limitations of CONALPEDIS.³⁴ Although there should be nine departmental committees in addition to the national committee, only six have been created, and only four have an annual budget. Even in those departments that have committees, many "do not have legal counsels [or a] budget to help those people who need to seek assistance from an attorney."³⁵ The CONALPEDIS has an annual budget of 195,923 Bs (US\$25,779) for personnel and operating costs.³⁶ The total amount allocated to the departmental committees amounts to 373,023 Bs (US\$49,082).³⁷

28. Ombudsman, *Ley de la Persona con Discapacidad*, 40.

29. Interview with the Executive Director of the Bolivian Institute for Blindness, La Paz, 17 November 2003; Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman's Office; Interview with the Executive Director of the National Committee of People with Disabilities.

30. *Ley del Defensor del Pueblo* [The Ombudsman Act], *La Tarjeta Jurídica*, (Communication Services, La Paz, 2002).

31. *Ibid.*

32. Director of the National Committee of People with Disabilities.

33. Interview with the Executive Director of the National Committee of People with Disabilities.

34. Ombudsman, *Verificación Defensorial Comités Departamentales Personas con Discapacidad* [Supervision of Departmental Disability Committees], (D.P., La Paz, 2002), 39-52.

35. *Ibid.*

36. Exchange rate applicable during this period of time: 7.60 Bs per 1 US Dollar.

37. Ombudsman, *Verificación Defensorial Comités Departamentales Personas con Discapacidad*.

Legal Barriers

Legal restrictions remain for some people with disabilities. The Civil Code declares that “deaf-mute and mute persons are incapable of making a will.”³⁸ They are likewise deemed “incapable” of serving as a witness as are people who are deaf. Going further, some people with disabilities are labeled as having “absolute incapacity” including persons who are “mentally deranged” or “blind and deaf.”³⁹

Civic Participation

Persons with disabilities have the right to elect and to be elected in both general and municipal elections. The Electoral Court has made an effort to allow people with visual disabilities to exercise their right to vote in general elections. At each polling station (typically located in schools), a “cercha” has been provided for people with visual disabilities to vote.⁴⁰ In 2002, the Electoral Court arranged for the “cerchas” and trained its staff in the use of the ballots. No alternative format information is available for persons who are deaf.⁴¹

The only immediate provision for people with other disabilities is the opportunity to vote without waiting in line.⁴² According to the National Electoral Court, voting places are generally located in the yard or ground floor. They estimate that polling stations are 60 to 80% accessible.⁴³ Conversely, CONALPEDIS reports that “voting centers are often, if not always, full of barriers preventing people with physical disabilities from reaching voting places.”⁴⁴

Inclusion

Communication

There is no Braille or audio-cassette version of the Political Constitution, nor are there any other Braille materials available in National Libraries. There is a plan underway at the Bolivian Institute for Blindness (IBC) to create a national Braille library. Today, Braille texts are only available at IBC special education centers.⁴⁵ People who are blind or visually impaired must typically resort to having others read texts to them.

³⁸. *Ibid.*

³⁹. Justice and Criminal Matters of the Andean Jurist Committee, *Código Civil y Procesal Civil*.

⁴⁰. Interview with a member of the National Electoral Court, La Paz, 17 September 2003. The “cercha” is a form including the initials of the political parties printed in Braille as well as the names of uninominal districts. It is an exact copy of the ballot paper. An “X” is marked next to a punched mark to cast the vote. It is edited in Bristol card material.

⁴¹. Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman’s Office.

⁴². Interview with a member of the National Electoral Court.

⁴³. *Ibid.*

⁴⁴. Interview with the Executive Director of the National Committee of People with Disabilities.

⁴⁵. Interview with the Executive Director of the Bolivian Institute for Blindness.

National news broadcasts on both public and private television stations are not captioned for viewers who are hearing impaired.⁴⁶ Televisión Boliviana, the official channel, has an agreement with the Bolivian Federation of the Deaf to implement sign-language interpretation in television news beginning in 2004.⁴⁷ This project will be supported by Ministry of Education efforts to create Bolivian sign language and Braille alphabets.⁴⁸

There are no methods or strategies in place for people with disabilities to communicate with emergency centers in the event of a natural disaster or criminal assault.

Education

The Ministry of Education's special education representative reports that no valid estimates of the number of school-aged children with disabilities are available from the INE.⁴⁹ In Bolivia, 130 elementary schools integrate 478 children with special education needs.⁵⁰ In 2002, an additional 7,390 students were enrolled in the special education system.⁵¹ According to the INE, the total population of school-aged children is 2,983,768. This includes both elementary and high-school aged children.⁵² Of those, 2,197,930, or about 74%, are actually enrolled in school.⁵³ The number of school-aged children with disabilities could range anywhere from approximately 30,000 to near 300,000. Assuming even the lowest number, no more than 26% of children with disabilities are enrolled in the public educational system. Thus, somewhere between 74 to 97% of children with disabilities are excluded from Bolivian schools.

Considering the small number of students with disabilities who are enrolled, special education and school integration programs are provided with adequate infrastructure and human resources in all capital cities of the departments countrywide. In addition, four departments have rural special education centers, namely, Santa Cruz, Cochabamba, Tarija and Beni.⁵⁴

⁴⁶ Interview with the Programming Director of Channel 7 of Televisión Boliviana (official channel), La Paz, 25 September 2003.

⁴⁷ *Ibid.*

⁴⁸ Interview with the National Coordinator of Special Education, La Paz, 24 November 2003.

⁴⁹ *Ibid.*

⁵⁰ National Institute of Statistics, *Censo Nacional de Población y Vivienda de 2001*, 9.

⁵¹ National Institute of Statistics, *Anuario Estadístico 2002* [Statistical Annual Report 2002], (La Paz: INE-CD, 2003), 2-3.

⁵² Interview with the person in charge of the Team of Special Intercultural and Bilingual forms of Education, La Paz, 7 September 2003.

⁵³ Interview with the National Coordinator of Special Education.

Decree 24807, which regulates the People with Disabilities Act, establishes that schools for people with disabilities must be physically accessible, and that appropriate communication, teacher training, and teaching materials should be available.⁵⁵ These provisions are supplemented by municipal ordinances in the country's major cities. Legislation remains largely unenforced. New schools are few, and many refurbished schools have failed to remove steps or other barriers to free access. The compliance rate is estimated to be less than 20%.⁵⁶

The Ministry of Education, in compliance with the Educational Reform Act, has been working with an educational resource center to verify that all educational materials are transcribed in Braille, and that the educational reform modules be sign-language interpreted with iconography to help reading by students who are deaf.⁵⁷

The national teacher curriculum includes a six-month training course on integrated education that is required to obtain a degree in education.⁵⁸ In addition, there is a two-year post-graduate distance learning program for special education teachers that includes materials developed by the Distance Learning National University of Spain (UNED). This program was proposed in 1998 and approved in 2001. The Episcopal Education Committee of the Bolivian Episcopal Conference and the Ministry of Education jointly run the program through FEDIA. While the program will be available to all teachers, priority will be given to the specialization of teachers who are currently working but who have no formal training. Persons with disabilities who wish to become teachers receive support.⁵⁹

The Ministry of Education's National Bureau of Special Education is implementing a "Parent School." Parents of children with disabilities meet regularly at special education centers. One assistance center for children and youth with mental disabilities, the Child Rehabilitation Institute (IDAI) under the departmental government of La Paz, requires parents with children at the center to attend special courses where they learn to better assist their children. The Bolivian Institute for Blindness (IBC) is also trying to involve the parents and siblings of children who are blind in the educational process by learning how to read and write in Braille and assisting blind children who do not attend a special school.⁶⁰

⁵⁵. Ombudsman, *Ley de la Persona con Discapacidad*, 25.

⁵⁶. Interview with the Executive Director of the National Committee of People with Disabilities.

⁵⁷. Interview with the National Coordinator of Special Education.

⁵⁸. Interview with the person in charge of the Team of Special Intercultural and Bilingual forms of Education.

⁵⁹. Interview with the National Coordinator of Special Education.

⁶⁰. Interview with the Executive of the Bolivian Institute for Blindness.

No effective official disability detection program is currently available. Although some programs exist, most disabilities are detected at a later stage.⁶¹ A Community-Based Rehabilitation pilot program run by CONALPEDIS is funded by the Pan American Health Organization and the WHO. Currently, the program is concentrated in three cities: El Alto, Tarija, and Cochabamba.⁶² As part of the program, the departmental committees provide Disability Detection cards, which offer information on screening children for visual, hearing and mental disabilities.⁶³ Additional programs include a Ministry of Health initiative to test reflexes of children aged under age 4, and the White Tent program. Under that program, a white tent is erected in a small town square for a week, and health workers gather information on the general nutrition level of the community that can then be used for disability detection and prevention.⁶⁴

Education and training opportunities for older adolescents and young adults with disabilities are scarce.⁶⁵ Only 30% of the 90 special education centers across the country offer occupational training and employment services. The departments of Pando and Beni have no such services.⁶⁶ The Ministry of Education has plans to establish an office within the framework of Technical and Technological Education that will address the issue of vocational training.⁶⁷



Entry to the Ministry of Education in Bolivia

⁶¹. Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman's Office.

⁶². Interview with the Executive Director of the National Committee of People with Disabilities.

⁶³. Interview with the person in charge of the Team of Special Intercultural and Bilingual forms of Education.

⁶⁴. Interview with the National Coordinator of Special Education.

⁶⁵. Interview with the Executive Director of the National Committee of People with Disabilities.

⁶⁶. Interview with the National Coordinator of Special Education.

⁶⁷. Clarita Franco de Machado and Rodrigo De Urioste.

Employment

The largest sector of the labor market (36.55%) is informal employment, characterized by self-employment and consisting of micro-businesses, small business, and small farms.⁶⁸ The nature of these jobs makes it difficult for the Industry Chamber and the Ministry of Labor to obtain statistical data or employment records for many workers, including substantial numbers of people with disabilities. However, the unemployment rate for people with disabilities as estimated by disability organizations ranges from 60% to 85%.⁶⁹ The major barriers to employment are lack of jobs, lack of technical or vocational training for persons with disabilities, and discrimination.⁷⁰

Although there are general employment protections for people with disabilities, they remain unenforced. The Ministry of Labor and the National Committee of People with Disabilities are working on a preliminary Labor Act for people with disabilities.⁷¹ The draft is under review by disability organizations, the government, and the private sector.

None of the major industries currently have explicit labor policies encouraging the employment of persons with disabilities and prohibiting discrimination. Some government agencies have offered a limited number of employment opportunities to people with disabilities. This achievement was the result of advocacy efforts on the part of departmental disability committees and disability organizations, including the Bolivian Disability Confederation (COBOPDI) and the Bolivian National Federation for the Blind (FENACIEBO). Employment of people with disabilities is also regulated by municipal ordinances in force in the major municipalities of the country and by some Departmental Resolutions. For example, in the municipality of La Paz, 1% of its administrative staff is made up of people with disabilities. In the City of El Alto, 3.5% of positions should be filled by people with disabilities, although the actual percentage is likely somewhat lower.⁷²

The INFOCAL Foundation, a project run by the Bolivian Private Entrepreneur Association, provides training in various types of skilled labor. Although the foundation does not specifically focus on people with disabilities, the courses are open to persons with disabilities who wish to be included. The program is focused in the country's major cities, with particular significance in Oruro, Cochabamba, Santa Cruz, Tarija, El Alto, and La Paz.

⁶⁸. National Institute of Statistics, *Anuario Estadístico 2002*, 7-10.

⁶⁹. Interview with the Executive Director of the National Committee of People with Disabilities and Interview with the Executive Director of the Bolivian Institute for Blindness.

⁷⁰. Interview with the Executive Director of the National Committee of People with Disabilities; Panel discussion with leaders of disabilities organizations, facilitated by author, La Paz, 29 September 2003.

⁷¹. Interview with the General Director of Industrial Safety of the Ministry of Labor and Delegate to the National Committee of People with Disabilities, La Paz, 23 September 2003.

⁷². Interview with the Executive Director of the National Committee of People with Disabilities.

Training programs include: computing, mechanics, baking, electricity, gas installation, sewing and dressmaking, pattern designing for sports uniforms, fabric painting, and accounting, among others. Upon the completion of training courses, INFOCAL attempts to place workers with private businesses. Unfortunately, very few persons with disabilities have attended INFOCAL courses.⁷³

Health Services

In Bolivia, access to health insurance and medical assistance is often inadequate for people with disabilities. A National Disability Register project by the Ministry of Health is currently working to determine how many persons with disabilities need medical insurance and to identify funding sources.⁷⁴ The Social Security Code provides protection for people who have acquired a disability in the course of employment.⁷⁵ People with visual impairments are covered by the short-term insurance and health care system of the Bolivian Institute for Blindness, which offers comprehensive short-term medical insurance covering people who are blind. Funds are provided to the Institute by the National General Treasury (TGN) and 5% of these funds are annually allocated to short-term insurance.⁷⁶

The government does not generally allocate financial resources for providing health services to people with disabilities.⁷⁷ The Rehabilitation Bureau of the Ministry of Health was closed in 1994, but efforts are underway to reopen the bureau.⁷⁸ For people who have health insurance and have acquired a disability in an accident, some resources are available through the National Health Fund's National Rehabilitation center in La Paz. The center provides reconstructive medicine and rehabilitation services. Financial support has been restricted to physical rehabilitation.⁷⁹ Rehabilitation services funded by the public and semi-public organizations are available in the major cities, namely, La Paz, El Alto, Santa Cruz, Sucre, and Cochabamba.⁸⁰

Technical aids for disability rehabilitation are state-funded.⁸¹ Some private organizations provide orthopedic instruments to people with disabilities. The Association for the Rehabilitation of Blind and Visually Impaired Persons (APRECIA) in Santa Cruz provides important technological resources to people who are blind.

⁷³. *Ibid.*

⁷⁴. Interview with the Head of Social Security Unit of the Disability Area of the Ministry of Health, La Paz, 12 September 2003.

⁷⁵. Interview with Social Security Director of the Ministry of Health and Sports, La Paz, 28 November 2003.

⁷⁶. Interview with the Executive Director of the Bolivian Institute for Blindness.

⁷⁷. *Ibid.*

⁷⁸. Interview with the Executive Director of the National Committee of People with Disabilities.

⁷⁹. *Ibid.*

⁸⁰. Mirjam Guevara, *Ofertas Educativas para Personas con Necesidades Educativas Especiales en Bolivia* [Educational Offers for People with Special Education Needs in Bolivia], (UNESCO, UNICEF and German Adult Education Association, La Paz, 1997), 14-15.

⁸¹. Interview with the Social Security Director of the Ministry of Health and Sports.

In La Paz, an organization called the Wheelchair Bank (BANDESIR) lends wheelchairs to low-income people, and RTP (Popular Radio Television) develops fund-raising campaigns to help people in need who require wheelchairs, other orthopedic devices, or specialized rehabilitation treatments.⁸² The Rotary Club, the Lions Club, and Caballeros de Malta are also involved in these campaigns to provide assistive technology.⁸³ In addition, CONALPEDIS and the Cabinet of the First Lady solicit foreign donations for some technical aids.⁸⁴

According to the Ministry of Health, there is no specific training available to medical students in the provision of care to people with disabilities. Medical professionals acquire basic knowledge on the provision of services to people with disabilities during their general courses or during special courses in traumatology, ophthalmology, and otorhinolaryngology.⁸⁵ Medical residencies are available in some specialized subjects including occupational therapy, physical therapy, physiatry, and prosthetics and orthotics.⁸⁶

Although such specialized training on the provision of care to people with disabilities is accessible to all physicians, actual interest and participation is low. The Ministry of Health reports that 2% of primary care physicians, 4% of pediatricians, and 1% of medical assistants attend such courses. There are 12 rehabilitation specialists in Bolivia with a professional degree. In addition, there are about 70 self-trained rehabilitation physicians.⁸⁷

The Ministry of Health has not yet implemented a community-based rehabilitation strategy; however, plans are scheduled to begin doing so in 2004.⁸⁸ A pilot program including the early detection initiatives has been underway since 1999. Work has focused in Cochabamba department, in marginalized areas and rural municipalities of La Paz, and in the department of Tarija. Executive directors of all Departmental Committees were provided training on community-based rehabilitation to facilitate the introduction of the CBR program.⁸⁹

Housing

Leaders of disability organizations estimate that close to 90% of people with disabilities live with their families while most others reside in institutions.⁹⁰ There are no independent living centers in Bolivia.⁹¹

⁸². Panel discussion.

⁸³. Interview with the Executive Director of the National Committee of People with Disabilities.

⁸⁴. *Ibid.*

⁸⁵. Interview with the Social Security Director of the Ministry of Health and Sports.

⁸⁶. Interview with the Executive Director of the National Committee of People with Disabilities.

⁸⁷. Interview with the Social Security Director of the Ministry of Health and Sports.

⁸⁸. *Ibid.*

⁸⁹. *Ibid.*

⁹⁰. *Ibid.*

⁹¹. Interview with the Executive Director of the National Committee of People with Disabilities.

People with disabilities are not eligible for public housing, and there are currently no subsidies or support for buying or building a house.⁹² The Vice-Ministry of Housing is developing regulations regarding the accessibility of housing units for people with disabilities. The regulations establish a preferential scoring for people with disabilities, so that any person having some kind of disability will have priority access to housing programs.⁹³ This work is jointly coordinated by the CONALPEDIS, IBC and the Vice-Minister of Housing. The Ombudsman has been monitoring the progress of this program.⁹⁴

Institutionalization

There are around a dozen institutions in Bolivia operating with exclusive mission of providing long-term housing and care to people with disabilities. Combined they accommodate about 400 people. The institutions are listed in table one.⁹⁵

Table 1: Long-term institutions for people with disabilities in Bolivia

Facility	# of Residents	Population served	Location
Villa Victoria Home	30	Women w/ mental disabilities	La Paz
Eric Boulter Special Education Institute	27	People w/ hearing disabilities	La Paz
Child Adaptation Departmental Institute	70	People w/ mental disabilities	La Paz
Child Rehabilitation Institute	25	Children w/ physical disabilities	La Paz
Calcutta's Sisters Home	60	People w/ disabilities	El Alto
Luis Braille and Santa Cecilia School	30	People w/ visual disabilities	La Paz
Wenceslao Alba	20	People w/ visual disabilities	Potosi
Manuela Gandarillas School	20	People w/ visual disabilities	Cochabamba
Maria Antonieta Suárez	20	People w/ disabilities	Oruro
Aprécia Sucre	8	People w/ disabilities	Sucre
Bolivian Society of Psychiatry	40	People w/ psychiatric disabilities	Sucre
Gregorio Pacheco Hospital	40	People w/ psychiatric disabilities	Sucre

⁹² Interview with the Director of Housing Policies of the Vice-Ministry of Urban Development and Housing, La Paz, 4 November 2003.

⁹³ *Ibid.*

⁹⁴ Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman's Office.

⁹⁵ Interview with the Executive Director of the National Committee of People with Disabilities and Interview with the Executive Director of the Bolivian Institute for Blindness.

These centers offer psychological counseling, psychiatric counseling, rehabilitation services, intensive-care services and education/training.⁹⁶

People living in these institutions are often unaware that they have the right to refuse treatments. The CONALPEDIS reports that “treatment and institutionalization of persons with disabilities [are] generally decided against their will.” Children are often institutionalized after having been abandoned or at the request of their families. Although many of the homes “are intended for a certain age group...[most] centers cover a wide variety of ages” because institutions for adults are largely absent.⁹⁷

One exception to generally poor conditions found in institutions are the educational centers of the Bolivian Institute for Blindness. These centers will not accept residents against their will. They focus on education and are sometimes able to integrate students into the mainstream school system.⁹⁸

Accessibility

The Regulatory Decree of Law 1678 and various municipal ordinances establish that new buildings and facilities must be accessible to people with disabilities, and all architectural barriers must be removed.⁹⁹ Existing buildings and facilities should also be remodeled to make them accessible. The overall level of compliance with these regulations is low. In the La Paz, the country’s capital city, post offices are not accessible to wheelchair users.¹⁰⁰ Only three buildings in the capital have elevators with Braille numbers; none is equipped with a sound system.¹⁰¹ It is estimated that only 1% of public buildings in the city are accessible to people with disabilities, although there are some notable exceptions.¹⁰² Some public buildings such as supermarkets are being adapted by the addition of entrance ramps. Major squares and streets of all departmental capital cities also have ramps. These accessibility measures are not comprehensive, however, because intersections do not have adequate signaling.¹⁰³

No courses on universal design are regularly available to architects in Bolivia. The Bolivian Institute of Standards and Quality (IBNORCA) offered a course on standardization and quality in August 2003. They reported that the course was poorly attended, with only five or six architects enrolled.¹⁰⁴

^{96.} *Ibid.*

^{97.} Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman’s Office.

^{98.} Interview with the Executive Director of the Bolivian Institute for Blindness.

^{99.} Ombudsman, *Ley de la Persona con Discapacidad*, 33.

^{100.} *Ibid.*

^{101.} Interview with the Executive Director of the Bolivian Institute for Blindness.

^{102.} Interview with the Executive Director of the National Committee of People with Disabilities.

^{103.} Interview with the Director of Housing Policies of the Vice-Ministry of Urban Development and Housing.

^{104.} Interview with a Standardization Expert of the Bolivian Institute of Standardization and Quality (IBNORCA), La Paz, 6 November 2003.

Rural, urban, and interdepartmental transportation services are currently not accessible to wheelchair users, and no adapted or special transportation is available. People with disabilities must resort to costly taxis or their own private means of transportation, if they are financially able to do so.

The Vice-Ministry of Public Transportation is currently drafting National Transportation Regulations. Some provisions are aimed at ensuring that interdepartmental transportation vehicles have special seats reserved for persons with disabilities, areas to place devices used by people with disabilities, direction signaling, and vehicles with suitable external and internal access.¹⁰⁵

Disability Action & Awareness

The National Committee of People with Disabilities (CONALPEDIS), created by Law 1678, is the official agency coordinating disability policy in Bolivia. It was designated an independent agency of the former Ministry of Human Development, but it is not associated with the Ministry of Health and Sports. The main purpose of CONALPEDIS is to coordinate, control, and advise on disability policies and actions.¹⁰⁶ It is composed of officials from government ministries and representatives of both governmental and non-governmental disability organizations. Half of the members of the National Committee of People with Disabilities are people with disabilities.¹⁰⁷

Current CONALPEDIS activities are not based on any long-term national plan. Instead, its work is based on an Annual Operating Plan (POA). Departmental Committee activities are organized in a like manner. Each committee performs its own activities as established in its respective POA, with no centralization or general direction. In an effort to remedy this lack of a national disability action plan, the CONALPEDIS has begun coordinating national meetings bringing together various agencies responsible for enforcing Law 1678.¹⁰⁸

Disability units have recently been established in the City Hall of La Paz and the city of Caranavi, a medium-sized city in the La Paz Department.¹⁰⁹ Cochabamba's and Oruro's departmental governments also have Disability Units reporting to the Social Management Bureau.¹¹⁰

¹⁰⁵. General Director of Ground Transportation of the Vice-Ministry of Transportation, La Paz, 26 de September 2003.

¹⁰⁶. Ombudsman, *Ley de la Persona con Discapacidad*, 11.

¹⁰⁷. *Ibid.*, 11-16.

¹⁰⁸. Ombudsman, *Verificación Defensorial Comités Departamentales Personas con Discapacidad*, 39-52.

¹⁰⁹. Interview with the Executive Director of the National Committee of People with Disabilities.

¹¹⁰. Interview with the person in charge of the program on Human Rights of People with Disabilities of the Ombudsman's Office.

Bolivia has one cross-disability organization, the Bolivian Confederation of Persons with Disabilities (COBOPDI), which was established in 1989.¹¹¹ Its affiliate members are: the Bolivian Federation of the Blind (FEBOS),¹¹² the Bolivian Association of Integrated Sports (ASODEIN),¹¹³ the Bolivian Association of Parents and Friends of Persons with Mental Disabilities (ABOPANE),¹¹⁴ and the Christian Fraternity of Ill and Disabled Persons (FCPEDB). Another important disability organization is the Bolivian National Federation for the Blind (FENACIEBO), which founded the Bolivian Confederation of Persons with Disabilities.¹¹⁵ National and departmental congresses are held every two years to help coordinate the activities of these organizations. Organizations of people with visual impairments are not involved in these coordinated efforts, but in some departments their members participate in activities of the COBOPDI.¹¹⁶

In general, funding of disability organizations is largely derived from fund-raising efforts and contributions made by their own leaders. Members of these institutions can very seldom make financial contributions.¹¹⁷ The government provides a small amount of financial support to some organizations including the Bolivian National Federation for the Blind and the Bolivian Association of Integrated Sports.¹¹⁸ In the past, the Christian Fraternity of Ill and Disabled Persons obtained financial support from international cooperation organizations of the Catholic Church.¹¹⁹

Broadly speaking, ongoing courses about disability policies, the rights of persons with disabilities, inclusive education, and other disability-related subjects are not sponsored by universities or advanced education institutions. Two pilot programs are worthy of mention. First, the Disability Advanced course was sponsored by the Association of Comprehensive Community Rehabilitation (CCR), through the University of San Simón in Cochabamba and the Technical University of Oruro (UTO) it was available in the city of Oruro from 1999 to 2001.¹¹⁷ Second, the Advanced Distance Learning Course was sponsored by CONALPEDIS and the Fund for Strengthening Civil Society Organizations (FOSC) in 2003.¹¹⁸

The Ombudsman's Office representative stated that "disability is still a concealed issue" in Bolivia. With regard to strategies for improving the state of disability rights, the office suggested that "it is important to disseminate information about disability issues and to raise awareness on the major obstacles people with disabilities encounter as a strategy for the gradual enforcement of legislation...it is important to achieve a change in social behavior, to raise awareness among the authorities as well as in society at large."¹¹⁹

¹¹¹ Departmental Government of La Paz, *Testimonio Notariado* [Notarial Certificate], Government Notary's Office, La Paz, 1996.

¹¹² Interview with the Executive Director of the Bolivian Institute for Blindness.

¹¹³ Departmental Government of La Paz, *Testimonio Notariado*.

¹¹⁴ Panel discussion and Interview with the Executive Director of the National Committee of People with Disabilities.

¹¹⁵ Interview with the Executive Director of the National Committee of People with Disabilities.

¹¹⁶ *Ibid.*

¹¹⁷ Interview with the National Coordinator of the Association of Integral Rehabilitation in the Community, Cochabamba, 29 August 2003.

¹¹⁸ National Committee of the People with Disability, *Cursos* [Courses], La Paz) www.conalpedis.org.

¹¹⁹ *Ibid.*

Brazil



Key Factors: Brazil is one of the largest countries in the region, and thus has a large population of people with disabilities. The country's legal framework provides multiple protections for the rights of people with disabilities including Law 7853, which criminalized discrimination based on disability.

Terminology

The Portuguese term “pessoas portadoras de deficiência”, has been translated in this report as “people with disabilities.” This comes closer to the meaning of the Portuguese expression as it is used than the literal translation, “persons having an impairment.” The term “transtornos mentais” (mental disorders) has been literally translated from the official documents, and refers to “psycho-social and/or psychiatric disabilities.” Also, “doença mental” (mental disease) is used in official documents in lieu of psychiatric disability.

Definition of Disability

Section 3 of Decree 3298/99, which contains the regulatory provisions of Law 7853/89, defines disability as follows: “any loss or abnormality of a psychological, physiological or anatomic function or structure resulting in a lack of ability to perform an activity within the range considered normal for the human being.”¹

Disability Population

The most recent Brazilian census was conducted in 2000. It found that 14.5% of the Brazilian population, or about 24.5 million people, have some degree of activity/functional limitation.² This figure represents a significant increase from the disability rate of 1.41% reported by the 1991 census. The approach used in the 1991 Census only identified a small portion of the disability population. Because the rate was far different from international estimates, various studies were conducted to understand the reasons for the discrepancy.³ The low number of people with disabilities reported in that census was due to the methodology used

¹ Decree 3298, 20 December 1999, <http://www.mj.gov.br/sedh/dpdh/corde/dec3298.htm>.

² Brazilian Institute of Geography and Statistics, <http://www.ibge.gov.br/>.

³ Izabel Madeira de Loureiro Maior (General Coordinator of the National Coordination Office for the Integration of People with Disabilities – CORDE).

⁴ Ana Maria de Resende Chagas Renato Baumgratz Viotti, *Retrato da pessoa com deficiência no Brasil segundo o censo de 1991*, [Portrait of People with Disabilities in Brazil, 1991 Census] Brasília, August 2003, http://www.ipea.gov.br/pub/td/2003/td_0975.pdf.

to verify the information, the concept of disability, and the restrictive categories used at that time.⁴

In contrast, the Brazilian Institute of Geography and Statistics (IBGE) reports that the 2000 census was compatible with the International Classification of Functioning, Disability and Health (ICF), which was released in 2001 by the World Health Organization. The new methodology allowed the IBGE to identify a larger number of people with disabilities through a more comprehensive approach.⁵ Specifically, persons with mild disabilities were much more likely to be identified by the 2000 census than the 1991 census.⁶ The questions asked by the 2000 census included:

Do you have any permanent mental disability restricting your daily activities? (Such as working, attending school, jumping, etc.)⁷
(yes/no)

How do you assess your ability to see? (If you wear glasses or contact lenses, state how well you can see with them)
(Unable/Severe permanent difficulty/Some permanent difficulty/No difficulty)

How do you assess your ability to hear? (If you wear hearing aids, state how well you can hear with them) (Unable/ Severe permanent difficulty/ Some permanent difficulty/No difficulty)

How do you assess your ability to walk / climb stairs? (If you wear a prosthesis, walking stick or an auxiliary device, assess how well you can move with it) (Unable/Severe permanent difficulty/Some permanent difficulty/No difficulty)

Do you have any of the following impairments?: (Choose only one item, giving priority to the largest impairment)(Total permanent paralysis/ Permanent paralysis of both legs/~~P~~ermanent paralysis of one [or] two sides of the body/Lack of a leg, arm, hand, foot or thumb/None of the above)⁸

⁵ IBGE, *Comunicação Social* [Social Communication], 8 May 2002, <http://www.ibge.gov.br/>.

⁶ Center of Social Policies, *Retratos da Deficiência no Brasil* [Portrait of disability in Brazil], Getulio Vargas Foundation, (2003), http://www.fgv.br/cps/deficiencia_br/PDF/PPD_Sumario_Executivo.pdf.

⁷ Decree 3298/99, Mental disability in this context means, as defined by Decree 3298/99, "a functional intellectual capacity, significantly below the average, evidenced before the age of 18 and accompanied by limitations related to two or more areas of adaptive abilities, such as communication, personal care, social skills, utilization of community resources, health and safety, functional learning abilities, leisure, and work."

⁸ Decree 3298/99.

The largest rate of people with disabilities was found in the Northeast (16.8% of the total population) and the lowest in the Southeast (13.1%).⁹

A series of press releases issued by IBGE on 20 December 2002 and 27 June 2003, described certain features of the results. The disability rate is higher in small-sized municipalities of up to 20 thousand inhabitants (16.3%) than it is in the largest municipalities (13%). Not only were municipality size differences discovered, but ethnic differences were also found in the disability population. The disability rates for indigenous and black populations are 17.1% and 17.5%, respectively, whereas the disability rates for the white and Asian population are below 14%.¹⁰ Overall, the rate of people with disabilities as reported by the IBGE grows with age, rising from 4.3% in 14-year-old children to 54% of the total number of people older than 65.

Among people with disabilities, visual impairments predominate. About 48.1% had visual impairments, 8.3% had mental impairments, 4.1% had physical impairments, 22.9% had mobility impairments, and 16.7% had hearing impairments. Rates of mental disabilities, physical disabilities, and hearing disabilities were higher among men than among women. On the other hand, permanent visual impairment, as well as the use of glasses, was reported by 16.6 million people, more of whom were women than men.¹¹ The predominance of visual disabilities has caused some concern over the methodology and accuracy of the results. Mental disabilities and physical disabilities appear seriously undercounted by the 2000 Brazilian census.¹² In the 1991 census, only 9% of persons with disabilities reported having visual impairments while close to 40% reported having a mental disability.¹³

Legislation & Disability Rights

Legal Protections

Brazil ratified the OAS Inter-American Convention on Disability on 17 July 2001 and deposited the instrument on 15 August 2001. The Brazilian diplomatic mission, in accordance with the Brazilian government, has supported the process to negotiate a UN convention on disability rights. Even though it was not part of the Commission for the Economic and Social Development of the United Nations in 1997, government and NGO delegations worked to support the extension of the Special Rapporteur's mandate.¹⁴ Brazil has also included the principles of the Standard Rules in its national legislation.¹⁵

⁹. IBGE, *Comunicação Social*.

¹⁰. *Ibid.*

¹¹. *Ibid.*

¹². Carlos Roberto Miranda, *Oportunidades de Trabalho Para Portadores de Deficiência* [Opportunities to Work for People with Disabilities], <http://www.saudeetrabalho.com.br/download/oportunidades-miranda.doc>.

¹³. IBGE, *Census of Brazil*, 1991.

¹⁴. Izabel Madeira de Loureiro Maior.

At the national level, the primary document protecting the rights of people with disabilities is the Federal Constitution of 1988.¹⁶ The Constitution guarantees financial support, social integration, disability prevention, and comprehensive rehabilitation, including health care, educational assistance, and occupational training for people with disabilities. It also prohibits employment discrimination and established a quota for the number of people with disabilities to be hired by the government. Lastly, the Constitution mandates the creation of accessibility standards for public buildings, facilities, and transportation.¹⁷

Law 7853, enacted on 24 October 1989, specifically protects the rights of people with disabilities.¹⁸ This statute contains provisions regarding the support of people with disabilities, their social integration, and the National Coordination Office for the Integration of People with Disabilities (CORDE). Other protections include:

- Law 10754, enacted on 31 October 2003 and amending Law 8989, which provides that automobile purchases to be used in the transportation of individuals with disabilities and school transportation are exempt from the Tax on Industrialized Products (IPI)
- Law 8213/91, which establishes a quota of employees with disabilities.¹⁹ Under this law, a company with one hundred or more employees is required to fill between 2-5% of its positions with rehabilitated employees or employees with disabilities.²⁰

¹⁵. OAS, *Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With Disabilities*, <http://www.oas.org/main/main.asp?sLang=E&sLink=http://www.oas.org/documents/eng/documents.asp>.

¹⁶. Izabel Madeira de Loureiro Maior.

¹⁷. Federal Constitution of 1988, <http://www.senado.gov.br/bdtextual/const88/Con1988br.pdf>.

¹⁸. Law 7853, *Presidência da República Subchefia para Assuntos Jurídicos*, 24 October 1989, <http://www.planalto.gov.br/CCIVIL/Leis/L7853.htm>.

¹⁹. Law 8213, 24 July 1991, http://www.planalto.gov.br/ccivil_03/Leis/L8213cons.htm. Companies with between 100 and 200 employees must hire 2%; companies with 201-500 employees must hire 3%; those with 501-1000 employees must hire 4%, and companies with over 1,000 employees must hire 5%.

²⁰. *Report of the Attorney General Office in Labor matters on the insertion of people with disabilities in the labor market*. Ed. No.5. (Brazil, February 2002), <http://www.pgt.mpt.gov.br/ascom/infespecial/indexInfEspec5anexo3.htm>.

- Law 10048/2000, which gives priority to the assistance of people with disabilities, among other groups, in state agencies and companies that receive concessions from the State.²¹
- Law 10436, enacted on 24 April 2002, which recognizes Brazilian Sign Language (Libras) as a legal means of communication and expression.²²
- Law 10216, enacted on 6 April 2001, which provides for the protection of the rights of people with “mental disorders” and establishes a new approach in attempt to shift away from the traditional mental health assistance model.²³
- Decree 3298 issued on 20 December 1999, which contains the regulations for Law 7853 and includes provisions on the National Policy for the Integration of People with Disabilities.
- Decree 4360 issued on 5 September 2002, which amended a previous decree regulating the permanent assistance benefit for people with disabilities and the elderly established by Law 8742, enacted on 7 December 1993.²⁴
- Decree 4229 issued on 13 May 2002, which established the National Program on Human Rights.²⁵
- PNDH II, which contains the policy recommendations of the National Program on Human Rights.²⁶
- Guidelines issued by the Ministry of Justice for the creation of State and Municipal Councils on Disability Rights.²⁷

²¹. Law 10048, 9 November 2000, <http://www.pgj.ce.gov.br/centros/caogsdat/Lei10048.DOC>.

²². Law 10436, 24 April 2002, <http://www.mj.gov.br/sedh/dpdh/corde/pl4857.htm#10436>.

²³. Law 10216, 6 April 2001, <http://www.mj.gov.br/sedh/dpdh/corde/lei10216.htm>.

²⁴. Decree 4360, http://www.planalto.gov.br/ccivil_03/decreto/2002/D4360.htm. Benefits were first established by Law 8742, enacted on 7 December 1993 and regulated by Section 36 of Decree 1744, issued on 8 December 1995.

²⁵. National Program on Human Rights, <http://www.mj.gov.br/sedh/pndh/>.

²⁶. National Program on Human Rights, PNDH II (2002), <http://www.mj.gov.br/sedh/pndh/pndhII/Texto%20Integral%20PNDH%20II.pdf>.

²⁷. *Conselho Nacional dos Direitos da Pessoa Portadora de Deficiência* [National Council on Disability Rights], (Brasília: Ministério da Justiça, O Conselho, 2002)21.

Penalties for non-compliance exist for some of the disability laws. Section 8 of Law 7853/89 makes the violation of the rights of persons with disabilities punishable with fines and imprisonment of one to four years.²⁸ However, the treatment of prejudice against people with disabilities as a crime is not widely recognized or enforced.²⁹ Penalties are also specified for noncompliance with employment laws.³⁰ Fines are being increasingly used by regional labor agencies under the supervision of the Ministry of Labor and Employment. The Attorney General Office of Labor Matters is also involved in the defense of the quota of employment.³¹

Legal Barriers

Brazilian law provides that a judicial court may find that an individual who, by reason of a mental disability, is unable to make informed decisions concerning actions of civil life may be subject to guardianship. Provisions for guardianship are contained in the Civil Code.³² Section 1769 establishes that proceedings leading to the declaration of legal incapacity may be requested by any relative or the Attorney General's Office.³³ When proceedings are requested by the family, the Attorney General's Office represents the person with disabilities in the hearing. When they are requested by the Attorney General, a public defender is appointed.³⁴

Civic Participation

Persons with disabilities have the right to vote like all other citizens. However, disability advocates estimate that on average only 20% of polling places are accessible indicating that major barriers to exercising the right remain. In the 2000 election, the Supreme Electoral Court launched a television advertising campaign explaining the procedures for voting by means of Brazilian Sign Language (LIBRAS).³⁵

In 2002, Brazil introduced electronic ballot boxes. As part of the effort to ensure that these new ballot boxes would improve the voting situation for people with disabilities, the Supreme Electoral Court ordered that, if possible, the electoral justice should adapt voting places to make them accessible to people with disabilities.³⁶ Jurisdictions unable to provide adapted facilities should

²⁸ Law 7853/89, <http://www.planalto.gov.br/CCIVIL/Leis/L7853.htm>.

²⁹ Izabel Madeira de Loureiro Maior.

³⁰ Law 8213, 24 July 1991, http://www.planalto.gov.br/ccivil_03/Leis/L8213cons.htm.

³¹ *Ibid.*

³² Theotonio Negrão, *Commented Civil Code*, <http://www.tabelionatomanica.com.br/tutela.htm>.

³³ *Ibid.*

³⁴ *Ibid.*

³⁵ Izabel Madeira de Loureiro Maior.

³⁶ Resolution 20997, Federal District Brasília, 26 February 2002.

designate a special voting location. With prior notice, people with disabilities should be provided transportation to these specially adapted facilities to cast their votes.³⁷ The Court also reported that 10,000 electronic ballot boxes would be adapted for use by people who are blind. Those who do not have access to an electronic ballot may sign their paper ballots in writing or in Braille.³⁸

Inclusion

Communication

Braille versions of the Constitution are available at the Senate's Library, in libraries of specialized education centers for the blind, and in other public libraries. However, the government does not communicate its activities in Braille on a regular basis.³⁹ The National Library provides texts in alternative formats, which are updated on a regular basis. Educational materials in Braille are free for elementary school education, although the books in highest demand are only available at special education schools.⁴⁰ Schools request these materials in Braille from the government.

The Electronic Government Program and Law 10098/2000 require web sites to be accessible.⁴¹ The CORDE's website, for instance, is accessible to people who are blind and to users of voice command software.⁴² In addition, the IBGE web site allows persons who are blind or visually impaired to access the results of the 2000 Census.⁴³ The Brazilian Technical Standards Association (ABNT) has recently created a working team for the development of a technical standard on accessibility to Internet contents for people with disabilities.

There is an electronic network in place for the dissemination of National Disability information, called the "SACI Network" (Rede SACI). Its users include people with different types of disabilities as defined by the network website, as well as families, specialized professionals, government officials, journalists, and educational and research centers. It is mainly focused on Education and Labor issues. Products and services of the SACI Network are free. The Network operates through its website (www.saci.org.br) and at Information and Communal Life Centers (CIC), which are equipped with PCs, adapted software, and special monitors.⁴⁴

³⁷ Supreme Electoral Court, (Press release), Brasilia, 08 March 2002, <http://www.tre-ms.gov.br/noticias/noticia26.html>.

³⁸ Resolution 20997.

³⁹ Izabel Madeira de Loureiro Maior.

⁴⁰ "Conheça o acervo em braile da Biblioteca do Senado", Rede SACI, 16 June 2004, <http://www.saci.org.br/>.

⁴¹ Federal Law 10098/2000, Brasilia, 19 December 2000, <http://www.pgj.ce.gov.br/centros/caogsd/Lei10098.doc>.

⁴² Izabel Madeira de Loureiro Maior.

⁴³ IBGE, *Comunicação Social*.

⁴⁴ Rede SACI, <http://www.saci.org.br/index.php?modulo=akemi¶metro=1568>.

There is a telephone center system with intermediation for people who are deaf that covers 70% of the country. It is also possible to communicate through text messages (SMS) via the mobile telephone service.⁴⁵

Education

The Constitution establishes equal access to school facilities as one of the basic principles of education.⁴⁶ However, IBGE's 2000 census findings reveal some serious barriers affecting people with disabilities. Their overall level of achievement in education is consistently below that of the population as a whole. The literacy rate of people aged 15 or over was approximately 87.1% generally, but for people with disabilities the rate was only 72.0%. Out of the total persons over the age of 15 who had three years of education or fewer, 32.9% had some disability. At the regional level, similar trends were observed.

In Brazil, there was nearly universal school attendance for persons aged 7 to 14 (94.5%), but for people with at least one disability, the rate was lower (88.6%), and dropped to 74.9% for children with severe disabilities. The lowest school attendance rate was observed among persons with a permanent physical impairment (61.0%).⁴⁷ Data on elementary education shows a major difference: the rate of persons with disabilities completing eighth grade, thus achieving the nationally mandated level of education, is only 10%.

The Act on National Education Guidelines and Bases (Section 58 and following sections) defines special education as the education provided to people with disabilities.⁴⁸ It also specifies that, if possible, children with disabilities should be included within the framework of regular schools.⁴⁹ Although a national policy requires schools to be accessible, only an estimated 20% of the schools meet this requirement. Ministry of Education facilities are accessible to wheelchair users.

Special school enrollment figures are the only reliable data available on the distribution of students with disabilities. Based on these figures, around half of all students with disabilities attend special schools. Most of the remaining students are either taught in integrated classrooms or in special classes within regular schools. A much smaller number study at home or in separate residential schools. Elementary schooling for people with disabilities and special schools are available in the main cities and most of the towns.⁵⁰ In rural areas specialized assistance for people with disabilities that is provided in ordinary classes is often insufficient, causing many people with disabilities to migrate to large towns.⁵¹

There are no data on students with disabilities in high school because this level of education is not mandatory. People with disabilities normally do

45. Izabel Madeira de Loureiro Maior.

46. Commented Civil Code, *Theotônio Negrão*.

47. IBGE, *Comunicação Social* (Social Communication), 27 June 2003.

48. Law 9394, 20 December 1996, http://www.capes.gov.br/Documentos/Legislacao/Lei_9394_Diretrizes_Bases_1996.doc.

49. Izabel Madeira de Loureiro Maior.

50. *Ibid.*

have access to high school, and in the case of sensory impairments, they usually receive education in specialized schools.⁵²

With regard to continuing education, the government of the State of Sao Paulo has established a digital inclusion program. Among the efforts of this program is the creation of a CD-ROM intended to increase the Brazilian Sign Language (Libras) vocabulary of people with hearing disabilities.⁵³

A program for the detection of sensory impairments is available in elementary schools, and between 20 and 40% of schools participate.⁵⁴ Children with sensory impairments are referred to educational support centers to supplement their regular education. The Ministry of Health has an early intervention program to detect phenylketonuria, congenital hypothyroidism, haemoglobinopathies, including sickle cell disease and thalassemia, and hearing problems in newborn infants.⁵⁵

Teachers are routinely trained in providing education to people with disabilities and special education is available as a focus area. Teachers wishing to receive postgraduate training in special education can attend public and private teaching institutions.

^{51.} *Ibid.*

^{52.} *Ibid.*

^{53.} *Deficientes auditivos ganham dicionário digital*, Panorama Brasil, São Paulo-P, 27 September 2002.

^{54.} *Ibid.*

^{55.} Sheila Miranda da Silva (National Health Coordinator for People with Disabilities of the Ministry of Health in charge of Health Policies for People with Disabilities).

Employment

According to the 2002 census, of the 66.6 million people aged 10 or over who make up the working population of the country, 9 million are people with disabilities.⁵⁶ The census found that the overall employment rate of people with disabilities is lower than that among people without disabilities. The rate of employment for people without disabilities is just under 50% while the rate for people with disabilities is about 10% lower. People with mental disabilities have the lowest rate of employment with only 19.3%. People with other types of disabilities have somewhat better rates of insertion in the employment market: physical or mobility disabilities (24.8%), hearing disabilities (34.0%), and visual disabilities (40.8%). Of the 9 million people with disabilities employed at the time of the census, 5.6 million were men and 3.5 million were women. Thus, almost 52% of men with disabilities have work while only 27.3% of women with disabilities are employed.

Not only are fewer people with disabilities employed, they are also more likely than the population as a whole to earn less than the minimum wage. While 29.5% of people with disabilities reported earning less than the minimum wage, the figure dropped to 22.4% for people without disability.⁵⁷ Although the 2002 census reported that employment is about 10% lower among people with disabilities, the 1991 census reported an employment rate for people with disabilities that was slightly more than 20% below that of the general population.⁵⁸ Other government offices estimate that the unemployment rate for people with disabilities is two to three times higher than the general unemployment rate.⁵⁹

Some employers are in compliance with the requirements of Law 8213/91. For example, Carrefour, the largest private employer in Brazil, has a specific non-discrimination policy for people with disabilities and has implemented a priority job application system.⁶⁰ The Government is also required to comply with a quota of employees with disabilities.⁶¹ To set the standard, the Special Secretary for Human Rights established that 5% of high-level positions in its office must be filled by persons with disabilities. The CORDE reports that the office is complying with this rule.⁶² In general, however, the main barriers to employment for people with disabilities are the lack of awareness and accessible transportation, the low level of education and training, and employer refusal to provide reasonable accommodation.⁶³

⁵⁶. This figure includes both those working for remuneration as well as those engaged in regular but unpaid economic activities.

⁵⁷. IBGE, *Comunicação Social*.

⁵⁸. IBGE, *Census of Brazil*, 1991.

⁵⁹. *Ibid.*

⁶⁰. Carrefour, <http://www.carrefour.com.br/carrefour/carreiras.asp>.

⁶¹. Izabel Madeira de Loureiro Maior.

⁶². *Ibid.*

Health Services

The Single Health System covers healthcare and rehabilitation services for people with disabilities. The Ministry of Health finances rehabilitation for people with hearing, visual, mobility, and mental disabilities and also provides prosthetics and orthotics. In 2003-2004, priority was given to the Amazonian region. Various levels of government also provide free technical aids. Capital cities and municipalities implement regional rehabilitation programs, as well as prosthesis and orthotics provision programs. Overall, the state provides 90% of the rehabilitation services.⁶⁴

The Supplementary Health Agency (ANS) is in charge of regulating private health and similar services, and must ensure the inclusion of people with disabilities and prevent discrimination against people with disabilities. Measures aimed at preventing discrimination against persons with disabilities have been taken by the National Council on Disability Rights (CONADE).⁶⁵

There are some isolated community-based rehabilitation programs in Brazil and the current government has proposed the implementation of a community-based rehabilitation strategy in partnership with the Family Health Program.⁶⁶

Health professionals who have access to training in the care of people with disabilities include medical doctors, pediatricians and nurses. Physicians may receive such training before and after they acquire a medical degree. Some of these training programs are at an early stage of development,⁶⁷ and among the 96 medical schools existing in the country, less than 20 offer Physical Medicine and Rehabilitation training. There are about 30 vacancies per year in post-graduate courses, medical residencies, and specialization courses. About 850 psychiatrists work in Brazil.⁶⁸

Housing

Independent living pilot programs, which are funded by multiple sources, have been implemented in Rio de Janeiro, Paraná, and Goiás. There are no home purchasing subsidies for people with disabilities.⁶⁹

Institutionalization

The institutionalization of people with disabilities without their consent sometimes occurs in the cases of people with disabilities who have been

^{63.} *Ibid.*

^{64.} Sheila Miranda da Silva and Izabel Madeira de Loureiro Maior.

^{65.} *Ibid.*

^{66.} *Ibid.*

^{67.} *Ibid.*

^{68.} Sheila Miranda da Silva.

^{69.} Izabel Madeira de Loureiro Maior.

abandoned by their families, primarily those with severe mobility impairments⁷⁰ and there is no mechanism for reporting incidences of abuse in these institutions. However, there is a mechanism for reporting incidences of death of persons with disabilities. Once the death is verified, the Division of Health Statistics and Epidemiology of the Ministry of Health must follow up on each case.⁷¹

Accessibility

National Law 10098 requires that public buildings be accessible and establishes general accessibility guidelines in that area.⁷² Ultimately, accessibility is defined as allowing the safe and independent use of all public facilities, transportation and communication systems. Accessibility manuals have been issued by the Brazilian Technical Standards Association⁷³ and EMBRATUR, the Brazilian Tourism Institute.⁷⁴ An informal survey conducted by the IDRM research team, however, found that only about 10% of public buildings are accessible.

In 2002, CORDE and the Federal Engineering and Architecture Council trained about 800 architecture and engineering professionals in the principles of universal design and accessibility for people with disabilities.⁷⁵

Some major cities and areas, such as Porto Alegre, Curitiba, Sao Paulo, and Goiania, provide accessible public transportation systems and parallel door-to-door services.⁷⁶ Law 8899/94 provides for the free inter-state transportation of people with disabilities.⁷⁷

Culture, Sports, & Recreation

The Ministry of Sports supports organizations that encourage the participation of persons with disabilities in sports activities. The Ministry reports that this support has increased the quality and quantity of Brazil's athletes with disabilities.

⁷⁰ Izabel Madeira de Loureiro Maior.

⁷¹ Sheila Miranda da Silva.

⁷² Law 10098, 19 December 2000, <http://www.saci.org.br/?modulo=akemi¶metro=17>.

⁷³ Brazilian Technical Standards Association, NBR 9050: 1994, *Acessibilidade de pessoas portadoras de deficiência a edificações, espaço mobiliário e equipamento urbano / Associação Brasileira de Normas Técnicas - ABNT [Access of People with Disabilities to Buildings and Urban Spaces, Furnishings and Equipment / Brazilian Technical Standards Association – ABNT]*, (Rio de Janeiro, 1997).

⁷⁴ Brazilian Tourism Institute, *Manual de Recepção e Acessibilidade de Pessoas Portadoras de Deficiência a Empreendimentos e Equipamentos Turísticos*, (Embratur, 1999), www.embratur.gov.br.

⁷⁵ Izabel Madeira de Loureiro Maior.

⁷⁶ *Ibid.*

⁷⁷ Law 8899, 29 June 1994, <http://www.pgj.ce.gov.br/centros/caogsdat/Library/Lei8899-94.doc>.

Disability Action & Awareness

There are two organizations concerned with disability issues: the National Coordination Office for the Integration of People with Disabilities (CORDE) and the National Council on Disability Rights (CONADE). Both agencies report to the Special Human Rights Secretary of the President's Office.

The office is also in charge of promoting the exercise of citizenship by people with disabilities. Based on CORDE's recommendations, Brazil has implemented a national action plan aimed at the inclusion of people with disabilities. The CORDE is comprised of 15 technical professionals, of whom three are wheelchair users, one has reduced mobility, and one is deaf. The annual budget for CORDE is approximately US\$ 2,000,000.⁷⁸ The office's two main objectives are establishing disability policies and regulatory measures for action at the federal level and coordinating public policies that exist at different levels of government (national and others)⁷⁹

The CONADE is composed of representatives from government ministries and civil society (federations and groups representing people with different kinds of disabilities, as well as cross-disability groups)⁸⁰ The mission of the Council is to evaluate the implementation of the National Policy for the Integration of People with Disabilities and the sectoral policies on education, health, employment, social welfare, transportation, culture, tourism, sports, and recreation, as well as urban policies targeted at this social group.⁸¹

For the effective defense of the rights of people with disabilities, there needs to be more cooperation between the Attorney General's Office, the Executive Branch, and disability organizations.⁸⁰ There are currently about 1,000 governmental and non-governmental agencies promoting disability rights all of which are funded by the Ministry of Social Welfare's SEAS network.⁸¹



A Brazilian advocate delivering pamphlets during the National Day of People With Disabilities Struggle in Rio de Janeiro, Brazil

⁷⁸. Izabel Madeira de Loureiro Maior.

⁷⁹. CONADE, <http://www.mj.gov.br/sedh/ct/CONADE/index.asp>.

⁸⁰. Izabel Madeira de Loureiro Maior.

⁸¹. *Ibid.*



Canada

Key Factors: Canada has a history of victimization of people with disabilities including forced sterilization. In reaction to that past, today Canada has constitutional and other legislative guarantees protecting the rights and equality of people with disabilities. The growth of human rights movements in Canada has led to initiatives of deinstitutionalization, more individualized funding, and increased visibility of the issues faced by the disability population in recent history.

Terminology

Canada now officially recommends the use of person first language in discussions of disability. A recent publication for media producers regarding appropriate language to be used with respect to people with disabilities stated that “the word “disabled” is an adjective, not a noun. People are not conditions.”¹ However, earlier documents sometimes used terms that are now considered problematic. For example, one important document from the early 1980’s uses the term “handicapped.” When directly quoting documents, the original terminology has been retained.

Definition of Disability

Across Canada and within the numerous factions of the disability community, the definition of disability is a continuously debated subject. Consequently, there is no general definition of disabilities.

¹ *A Way with Words And Images: Guidelines for the portrayal of persons with disabilities*, 2002, http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/documents/wayWithWords/00_toc.shtml&hs=pyp.

Instead, much of the country's legislation either does not specifically define disability or merely defines it in reference to a particular act. With little consensus on the definition of disability, governments and organizations have turned to operational definitions and classifications of disability.

Operational definitions of disability originated out of a need to define eligibility criteria for services, programs, membership, rights and resources, and the analysis of health related issues. Thus, they vary according to the services being rendered. This research focuses on definitions written into government documents, legislation, and programs. The Pension Plan Act, for example, defines when someone is considered to be a person with a disability and when they have ceased to be a person with a disability. It states "a person shall be considered to be disabled only if he is determined in a prescribed manner to have a severe and prolonged mental or physical disability."² It goes on to say that "in no case shall a person be deemed to have become disabled earlier than fifteen months before the time of the making of any application."³ In this example, both the severity and the duration of a prescribed condition are subjective in nature.

In its attempts to enumerate the disability population, Statistics Canada has turned to international definitions of disability put forward by the World Health Organization (WHO). Surveys in the 1980s and 1990s followed the WHO's 1980 report, *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*, which defines disability as "... any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal for a human being."⁴ The most recent disability survey moved to a definition based loosely on the WHO's newer ICF framework. The definition provided in the survey report states that a disability is "an activity limitation or a participation restriction associated with a physical or mental condition or a health problem."⁵ The Canadian government, however, has not officially adopted the ICF definition, and disability continues to be defined inconsistently. For example, a recent government publication defined disability in language very close to the ICIDH, calling it "a functional limitation or restriction of an individual's ability to perform an activity."⁶

Disability Population

As of 2003, the Canadian population exceeded 32 million people.⁷ The most recent Participation and Activity Limitation Survey (PALS) found that 3.6 million Canadians, or 12.4% of the population, reported having a disability.⁸

² *Defining Disability: A Complex Issue* (Her Majesty the Queen in Right of Canada, Gatineau, 2003), 29-30.

³ *Defining Disability: A Complex Issue*.

⁴ World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*, <http://www3.who.int/icf/icftemplate.cfm>.

⁵ Human Resources Development Canada, *Disability in Canada: A 2001 Profile*, 2003, <http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/documents/PALS/PALS000.shtml&hs=pyp>.

⁶ *A Way with Words And Images*.

⁷ *CIA The World Factbook*, <http://www.cia.gov/cia/publications/factbook/geos/ca.html>.

⁸ Lucie Cosette and Edith Duclos, *Participation and Activity Limitation Survey (PALS)*.

This figure is lower than the previous estimate of 14.7% reported by the 1991 Health and Activity Limitation Survey (HALS).⁹ The difference is the result of numerous methodological changes made by Statistics Canada since 1991. Operational definitions of disability, sampling plans, questionnaires and target populations varied greatly between the PALS and HALS documents making comparisons between population rates difficult. Both surveys used filter questions included on the long form of the Canadian census as the basis for the sampling frame. Because surveys are imperfect instruments, however, some individuals with disabilities are not identified by the filter questions. The HALS included respondents who had not reported an activity limitation on the census in order to detect these “false negatives.” For 2001, the filter questions were changed to make them more neutral and better able to detect persons with mild disabilities. The rewording appears to have reduced the number of false negatives, but it has not eliminated them entirely.¹⁰ Thus, disability rates are likely higher than estimated by the PALS report.

Additional problems are presented by the use of census data as the sampling frame. The 2001 census data excluded persons living in the Yukon, Northwest Territories, Nunavut, institutions, and First Nations Reserves where there are a large number of aboriginal people.¹¹ Thirty percent of people of aboriginal heritage in Canada have a disability, suggesting that there are more persons with disabilities in Canada than currently are being reported.¹²

Although the size of Canada's disability population has not changed significantly in the last ten years, the population of the country is aging. Within the next 20 years a significant portion of Canada's population will be over 65 years of age, meaning people with disabilities will make up a greater portion of the population. Approximately 40.5 percent of the population in this age group has a disability.¹³

Legislation & Disability Rights

Legal Protections

Canada has not signed the OAS Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities. However, international law has had an important influence on Canadian law and policy. First, in 1948, the UN passed the Universal Declaration on Human Rights. Second, the UN National Assembly passed the Declaration of the Rights of Disabled Persons in 1975. Third, in 1981 the UN announced

⁹. This figure is lower than the previous estimate of 14.7% reported by the 1991 *Health and Activity Limitation Survey (HALS)*. The difference is the result of numerous methodological changes.

¹⁰. Behnaz Behnia, *A New Approach to Disability Data: Changes between the 1991 Health and Activity Limitation Survey (HALS) and the 2001 Participation and Activity Limitation Survey (PALS)*, Statistics Canada, 2001.

¹¹. *Ibid.*

¹². Edward Ng. “Disability among Canada's Aboriginal Peoples in 1991,” *Health Reports* 8, No. 1 (1996): 25-32.

¹³. Lucie Cosette and Edith Duclos.

The International Year of Disabled Persons and designated 1983 through 1993, the International Decade of Disabled Persons. Canada's response was the creation of a Special Committee on the Disabled and the Handicapped.¹³ In 1981, this committee released a report entitled *Obstacles* that set the direction for Canadian disability policy.¹⁴

Following a period of growth in institutional care that began in the 1920's, human rights movements began to grow in North America during the 1960's and 1970's. These movements catalyzed much of the anti-discriminatory and disability related protection that Canada implemented in the 1980's. Prior to that time, legal protections for people with disabilities were almost nonexistent.

In 1982, the Canadian government passed a Constitutional Act that patriated the Constitution and included The Charter of Rights and Freedoms. Section 15 of this charter guarantees "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."¹⁵ This amendment came into force in 1985.¹⁶ Further, Section 15 states that this policy "does not preclude any law, program, or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups, including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."¹⁷ This reference to affirmative action programs emphasizes that proactive measures may be necessary to correct circumstances of disadvantage.¹⁸

Canada has a number of other laws that specifically reference and protect the rights of people with disabilities. All of Canada's human rights codes prohibit discrimination on the grounds of disability. In 1977, Canada passed the Canadian Human Rights Act (CHRA), which ensures equal opportunity and freedom from discrimination for all Canadians.¹⁹ The CHRA has quasi-constitutional status, being that it prevails over ordinary legislation in the case of ambiguity. Other anti-discrimination laws include: the Employment Equity Act, the Immigration and Refugee Protection Act, the Broadcasting Act, the Canada Transportation Act, the Canada Evidence Act, and the Canada Elections Act.

There are no criminal penalties in cases involving discrimination against people with disabilities in Canada. Only severe violations, in cases of abuse or death, which go beyond non-discriminatory law, have criminal penalties. Abuse of persons with disabilities, especially women and girls with disabilities and persons with intellectual disabilities, remains a human rights concern in Canada.

¹³. Roeher Institute, *Disability Community and Society: Exploring the Links*, (The Roeher Institute, North York, 1996), 9.

¹⁴. Special Committee on the Disabled and the Handicapped, *Obstacles*, 1st sess., 32nd Parliament, 1981e Jerome E. Bickenbach, *Physical Disability and Social Policy*, (University of Toronto Press, Toronto, 1993).

¹⁵. *The Constitution Act*, 1982, <http://laws.justice.gc.ca/en/const>.

¹⁶. Roeher Institute, *Disability Community and Society: Exploring the Links*.

¹⁷. *The Constitution Act*.

¹⁸. Government of Canada Report, *Defining Disability: A Complex Issue*, (Gatineau: Her Majesty the Queen in Right of Canada, 2003), 1, 13-20 <http://canada.justice.gc.ca/en/index.html>.

¹⁹. Canada Human Rights Act, <http://laws.justice.gc.ca/en/h-6/31077.html>.

There is little information gathered on the subject and numbers appear to be lower than estimated due to issues of data collection, disclosure and the nature of care, education and communication of persons with disabilities.

Civil remedies in cases of discrimination usually are monetary and action-based.²⁰ There is little information gathered on the subject, and the number of reported cases appears to be lower than estimated due to issues of data collection, disclosure and the nature of care, education and communication of persons with disabilities.²¹ However, court cases have been an effective method of social action against discrimination for people with disabilities. Important public cases of discrimination of people with disabilities have set precedence in Canada for the law to be upheld, and to recognize and compensate the violations of human rights experienced by many people with disabilities in Canada's past.

Canada has many organizations and entities whose responsibilities include monitoring and keeping records of human rights violations and discrimination against persons with disabilities. They include: Human Rights Commission, Canadian Council on Social Development, Office for Disability Issues, Law Commission of Canada, National Clearinghouse on Family Violence (Health Canada), The G. Allan Roeher Institute, Disabled Women's Network Canada, Canadian Civil Liberties Association, Council for Canadians with Disabilities, Disabled Peoples International, and the Canadian Association of Independent Living Centres. These are but a few of the organizations in Canada dedicated to the awareness and enforcement of the rights of persons with disabilities.

Canada may have anti-discrimination laws, yet systematic barriers continue to hinder the capacity of people with disabilities to exercise their legal rights. There are many reasons people with disabilities do not seek recourse when they experience discrimination in policy areas where anti-discrimination legislation offers protection. Lack of knowledge of their rights, lack of support in exercising their rights, fear of negative consequences, isolation, a slow judicial process, poverty, and barriers to accessing the physical or written environment are some of the obstacles people with disabilities still face.

Legal Barriers

Until 2001, when Canada enacted the Immigration and Refugee Act, disabilities and health impairments were criteria for inadmissibility to the country.²² Instead of fully removing the discriminatory elements of the prior immigration law, the 2001 Act shifted inadmissibility criteria to "health grounds" rather than "disability." Specifically, Section 38 states that a foreign national is inadmissible on health grounds if their health condition "might reasonably be expected to cause excessive demand on health or social services."²³ This new category may remove "disability" but the new "health grounds" stipulation retains the potential for discrimination.

²⁰ Interview with lawyer and member of the Council of Canadians with Disabilities (CCD) International Development Committee, January 2004.

²¹ Interviews with university professors conducted in British Columbia and Manitoba, November 2003- January 2004.

²² Immigration and Refugee Act, <http://laws.justice.gc.ca/en/1-2.5/64155.html>.

²³ *Ibid.*

People with disabilities have historically had their decision-making rights removed through the establishment of guardianship. In recent years, the need to evaluate the role of guardianship in Canada has come into particular attention due to key cases in Canadian courts. Among these is Robert Latimer's murder of his young daughter who had a disability.²⁴ Homicide and filicide (the murder of a child by a parent) deserve special attentions in Canada. In the last ten years, such crimes against people with disabilities have been increasing, yet there has been a decrease in the rates of homicide among the general population. Other cases regarding rights violations have gone through civil court. For example, in 1986, the Supreme Court of Canada ruled that no one can be legally sterilized without personally consenting to the procedure. This ruling was handed down with regard to a woman, Eve, whose mother sought permission to have her sterilized without Eve's informed consent. In the case of Stephen Dawson, his parents wanted to deny him medically necessary treatment because of his disability. Stephen was removed from his parents' custody and permitted to receive appropriate treatment. Lastly, Justin Clark won his release from an institution where he had been kept against his will. These cases demonstrate the continued need for reforms of guardianship.²⁵

Canadian law and support systems for persons with disabilities are now beginning to explore alternatives to legal guardianship for people with disabilities. New ideas encourage a "supported autonomy" rather than the removal of the rights of certain individuals with disabilities. Family networks, advocacy groups and health service professionals can create a network to safely deal with medical treatment issues for certain people with disabilities, thereby maintaining a degree of autonomy for the individual requiring care. Partial guardianship is also an option that allows some decision-making authority to remain with the person with the disability.

Civic Participation

In Canada, every person who is a Canadian citizen and over the age of 18 is entitled to vote.²⁶ People with disabilities also have the right to be elected to public office in Canada although this is rare in practice.

Elections Canada is the agency responsible for conducting federal general elections, by-elections and referendums. It provides services, information, and education to persons who have a disability, seniors, persons with limited reading and writing skills, and persons living in transitional situations such as homeless individuals or persons living in a shelter for victims of abuse.

²⁴. In October 1993, Robert Latimer confessed to killing his 12-year-old daughter with disabilities by running a hose from the exhaust pipe into the cab of his truck where he put his daughter to die. A key case in Canadian history, it was complicated by public feelings that it was a "compassionate homicide."

²⁵. Roeher Institute, Disability Community and Society.

²⁶. Canada Elections Act, <http://www.elections.ca/content.asp?section=gen&dir=bkg&document=ec92610&lang=e&textonly=false>.

²⁷. *Ibid.*

The Canada Elections Act guarantees that electoral material is available in alternative formats and polling stations are accessible.²⁷ In practice this means, when a station is found to be inaccessible or does not accommodate a person with a disability's specific accessibility needs, mobile voting stations are made available or the specific disability is accommodated through other means. As a result 80 percent to 100 percent of polling stations are accessible to people with disabilities in Canada based on the availability of services provided by Elections Canada.²⁶

In the area of information access, Elections Canada provides a special ballot registration forms available on the Internet; documents specifically for persons with disabilities; open and closed captioned videotapes for persons who are deaf or hard of hearing, a voting template for persons with a visual disability; a toll-free information line for persons who are deaf or hard of hearing; and a special ballot, which allows early voting by mail, in person at the office of the Returning Officer, or at home in the case of electors who cannot go to the office of the Returning Officer because of a physical disability.²⁷

To ensure accessibility of polling stations, Elections Canada provides mobile polling stations for certain institutions where seniors or persons with disabilities reside; advance polls and election offices with guaranteed level access; polling stations with full level access, with accessibility indicated on the voter information card; transfer certificates permitting electors with physical disabilities to vote at accessible polls if, in exceptional cases, their own polling stations do not have level access; assistance available at the request of the elector to mark the ballot; and transportation of the ballot box from room to room to facilitate voting in hospitals and certain residential institutions.²⁸ Elections Canada also provides election officials and personnel with specialized training on the accessibility issues for people with disabilities.

Access to voting is a democratic right in Canada, which is made highly accessible to people with disabilities. However, although the rights are there it is often questionable as to whether they are always exercised.

Inclusion

Communication

Barriers to equal access to communication exist, although Canada is working to enact its equality laws by supporting and providing a number of accommodations to people with disabilities. Legislation is currently focused on accommodations for persons who are deaf and persons who are blind. However, communications policy is increasingly recognizing physical disabilities and learning disabilities.

In support of this goal, NLC encourages the sharing of materials in alternative formats and supports Canadian libraries in serving their clients with disabilities.

²⁶ *Ibid.*

²⁷ *Ibid.*

²⁸ Frank Smith (National Coordinator of the National Educational Association of Disabled Students), interviewed by author, Carleton University, Ottawa, January 2004).

Most federal and provincial government documents are available in alternative formats free of charge, including a Braille version of the Constitution. T-Base Communications does the alternative format document conversion for the government. The Canadian government mandates that the National Library of Canada (NLC) promote equitable access to library and information resources. In 2001, by recommendation of the Task Force on Access to Information for Print-Disabled Canadians, the National Library of Canada established the Council on Access to Information for Print-Disabled Canadians. The Council's role is to provide advice, identify funding requirements, monitor progress, and make recommendations for improving access to information for print-disabled citizens. The Council is currently engaged in a pilot project aimed at developing a clearinghouse for Canadian publishers to make their works available to alternate format producers.²⁹

The Canadian Radio-television Telecommunications Commission (CRTC), which regulates the Canadian Broadcasting System, is responsible for administering the Broadcasting Act of 1991. This act sets out specific policy regulations on broadcasting via accessible formats to people with disabilities. Section 3 of the Broadcasting Act states, "programming accessible by disabled persons should be provided within the Canadian broadcasting system as resources become available for the purpose."³⁰ Services for persons with disability required by the CRTC include closed-captioning for at least 90 percent of programming and 100 percent of local news for all major broadcasters. The CRTC also requires the inclusion of the 24-hour news and information reading service, Voice Print Canada, on all major cable and satellite services.³¹ Voice Print Canada airs news and information from Canada's primary publications, including more than 100 newspapers and magazines.³²

In the case of a natural disaster, civil emergency or criminal assault a number of services are available in Canada for people who are hard of hearing or deaf. Medical interpreting is available in hospital settings or when a doctor is involved. Court-certified interpreters are provided in legal settings. In addition, accessible emergency services are federally mandated, and many telephone emergency services have TTY available. Persons who are deaf or hard of hearing are advised to call 9-11 and leave the phone off the hook, signaling help to arrive. Emergency interpreters are available within 20 minutes at all times. Such services are available throughout Canada, or are in the process of being established. With regard to provincial governments, more interpreting services are being established due to the outcome of court cases that have upheld the right to an interpreter.³³ In interveners for persons who are deaf-blind are more difficult to locate. As a result, after the age of 19 many high functioning individuals are provided with no or little interpreting services.

²⁹. Council on Access to Information for Print-Disabled Canadians, National Library of Canada and National Archives of Canada, <http://www.nlc-bnc.ca/6/36/s36-120-e.html>.

³⁰. The Canada Broadcasting Act of 1991, http://laws.justice.gc.ca/en/index/157848_2813.html.

³¹. *Defining Disability: A Complex Issue*.

³². *abilities Magazine*, spring 2004, <http://www.enablelink.org/abilities.html>, 44.

³³. Scott Wilson (Coordinator of Interpreting at The Island Deaf and Hard of Hearing Centre), telephone interview by author.

The Canada Evidence Act was amended to remove communication barriers to the participation of persons with disabilities in the justice system. Section 6 provides for communication assistance for persons who have special communication needs. It states that "if a witness has difficulty communicating by reason of a physical disability, the court may order that the witness be permitted to give evidence by any means that enables the evidence to be intelligible."³⁴ Section 6.1 permits the admissibility of auditory and tactile methods of identifying the accused.³⁵ In addition, several amendments to the Criminal Code were made to enable greater participation by people with disabilities. They permit people with mental or physical disabilities to provide testimony through videotape, enable persons with disabilities to serve as jurors, and improve protection of persons with disabilities from physical and sexual violence. The Department of Justice provides a variety of services for persons with disabilities, including sign language interpreters for interviews or meetings, and access to offices and resource centers.

Education

There is no precise count of the number of school-aged children with disabilities in Canada. According to the PALS, 1.6 percent of all children 0-4 years and 4.3 of children 5-14 years have a disability.³⁶ In contrast, the National Longitudinal Survey of Children and Youth in Canada and the Canadian Council on Social Development concluded that 13 percent of all children aged 11 or younger had a chronic condition or activity limitation excluding allergies, emotional problems and learning disabilities.³⁷

Education is mandatory for all children between the ages of 6 and 16 years in Canada. Statistics Canada reports that 94 percent of the 5.5 million elementary and secondary students are enrolled in the public school system. Approximately, 5.4 percent of students attend a private educational institution. In addition, .4 percent of school-aged children have received approval by their local school boards to be taught at home. About 1600 students in Canada attend separate special schools for students who are visually and hearing impaired.³⁸

By virtue of legislative and judicial action, Canada has generally moved toward an inclusive educational system for students defined as having special needs. A Supreme Court ruling on the Charter of Rights and Freedoms, established that education for students with disabilities should be provided in a regular class environment with reasonable but not excessive adaptation provided to promote equal opportunity in the classroom. In addition, provincial education laws require that school boards make education available to all school aged persons in a district.³⁹ This rule is not consistently implemented across the country because

³⁴ Canada Evidence Act, <http://laws.justice.gc.ca/en/c-5/>.

³⁵ *Ibid.*

³⁶ Lucie Cosette and Edith Duclos.

³⁷ If children with allergies are included, the equation the percentage rises to 23%, and if children with emotional problems are added, the number of disabled children rises to over 30%.

³⁸ Lucie Cosette and Edith Duclos.

³⁹ The School Act, http://www.qp.gov.bc.ca/statreg/stat/S/96412_00.htm.

school districts can interpret both provincial and federal legislation as they deem fit for their unique jurisdiction. Moreover, all institutions and educational authorities do not share the same views on the definition of disability or inclusion.

Because inclusive education is legally required, schools must have a means of identifying those students who are not completely able to adjust to a standard classroom situation as a result of a disability. Students with disabilities go through an assessment and identification process to qualify for teaching assistance, and a modified Individualized Education Plan (IEP) is developed. In some situations, where there is no specifically trained special education assistant or teacher available (for example, in a more isolated rural setting), the school or school board may authorize and provide training for the teaching personnel at a relevant special needs workshop.

Training in special education is available in some of the post-secondary universities and colleges that offer teachers training. There is, however, no nationwide curriculum. At the post secondary level, each college and university offering training for teachers is free to set its own program of study.⁴⁰

The process of detecting disability rests with each individual province or territory. In cases where children with disabilities have been identified prior to enrolling in school, existing assessment and other relevant information will expedite the assessment and implementation of an IEP. Otherwise teachers request assessments for students who are perceived to have a disability. In many cases, a school-based team of professionals responds to the request and initiates the assessment process. The disabilities included within these assessments are hearing, seeing, speech, mobility, dexterity, developmental, learning, and chronic illnesses or disability.⁴¹

Like childhood education, access to post-secondary education is a right, however it is a costly process with many hurdles for people with disabilities wishing to get an education and enter a desired career path. Limitations and barriers within accommodation, access to academic material, attitudes, and financial assistance all provide obstacles for students with disabilities. Access to post-secondary education has become a highly political issue for many Canadians with disabilities — limitations imposed through income assistance programs, intense need to get out of poverty, the right to choice, increasing tuition and the issues of "the duty to accommodate" have all become key issues of students with disabilities. There is some infrastructure in place to support students with disabilities. This includes campus groups, university disability resource centre support staff, financial assistance/grants, loan programs/banks for assistive technology, and federal/provincial/territorial vocational rehabilitation programs. The Canadian Association of Disability Service Providers in Postsecondary Education is a national group of professionals who assist university and college students who have a disability.⁴² Their role is to work towards the removal of institutional barriers, both physical and attitudinal, and ensure that students receive academic and other accommodations which permit them to pursue their studies in an environment of equality.

⁴⁰. Canadian Ministers of Education, *Ministerial Order*, <http://www.cmec.ca/index.en.html>.

⁴¹. Ministry of Education of the Government of British Columbia, http://www.bced.gov.bc.ca/specialed/ppandg/iep_1.htm.

⁴². Canadian Association of Disability Service Providers in Post-Secondary Education (CADSPPE), <http://www.cacuss.ca/en/11-cadsppe/details.lasso?id=319>.

The National Educational Association of Disabled Students (NEADS) is a consumer organization that advocates for increased accessibility at all levels so that students with disabilities may gain equal access to higher education. The association provides information on the resources available to students with disabilities nationwide.

Technology providers like Special Education Technology British Columbia (SET-BC) may provide services including training, loans, and products that enable students to access academic materials in a variety of alternate formats. Some financial assistance for students with disabilities is available through the Canada Student Loans Program (CSLP) and the Canada Study Grant.

Another important initiative is the Multilateral Framework for Labour Market Agreements for Persons with Disabilities, formerly the Employability Assistance for People with Disabilities (EAPD). This initiative supports a broad range of programs and services to respond to the employment and education needs of people with disabilities including: higher education, employment planning, skills training, and assistive devices. The programs are available only to eligible Canadians with disabilities who have clear educational plans. Eligibility criteria vary, and intensive testing may be involved for determining eligibility. Unfortunately, fiscal cutbacks to programs have dictated that fewer students are supported under these programs, and many of the resources have been directed toward short-term programs focused on employability.⁴³

Disability as a field of study in post-secondary institutions is expanding, although some resistance to the field has been encountered due to the cost of the necessary technological aids.⁴⁴ When available, disability subject matter can be seen across disciplines and departments. The University of Manitoba had the first Disability Studies Program. It is an interdisciplinary master's degree program linking the departments of Education, Social Work, and Architecture with a strong focus on disability theory. York University also maintains a Masters Program with a focus on Critical Theory in Disability. The University of Winnipeg and Ryerson also maintain disability studies programs.⁴⁵

There are few formal post-secondary educational options for persons with intellectual disabilities. Depending on the region of the country there may be technical training programs, volunteer opportunities, and learning through job placements. Some organizations such as STEPS Forward in British Columbia are actively working to facilitate inclusive education at colleges and universities.

Employment

The unemployment rate for people with disabilities in Canada is 26 percent, over five times higher than the 5% unemployment rate for people without disabilities. Fifty-six percent of working age adults with disabilities are either

⁴³. Multilateral Framework for Labour Market Agreements for Persons with Disabilities, http://www.sdc.gc.ca/en/hip/odi/08_multilateralFramework.shtml.

⁴⁴. *Ibid.*

⁴⁵. Kerstin Roger (Canadian Centre on Disability Studies), telephone interview by author.

unemployed or not in the labour force, compared to less than a quarter, 24 percent, of working age adults without disabilities.⁴⁶ Thus, more than one million adults with disabilities are unemployed or outside the labour force in Canada. Women and Aboriginal people with disabilities generally face more barriers to employment, and as a result, are more likely to be unemployed. Moreover, once employed, people with disabilities continue to be subjected to discrimination. According to the Public Service-wide Employee Survey released in 2002, nearly 36 percent of federal employees with disabilities have been harassed in the past two years, and 37 percent have been subject to discrimination at least once.⁴⁷

Canada has three principle anti-discrimination laws in the area of employment for people with disabilities. The Canadian Charter of Rights and Freedoms stipulates the provision of interpreters and affirmative action incentives. Second, the Employment Equity Act (EEA) of 1995 ensures that persons with disabilities are granted full and equal access to employment and opportunity. It states that "no person shall be denied employment opportunities or benefits for reasons unrelated to ability and, in the fulfillment of that goal, to correct the conditions of disadvantage in employment experienced by women, aboriginal peoples, persons with disabilities and members of visible minorities."⁴⁸ This act requires the accommodation of difference. Finally, a 1998 amendment to the Human Rights Act further establishes the duty to accommodate.⁴⁹ Accommodation refers to a range of modifications to a given workplace and/or job to promote the employment of persons with disabilities. Modifications can focus on physical, procedural, or attitudinal barriers that prevent persons with disabilities from finding and retaining employment.

Despite these laws, ongoing audits required by the Employment Equity Act have found persons with disabilities severely under-represented in the federally regulated private sector. The most recent 2003 report states that "since the first Employment Equity Act was put in place, of the four designated groups, persons with disabilities have benefited least. Their representation in 2002 remained at 2.3%, virtually unchanged since 1997."⁵⁰ Additionally, they show that the majority of employers are required to sign up undertakings and undergo a follow-up audit before they are in compliance with the law.⁵¹

There are some programs in Canada geared toward training and job placement for people with disabilities. Until the late 1990's, there was one main program that dealt with the employment issues of people with disabilities. The Vocational Rehabilitation for Persons with Disabilities Program (VRPD) was a jointly funded rehabilitation effort on the part of the federal, provincial, and territorial governments. In 1997, the government launched an initiative to develop greater employability and made attempts to improve the VRPD program. Funding

⁴⁶. Statistics Canada, *Participation and Activity Limitation Survey (PALS)*.

⁴⁷. Canadian Human Rights Commission, *2002 Annual Report: Human Rights Challenge*, (2002), http://www.chrc.ccdp.ca/publications/2002_Annual_Report/page2-en.asp.

⁴⁸. Employment Equity Act (EEA), 1995, <http://laws.justice.gc.ca/en/E-5.401/49886.html>.

⁴⁹. Canada Human Rights Act.

is also available through the Opportunities Fund of the Employment Insurance (EI) Program. Nevertheless, there are still barriers in the labour market, and a greater awareness of accommodation needs to exist for both employers and persons with disabilities who are entering the workforce. Thus, despite the programs and anti-discrimination laws that exist in Canada with relation to the employment of people with disabilities, high rates of unemployment continue to persist for people with disabilities.

Health Services

Health services in Canada are highly subsidized; insurance premiums are low in cost and affordable, and certain jobs, including all government positions, offer basic and extended health care benefits free of charge for employees and their immediate families. Canadians considered to be low-income individuals do not pay any premiums and receive the same level of care.

The Canada Health Act, Canada's federal health insurance legislation, has measures in place that prevent discrimination in health insurance coverage for people with disabilities in Canada.⁵⁰ In Section 10 of the Act, the Universality clause states "...all insured residents of a province or territory must be entitled to the insured health services provided by the provincial or territorial health care insurance plan on uniform terms and conditions."⁵¹ Under the Canada Health and Social Transfer, provinces and territories receive a federal cash contribution to administer the conditions stipulated by the Act. There has never been a national strategy of Community-Based Rehabilitation in Canada.

Very little funding is provided specifically for promoting health and rehabilitation of people with disabilities in Canada. For persons with disabilities on income assistance or on medical referral from a physician, medical insurance coverage includes the subsidized cost of medical supplies, medications, and technical aids, like wheelchairs. Occupational therapy is also available to determine the technical aids and environmental modifications needed. In addition, the Worker's Compensation Board will pay for rehabilitation if someone is injured while working.⁵²

Specialized services, like rehabilitation, and prevention are mostly available in larger cities. There are substantial differences between the services available in large cities as compared to smaller cities and towns. Depending on how rehabilitation is defined, services may also vary. Access to rehabilitation and health services mainly applies to people who are acutely ill rather than the chronically disabled. Services may be available for a person with disabilities if his or her disability and rehabilitation fits into the mandate of a specialized centre, like the Arthritis Centre.⁵³ For rehabilitation services from private service providers, one pays for oneself.

⁵⁰ Canada Health Act, <http://www.hc-sc.gc.ca/medicare/chaover.htm>.

⁵¹ *Ibid.*

⁵² "Vocational rehabilitation services," http://www.worksafebc.com/for_employers/vocational_rehabilitation_services/default.asp.

⁵³ Canada Health Act, <http://www.hc-sc.gc.ca/medicare/chaover.htm>.

There is training for physical therapy, occupational therapy, psychiatry for nurses, prosthetic and orthotic training, speech therapy, and the specialized training of physicians, specialists, physiotherapists, and occupational therapists through post-secondary institutions in Canada. Apart from medical specialists dealing mainly with patients with disabilities, few courses for physicians on the specific needs of people with disabilities are available. When it is available, training is run by other health care professionals using a medical model of disability. Attempts are being made to update ideologies of disability within the health care system, however, and rehabilitation is starting to consider individuals with disabilities in a more holistic sense.

Housing

Access to affordable, safe, and accessible housing for people with disabilities has received special attention especially in the last twenty to thirty years as a response to deinstitutionalization. Support includes: subsidized housing, subsidized housing with supportive services, the Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP-Disabilities), the Canada Mortgage and Housing Corporation, and national non-profit organizations. In all cases, programs vary across Canada.

Subsidized housing initiatives are provincially run in conjunction with local health authorities, the private sector, and non-profit organizations. Housing is available to people with disabilities who can live independently and qualify for disability pensions or cannot work because of a disability. Subsidized housing does not cost more than 30 percent of a household's gross monthly income.⁵³ There are three types of affordable housing: directly managed or public housing, non-profit housing, and co-operative housing, which are jointly owned and managed by the members who live in them.

Subsidized housing with a supportive service component is an intermediate option between home care and residential care. Community living options such as group homes for people with intellectual disabilities, supported housing programs for people with mental illness, and Independent Living Units are all examples of Supportive Housing Services for people with disabilities in Canada.

Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP-Disabilities), a program of the Canada Mortgage and Housing Corporation, provides financial assistance to homeowners and landlords who wish to undertake accessibility modifications for dwellings intended for or inhabited by low-income persons with disabilities.⁵⁴

⁵³. BC Housing, <http://www.bchousing.org>.

⁵⁴. Canada Mortgage and Housing CMHC, http://www.cmhc-schl.gc.ca/en/prfias/rerepr/readaspr_005.cfm.

Homeowners are eligible for the forgivable loans if their home is valued below a certain amount and their household income is at or below designated limits based on household size and area. Landlords are eligible for the forgivable loans if the rent price of the units is at or below established levels and tenants with incomes at or below the income limits occupy the units.

There are numerous peer-counselling and referral services available in Canada related to all types of disability needs and services. Most are connected to a national network, where information is shared locally, provincially and nationally. The Canadian Housing and Renewal Association, Canadian Association of Independent Living Centres, Canadian Association of Community Living, Canadian Abilities Foundation, Active Living Alliance for Canadians with Disabilities, and the Council of Canadians with Disabilities, are just a few of the cross-disability non-profit organizations with referral information, advocacy, and research for people with disabilities.

Institutionalization

In 2002, approximately 20,000 Canadian citizens with disabilities were living in long-term care environments, personal care homes, and nursing homes.⁵⁵ More than 12,000 individuals with intellectual disabilities were living in institutional facilities designed specifically for the housing of persons with intellectual disabilities.⁵⁶

Deinstitutionalization has been an on-going process for the last twenty years in most provinces across the country. Available within Canada's Health Act, specialized programs allow children with disabilities to be raised at home, eliminating reliance on institutions. Services provided across Canada include: home care, respite, hospice, and individualized funding as well as outpatient health services like physiotherapy and occupational therapy. There are however obstacles to accessing these services for many families, including variation in eligibility criteria within and across provinces. Moreover, not all families know about the services available to them. Despite policy commitments from provinces during the 1990's to move from institutional to community living arrangements, political, social and economic roadblocks continue to afford limited options.⁵⁷

Institutions have also been the site of extreme victimization and abuse of persons with disabilities, which has included unauthorized sterilization, sexual abuse, neglect, financial victimization, verbal abuse, emotional abuse and physical abuse. Recent studies have found that children with intellectual disabilities were 3.7 times as likely to experience neglect, 3.8 times as likely to experience physical and emotional abuse, and 4 times as likely to be sexually abused. Children with

⁵⁵. "Proposed National Plan on Deinstitutionalization," (discussion paper presented at Canadian Association of Community Living, 2003).

⁵⁶. *Ibid.*

⁵⁷. *Ibid.*

additional disabilities (e.g., intellectual and behavioral disabilities) were even more likely to experience maltreatment. Numbers are similarly high in adults with intellectual disabilities.⁵⁸

There are mechanisms for reporting incidences of abuse in such institutions, such as a Critical Incident Report, but these are internal review processes that can be highly problematic in terms of anonymity.⁵⁹ These reports are compounded with an array of other reporting issues such as unequal power relations, communication, safety and accurate disclosure of abuse in reporting. Thus, by nature, abuse of all forms can be highly underreported, including those cases dealing with persons with disabilities.

There are a number of organizations and entities in Canada that keep records of abuse and violence against people with disabilities; these include: Law Commission of Canada, Canadian Human Rights Commission, Provincial Health Officers (or a congruent provincial position), National Clearinghouse on Family Violence (Health Canada), The G. Allan Roeher Institute, Disabled Women's Network Canada and others.

Accessibility

Currently, provincial building codes uphold Canada's regulations stating that public buildings and facilities must be accessible to people with disabilities.⁶⁰ A national building code is being revised, and there is some debate over how to deal with issues of accessibility. The Canadian Council of Disabilities recommends the use of less subjective language regarding disability accommodation. They suggest that the language of "reasonable accommodation" be replaced with "duty to accommodate". Some NGO's advocate creating more cohesion and consistency across provincial codes, and others are concerned doing so might weaken the building codes in some provinces.⁶¹

Building codes went into effect in 1998. They cover public buildings, including facilities built with public funds or on behalf of the public. Small buildings and houses are exempt from these codes.⁶² The percentage of public buildings that are accessible to people with mobility disabilities is unknown. Most buildings existing prior to 1998 and many built since that time still pose partial to complete barriers for people with disabilities accessing their environment, including safety issues for many persons with disabilities. Barriers that appear minor to most

⁵⁸. Canada Health Act.

⁵⁹. Health Canada, *Family Violence and People with Intellectual Disabilities*, (National Clearinghouse on Family Violence Publication), http://www.hc-sc.gc.ca/hppb/familyviolence/html/fvintelectu_e.html.

⁶⁰. National Research Institute of Canada, http://www.nationalcodes.ca/nbc/questions5_e.shtml.

⁶¹. CCD, "Input Needed to National Building Code," Equality Matters, 13 December 2002, <http://www.ccdonline.ca/publications/equality-matters/1200.htm>.

⁶². British Columbia Building Code, sec. 3.8, 1998, http://www.qp.gov.bc.ca/statreg/reg/L/LocalGovernment/295_98.htm; Telephone interview with employee at BC Building Corporation, Victoria, BC.

people without disabilities often go unnoticed and unfixed. One small step into a shop or restaurant is very common yet makes a building completely inaccessible to someone with a mobility impairment.⁶² Accessible entrances are sometimes dangerous and poorly marked.

Across Canada, concepts of universal design are a component of studio programs in architecture. Post-professional courses are offered across Canada through private universities and colleges and independent publishers and designers.⁶³ Yet universal design is not fully implemented in most plans, and it is not a part of engineering programs.

The Canadian Transportation Agency (CTA) administers the Canada Transportation Act of 1996. The Agency is responsible for enforcing the act, which addresses issues of accessibility and obstacles for people with disabilities within the Canadian transportation system. The act states that "a safe, economic, efficient, and adequate network of viable and effective transportation services accessible to persons with disabilities" must be available in Canada.⁶⁴ Regulations recommend the design, construction, and modification of accessible signage, the training of personnel, special consideration of the cost of transportation to people with disabilities, and the communication of information in accessible formats. The CTA addresses accessibility violations on a case-by case basis, as well as addressing the systemic barriers in the Canadian transportation system.⁶⁵

There is an accessible bus system in all major cities in Canada, including the capital city of Ottawa. In Toronto, Canada's largest city, four GO Bus routes are accessible, and a number of busses "kneel" with the use of hydraulics, lowering the bus and a ramp to allow people with mobility disabilities access to the bus. Additionally, thirty-six of GO's 53 train stations are fully accessible to passengers who use mobility devices.⁶⁶ In Ottawa, the OC Transpo, Ottawa's public transportation system, has three categories of accessible public transit; ParaTranspo, which provides door-to-door transportation service for persons with disabilities; designated bus routes, which are fully accessible low floor buses; and additional bus routes that provide some accessible service.⁶⁷

⁶². Further examples include, bathrooms located in the basement of a building, or cubicles too small to enter, double doors/heavy doors, no Braille signage, no elevators to a second storey, elevator buttons that are unreachable or unclear, lighting so poor in a library or book store so that people with visual impairment can't see, only audio emergency instruction or information available, ramp inclines that cause a wheelchair to flip, no "cut-outs" in curbs to access a side walk, counters too high to see over or reach the surface of, bank machines with no Braille and buttons that cannot be reached from a wheelchair.

⁶³. Information provided by the University of Victoria Engineering office and the University of British Columbia.

⁶⁴. Canada Transportation Act, <http://laws.justice.gc.ca/en/C-10.4/24543.html>.

⁶⁵. Canadian Transportation Agency, Accessible Transportation, http://www.cta-otc.gc.ca/access/index_e.html.

⁶⁶. GO Transit website, *Accessible GO Transit Services in Greater Toronto Area*, <http://www.gotransit.com/public/aboutgo/accessibility.htm>.

⁶⁷. Ontario's Public Transportation, *Accessibility Services for persons with disabilities*, http://www.octranspo.com/acc_menue.htm.

The city of Victoria, the capital of the province of British Columbia exemplifies the wide range of ground transportation options for people with disabilities. The city of Victoria offers accessible low-floor public-use buses that “kneel”; the Community Travel Training Program, a free service that provides training to seniors and individuals with cognitive or physical disabilities who wish to use the conventional transit service; HandyDART, a door-to-door shared-ride custom transportation service; and a Taxi Saver Program, which provides a 50% subsidy towards the cost of taxi rides.⁶⁸

Many cities in Canada have a combination of similar types of services available in their city as in Victoria, Ottawa and Toronto. Transportation for people with disabilities, however, is not always a smooth process. Barriers within the accessible transportation system include a wait-list for door-to-door services and required advance booking; the small number of accessible taxis; and flat rate charges by many taxis, which are costly. In addition services are often over-booked and are unreliable with respect to pick-up time. Not all train stations are accessible, and limited space may be available in accessible seating. Overall, however, there is a good variety of accessible and often affordable transportation in Canada.

Air transportation has pre-boarding, assistance on and off the airplane and special seating to accommodate disability needs of passengers. Certain airlines offer “attendant” rates, at as much as half off the price of a regular price ticket. However, one has to give explicit direction for care of a wheelchair, to assure it does not get broken or damaged during the transport. Air travelers with disabilities must often actively demand these rights with air carriers, for they are rarely extended freely.

⁶⁸. Victoria Regional Transit System, *Guide to Accessible Transit Services*, http://www.busonline.ca/regions/vic/accessible/family_of_services.cfm.

Disability Action & Awareness

At the national level in Canada, disability policy development is coordinated by the Office for Disability Issues (ODI). Guided by the Canadian government's Disability Agenda, ODI has a mandate to foster policy and program coherence, build the capacity of the voluntary sector, and build awareness. Human Resources and Skills Development Canada maintains its programs. There are four divisions within the ODI.⁶⁹

The first division, the Programs & Network Development Division, manages three programs to support people with disabilities. The Social Development Partnership Program - Disability Component (SDPP-D) was founded in 1998 and provides grants to non-profit organizations working in social development. The Opportunities Fund (OF) for Persons with Disabilities is a \$30 million fund that aids eligible persons with disabilities to prepare for, obtain and keep employment or self-employment. The third program is the aforementioned Multilateral Framework for Labour Market Agreements for Persons with Disabilities (previously EAPD.) The second division, the Policy Coordination and Knowledge Management Division is comprised of two units, the Knowledge Development Unit and the Policy Coordination and Information Management Unit. These units are responsible for developing knowledge and research on disability-related issues. The Strategic Planning and Corporate Services Division provides overall corporate support such as, business planning, staffing, budgeting and so on.⁷⁰ Finally, the Disability Policy Division is responsible for the analysis and development of policy options and directions.⁷¹

Areas of priority in the Office for Disability Issues (ODI) Strategic Plan 2002-2007 include housing, assistive technology, inclusive early childhood development, access to post-secondary education and training, accessible transportation, personal services, inclusive communities, accessible information, employer needs and attitudes, incentives to work and workplace accommodation, and school to work transition. The ODI Strategic Plan is implemented through a variety of partnerships.⁷²

Apart from governmental initiatives in the area of disability action and awareness, Canada has an active NGO, non-profit and voluntary disability action and awareness movement. These organizations span the entire country and range from community-based grass-roots disability lobbying groups to cross-disability national organizations running on millions of dollars budgets. These organizations represent different types of disabilities and issues in the community and varying political or apolitical positions.

⁶⁹. Office for Disability Issues, http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/01_about.shtml&hs=py.

⁷⁰. *Ibid.*

⁷¹. *Ibid.*

⁷². Office for Disability Issues, *Office for Disability Issues (ODI) Strategic Plan 2002-2007*, (Her Majesty the Queen in Right of Canada, Gatineau, 2002).

Most of these organizations are run through a combination of fundraising, volunteerism, special project funding, and community support. These organizations create a national network for research, formal publications and e-zines/zines, information, resources, support, events, government consultations, and advocacy for people with disabilities.



Chile

Key Factors: A welfare-based approach to disability issues prevailed in Chile for many years.¹ After the departure of the military regime and the establishment of democracy in 1990, social issues became an integral part of the political agenda. Government resources have been redirected to develop programs that enhance education, health, housing, and the quality of life for the most needy, including people with disabilities. Law 19284 on the Social Integration of Persons with Disabilities was enacted in 1994 as part of this shift in the political landscape.² Ten years later, however, the pace of integration of people with disabilities into the various social sectors is still slow.

Terminology

Early legislation regarding people with disabilities focused primarily on protections rather than rights. Among the terms used in such laws were “lisiado” and “inválido”, translated as “crippled” and “handicapped,” respectively. In addition, the phrase “incapaz”, translated as “mentally retarded,” was used to refer to persons with mental retardation. When directly quoting from documents, the original language has been retained.

¹ Office of Multilateral Policy of the Ministry of Foreign Affairs, 24 September 2003.

“During the government of Augusto Pinochet no global or social integration policies were in place concerning persons with disabilities. Things only began to change in 1994 when Law 19284 on the Social Integration of Persons with Disabilities was enacted. Until the 70s in Chile there was no specific piece of legislation regarding persons with disabilities. Most provisions concerning the disability sector could be found in general laws that more often than not established protection measures (incapacity) and certain prohibitions based on the actual or presumed difficulty and incapacity to carry out some legal actions such as to make a will, to adopt children, to bear witness, to marry, etc. Very few specific laws on disability existed including a law on vehicle import for crippled persons and a law establishing a Social Security Pension Scheme for handicapped and mentally retarded persons.”

² Law 19284, *Integración Social de las Personas con Discapacidad* [Social Integration of Persons with Disabilities Act], (Santiago, Chile, January 1994), www.fonadis.cl.

Definition of Disability

The Ministry of Health defines a person as having a disability when they cannot “meet the demands of the environment as compared with a non-disabled individual of the same age, gender, training, social status, family status, and geographical location as the individual to be assessed.”³ The Ministry's definition of both impairments and disabilities is in accordance with those of the World Health Organization. Impairments include “intellectual/mental impairments,” “sensory impairments,” and “physical impairments.” Disabilities are categorized as learning, labor, or social integration disabilities.

The definition found in section 3 of Law 19284 identifies a person with disabilities as “any individual who is restricted in at least one third of his or her ability to perform educational, labor or social integration activities, as a result of one or more congenital or acquired physical, mental or sensory impairments, and which can be expected to be permanent, regardless of their cause.”⁴ According to Decree Law 869 on Social Security Pensions, persons may be classified as low-income individuals with disabilities when they are over the age of 18 and under the age of 65, meet the disability criteria established by Law 19284, and do not have an income of their own or have an income lower than the minimum monthly wage as established by law.⁵

Disability Population

Disability statistics in Chile are not reliable.⁶ According to the last census conducted in 2002, Chile has a total population of 15,401,000 people of whom 334,377 (2.2%) are persons with disabilities.⁷ Other national surveys of people with disabilities have obtained very different figures.

³ Mauricio Zepeda Sanchez (Deputy Director for Studies and Planning) and Eladio Recabarren Hernández (FONADIS Deputy Director's Office), email response, 9 September 2003.

⁴ Law 19284, www.fonadis.cl; Proposed amendments to Law 19284 on the Definition of person with disabilities states that: Leonor Cifuentes (Head of the FONADIS Legal Department), interviewed by author, Santiago, 12 August 2003. “...any individual who, as a result of one or more physical, mental or sensory impairments, has objective difficulties for his or her social integration, personal development or autonomy.”

⁵ Decree Law 869, (1975), http://www.bcn.cl/publicadores/pub_leyes_mas_soli/admin/listado_leyes_mas_soli.php.

⁶ Georgina Trincado (Documentation Center of the National Statistics Institute), interviewed by author, Chile, 7 October 2003.

⁷ *ibid.*

The 2000 National Social and Economic survey (CASEN) found 788,509 (5.3%) persons with disabilities, more than twice the number identified by the census.⁸ An even greater discrepancy may be found in the results of the “Quality of Life and Health” survey (ENCAVI), conducted by MINSAL in 2000, which found that 21.7% of the population has at least one disability.⁹ The fluctuation in these numbers may be the result of insufficient training of interviewers, differences between survey methods, and the underreporting of disabilities among elderly people.¹⁰

Table One shows the variation in size of the disability population resulting from different definitions and methodological approaches. According to the CASEN survey, people aged 60 and older make up the largest segment of the population affected by disabilities, comprising 37.5% of the total disability population.¹¹ Thus, any undercount of this population segment could greatly impact the final results.

Table 1: Number of persons with disabilities by survey

	Question frame	%	# of persons
CENSUS 2002 (INE) ¹²	Impairments (“Total”)	2.2%	334,377
CASEN 2000 (MIDEPLAN) ¹³	Impairments (Moderate and Severe)	5.3%	788,509
ENCAVI 2000 (MINSAL– NE) ¹⁴	Difficulties (Mild and Severe)	21.7%	3,292,296

⁸ Ministry of Planning and Cooperation, *Encuesta de Caracterización Socioeconómica Nacional (CASEN)* [National Social and Economic Survey], Chile, 2000, <http://www.mideplan.cl/sitio/Sitio/estudiosdiscapacidad2000.pdf>. Data from the 1996 CASEN survey found that 4.3% of the country’s population were persons with disabilities.

⁹ Chilean Ministry of Health (MINSAL), Epidemiology Department, Health Promotion Department, MINSAL/PAHO/WHO.

¹⁰ Mónica Vial (an elderly woman from the Providencia Center for Senior Adults,) interviewed by author. When asked about why she had not told the CENSUS interviewer that she had bad eyesight, she answered: “He didn’t ask me anything like that, and it must be due to my age”. Similar reply given by another senior whose hearing was much below normal: “The interviewers only asked if I suffered from some kind of disability and I don’t.”

¹¹ *Encuesta de Caracterización Socioeconómica Nacional*. According to the survey, more than half the persons with disabilities in Chile actually or potentially have difficulties in seeing and hearing. A total of 283,842 people stated that they had visual impairments, and 224,874 had hearing impairments. These are followed by persons with physical disabilities (130,363), mental disabilities (71,259), speech disabilities (45,725) and psychiatric disabilities (32,446). A total of 40.4% of this population segment lives in the Metropolitan Region, followed by 12.8% in the Bio-Bio region, and 10% in the region of Valparaíso. The greatest number of persons with disabilities live in rural areas.

¹² National Statistics Institute (INE), *CENSUS*, Documentation Center, Chile.

¹³ *Encuesta de Caracterización Socioeconómica Nacional*.

¹⁴ National Statistics Institute and the Ministry of Health, *Encuesta sobre Calidad de Vida* [Quality of Life Survey], Chile, 2002, <http://www.minsal.cl>.

Unlike the census and CASEN surveys, the ENCAVI project is a health survey, designed using newer health and disability models. The increased percentage of persons with disabilities is at least partially accounted for by the use of these new conceptual frameworks defining disability in social terms rather than strictly as a health condition.¹⁵

Because of the differences in survey results, the Disability Councils in several municipalities are promoting initiatives to obtain more accurate data. This work is especially important since the conditions under which people with disabilities live varies widely throughout the country, and the current data set does not provide a sufficient basis from which to draw more locally relevant conclusions.¹⁶ The National Disability Fund (FONADIS) is preparing a national survey to gather disability data in 2004. FONADIS director, Andrea Zondek, referred to the initiatives of grassroots organizations and stated: "I would suggest that the municipalities should be patient, and should not spend funds which they could invest directly on integration measures. In 2004, we will carry out a survey using an instrument that is supported by the Pan-American Health Organization and has been used in other countries."¹⁷

Legislation & Disability Rights

Legal Protections

The Universal Declaration of Human Rights, which was adopted by the General Assembly of the United Nations on 10 December 1948, provides a foundation for the inclusion of all Chileans in the public agenda, government policies, and social plans. Chile has since, signed the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Rights of the Child, and various other international agreements.¹⁹ Chile signed the Inter-American Convention on the Elimination on All Forms of Discrimination Against Persons with Disabilities on 6 August 1999, ratified it on 12 April 2001 and deposited the relevant instrument on 26 February 2002.¹⁸ With regard to the United Nations Standard Rules, Chile answered the questionnaire solicited by United Nations Special Rapporteur on Disability Bengt Lindqvist, and the relevant report was submitted to the permanent delegation at the United Nations on 8 April 1996.²⁰

¹⁵. Mauricio Zepeda Sanchez and Eladio Recabarren Hernández, 9 September 2003.

¹⁶. Mauricio Zepeda Sánchez.

¹⁷. MERCADIS, *Noticias: Al Detalle* [News: To the Detail], (Santiago, 10 July 2003), <http://www.emol.cl>.

¹⁸. Organization of American States, *Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities*, www.oas.org.

¹⁹. United Nations, *International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and Convention on the Rights of the Child*, 10 January 2003, <http://www.un.org>.

²⁰. Bengt Lindqvist visited Chile in November 1996 and again in January 1998.

Chile has expressed support for the creation of a United Nations Comprehensive and Integral Human Rights Convention on Disability. The Ministry of Foreign Affairs and FONADIS reported that “Chile adheres to the idea that human rights and disability are closely related, within the general context of the struggle against discrimination. From that standpoint and as a member of the United Nations Organization, Chile clearly faces the challenge of contributing to and extending the scope of International Public Law, a field of Law under development, which plays an increasingly predominant role in protecting the rights of persons with disabilities.”²¹

With regard to national legislation, the Political Constitution establishes rights for all Chileans.²² There are, however, no specific protections for persons with disabilities provided under the constitutional guarantees.

On 5 January 1994, Law 19284 on the Social Integration of Persons with Disabilities was enacted, using the UN Standard Rules as a guideline. Its purpose is “to establish the manner and conditions for the full integration of persons with disabilities into society and ensure the full enjoyment of rights recognized in the Constitution and the law to all persons.”²³ It obligates the state to provide programs in the area of disability prevention and rehabilitation, as well as access to culture, information, communication, the built environment, education, training, labor insertion, and customs exemptions to help import technical aids. The law created a National Disability Register under the Civil Registry and Identification Office and FONADIS.

Law 19284 also establishes that any person who, “due to an arbitrary or illegal act or omission, is discriminated against or is threatened in the enjoyment of the rights or benefits recognized by the law, may appear by himself or herself or be represented by any person before the competent Local Police Court of his or her domicile, which must take immediate steps to ensure and reestablish the right that has been affected.”²⁴ Penalties include fines and the potential removal from the National Disability Register. Individuals and corporations are both subject to this provision.

²¹. Office of Multilateral Policy, Ministry of Foreign Affairs and FONADIS, Chile, 24 September 2003.

²². La Constitución Política del Gobierno de Chile [The Political Constitution of the Chilean Government], art. 1, 8 August 1980 sets forth: “Men are born free and equal, in dignity and rights. (...) The State is at the service of the individual and its goal is to promote common welfare. To this effect, it must contribute to the creation of the social conditions which permit each and every one of the members of the national community to achieve the greatest possible spiritual and material fulfillment, with full respect for the rights and guarantees established by this Constitution. It is the duty of the State to safeguard the national security, to provide protection for the people and the family, to promote the strengthening of the latter, to further the harmonious integration of all the sectors of the Nation and to ensure everyone the right to participate in the national life with equal opportunities”. Also, article 19 guarantees to all persons: Equality before the law. In Chile there are no privileged persons or groups. (...) Freedom to work and protection of that freedom. (...) Any discrimination which is not based on personal skills or capability is prohibited, although the law may require Chilean citizenship or age limits in certain cases”.

²³. Law 19284.

²⁴. *Ibid.*

In addition to the provisions of Law 19284, some laws specify penalties for violations of the rights of persons with disabilities these include the Criminal Code and the Minors Act, among others.²⁵ The National Service for Minors (SENAME) assists children both with and without disabilities who are under the age of 18 and have been subjected to any kind of abuse. However, there are no specific procedures for reporting abuses against most persons with disabilities.

Municipal governments, which are independent from the central administration, implement policies issued by the central government. There are 12 municipal offices within the Santiago Metropolitan Region that provide social services and assistance in obtaining assistive devices and scholarships that are available through FONADIS.²⁶

Legal Barriers

The Civil Code establishes that persons who are deaf and cannot speak are declared “legally incapable” if they cannot make themselves understood in writing. Once declared legally incapable, persons cannot marry or administer their property. These provisions are currently under review. Amendments have been proposed that would eliminate these restrictions along with others prohibiting some persons with sensory impairments from becoming judges or notaries public and from acting as witnesses.²⁷

Similarly, the law states that “any adult who is under a permanent state of insanity must be deprived of the power to manage his or her own property, even if he or she has lucid intervals.”²⁸ Section 16 of Law 18825 states, “the right to vote will be suspended when a person is declared legally incapacitated on the grounds of insanity.”²⁹ In the case of both persons who are deaf and persons with severe mental disabilities, guardians are appointed to, in theory, protect their interests.

Civic Participation

Voting is compulsory in Chile unless a citizen has a qualified exemption. Among those exempted are those who cannot reach polling stations, such as people who are bedridden or in the hospital, people over the age of 70, and people with disabilities who cannot vote because they have no one to accompany them. Exemptions must be certified at the nearest police station. A family member or any person who presents the voter’s identity card may obtain a certification of exemption.

²⁵. Código Penal Chileno [Chilean Criminal Code], sec. 363, www.cajpe.org.pe/rij/bases/legisla/chile/codpench.htm. Section 363 of the Chilean Criminal Code establishes specific penalties for the rape of a young person with mental disabilities.

²⁶. FONADIS, Ñuñoa Municipal Disability Council, Directorio Metropolitano de la Discapacidad [Metropolitan Disability Guide Book], (2002); Emma Lohaus (social worker responsible for Community Promotion in the Municipality of La Pintana), interviewed by author, 2000 and 2001. There is neither coordination nor are there any common guidelines across these offices.

²⁷. Leonor Cifuentes (Head of the FONADIS Legal Department), email response, Chile, 12 August 2003.

²⁸. Civil Code, Sec. 456.

²⁹. Law 18825, <http://www.bcn.cl>.

Leaders of disability organizations estimate that around half of polling stations are accessible during elections. Temporary ramps are often installed, and Civil Defense or military personnel provide assistance to persons with mobility impairments. People with disabilities may be accompanied to the voting booth by a person they trust.³⁰ There are special ballots for the blind.³¹

Since over half of the polling stations remain inaccessible, fulfilling the obligation to vote is still very difficult for many people with disabilities. According to one report, "officials who are responsible for implementing the law determine which facilities should be available to this group (people with disabilities). In practice, this situation has led to abuses including flagrant violations of these voters' rights on the part of various officials in the electoral process, bringing greater 'political apathy' than is usual in average citizens of this country."³² In addition to facing architectural barriers, people with disabilities who wish to vote may also lack access to information on candidates or their political platforms, as this type of information is often not available in alternative formats.

Inclusion

Communication

Section 20 of the Integration of Persons with Disabilities Act states that "public libraries shall gradually make available materials and facilities usable by persons with visual impairments." The Chilean National Library, which is located in the capital of Santiago, does not contain a Braille version of the Political Constitution, although some other publications are available for persons who are blind.³³ The Tape-Recording Center, the National Library for the Blind, and the Special Schools for the Blind have alternative format versions of the Constitution.³⁴ The Central Library for Blind Persons publishes the first Braille magazine for children and youth with visual impairments.³⁵ The magazine was launched in response to the lack of educational and informational resources in alternative formats.

Although the Integration of Persons with Disabilities Act mandated that stations "implement audiovisual communication mechanisms and provide persons with hearing disabilities with access to information in news shows," historically broadcasters had been very reluctant to do so.³⁶ Both the Televisión Nacional of Chile and the television station associated with the Catholic University of Chile have a daily news program with simultaneous sign language interpreting.³⁶

³⁰. Panel discussion with leaders of the disability organizations, discussion facilitated by author, Santiago, Providencia, 30 August 2003.

³¹. Mauricio Zepeda Sánchez and Eladio Recabarren Hernández, 9 September 2003.

³². Maria Soledad Cisternas Reyes (Associate researcher of the Center of Legal Research and Director of the Legal Program on Disability), "Examining Chilean Election Laws and the Rights of Voters with Disabilities," (School of Law, Diego Portales University, Chile, November 2001, http://www.electionaccess.org/publications/BP_TOC.htm).

³³. Interview with a National Library Official, Santiago, 30 June 2003.

³⁴. The National Library for the Blind and the Special Schools for the Blind are subsidized by the government.

³⁵. FONADIS, <http://www.fonadis.cl/index.php?seccion=37>.

³⁶. This system was first implemented in Chile in the 1980s. However, TV stations discontinued it. In 2002 it was restored thanks to efforts made by the Chilean Club of Deaf Persons in lobbying television executives.

In 2003, the National Television Association (ANATEL) came to an agreement with organizations of people who are deaf, committing to offer sign language interpretation of the noon news. Each of the five networks airs the news with sign language interpretation for a three-month period. This alternation allows for broad participation by the networks affiliated with ANATEL and permits access to news programs with various viewpoints for persons who are deaf.³⁷ The advocacy efforts of deaf organizations was extremely important to this initiative.

The FONADIS has a website that is accessible to persons who are blind or have visual impairments.³⁸ However, the National Emergency Plan contains no method or strategy for persons with disabilities to communicate with authorities in case of emergencies or natural disasters.³⁹

Resolution 316, issued by the Undersecretary of Telecommunications, mandates the installation of accessible public telephones by telecommunications companies. Necessary adaptations include volume control for people with moderate hearing disabilities and large keys and Braille instructions for people who are blind or visually-impaired. Maximum and minimum heights are also established.⁴⁰ Nationally, the adaptation of the Chilean telephone service is just beginning. A positive example is a telephone for the deaf that is available in the headquarters of the electrical utility, Chilectra, in Maipú, Santiago.

Education

The Integration of Persons with Disabilities Act specifies that equal educational opportunities be available for persons with disabilities. Only under exceptional circumstances should they be directed to special schools. The Ministry of Education has issued a regulatory order, intended to ensure that the law is implemented. The Ministry of Education also oversees the funding and evaluation of programs. Schools that integrate students with disabilities can request special subsidies for additional human and material resources.⁴¹

As with the larger disability population, Chile lacks reliable data on the number of school-aged children with disabilities. Table one shows the number of children enumerated by the census and CASEN surveys. No accurate information is available regarding the population aged 6-16.⁴²

³⁷ FONADIS, www.fonadis.cl/index.php?seccion=17&articulo=693#centro. TVN and Channel 13 participate in the rotation of providing sign language interpretation of the news.

³⁸ Law 19284, sec. 9.

³⁹ FONADIS, <http://www.fonadis.cl/index.php?seccion=37>.

⁴⁰ FONADIS, <http://www.minterior.cl>.

⁴¹ <http://www.fonadis.cl/index.php?seccion=15&articulo=413>.

⁴² Ministry of Education, *Reglamento del Título IV de la Ley 19.284 que establece Normas para la Integración Social de Personas con Discapacidad* [Regulations for Law 19284 establishing rules for the Social Integration of Persons with Disabilities], <http://www.inclusioneducativa.cl/documentos/ley19284reglamento.pdf>.

⁴³ Documentation Center of the National Statistics Institute (INE), *2002 Censo de Población Año* [Population Census].

Table 2: Population of Children with Disabilities by Age Range⁴⁴

Survey	Age range	# of persons
Census	5-9	10,538
	10-14	15,304
	15-19	14,815
	Total	40,701
CASEN	0-5	26,021
	6-18	121,430
	Total	147,451

Figures are approximated using the percentages provided in the CASEN report.

According to the CASEN survey, 87.6% of children with disabilities receive some level of education as compared to 93.4% of children without disabilities. The students with disabilities also receive less education on average than those without disabilities, completing 6.4 years of schooling and 10 years of schooling, respectively.

Integrated education is available in most small and large towns, while special education schools are located in major cities of the country. Approximately 19% of elementary school children with disabilities receive their education in an inclusive setting, one where students are grouped in classes by age. For example, the Cardenal Antonio Samoré School, situated in the metropolitan region, has 1,500 students. It is one of the most active educational establishments, and has been integrating children and youth with physical disabilities since the early 1990s. Most elementary schools, however, do not have trained support staff for children with disabilities. Instead, family members may be allowed to assist the students with some activities.

All students who are advancing to high school are integrated into regular schools regardless of whether they completed their elementary education at a regular or a special school. Thus as noted above, many children with disabilities do not participate in secondary schooling. The Special Education Unit of the Ministry of Education (MINEDUC) has reported that there are currently about 1,000 high school students with different kind of disabilities enrolled in integration projects. Most secondary school students are taught in special classes in regular schools.⁴⁵

⁴⁴. *Censo de Población Año 2002*, MIDEPLAN, División [Social Division], CASEN, *Encuesta de Actividad Económica* [Survey - Employment], www.mideplan.cl/sitio/Sitio/estudio/discapacidad2000.pdf.

⁴⁵. Mauricio Zepeda Sanchez and Eladio Recabarren Hernández, 14 October 2003.

The MINVU General Ordinance on City Planning and Construction states that educational establishments with over 300 students must have wheelchair-accessible toilets.⁴⁶ The Ministry of Education is drafting additional regulations.⁴⁷ Although there are no data on the number of educational establishments meeting the MINVU requirements, 600 schools had "integration projects" as of 2001.⁴⁸ The main office of the Ministry of Education in Santiago is accessible for persons with disabilities.

The Ministry of Education is responsible for the distribution of textbooks in Braille to children with visual impairments who are integrated into regular elementary schools. The FONADIS works with public agencies and private institutions to finance projects aimed at the development of materials and technical aids for people with visual impairments (books, scale models, manuals, educational materials, etc.).⁴⁹ For example, one remarkable project provided Braille spelling books to 400 children who are blind and from low-income families. The initiative was financed by FONADIS with the assistance of the Gendarmery and the Santa Lucía Residential School for the Blind.⁵⁰

In Chile, special education training is not required by the national teacher curriculum, but optional courses are available. Teachers may obtain a degree in "Differential Education," which is specifically concerned with disability-related issues.⁵¹ A new distance learning course on "Integration into Regular Education" is being targeted at 4,500 elementary education teachers throughout the country.⁵²

In October of 1998, the Educational Integration Network (RIE) organized a one-day seminar on "School Integration in Chile" at UNESCO headquarters. Participants included 52 education professionals, who are working, directly or indirectly, to mainstream children and youth with disabilities within the education system. As a result, a committee was established which suggested that the topic of integration be included in elementary education curriculum, programs, and teacher training. The committee also proposed increased research on the topic of integration.⁵³ The Ministry of Health is in charge of two programs for the early detection of disabilities, namely, the High Risk Pregnancy Program and the Healthy

⁴⁶. The Ministry of Housing and City Planning, by means of Order dated 29 December 1998, www.minvu.cl, established that: "Within a three-year term, as from the date of publication of this order in the official gazette, the existing buildings for public use, the construction of which has been duly authorized and verified upon completion of works, especially such buildings where health services are provided or teaching/learning activities are carried out shall meet the minimum requirements established under section 4.1.7 of Executive Order 47."

⁴⁷. Cecilia Leiva (Architect from the Urban Development Division of the MINVU), interviewed by author, Chile, 17 June 2003.

⁴⁸. Enrique Norambuena, "*Inclusión de Niños con Discapacidad en la Escuela Regular*" [Inclusion of Children with Disabilities in Regular Schools], (debates, Challenges in Educational Policy, HINENI, UNESCO, UNICEF. Chile, December 2001).

⁴⁹. Mauricio Zepeda Sanchez and Eladio Recabarren Hernandez, 9 September 2003.

⁵⁰. FONADIS, <http://www.fonadis.cl/index.php?seccion=17&articulo=693#centro>. The spelling books were made by 11 prison inmates of the Zenda Workshop of the Chilean Penitentiary.

⁵¹. Maria Herrera (Spanish Teaching student at the Teachers' University of Santiago), interviewed by author, June 2003.

⁵². The course is being implemented by FONADIS and is financially supported by MINEDUC.

⁵³. <http://www.inclusioneducativa.cl/documentos/jornada.pdf>

Child Monitoring Program, both implemented by Primary Health Care Clinics.⁵⁴ These programs cover mental, intellectual, sensory, and physical disabilities. Once a disability has been detected, the family is given information and advice concerning subsidies, pensions, and procedures to obtain a disability certificate from the National Disability Register. They are also given information on treatment and rehabilitation services available in the various health care networks.⁵⁵

Persons with disabilities over the age of 18 may attend vocational workshops offered by 346 Special Schools across the country. Sheltered workshops are also available at both public and private health institutes.⁵⁶ There are no University-level courses on disability policy, disability rights, or inclusive education.

Employment

The Social Integration of Persons with Disability Act requires the state to “create favorable conditions for the employment of persons with disabilities in order to ensure their independence and personal development, and to enable them to exercise their right to have a family and to live a dignified life.”⁵⁷ However, unemployment is still an important problem for people with disabilities and a main focus of the current national disability policy. Only 25.1% of persons with disabilities have some form of employment in comparison to 51.6% of the general population.⁵⁸ The difference is even more striking with regard to full time employment. About 13% of people with disabilities have full time employment, which is approximately 1/3 the 38.8% employment rate of the general population.⁵⁹

Job training for people with disabilities is available from the National Training and Employment Service (SENCE) and the Technical Training Agency (OTEC). FONADIS, regional governmental organizations, secular organizations, corporations, and community organizations of persons with disabilities all finance these programs. The FONADIS finances a job placement program as well as other projects including sheltered workshops and employment support for persons with disabilities who are already working. In addition, Rotary Funds, distributed by organizations in the private sector, are available for micro-enterprises run by persons with disabilities.⁶⁰ Finally, Law 19284 extends the age until which a person with disabilities can enter into a traineeship agreement from 21 to 24.

⁵⁴ Mauricio Zepeda Sanchez and Eladio Recabarren Hernandez, 9 September 2003.

⁵⁵ *Ibid.*

⁵⁶ *Ibid.*

⁵⁷ Law 19284, sec. 37.

⁵⁸ FONADIS, <http://www.fonadis.cl/tools/resources.php?id=103>.

⁵⁹ *Ibid.*

⁶⁰ Mauricio Zepeda Sánchez and Eladio Recabarren Hernández, 9 September 2003.

Obstacles to labor integration include physical barriers, a lack of workplace accommodations, and a lack of awareness by employers. The FONADIS concluded that employers are not necessarily prejudiced against people with disabilities, but lack information about the possibilities of, and advantage to, hiring them. Evaluations conducted of the employers who have hired people with disabilities, such as Fantuzzi and Telefonica de Chile, show satisfaction with the skills, performance, and commitment of their employees with disabilities.⁶¹ Consequently, some employers have begun hiring persons with disabilities. Examples include IBM, which has a policy for hiring persons with disabilities, and the State Bank, which does not have a specific policy. With regard to government employment, there are currently a large number of public officials with disabilities (approximately 700), and some hold mid-level positions.⁶²

One additional barrier to employment is the lack of job security in Chile. Upon obtaining work, people with disabilities lose their Social Security Disability Pension (PASIS) and other social benefits. A person is more financially secure living on his or her pension than entering the workforce. In response to this problem, Congressmen Antonio Leal and Enrique Acorssi have submitted a bill to the Chamber of Deputies, which aims to change the current policy.⁶³

Other proposed changes to employment laws and policy include a plan allowing employers a tax deduction when hiring persons with disabilities, establishing more flexible health requirements for prospective applicants to public service jobs, and establishing a 3% employment quota for persons with disabilities in the public service.⁶⁴

Health Services

Chile has two health care provision systems, ISAPRE (Social Security Health Institute) and FONASA (National Health Fund). The ISAPRE is comprised of private institutions offering health insurance for typically high fees, while FONASA is a public agency, which provides service at more modest rates or no cost for those who qualify. According to the records of the Preventive Medicine and Disability Committee (COMPIN), the majority of persons with disabilities (59.3%) belong to the FONASA health system, while only 7% belong to ISAPRE.⁶⁵

⁶¹. *Ibid.*

⁶². *Ibid.*

⁶³. Leonor Cifuentes.

⁶⁴. Emma Lohaus; Leonor Cifuentes.

⁶⁵. Caracterización de la Población con Discapacidad Diagnosticada por las Comisiones de Medicina Preventiva e Invalidez en Chile [Characterization of the Population with Disabilities diagnosed by the Commission of Preventive Medicine and Handicap of Chile], (1999), <http://www.mideplan.cl/estudios/discapa.pdf>.

The health care system used by the remaining 33.7% of persons with disabilities was unknown. Results from the latest CASEN survey show an even higher percentage of persons with disabilities covered by FONASA (81.2%). This percentage is substantially greater than that for persons without disabilities, of whom only 65.6% are enrolled in FONASA. Similarly, a total of only 7.1% persons with disabilities are covered by ISAPRE, whereas a total 20.6% non-disabled persons are covered. A greater number of persons with disabilities are assisted in health care services that are free of charge as compared to persons without disabilities.⁶⁶

The Ministry of Health recently implemented the Universal Access with Explicit Guarantees (AUGE) Plan. This plan consists of a set of guarantees concerning the right to health care for all the inhabitants of the country. The plan benefits all persons living in the country, whether or not they contribute to FONASA or ISAPRE.⁶⁷

There is no publicly funded organization where persons with disabilities can regularly obtain assistive devices. However, organizations can submit special projects proposals for public funding through FONADIS. The FONADIS is the main provider of assistive devices for low-income persons in the National Disability Register. The number of devices provided has increased substantially over the last decade. From 1994-1999, FONADIS supplied 12,096 devices, while between 2000 and 2002, 16,689 were supplied. The FONADIS office estimates that coverage has increased by 176%.⁶⁸ Many other institutions, non-profit organizations, and foundations also help meet the needs of persons with disabilities.⁶⁹ By law, the government will reimburse the duty on imported "equipment, machinery and devices which are specifically designed or adapted for use by persons with disabilities" and "special tools to facilitate communication, information and signaling for persons with disabilities."

In Chile, there are some projects built on a Community-Based Rehabilitation (CBR) model. These mostly consist of rehabilitation projects with community elements or active community participation. For example, FONADIS is financing the creation of a "stimulation room" at Sotero del Rio Hospital. Mothers with children who may develop disabilities can learn stimulation techniques at the facility.⁷⁰

⁶⁶. MIDEPLAN, *Situación de las Personas con Discapacidad en Chile* [Situation of People with Disabilities in Chile].

⁶⁷. Ministry of Health, <http://www.minsal.cl>. Approximately 19 diseases that affect persons with disabilities are covered by the AUGE Plan.

⁶⁸. FONADIS, *Informe Público* [Public Account], March 2003; Mauricio Zepeda Sanchez and Eladio Recabarren Hernandez, 9 September 2003.

⁶⁹. *Ibid.*

⁷⁰. Eladio Recabarren Hernández; "hospital sotero de Rio: Apoyo terapeutico a padres de recién nacidos con discapacidad" [Sotero del Rio Hospita: Therapeutic support for parents of children with disabilities], *Atrévete* magazine, No. 54, February 2003.

With regard to disability prevention, the Disability Act mandates that the state “channel resources to support prevention and rehabilitation activities through programs aimed at improving access to these activities for low-income persons with disabilities.”⁷¹ The Chilean government recently began a program aimed at preventing nutritional deficiencies in infants and young children. Since September 2003, the National Complementary Food Program (PNAC) has supplied special formula for low-weight premature infants under the age of one, as well as phenylalanine-free milk for children up to the age of 14 who have difficulties in metabolizing this amino acid. Chile is the only country in the region running such a program.⁷²

Training on the provision of care for persons with disabilities is available for physicians, before and after they acquire a medical degree.⁷³ Training programs for physical therapy, occupational therapy, psychiatry, orthotics, and speech therapy also exist. There is no prosthetics training in Chile.

Housing

According to the CASEN survey, almost 92% of people with disabilities live with their families. Of these, only 7.8% are the head of household. The remainder live in the homes of their relatives.⁷⁴ In Chile there are no independent living centers that provide peer counseling and referral services to people with disabilities.

Chile has a subsidized housing system, run by the Ministry of Housing and City Planning, which is used by many people with disabilities. Housing applicants answer a series of social and economic questions, and the answers are then scored to determine eligibility. In 1995, the Ministry of Housing and City Planning amended the housing subsidy system, incorporating disability into the eligibility criteria. The order allocated an additional 10 points for applicants with a disability or with family members who have a disability.⁷⁵

Once subsidies are granted inaccessibility of the homes presents further barriers. Disability advocates report that few people with disabilities live in adapted, accessible housing. Typically, housing units have not been architecturally adapted for inhabitants with disabilities.⁷⁶ Moreover, low cost housing is often small, making it difficult for wheelchair users to move around the interior. There

⁷¹ Law 19284.

⁷² FONADIS, www.fonadis.cl/index.php?seccion=17&articulo=693#centro.

⁷³ Fernando Moncayo (Anesthesiologist, Pulmonary anesthesiology student).

⁷⁴ Resultados de la VIII Encuesta de Caracterización Socioeconómica Nacional.

⁷⁵ Cecilia Leiva, 17 June 2003.

⁷⁶ Executive Order 41, *Official Gazette*, 12 June 1995, www.minvu.cl. The order mandates that: “Ten additional points will be given to the applicant or applicants, should he or she or they, or his or her spouse, or one or more members of the family group, recognized as such, be enrolled in the National Disability Register. The disability will be shown pursuant to subsection 1 of section 14.”

is no financial support available from the government for the adaptation of private housing.⁷⁷

Additional proposals have been made to further facilitate access to housing subsidies. These include a proposal that additional points be awarded to each family group that includes a person with disabilities, thereby improving the likelihood that such families would qualify for a subsidy. A second proposal suggests that five percent of units in housing developments be allocated to persons with disabilities. Lastly, there is a proposal to create a subsidy for the adaptation of housing for persons with disabilities. None of these proposals has yet been implemented.⁷⁸

Institutionalization

Chile has no special records of full-time residential facilities, and there is no mechanism for reporting incidences of abuse or death in such institutions. The Metropolitan Disability Guide has information about public and private institutions in the region. The Municipal Disability Council of Ñuñoa (a municipality in the Metropolitan Region) prepared the guide in collaboration with FONADIS, in 2002.⁷⁹

Institutions provide psychological and psychiatric counseling services, rehabilitation, education, and training. Some of the most important institutions in the country include: 4 public psychiatric hospitals accommodating long-term patients, located in the Metropolitan Region; a public sector network of 54 homes around the country for adults with psychiatric disabilities and the elderly, run by the Hogar de Cristo Foundation; 16 homes for children and youth with intellectual and physical disabilities, associated with the Corporation in the Aid of the Limited Child (COANIL)⁸⁰ and 40 homes for the elderly assisting 2,450 people, run by the Las Rosas Foundation.⁸¹ The recently established National Service for Senior Adults will provide resources for the care of elderly persons with disabilities. As yet, it has not been allocated significant funding, although funds are expected to be available in the near future. Chilean institutions will then be invited to compete for grants.⁸²

The Committee on the Protection of the Rights of Patients with Psychiatric Disabilities, a part of the Mental Health Unit of the Ministry of Health, has recently published guidelines on protecting the rights of institutionalized people with psychiatric disabilities.⁸³

⁷⁷. Cecilia Leiva, 21 October 2003.

⁷⁸. Leonor Cifuentes.

⁷⁹. Municipal Disability Council of Nunoa and FONADIS, Directorio Metropolitano de la Discapacidad [Metropolitan Disability Guide], 2002.

⁸⁰. Mauricio Zepeda Sánchez and Eladio Recabarren Hernández, 9 September 2003.

⁸¹. Andrea Valdivieso (Manager of Projects, Rose Foundation), 14 October 2003. Half of the residents are bedridden and another 443 are wheelchair users. Most have been placed there by their families. Another 60 patients will be soon referred to by the National Service for Senior Adults.

⁸². Andrea Valdivieso in reference to Law 19828, 27 September 2002.

⁸³. Ministry of Health, *Executive Order 570*, 28 August 1998. The order mandates that: "certain decisions, which may be potentially harmful for individual rights, be taken with the highest number of guarantees and transparency, and to help individuals make informed decisions about possible their own health."

In an effort to reform the care system for persons with chronic psychiatric disabilities, the Ministry of Health created "Day Care Hospitals." The outpatient care provided by these facilities reinforces family and community participation.⁸⁴

Any legally competent person may refuse a course of treatment. Patients may also refuse prescribed treatment by submitting a request in writing to the managing board of the facility. In cases where their wishes are violated, legal remedies can be sought through the courts.⁸⁵

People may be institutionalized against their will in three situations. A doctor may order institutionalization in an emergency. Hospitalization cannot exceed a 72-hour period in such situations.⁸⁶ Administrative institutionalization can be requested by health authorities when a person's behavior is believed to endanger him or herself or others. The police, a person's family, his or her treating physician, or any community member may petition health authorities for such an order. Lastly, a court in consultation with a psychiatrist may order judicial institutionalization in cases where criminal behavior is linked to psychiatric disturbance.⁸⁷

Accessibility

Section 21 of the Disability Act states that "new constructions, public roads, public transportation, parks, gardens and squares shall be readily accessible to and usable by wheelchairs users."⁸⁸ Consequently, the Ministry of Housing and City Planning has issued accessibility regulations as part of the General Ordinance on City Planning and Construction. These include specifications for street intersections, ramps, elevators, passageways sizes, and toilets, among others.⁸⁹

⁸⁴. Ministry of Health, *Orientaciones Técnicas para el funcionamiento de Hospitales de día en psiquiatría* [Technical Guidelines on Day Care Hospitals in the Field of Psychiatry], December 2001, www.minsal.cl. In the national disability plan, day care hospitals are defined "as an alternative to institutionalization for seriously ill patients, who have a Social Support Network, and to shorten the length of stay. These hospitals admit patients that are referred to by the mental health and outpatient psychiatry team, and the Short Stay Psychiatric Service."

⁸⁵. Mauricio Zepeda Sánchez and Eladio Recabarren Hernández, 9 September 2003.

⁸⁶. *Ibid.*

⁸⁷. *Ibid.*

⁸⁸. Leonor Cifuentes. A proposal has been made to amend the law in order to establish that the concept of universal design be included in all regulations concerning city planning, constructions and telecommunications. It has also been proposed to change the legal status of construction regulations and sign them into law.

⁸⁹. OGUyC, www.minvu.cl.

A recent order requires that all public accommodations comply with the regulations, especially in those buildings that provide health services or education.⁹⁰ Penalties for non-compliance include fines. The following amendments to the General Ordinance on City Planning and Construction have been proposed: to build anti-slip ramps at street corners and intersections, to change the width of existing ramps in accordance with appropriate universal design specifications, to place traffic lights with audible signals on streets with heavy traffic, to locate parking lots in obstacle-free areas that are close to entrances, and to create parking spaces of appropriate size for persons with disabilities.⁹¹

There are no records on the number of public buildings that have been adapted or that are adequately accessible for persons with disabilities. The MINVU is gathering this information on a national scale.⁹² Efforts have been made to improve accessibility in several public offices, including the National Social Security Institute (INP), the National Training and Employment Service (SENCE), the Ministry of Housing and City Planning (MINVU), the National Tourism Service (SERNATUR), the main courtyards at the Mint, and the Presidential Palace.⁹³ There are still many governmental buildings that have not been adapted and are inaccessible to wheelchair users, such as the Ministry of Transportation and Telecommunications, and the Municipal Library in Providencia.⁹⁴

In the city of Santiago, several public buildings have been adapted or remodeled for access to persons with disabilities. The Postal Service of Chile has adapted its main post office, however access is only available via a side street entrance. Since the end of 2002, the postal service's architect has been collecting information on accessibility in corporate branches throughout the country, in order to perform the necessary adaptations.⁹⁵

In many municipalities, infrastructure has been improved by including ramps at street intersections although, barriers have been placed at these ramps hindering their use.⁹⁶

⁹⁰ Executive Order 201, 1998. The order states: "Requirements to be complied with by existing buildings for public use, the construction of which has been duly authorized and verified upon completion of works, in order to facilitate access to and movement of persons with disabilities". "Within a three-year term, as from the date of publication of this order in the official gazette, the existing buildings for public use, the construction of which has been duly authorized and verified upon completion of works, especially such buildings where health services are provided or teaching/learning activities are carried out must meet the minimum requirements established under section 4.1.7 of Executive Order 47."

⁹¹ Cecilia Leiva, 21 October 2003; Leonor Cifuentes.

⁹² Cecilia Leiva, 17 June 2003. The results were scheduled to be published in December 2003 and were not yet available at the time of this writing.

⁹³ Enrique Norambuena, UNPADE, email response.

⁹⁴ Natalia Toledano, *Descanso y Recreación para Todos* [Rest and Recreation for All], SERNATUR; Pilot Plan in the Metropolitan Region, 2002, <http://www.Fonadis.cl/index.php?seccion=15&articulo=427>.

⁹⁵ Patricio Pardo (Architect of the Postal Service Company of Chile), email response, Chile, 4 September 2003.

⁹⁶ Interview with a Municipal official, 15 October 2003.

In the city hall, in La Florida, there is a Braille sign with directions to locate offices. However, this practice is not widespread.⁹⁷

A number of national and international seminars on universal design have been sponsored by FONADIS and the Chilean Architect College in the last few years. They included: the International Seminar in 1998⁹⁸; the Seminar in Temuco Tenth Region, Chile in 2000; the International Seminar on Universal Design and Tourism in 2002; Sports Architecture / Universal Design in July 2003⁹⁹; and the International Seminar on Universal Design in August 2003. A total of 120 architects participated in these seminars.⁹⁸

The transportation system in Chile is not fully accessible. In Santiago, only Line 5 of the metro is fully accessible. Line 1 of the metro, which is the oldest in the city, is in the process of being adapted. A three-level elevator was recently installed at the Chile University station where two lines intersect. Disability advocates report that station elevators can only be operated with the help of an official, and people with disabilities must sometimes wait a long time for assistance. Some transportation services are subsidized. The Metro offers discount fares for senior citizens, and because of an agreement recently signed in the town of Temuco, three bus lines provide free tickets to people with disabilities.⁹⁹ Private taxis or special vans can also provide transportation for wheelchair users, although these services are extremely expensive. Wheelchair users often share taxis or ask for help when they need to use the metro.

According to a government plan, a bus system adapted for people with disabilities will begin operating by 2005.¹⁰⁰ The initiative was announced on television, and funding began in December 2003. The system will be based on the Transantiago project and will incorporate ramps and lifting platforms for wheelchair users. The full project is scheduled to be completed by 2010.¹⁰¹

In August 2003, a law established rules on the use of designated parking spaces for persons with disabilities. Formerly these regulations were issued by municipal governments.¹⁰² Recent laws also require the placement of metal signs on traffic-light posts with information about street names and directions.¹⁰³

⁹⁷ Paulina Cavada and Adriana Lagos (Architects), Proyecto Integración de las Personas Discapacitadas a la vía Urbana [Project for the Integration of Persons with Disabilities into All Streets], financed by FONADIS in cooperation with the La Florida municipal government, 1995.

⁹⁸ Chilean Architect College.

⁹⁹ Boletos rebajados de locomoción colectiva para adultos mayores de Temuco y Padre Las Caras [Reduced Public Transportation Tickets for Temuco Seniors], <http://www.segegob.cl/>.

¹⁰⁰ Interview with an Official of the Undersecretary of the Ministry of Transportation and Telecommunications, Santiago, 25 June 2003.

¹⁰¹ "24 horas Televisión Nacional," *Noticias*, 23 October 2003; <http://www.tvn.cl.>, <http://www.gnv.cl> and <http://www.moppt.cl/documentos/otros/Transantiago.pdf>.

¹⁰² This amendment will establish who can use these parking areas as well as penalties for non-compliance.

¹⁰³ Ministry of Transportation and Telecommunications, Undersecretary of Transportation, *Modifies annex to 1986 Order 20*, Executive Order 171, 7 January 2000.

Culture, Sports, and Recreation

Some sports programs and facilities are available to persons with disabilities. The Metropolitan Sports School for Persons with Disabilities opened in April 2003. It is operated by the Metropolitan Office of Chilean Sports in cooperation with the Chilean Paralympic Federation, and it is sponsored by the Chilean Olympic Committee. Children, youth, and young adults with a variety of disabilities can learn sports including swimming, table tennis, and fencing.¹⁰⁴ Also in April 2003, the Pan-American Sports Federation for Cerebral Palsy (FEPAN/CP-ISRA) and the Chilean Paralympic Federation offered a course on sports and recreation for persons with cerebral palsy. The course was taught by a team of professionals from the Cerebral Palsy International Sports and Recreation Association (CP-ISRA) and was certified by this international association.¹⁰⁵ In September 2003, persons with disabilities participated in the national table tennis and target shooting championships.

The "Garden of Senses" in Mundo Granja was opened in the town of La Pintana on 10 September 2003.¹⁰⁶ The initiative, which is financed by FONADIS, will allow visitors who are blind to have greater exposure to the natural and animal world. There are signs in Braille and large type. Eventually, an electronic sound system will be installed to reproduce typical animal noises. Veterinarians and teachers associated with the garden have been trained to work with children who are blind.¹⁰⁷

The National Tourism Service (SERNATUR) is implementing a pilot plan in the Metropolitan Region for the integration of persons with disabilities as both tourists and tourguides. The initiative is intended to encourage the tourist industry to adapt facilities and create areas for visitors with disabilities. The SERNATUR has prepared a list of tourist attractions in the Metropolitan Region that have accessible facilities and toilets for persons with disabilities.¹⁰⁸

Disability Action & Awareness

In Chile, there is no national coordinating agency that develops disability policy. However, the Chilean government collaborates with organizations from all sectors (people with disability, women, and ethnic groups, among others) in establishing guidelines and policies for the equalization of opportunities. Chile has developed a National Disability Action Plan for 2002-2012. The MIDEPLAN and FONADIS are working with a committee of representatives from various sectors and government ministries to design, implement, and monitor the plan. Civil society is also involved through a Consultative Civil Society Committee. Law 19284 and the National Policy for Social Integration serve

¹⁰⁴ FONADIS, <http://www.fonadis.cl/index.php?seccion=17&otros=articulos=685>.

¹⁰⁵ Gloria Aravena O'Kuinghttons. The course was intended for Physicians, Physical therapists, Physical Education Teachers, Occupational Therapists, Special Education Teachers, Technicians, sports instructors, and advanced students of the mentioned areas.

¹⁰⁶ Mundogranja belongs to the School of Veterinary and Livestock Sciences of the University of Chile.

¹⁰⁷ FONADIS, <http://www.fonadis.cl/index.php?seccion=17&articulo=693#centro>.

¹⁰⁸ FONADIS, <http://www.fonadis.cl/index.php?seccion=15&articulo=427>.

as the framework, and the plan incorporates principles such as democratization and the need for persons with disabilities to take part in decision-making processes affecting them.¹⁰⁹ The 2004 budget for implementing the program is approximately 6 billion Chilean pesos, approximately US\$8,759,124.¹¹⁰

During July 2003, FONADIS organized the Workshop on the International Comprehensive and Integral Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities with the assistance of the Ministry of Foreign Affairs and a representative of the United Nations High Commissioner for Human Rights.¹¹¹ Government officials consulted with organizations from civil society regarding the issues NGO's hope to see the convention address. The recommendations included:

- Strengthen the associative movement of persons with disabilities.
- Member states should allocate budget resources as necessary for compliance with public policies regarding persons with disabilities.
- States should establish internal monitoring mechanisms to ensure compliance with the convention.
- Promote international solidarity and cooperation to support least developed countries, particularly in the fields of scientific research and technology transfer.
- Include provisions to prevent and punish ill treatment and abuse of children with disabilities and persons with disabilities in general, taking into consideration their special situation of vulnerability.
- Guarantee persons with disabilities access to regular education, at every level.
- Promote initiatives for persons with disabilities, who are unable to enter the competitive job market, to access special employment alternatives including sheltered employment, sheltered workshops, tele-commuting, etc.

¹⁰⁹ Mauricio Zepeda Sánchez and Eladio Recabarren Hernández, 9 September 2003.

¹¹⁰ *Ibid.*

¹¹¹ Office of Multilateral Policy of the Ministry of Foreign Affairs together with FONADIS, 24 September 2003. More than 200 representatives of various organizations of persons with disabilities, non-governmental organizations, and officials from different State agencies whose work is related to the rights of persons with disabilities, took part in the consultative workshop. All had the opportunity of examining and discussing the international instrument under development. A final Draft Report of the Workshop was prepared.

Member states should envisage systems for transition from education to employment as well as systems of employment promotion that take into account the special needs and circumstances of persons with disabilities.

The convention should envisage a preventive approach towards occupational risks in order to eliminate or reduce their incidence as a major cause of disability.”¹²

Under the military dictatorship, the government did not recognize disability organizations. Since the return to democracy in March 1990, such organizations have regained their status as valid entities. Most organizations are funded by contributions. For example, the Hogar de Cristo Foundation runs a membership program where each member contributes on a monthly basis. Financing for special projects is available from FONADIS, and SENAME finances some organizations that assist children and adolescents with disabilities. Other private foundations, such as the Andes Foundation and the Ideas Foundation, occasionally finance projects as do some foreign organizations.

Families participate actively in organizations of friends and family of persons with disabilities. Some of the most active include: the Union of Parents and Friends of Special Children (UNPADE), the Association of Parents with Autistic Children (ASPAUT), and the National Coordinator of Organizations of Families, Users and Mentally Ill Persons (CORFAUSAM). Some organizations work in collaboration with one another, for example, CORFAUSAM brings together different organizations focused on mental retardation. In addition, there are cross-disability organizations in Chile.¹³

In the area of disability awareness, disability advocates report that media campaigns are among the most effective strategies for bringing attention to human rights violations against persons with disabilities. Public demonstrations held by organizations of persons with disabilities have also been effective.¹⁴

¹² Office of Multilateral Policy of the Ministry of Foreign Affairs, Chilean Government together with FONADIS, 24 September 2003.

¹³ Miguel Rojas (National Coordinator of Organizations of Families, Users and Mentally Ill Persons), (seminar on “An End to discrimination, Social Reintegration and Rights of Persons with Mental Illness and Mental Disabilities,” September 2000).

¹⁴ Orlando Milesi, *Discapacidad: Hacia una Cultura de Integración* [Disability: Towards a Culture of Integration], www.bcn.cl/pags/dis/discatre.pdf. “Greater awareness regarding persons with disabilities has been evidenced by the recent marches and demonstrations by those concerned, which have been covered by the mass media that have also aired special programs on the subject.”



Colombia

Key Factors: For the last six years more forceful laws and regulations have been developed, enabling a larger number of people with disabilities to access education, public spaces, and the health and social security systems. However, these efforts have been diluted since actions aimed at the inclusion of persons with disabilities are often expensive and, therefore, not a high priority within the government.

Terminology

The current Disability Act does not use the term ‘disability’ but ‘limitation.’ This usage extends to the phrase “personas con limitación,” which has been translated as “persons with a limitation.”²

In addition, the Constitution refers to people with disabilities as “minusválidos”, translated as “handicapped.” When directly quoting documents, the original language has been preserved.

Definition of Disability

Colombia bases its definitions of disability on World Health Organization (WHO) guidelines. Thus, it has been responsive to changes in the concept of disability. Much of Colombia’s existing legislation is based on variations of the WHO’s ICIDH-1 definition. A national plan from the late 1990’s follows the ICIDH-1 closely, defining disability as “a restriction or lack, resulting from an impairment, of ability to perform an activity in the manner or within the range considered normal for a human being within his or her social context.”³

Other documents rely on similar definitions. According to Law 762, disability is “a physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of

¹ Hernan Perilla Prieto (Executive Director of Risaralda’s Association of Disabled Persons, Coordinator of Risaralda’s Departmental Disability Support Network), interviewed by author.

² Law 361, “Disability Act,” 7 February 1997, <http://www.secretariassenado.gov.co/leyes/LD361e97.htm>.

³ *National Plan for the Assistance of Persons with Disabilities 1999 – 2002*.

daily life, and which can be caused or aggravated by the economic and social environment.”⁴ Executive Order 1660 allows that “[Disability] is any restriction in participation and relationship to the social environment or any limitation in the performance of daily life activities as a result of an impairment affecting a body structure or the mobility, sensory, cognitive or mental function.”⁵ Although the focus on impairment versus activity restriction varies somewhat between the definitions, they all posit the same basic model of disability.

During the development of recent disability policy, Colombia has used definitions of disability more in line with those provided by the International Classification of Functioning, Disability and Health (ICF/ICIDH-2), where ‘disability’ is a multi-dimensional phenomenon resulting from the interaction of human beings with their physical and social environment. This policy differentiates the concept of “persons with disabilities” from that of the “disability situation.”

Disability Situation: A set of environmental, physical, biological, and social conditions that may affect the autonomy and participation of the individual, family, community, and general population at any given time of the life cycle, as a result of the interactions of the individual with the environment.

Person with Disabilities: A person with disabilities is any person who experiences limitations to the performance of daily life activities and restrictions to social participation due to a health condition or to physical, environmental, cultural, and societal barriers.⁶

The Presidential Advisory Council for Special Programs, which helped adopt these definitions, has provided technical advice to the National Congress on the amendment of the Disability Act. The resultant Bill 173 of 2004 updates the disability policy framework to correspond to the new model of disability.⁷

Disability Population

No accurate or current information is available regarding the disability population. The only survey through which the National Statistics Department (DANE) has collected data on people with disabilities was the 1993 Housing and Population Census. The survey instrument included only one question intended to identify the disability population.

⁴ Law 762, 31 July 2002. This law ratifies the OAS Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities.

⁵ Ministry of Transportation, Executive Order 1660, 16 June 2003.

⁶ Bill 173, January 2004, modifies Law 361 of 1997.

⁷ *Ibid.*

As shown in Table One, the number of people with disabilities identified by the 1993 census was 593,618 people, or 1.85% of the population at the time. Based on that rate, the disability population in 2002 would have totaled 813,000.⁸

Table 1. Results of Housing and Population Census 1993

Kind of Disability	Total	%
Blindness	235,017	34.47
Deafness	169,443	24.85
Speech Impairments	41,315	6.06
Mental retardation or impairment	113,319	16.62
Paralysis or Loss of Upper limbs	60,737	8.91
Paralysis or Loss of Lower limbs	62,007	9.09
Total disabilities	681,838	100
TOTAL DISABILITY POPULATION	593,618	

Source: DANE Census 1993

Numerous sources suggest that these numbers are of limited usefulness. The DANE acknowledges that “the methodology used had serious difficulties obtaining such information.”⁹ Moreover, a Ministry of Health report suggests that “due to widespread violence and the conditions of social, economic, technical and demographic development prevailing in the country, the disability issue has become a growing public health problem (Ministry of Health, 1998).”¹⁰

The 1993 DANE figures sharply contrast with the WHO estimate that up to 12% of the total population consists of persons with some kind of disability. With a present population of approximately 44 million people, the WHO estimate would imply a disability population of 5,280,000 persons.¹¹

As a result of the lack of information regional governments in the Quindío and the Valle del Cauca districts and in the cities of Soacha and Cundinamarca have undertaken research and surveys on the living conditions of persons with disabilities.¹² The regional surveys were conducted using a variety of data gathering strategies as well as different approaches to the concept of disability. As a result, it is not possible either to contrast them or to make any generalizations.

⁸ DANE, *Census, 1993*, <http://www.dane.gov.co/>.

⁹ DANE, *Proyecto diseño y validación Sistema Nacional de Información Estadística sobre la Discapacidad: Diagnóstico Convenio DANE* [Project for the Design and Validation of the National Disability Statistical Information System – Diagnosis DANE], MEN Agreement, Bogotá, 2002, 4.

¹⁰ Bogotá Health Secretary, *Health Care Guidelines for Persons with Disabilities in Bogotá*, 2001, 14.

¹¹ WHO, “Resultado de la revisión de diversos documentos sobre Prevalencia de la discapacidad elaborados por los países, 1997-2000” [Revised results of the prevalence of disabilities by country 1997-2000], http://www.ops.org.ni/opsnic/tematicas/rehabilita/resumen_americas.htm#cifras_discapacidad.

¹² *Census, 1993*.

Legislation & Disability Rights

Legal Protections

Colombia has adopted recommendations made by UN organizations, including the International Labor Organization (ILO), the Organization of American States (OAS), and the World Health Organization (WHO). Colombia ratified the OAS Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities through Law 762 in 2002.¹³ The ratification document has not yet been deposited with the OAS General Secretariat.¹⁴

Colombia has been playing an active role in the preparation of a Convention on the Human Rights of Persons with Disabilities as promoted by the United Nations. The government has issued several documents supporting the creation of the convention.

With regard to national legal protections, early legislation provided assistance to the disability population, but it is only with the enactment of the Constitution in 1991 that disability rights became explicitly recognized.

Some sections of the National Constitution make express reference to persons with disabilities. Among these, Section 13 establishes that “the State shall especially protect those persons that due to their economic, physical or intellectual condition may be at a clear disadvantage and shall punish any abuse or ill-treatment against them.” Similarly, Section 47 says that “the State shall develop a policy intended to the prevention, rehabilitation and social integration of individuals suffering from physical, sensory or psychiatric impairments, and these will be provided with specialized care as required”. In addition, “other fundamental social, economic and cultural rights of a universal nature were also included aimed at encompassing persons with some kind of limitation or disability.”¹⁵ These include education and employment.¹⁶

Along with the Constitution, Colombia has a number of specific laws pertaining to disability issues. The broadest of these laws is Law 361/97,¹⁷ which makes reference to the protection of persons with disabilities, specifies various aspects related to their fundamental rights, and establishes obligations and responsibilities of the state. It addresses issues such as prevention, education, rehabilitation, labor integration, social welfare, and accessibility. The law establishes the obligations and responsibilities of the government in allowing persons with disabilities to achieve personal fulfillment and accomplish full social integration.

¹³. Law 762, <http://www.secretariassenado.gov.co/leyes/L0762002.HTM>.

¹⁴. Documents were issued after the third World Conference on Racism, when Mexican President Vicente Fox formally promoted the initiative during the 56th session of the UN General Assembly, and more recently, at the last meeting of the states of the hemisphere, held in Quito, Ecuador, on 9-11 April 2003.

¹⁵. Social Solidarity Network “Basis for the Development of Public Disability Policy for 2003-2006”, Presidential Advisory Council for Special Programs, Bogotá 2003, 13.

¹⁶. These are guaranteed by sections 68 and 54, respectively.

¹⁷. Law 361e

Law 100/1993, known as the *Comprehensive Social Security System Act*, establishes health benefits for people with disabilities and general “rights that cannot be waived in order to attain a quality of life that is in accordance with human dignity.”¹⁸ Some health care financing is provided by Law 643/2001.¹⁹ It specifies that 4% of all income from gambling sources allocated to the health sector must be used to subsidize mental health care and care for persons with various types of disabilities.

Orders issued by the former Ministry of Labor²⁰ regarding employment and support for people with disabilities include: 970/1994, which ratified ILO Convention 159; 692/1995, which adopted the Manual for the Qualification of Disability; 97/1999, which created a manual for quantifying lost labor capacity; and 1128/1999, which restructured the Ministry and assigned tasks related to disability issues.²¹ The promotion of programs providing “education for persons with limitations” is mandated by Law 115/1994, also known as the *General Education Act*.²² Additional orders and resolutions promote the right of persons with disabilities to education and accessibility to educational institutions. In addition, the *Minors’ Code*, Decree Law 2737/1989, sets forth the responsibilities of the family and the State for the care of children with disabilities.

Law 105/1993 and Presidential Order 1660/2003 provide for accessible transportation.²³

By means of Law 324/96, sign language was recognized as the official language of the deaf community. Law 335/1996, which created private television, mandates that television “programs must be captioned or sign language must be included so as to guarantee the access of deaf people or hearing-impaired persons to this service.”²⁴

Legislation promoting access of people with disabilities to culture, sports, and recreation includes Law 181/1995.²⁵ Law 582/2000 focused specifically on sports, creating the National Sports System for persons with disabilities and establishing the Colombian Paralympics Committee as the highest sports authority.²⁶ Also, it organized each of the sports federations according to types of disability. Law 397/97 on cultural heritage created the Ministry of Culture and specified “special consideration to persons with physical, sensory or psychiatric impairments.”²⁷

¹⁸. Law 100, http://www.secretariasenado.gov.co/leyes/L0100_93.htm.

¹⁹. Law 643, <http://www.secretariasenado.gov.co/leyes/L0643001.htm>.

²⁰. The Colombian government was recently restructured, the former Ministry of Health and the Ministry of Labor and Social Security were merged into the new Ministry of Social Protection.

²¹. Interview with the Director of Human Resources and International Humanitarian Rights, Ministry of Foreign Relations, New York, United Nations, 16- 27. June 2003.

²². Law 115, ch. 1, Title 3, sec. 46-49, http://www.secretariasenado.gov.co/leyes/L0115_94.htm.

²³. Law 105, http://www.secretariasenado.gov.co/leyes/L0105_93.htm.

²⁴. Law 335, sec. 12, http://www.secretariasenado.gov.co/leyes/L0335_96.htm.

²⁵. Law 181, http://www.secretariasenado.gov.co/leyes/L0181_95.htm.

²⁶. Law 582, <http://www.secretariasenado.gov.co/leyes/L0582000.htm>.

²⁷. Law 397, sec. 1, http://www.secretariasenado.gov.co/leyes/L0397_97.htm.

With regard to the creation of a coordinated disability policy, Law 361/97 established the National Disability Consultative Committee (CCN), an agency created to act as an advisory unit for monitoring the implementation of all disability-related policies, strategies, and programs.²⁸ Although the law was passed more than six years ago, the National Disability Consultative Committee is not yet operating. At present, the entity in charge of disability issues is the Office of Social Promotion of the Ministry of Social Protection. In coordination with the National Technical Committee, this office is in charge of making and following-up on disability policy.

Both the Constitution and the above laws pertain to government as well as some private institutions. Penalties for noncompliance are provided for in the laws. These penalties include both those of a civil and criminal nature. Most of the time, however, the penalties are not imposed effectively.

Colombia has no entity that records cases of discrimination, abuse, or violence against persons with disabilities. Leaders of the disability community reported that the most effective methods to redress violations of the rights of people with disabilities are commencing summary proceedings intended to protect Constitutional rights (*tutela*), exercising the right to petition the government, and commencing legal proceedings intended to seek compliance. Several amendments have been made to the Civil Code as a result of Constitutional Court decisions recognizing the rights of persons with disabilities.

Civic Participation

All citizens of Colombia have the right to elect and be elected to public office. Some steps toward the enforcement of these rights for people with disabilities can be seen in the implementation of Braille voting cards for use by people who are blind. The voting cards were first used during the Constitutional referendum in 1991.²⁹

Despite this progress, serious difficulties remain. It is estimated that less than 20% of polling booths are accessible. Architectural and communication barriers are still prevalent. Training of election officials in providing access to persons with disabilities is insufficient. Additionally, information about the overall election process is often not available to the general population and is rarely available in alternative formats.

²⁸. Law 361, sec. 6.

²⁹. There was a vote on the referendum on 25 October 2003.

Inclusion

Communication

The National Institute of Blind People (INCI) has translated the Constitution into Braille since 1992. Copies are distributed to all public libraries and national associations of people who are blind.³⁰ An updated Talking Book version of the Constitution is currently being created using Daisy digital technology.³¹ One compact disk contains the complete Constitution including comments. Unlike Braille documents, it can be easily and inexpensively updated.

Because the government does not typically communicate its activities in alternative formats, the INCI is also tasked with raising awareness within national, departmental, and local governments regarding the Constitutional obligation to guarantee access to public information. There are some positive examples. The Bogotá Capital District has made efforts to use alternative formats to inform citizens who are visually-impaired about issues pertaining to health, transport, and taxes. However, the government is not yet able to produce such materials on a permanent basis.

Resolution 1080/02 established criteria for television programming for people who are hearing-impaired. Publicly and privately operated national television stations must broadcast at least one accessible daily news program during a time segment with large audiences. Broadcasts may use any information systems available for viewers who are hearing-impaired, including sign language interpreters or closed captioning.

To date, very few national or regional television operators broadcast shows using the closed captioning system. Among those stations that provide the service are the 'Capital de Bogotá' channel, which regularly broadcasts three captioned programs, and the private channels RCN and CARACOL, which broadcast four closed-captioned programs. In January 2004, the CARACOL channel began broadcasting the last national news of the day using the closed captioning system. Some other television programs use sign language interpreting services, as is the case of the Teleantioquia regional channel. However, most national and regional channels do so very infrequently. Presidential addresses or broadcasts from the National Congress are among the occasional broadcasts using the closed captioning system. In addition, the National Television Committee issued Agreement 005 dated 13 March 2003, defining and regulating systems guaranteeing access to the public television service for people who are hearing-impaired. However, the accessible programs promoted through the National Television Committee failed after one year and all newly accessible programs both on private and public channels went off the air.

³⁰: Jorge Eduardo Carranza Pina (Subdirector General), interviewed by author, Bogota, 8 September 2003, www.inci.gov.co.

³¹: World Consortium that developed the standard structure for digital talking books.

The Ministry of Communications reports some advances in accessible communication. Technologies like relay services that enable people who are deaf to use public telephones are being implemented and are already operating in the cities of Bogotá and Medellín. Likewise, the JAWS® software for people who are blind or visually-impaired is expected to be installed on computers in inclusive schools and in strategic locations in municipalities around the country.³²

Although aimed at a limited group, some persons who are hearing impaired have begun using pagers and text message-enabled mobile phones. At present, emergency and assistance organizations are not adequately prepared to assist persons with hearing or speech impairments. The National Institute of the Deaf (INSOR) has recommended that these organizations have updated lists of sign language interpreters so that they can be located immediately when needed.³³

Education

As with the rest of the disability population, there are no accurate statistics on the number of school-aged children with disabilities. Official statistics from the last census conducted in 1993 indicated that 0.92% of children 6-16 years old have some sort of disability. As with other DANE statistics on the disability population, this figure almost certainly underestimates the number of people with disabilities. Nevertheless, the percentage of students with disabilities attending public schools in 2002 amounted to only 0.32% of the student population. Of 11,781,161 students in the Colombian educational system, 38,000 are students with some kind of disability.³⁴ Conservative estimates suggest that 450,000 children with disabilities may be excluded from the educational system.³⁵

Aware of this situation, the Ministry of Education has set a goal of increasing by 40,000 the number of new places for children with disabilities available at schools. According to the Disability Plan 2003-2006, these additional places should be available by 2006e

Of the children with disabilities who are currently attending school, 30,000 are in elementary schools, and 8,000 attend high schools. Approximately 80% of the students are in inclusive educational settings, and the remaining 20% are taught in special classes within regular schools.³⁶

³² Maria Fernanda Ardila Lopez (Advisor, Office of Access and Social Development), interviewed by author, Bogotá Ministry of Communication, 15 September 2003.

³³ Janeth Cepeda (Advisor, INSOR), interviewed by author, Bogotá, 26 September 2003.

³⁴ Fulvia Cedeño Angel (Special Education for those with Needs, Ministry of Education), interviewed by author, Bogotá, 9 September 2003.

³⁵ Departmental Health Secretary and the Javeriana University, *Prevalencia de discapacidad en el valle del Cauca* [Disability Prevalence in the Cauca Valley], August 2001. The report estimates the number of children with disabilities as 4% of all children.

³⁶ *Ibid.*

Each educational institution attended by students with disabilities is required to have a support teacher to guide and support the families of these students.³⁶ In addition, schools are required to be accessible,³⁸ although according to the Ministry of Education, as of 2003, fewer than 20% of schools are accessible. Most of these are located in major cities with a few in small towns.³⁹

Even within those schools that are taking part in the integration process being implemented in the country, teachers lack adequate training to handle the inclusion of students with disabilities. There are few material resources, limited physical space, and few qualified human resources available to provide support services.⁴⁰ Currently, the Secretary of Education in each department offers training programs depending on teachers' needs. If need for training in special education of children with disabilities arises within a certain department or municipality, the teacher training committee addresses it. Furthermore, there are universities offering special education training programs in the form of undergraduate, post-graduate, and diploma studies.

The Ministry of Education reported that, as of 2003, training of teachers on special education is now covered in the supplementary studies of at least 50% of teacher training institutions and in various university schools of education. These programs are located primarily in those departments where there is an interest in inclusive education. Although only a small number of teachers have so far received special education training, the results of this new initiative should be reflected in the availability of more resources for integration in the future.

There is no early detection program within the school system for children with disabilities. The Ministry of Education, the Ministry of Social Protection and the Colombian Institute for the Family Welfare are currently working jointly to identify and propose assistance alternatives in favor of people with severe disabilities that cannot be integrated into the education system.⁴¹



³⁷. A professional trained in special education or related matters who also has additional training and experience in the assistance of persons with special education needs.

³⁸. Legal documents requiring school accessibility include: Law 115 of 1994, Law 432 of 1996, Regulatory Order 2082 of 1996, Law 342 of 1996, Order 2369 of 1997, Law 361 of 1997, and Ministerial Resolution 2565 of 2003.

³⁹. Fulia Cedeño Angel.

⁴⁰. Gloria T. Zapata, *Reflexión "Familia y escuela: escenarios de desarrollo"* [Thoughts on "Family and School Education: Development Scenarios"], quoted in *Inclusión Social de las Personas con discapacidad: Reflexiones, realidades y retos* [Social Inclusion of Persons with Disabilities: Thoughts, Reality and Challenges], Institute for Human Development and Disability, National University of Colombia, and the Ministry of Communications, April 2003, 125.

⁴¹. Disability Plan 2003-2006, Objective 2.2.7, "Access, retention, and completion of education," located in section on "Equalization of Opportunities."

Employment

The unemployment rate reported by DANE fails to include the disability population. However, the National Plan for the Assistance of Persons with Disabilities, 1999-2002 refers to a 1995 demographic survey of people with disabilities in nine regional capitals carried out by Javeriana University with funding provided by the Ministry of Economy. This survey is reported to have found that 67.7 percent of people with disabilities are in need of employment.⁴² Of those persons with disabilities who are working, many are underemployed or work informally as peddlers or lottery and raffle sellers. Additionally, some persons with intellectual disabilities participate in sheltered workshops for bookbinding, linen production, painting, or the manufacture of rags. People with disabilities who have access to stable employment constitute a small minority.

This lack of employment opportunity exists despite the presence of employment provisions in both the Constitution and Law 361. Section 54 of the Constitution states that "it is the obligation of the State and of employers to offer vocational and technical training and qualification to those persons requiring them. The State must promote the labor insertion of the active population and guarantee to handicapped persons the right to an employment that is in accordance with their health condition." Furthermore, Law 361 requires the state to "take the appropriate measures in order to create and foster employment for persons with a limitation."

Changes in the national employment policy have begun to take into account the disability population by including training, offering incentives to employers, and fostering the creation of businesses of persons with disabilities by giving access to low-interest loans. Although some recent actions have begun to alter the conditions responsible for the serious unemployment situation of people with disabilities, the core issues remain problematic. Many persons with disabilities are illiterate or have attended school only briefly, and as a result, they are not adequately skilled to be competitive in the labor market. Other difficulties for employment include inaccessible workplaces, training centers, and transportation.⁴³

The National Learning Service (SENA) has begun to assist the disability population as a vulnerable population.⁴⁴ Assistance available from SENA does not make distinctions as to the kind or origin of the disability. However, SENA does not offer any vocational training or placement programs specifically for people with disabilities.⁴⁵ There are also several NGOs in the country that carry out training activities to facilitate the social and labor integration of persons with disabilities.

⁴². Quoted in the National Plan for the Assistance of Persons with Disabilities 1999-2002, Bogotá, www.logos-net.net/ilo/150_base/es/init/col_01.htm#Linea.

⁴³. Opinions gathered in panel discussion meetings held in four cities, Bogotá, 5 September, Barranquilla, 8 September, Medellín, 22 October and Pereira, 30 October 2003.

⁴⁴. *Naturaleza+y+Funciones.htm* For information on the mission of this governmental agency, see <http://www.sena.edu.co/Portal/quienes+somos/identidad+corporativa/>.

⁴⁵. Julia Gutierrez de Piñeres (Director of Employment, SENA), interviewed by author, Bogotá, 24 September 2003.

As for job placement, the Employment Information Center interviews persons with disabilities individually to provide them with information about the service and registration in their database. The center does not provide employment intermediation services.⁴⁶

There is no policy requiring the government to employ persons with disabilities. However, various government agencies have persons with disabilities employed among their staff at the different levels.⁴⁷ For example, the position of Managing Director of the Transport and Traffic Office of the Ministry of Transportation is currently held by a person with a disability.⁴⁸

Few private companies employ persons with disabilities, and most corporate policies do not establish that a person with a disability must not be discriminated against on the grounds of disability. Even the telephone company Empresa de Teléfonos de Bogotá (ETB), which does employ people with disabilities, reported that "ETB does not have any non-discrimination (written) policy. The skills, profiles and experience (if required) of applicants are simply reviewed in the selection processes without the disability condition being relevant for us depending on the position to be covered (if a specific physical condition is essential for the position, such condition is certainly assessed, as in the case of employees who must work in the heights, climb up stairs or antenna towers, etc.)."⁴⁹

Health Services

Law 100 of 1993 provides the statutory framework for the Colombian health system.⁵⁰ The law guarantees access to health services for all Colombians through the General System of Health Social Security (SGSSS). The current system has two tiers of membership that provide access to services included in the Mandatory Health Plan (POS). Contributory membership consists of those who are able to purchase coverage from Health Promotion Institutions (EPS), which are responsible for providing services.⁵¹ Subsidized membership is available for those who are unable to make contributions and who qualify for subsidies based upon financial need.⁵² Although EPSs may be either public or private, only contributory members are typically able to choose the private institutions.

⁴⁶ *Ibid.*

⁴⁷ Ministry of Social Protection, Bogotá, 2003.

⁴⁸ Dr. Oscar David Gómez Pineda (General Director of Transportation and Transit), interviewed by author, www.mintransporte.gov.co.

⁴⁹ Gabriela Posaba Venegas (Vice-President - Human and Administrative Resources Management, Telephone Industry of Bogotá), interviewed by author, Bogotá, January, 2004.

⁵⁰ Law 100.

⁵¹ Persons who have ability to pay (earning the equivalent of more than one minimum salary as determined by the SGSSS) and self-employed workers earning more than two times the minimum salary are considered able to pay and are not eligible for subsidized membership.

⁵² The population classified as being at the first and second levels of poverty according to the SISBEN survey and special groups such as the indigenous communities, the abandoned children in the charge of the ICBF, those displaced and those demobilized.

⁵³ Ministry of Social Protection.

This results in significant disparities in services provided to contributory versus subsidized members.⁵³

For people with disabilities covered by the POS, neither public nor private institutions are currently offering the required comprehensive rehabilitation services. They often also fail to provide technical aids, medicines, and even surgical procedures as appropriate. Numerous summary proceedings have been initiated by people with disabilities in order to protect their constitutionally guaranteed right to specialized health care and to compel ESPs to provide required health services.⁵⁴ Although many of these legal actions have been decided in favor of persons with disabilities, the government has not yet amended the health social security legislation.⁵⁵

Those who are not covered under either of these schemes are unable to participate in the POS and must resort to the public health service.⁵⁶ Persons with disabilities who fall within the uncovered population often wait for long periods of time for regional governments to hire medical services or grant assistive devices. Some privately-funded institutions working for persons with disabilities also provide assistive devices. However, their resources are limited and only cover a small portion of the community.

The Colombian government provides some additional funds for rehabilitation services for persons with disabilities through the Ministry of Social Protection. These services are funded with resources from the general budget through a project called *Implementation of Special Projects for the Population under Special Conditions: Mental Health, Disability and the Displaced*.⁵⁷ In 2003 a budget of 2.5 billion pesos (US \$ 926,000) was approved to be shared between fourteen departments.⁵⁸ The resources are sent to the Health Secretariats of all departments of the country to implement Disability Prevention and Care Programs, to develop Community-Based Rehabilitation (CBR) programs, and to create technical aid banks.⁵⁹ These technical aid banks are intended for persons who are not members of the SGSSS or for those who are on the subsidized scheme where the provision of assistive devices is excluded from the benefit plan.

Recently, the Ministry of Social Protection has begun to implement CBR strategies as called for in the National Plan 2003-2006. Some programs have attained extensive experience in this area. They are located in Cartagena, some municipalities of Antioquia and the Pacific Coast, and some towns of Bogotá.⁶⁰

⁵⁴. Law 100 and the resolutions 5361 of 1994 and 72 of 1997.

⁵⁵. Panel Discussion.

⁵⁶. Those persons who are not under any scheme given their poverty level. The SGSSS sets forth that until they become members of the subsidized scheme, they must be assisted by public and private institutions that have an agreement with the State.

⁵⁷. Lucy Wartenberg (Director of Social Promotions, Ministry of Social Protection), interviewed by author, Bogotá, 4 December 2003.

⁵⁸. Resolution 2529.

⁵⁹. Lucy Wartenberg.

⁶⁰. *Ibid.*

There is no official information on the number of health professionals who have access to training programs on the provision of care to persons with disabilities. However, university officials indicate that 40% of nurses and 50% of medical assistants receive basic training on the provision of care to persons with disabilities.⁶¹ Some medical schools offer an internship in Medical Rehabilitation for Adults.⁶² However, there are no training programs in physical therapy, occupational therapy, speech therapy, physiatry training for nurses, or prosthetics and orthotics in the country.

Housing

Leaders of disability organizations estimate that approximately 90 percent of persons with disabilities live with their families while the remainder live in residential institutions or are homeless.⁶³ The government does not offer public housing for persons with disabilities except for abandoned children with disabilities. The Colombian Institute for the Family Welfare (ICBF) seeks foster homes, which provide children with personal care. Each foster home receives financial support from the ICBF that must be spent on food, clothing, recreation, and educational materials. Health care is provided by registering the child under the Subsidized Health Scheme in the relevant city.⁶⁴ Adults with disabilities who have been abandoned by their families must rely on charitable institutions.

Law 361 establishes that “at least 10% of affordable housing projects” should be constructed in such a way as to make them accessible for people with disabilities. These provisions apply to all projects whether developed by governmental or private entities. It also mandates the “installation of elevators capable of carrying at least one wheelchair user.” Regulations for this law have not yet been issued.

To date, government efforts related to housing have primarily consisted of including disability as one of the criteria for affordable housing subsidies. People with disabilities are given additional points used in scoring eligibility for a subsidy. Not all persons with disabilities have access to affordable housing subsidies under the current national framework. In contrast, the municipality of Medellín, Colombia’s second most important city, established housing subsidies for all persons who have a proven disability exceeding 50%.⁶⁵

⁶¹. Carlos Felipe Rengifo Tello, (School of Medicine, Cauca University), interviewed by author, November, 2003.

⁶². Pereira Technological University, Pereira, Colombia.

⁶³. Panel discussions.

⁶⁴. Maria Victoria Alvarez Cordoba (Central Coordinator of the Northern American Zone, ICBF), interviewed by author, Armenia, 30 October 2003.

⁶⁵. Municipal Agreement No. 31 of 1999.

Accessibility

The Colombian Institute of Technical Standards (ICONTEC) has issued standards on accessibility. Technical Standards 4139, 4140 to 4145, 4201, 4339, 4279, 4407, 4695 and 4774 refer to accessibility. Colombia also has an manual that covers accessibility issues. The Manual on Accessibility to the Built Environment and the Means of Transportation was prepared with the support of the National University for the Road Accident Prevention Fund and the Ministry of Transportation.⁶⁶

The accessibility of public accommodations, public thoroughfares and public spaces is protected by Title Four of Law 361.⁶⁷ The law mandates the elimination of architectural barriers through the construction, extension, or alteration of all public facilities. All such facilities including those that are already existing or privately-owned are subject to the law. All necessary adaptations were to have been completed within four years of the law's effective date. Although the law came into effect in February 1997, compliance is still minimal. Full regulations on the elimination of architectural barriers have not been issued. Since the law makes adaptation of existing buildings mandatory, regulations are deemed counterproductive under the prevailing economic conditions.⁶⁸ Most municipalities have limited resources and would have difficulty complying with regulations.

Law 400 sets minimum requirements and criteria for the design, construction, and technical supervision of new buildings.⁶⁹ The Colombian Society of Engineers reported that 75% of the new buildings constructed in the past ten years are accessible.⁷⁰ Some public buildings such as the Murillo Toro post office building in Bogotá, which has an entrance ramp, as well as the Ministry of Education, are accessible. However, most of the public buildings in the country, especially those more than 10 years old, are not accessible.

Other accessibility related laws include Law 388, which addresses accessibility in public spaces, and Order 1504, which regulates the management of public spaces.⁷¹ The Ministry of Environment, Housing and Territorial Development is currently working on regulations for the section of Law 361 pertaining to the accessibility of public accommodations and housing.⁷²

⁶⁶. Oscar David Gomez Pineda (General Director of Transportation and Transit), interviewed by author, Bogotá, 5 September 2003, www.mintransporte.gov.co/Servicios/Biblioteca/documentos/Documentos.htm.

⁶⁷. Law 361.

⁶⁸. Pastora Murillo (Territorial Development Office, Ministry of Environment, Housing and Territorial Development), interviewed by author, Bogotá, 3 September 2003.

⁶⁹. Law 400, <http://www.secretariasenado.gov.co/Antecedentes21.asp>.

⁷⁰. Martha Lucia Jara Acuña (Executive, Colombian Society of Engineers), interviewed by author, Bogotá, 1 September 2003.

⁷¹. Law 388, http://www.secretariasenado.gov.co/leyes/L0388_97.htm.

⁷². Pastora Murillo.

Some educational resources on accessibility and design are available in Colombia. Section 47 of Law 361 requires schools of architecture, engineering, and design to offer seminars “with the primary objective of fostering the culture of elimination of architectural barriers and construction limitations.” As of this writing there is one course on disability and engineering in Colombia.⁷³

Most public transportation systems in the country are not accessible, impairing the free movement of people with disabilities. This situation can lead to the effective discontinuation of rehabilitation services as well as the inability to reach education and employment facilities. The majority of people with disabilities must reach their destination by their own means. For those who can afford individual transportation services, this can include taxis, which are very expensive for most Colombians. Others report having no choice other than to crawl in order to use the existing bus system.⁷⁴

The Transmilenio system in the capital city Bogotá has begun the process of making public transportation accessible for wheelchair users. However, the system does not cover the entire city. As of October 2003, 12% of public transportation routes in the capital city were accessible.⁷⁵ Additionally, the city of Medellín instituted a program beginning in 1998, which was aimed at creating accessible public transportation. Most recently, Medellín adopted Agreement 02 in 2001, which obligated the adaptation of the city metro stations to make them accessible to persons with disabilities.

Finally, through the Ministry of Transportation, the national government issued Order 1660 dated 16 June 2003. The order establishes that after 2005 a percentage of the new buses purchased each year must be accessible to persons with disabilities. The goal is for 100% of new buses to be accessible by the year 2010. The order also provides for the training of staff in charge of transportation issues, signaling, and accessibility of all transportation terminals including metro stations, railway stations, airports, and piers, among others.

Disability Action & Awareness

One of the most significant features of Law 361 was the creation of a body in charge of the coordination of disability-related actions.⁷⁶ Section 6 created the National Disability Consultative Committee (CCN), an institutional advisory unit responsible for coordinating and monitoring disability policies.

⁷³. Colombian Society of Engineers.

⁷⁴. Panel discussions.

⁷⁵. Ricardo Salaanca Correa (Technical Undersecretary, Secretary of Transit and Transport), interviewed by author, Alcaldía Mayor, Bogotá, 1 October 2003.

⁷⁶. Law 361, sec. 6.

The committee is composed of 16 members. Eleven of the members represent civil society organizations, with five members from disability associations.⁷⁷ At the last meeting of the committee, only two of the members of the CCN were persons with a disability.⁷⁸ In October 2002, CCN's current term expired. To date there are no signs of renewal. The CCN has not been widely accepted by the disability community due to charges of inefficiency and lack of adequate representation of persons with disabilities. The Ministry of Social Protection chairs this Committee and is responsible for its operation. Some tasks of the Committee have been undertaken by various institutions in coordination with the Ministry of Social Protection's General Office of Social Promotion.

Among the work that has been performed through cooperative efforts is the creation of the Public Disability Policy. A set of guidelines was created through the joint efforts of a wide range of organizations. They included: various governmental agencies, the National Technical Committee, the Sectoral Liaison Groups, Departmental Disability Support Networks, Departmental Technical Committees, and disability organizations. The guidelines include planning and management instruments dealing with conceptual, technical, and methodological issues.⁷⁹

One major achievement of this effort was the creation of the Disability Plan 2003-2006, which was based on components of the Public Disability Policy. The Disability Plan was also developed jointly by governmental and non-governmental organizations during the implementation of a project known as "Strengthening of Institutional Capacity and Departmental Disability Support Networks."⁸⁰ The plan includes a three-pronged approach with objectives in each of the following areas: disability prevention, equalization of opportunities, and habilitation/rehabilitation with the goal of increased independence for people with disabilities. This plan contains provisions regarding responsibility for assuring implementation.

With regard to civil society, disability associations are not currently well organized. One exception is the Colombian National Federation of Deaf People which has brought together 22 associations of people who are deaf that are located throughout the country.

This lack of organization in civil society has hindered dialogue with the Colombian government, resulting in weaker protection of disability rights. The disability rights movement is aware of the need for cooperative activities intended to improve the quality of life of the disability population.

⁷⁷. Members from civil society organizations were appointed pursuant to Order 2333 of October 2000 for a two-year term.

⁷⁸. Henry Mejía Roye (Executive Director, Colombian National Federation of Deaf People), interviewed by author.

⁷⁹. Advisory Council for Special Programs, *Social Solidarity Network: Basis for the Development of Public Disability Policy for 2003-2006*, Bogotá 2003.

⁸⁰. September 2002 - July 2003.

Recent initiatives have been formed to create federations of disability associations regardless of the type of disability served, as well as smaller federations of associations focused on particular types of disability. Associations working for disability rights are typically self-funded, although some receive financial support from the Colombian government and/or international organizations.

Some awareness-raising campaigns have been mounted in Colombia by the National Television Committee, Colmundo radio, and regional radio and television programs sponsored by the disability community. One especially important awareness-raising tool is the product of the news agency called DISNNET PRESS. DISNNET distributes an e-newsletter Monday through Friday. Thousands of people both with and without disabilities receive the newsletter through e-mail.⁸¹ Its mission is to disseminate information about disability-related issues and to raise awareness of the human rights of persons with disabilities.

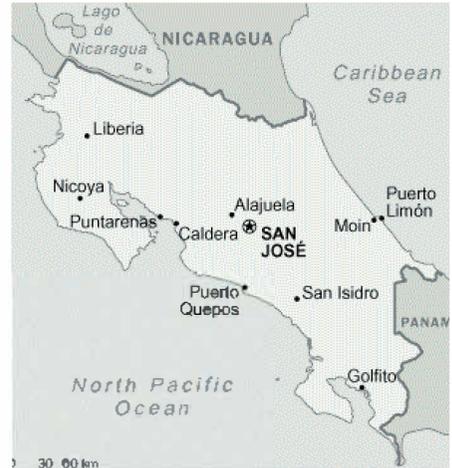
In summary, barriers to effective disability action include lack of political will and bureaucratic red-tape. Despite being recognized as a vulnerable population, people with disabilities are not a priority group. Cultural norms such as the attitude of the general population regarding the issue of difference present additional problems as do issues such as the lack of adequate human resources within civil society. General organizations are often unaware of the issues facing people with disabilities, while disability organizations lack the necessary organization for effective advocacy.

There are a handful of officials at various levels of the Colombian government who are conscious of the problematic situation that persons with disabilities face everyday. However, many of them see disability action as very costly and therefore not a priority. For example, it has taken almost two years to create a decree regulating the accessibility provisions of Law 361 because the removal of architectural barriers is not seen as economically viable. Thus progress is slow.

81. “‘DISNNET’ el periodismo a favor de la inclusion social” [‘DISNNET’media in favor of social inclusion], Step by Step Foundation interview with Hernando Ayala Melgarejo, *Cyberpasos - Interviews* 2, no.10 (22 May 2002), http://www.pasoapaso.comve/cyber/cyberpasos_archivo_entrevistas_disnnet.htm.

Costa Rica

Key Factors: After a half century of economic performance that was well above average for the region, Costa Rica has begun to experience a significant slowdown. The worsening economic situation is reflected in a stagnant poverty rate, which has remained constant at 21% over the last eight years, and an increasingly large gap in the distribution of income between rich and poor.¹ These economic problems have seriously hindered efforts to protect the human rights of people with disabilities. According to the Ombudsman's Office the population with disabilities is among the most excluded sectors of Costa Rican society.²



Definition of Disability

There are two main definitions of disability used in Costa Rica. One appears in the Equal Opportunities for Persons with Disabilities Act (Law 7600), which came into force on 29 May 1996. The law identifies a disability as:

Any physical, mental or sensory impairment that substantially limits one or more essential activities of an individual.³

The second definition, taken from Article 1 of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, characterizes the term "disability" as:

A physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic or social environment.⁴

¹ National Directorate of Statistics and Census, *Encuesta de Hogares y Propósitos Múltiples* [Home and Multipurpose Survey], Ministry of Economics, Industry, and Commerce, (Costa Rica, July 1998); Leonardo Garnier, "Columna Sub-versiones", *La Nación*, (26 December 2002), 15.

² *Annual Report of the Ombudsman, 1998-1999*.

³ Law 7600, *Igualdad de Oportunidades para las personas con Discapacidad en Costa Rica* [Equal Opportunities for Persons with Disabilities], *La Gaceta*, 2000, sec. 2.

⁴ Organization of American States, *Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities*, (OAS/ Ser. L/I.4 Rev. 8, Washington, 22 May 2001), 112.

Although the definition used most widely in official documents is that of Law 7600, there is a general understanding of the limitations of the definition's focus on impairments. Barbara Holst, Executive Director of the National Council for Rehabilitation and Special Education (CNREE), explained that CNREE "has been analyzing a potential update of these definitions in the past year, based on more recent considerations of the World Health Organization (WHO), on the International Classification of Functioning, Disability and Health (known as ICF), and on concerns raised by the movement of persons with disabilities, who believe that disability should be addressed as an issue of diversity and inclusion, without neglecting considerations of a personal nature, such as the impairment itself."⁵ The new definition being explored states that:

...[disability] is the result of an environment that does not offer timely, effective and accessible support and services to a person with impairments, limiting the execution of daily life activities and restricting his or her participation in essential life situations.

Holst points out that the new definition has had limited impact at this time, as "this concept is used for teaching purposes only, whereas the definitions of Law 7600 and the Inter-American Convention are used in legal documents."⁶

Disability Population

Two surveys conducted in the past five years provide information about the population of people with disabilities living in Costa Rica. One is the Multipurpose Household Survey, designed and carried out by the Ministry of Economics, Industry and Commerce under the National Statistics and Census Bureau (NSCB) in March of 1998. The second survey is the National Population and Housing Census carried out in 2000 by the National Institute of Statistics and Census (INEC), which replaced the NSCB. The number of people with disabilities found by the 2000 census was lower than that found by the 1998 Multipurpose Household Survey.

The Multipurpose Household Survey reported that the population of the country totaled 3,340,909 people, of whom 261,371 persons, or approximately eight percent, had a disability.⁷ In contrast, the 2000 Census found that the country's population totaled 3,810,179 with 203,731 persons, or approximately five percent, having some kind of disability.⁸

⁵ Barbara Holst-Quirós (Executive Director, National Council for Rehabilitation and Special Education), interviewed by author, Heredia, Costa Rica, 11 September 2003.

⁶ *Ibid.*

⁷ National Directorate of Statistics and Census, *Encuesta de Hogares y Propósitos Múltiples* [Multipurpose Household Survey], Ministry of Economics, Industry, and Commerce, Costa Rica, July 1998.

⁸ National Institute of Statistics and Census, *Censo Nacional de Población y Vivienda del año 2.000* [National Population and Housing Census of 2000], 2000.

In explaining the difference between attempting these two figures, the INEC noted the methodological challenges entailed in attempting to determine the number of persons with disabilities within a population. They explained that “results can be significantly biased by the concepts used and the questions asked to estimate disability rates.” Yet the Multipurpose Household survey and the census used similar strategies in asking about disabilities. The questions in both surveys focused on “impairments...based on the understanding that those questions included disabling impairments.” In addition, both surveys relied on the respondent's self-assessments. “This means that answers are extremely subjective, because they rely on what people perceive as an impairment and perceptions may vary widely. In view of this, questions asked by the interviewer may play a decisive role.”⁹

The IMNEC also acknowledged that while some disabilities are easily identified, the UN Populations Bulletin suggests, “minor hearing or visual disabilities very often go unnoticed during surveys or field research.”¹⁰ Thus, both surveys have elements that limit the confidence in, and ability to interpret, the results. The INEC also suggested that the discrepancies between the two surveys might have been anticipated because “when observing experiences in other countries, large differences in census and survey results are evident. According to the already mentioned [UN] bulletin: “Different data collection methods result in disability rates which are not strictly comparable both within and across countries. The data obtained from records or sampling surveys tend to give higher estimated disability rates than surveys based on a population census.”¹¹

Another potential source for enumerating the disability population is the CNREE register that has been in place since 1989. Despite being a detailed register of persons with disabilities, it does not encompass the entire population. The CNREE register is based on data recorded in hospitals and clinics, so only persons with disabilities who obtain medical assistance are included in its count.¹²

Legislation & Disability Rights

Legal Protections

Persons with disabilities living in Costa Rica have a series of legally binding instruments at the international, regional, and national levels, which recognize and serve as a basis for the protection of their human rights.

⁹ Elisabeth Solano (Coordinator for Surveys and Census, National Statistics and Census Institute) and Marita Beguerí (Coordinator for Information Services, National Statistics and Census Institute), interview by author, San José, 18 September 2003.

¹⁰ United Nations, *Population Bulletin*, Issue No.30, 1991, 72.

¹¹ *Ibid.*

¹² Rodrigo Jiménez (Information Unit Coordinator of the National Council of Rehabilitation and Special Education), interviewed by author, San José, September, 2003.

Costa Rica has traditionally ratified international human rights instruments.¹³ In addition to the fundamental UN conventions on human rights, Costa Rica has ratified the International Labor Organization's Discrimination (Employment and Occupation) Convention, and the Vocational Rehabilitation and Employment (Disabled Persons) Convention.¹⁴ It is in the process of ratifying the Human Resources Development Convention.¹⁵ This history of ratification suggests that the convention concerning the protection of human rights of persons with disabilities, currently being drafted by the United Nations, will be signed and ratified.

Within the context of the Americas region, Costa Rica signed the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities on 8 June 1999, at the OAS General Assembly in Antigua, Guatemala. Costa Rica ratified this Convention with Law 7948.¹⁶ It was the first country to ratify the treaty and deposit the corresponding ratification instrument with the OAS Secretary-General, Cesar Gaviria, on 8 February 2000.¹⁷

On 18 April 1996, the Legislative Assembly of Costa Rica passed Law 7600, which was inspired by the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities.¹⁸ The regulations of this law came into force two years after it was passed. The legal instrument states, "it is in the public interest that persons with disabilities be entitled to their full development, on an equal footing with the rest of society, in terms of living standards, opportunities, rights and duties."¹⁹ The purposes of Law 7600 are as follows:

- a) To serve as an instrument for persons with disabilities so that they reach their full potential, their full social participation, and the exercise of rights and duties as set forth under our legal system.
- b) To guarantee equal opportunities for Costa Rican population in areas such as health, education, employment, family life, recreation, sports, culture and all other specified areas.
- c) To eliminate any form of discrimination against persons with disabilities.
- d) To establish the legal and material foundations to allow the Costa Rican society to take the necessary measures for equalization of opportunities and non-discrimination towards persons with disabilities.²⁰

¹³ Marco Vinicio Vargas (Costa Rican Vice Minister of Foreign Affairs), (opening address at the Workshop on the Process towards an International Convention on Human Rights of Persons with Disabilities, Heredia, 26 May 2003).

¹⁴ Human Rights Internet, *Latin American and the Caribbean 4 of For the Record 2003: The United Nations Human Rights System*, 2003; International Labor Organization, *Convention concerning Discrimination in Respect of Employment and Occupation*, No. 111, 1958, <http://www.ilo.org/ilolex/english/convdisp1.htm>; International Labor Organization, *Convention concerning Vocational Rehabilitation and Employment (Disabled Persons)*, No. 159, 1983.

¹⁵ International Labor Organization, *Convention concerning Vocational Guidance and Vocational Training in the Development of Human Resources*, No. 142, 1975.

¹⁶ Law 7948, no. 238, La Gaceta [The Gazette], 8 December 1999.

¹⁷ OAS, *Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities*, "Signatories and Ratifications," <http://www.oas.org/Juridico/english/sigs/a-65.html>.

¹⁸ United Nations, *Standard Rules on the Equalization of Opportunities for People with Disabilities*, (20 December 1993).

¹⁹ Law 7600, sec. 1, 7.

²⁰ Law 7600, sec. 3, 8-9.

Other, early legislation specifically related to disability rights protection includes: the National Institute for the Protection of the Blind Act, Law 2171, dated 21 October 1957; the National Institute of Rehabilitation Act, Law 3695, dated 14 June 1966; and Law 5347 that created the CNREE, dated 3 September 1973.

The Ombudsman's Office has a Special Protection Unit for complaints concerning human rights violations against the socially excluded, such as persons with disabilities, the elderly, indigenous groups, migrant population, Afro-descendants, gay and lesbian groups, and those in prison. Many persons with disabilities or their families have filed complaints with the Special Protection Unit about violations of rights. As with the Human Rights Ombudsman's Office, the work of this unit is widely recognized throughout the country, and it is among the most prestigious public agencies. Nevertheless, its actions are not legally binding.²¹

Civic Participation

Broadly speaking, the government does not create the necessary conditions for most persons with disabilities in Costa Rica to fully exercise their citizenship rights. There are two primary obstacles to exercising the right to vote. First, persistent barriers prevent or limit physical access to voting stations as well as access to the information and communications necessary to make a fully informed vote choice. Second, demeaning attitudes and discrimination exist in the actual voting environment.

In February 2002, when the last national elections were held, the Supreme Electoral Court (TSE) began implementing measures to improve accessibility at polling stations.²² Leaders of the disability community estimate that less than 20% of polling stations are accessible as of 2003. In addition, they report that there are no Braille ballots, so persons who are blind or visually-impaired cannot vote secretly. Officers have been reported to force persons with disabilities to cast a "public" vote rather than accommodate them.²³

Although persons with disabilities are not restricted from standing for public office, political parties rarely nominate them.

²¹ National Ombudsman Office, www.dhr.go.cr.

²² Supreme Electoral Court, Communication 204-2003-CPE, 26 September 2003.

²³ Panel discussion with leaders of disability organizations, discussion facilitated by author, 6 September 2003, San José, Costa Rica.

Inclusion

Communication

Law 7600 requires that news broadcasts on national television be accessible to people with disabilities. These provisions are only partially implemented.²⁴ Most private and public television networks typically offer no more than one half hour of news per day that is interpreted through Costa Rican sign language (LESCO) and such news programs usually shown only in the mornings.

There is one private television channel that broadcasts multiple programs using the closed-captioning system. In addition, Channel 15 of the University of Costa Rica (UCR) broadcasts several programs with a LESCO interpreter.

There has been very little progress in terms of access to information in public libraries or documentation centers of public institutions. The National Library does not have any accessible format of the Constitution for persons who are blind or visually impaired.²⁵

The Costa Rican Electricity Institute (ICE), which is responsible for electrical utilities and telecommunications, has been installing accessible public telephones, as well as printing phone cards in Braille. It also established the "137" telephone line, which persons who are deaf can dial for assistance. The establishment of Institutional Commissions on Disability has also contributed to communication advances for people with disabilities, by providing employee-training in Sign Language and by offering services in Braille.²⁶

Education

A recent report by the Ministry of Public Education's Department of Special Education offered an overview of education for persons with disabilities. Students with special educational needs comprise about 10.13% of the total number of students. Thus, out of a student population of 937,154, there are approximately 95,000 students with disabilities. The majority are taught in mainstream classrooms, but some are taught in special classes or special schools.

²⁴ Law 7600, sec. 51, 22.

²⁵ Yamileth Solano Navarro (Director of the National Library, "Miguel Obregón Lizano"), interviewed by author, San José, 22 September 2003.

²⁶ Law 7600 required the Ministry of Labor and Social Security to create an Institutional Commission on Disability. Although not mandated by law, upon the recommendation of CNREE, approximately 60 additional institutions have created their own commissions.

Regarding inclusive education, the Ministry of Public Education (MEP) report states: “the model of teaching students with disability-related educational needs has shifted towards a new model that aims at providing schooling opportunities in less restricted environments. This is the regular school. According to preliminary data from the Statistics Department of the Ministry, based on growth rates in 2000-2001, approximately 79,600 students with educational needs related to different disabilities attended regular classes in 2002.”²⁷

Approximately 1.64% of students are taught at special education centers, which are the most segregated type of educational institution. There are 23 such special education centers in Costa Rica. Students who attend these centers require intensive full-time support. They include students with developmental disabilities, total or partial hearing impairments, psychiatric disabilities, visual disabilities, and multiple disabilities. These centers are primarily located in major towns, with most located in the greater metropolitan area. In 2002, 5,280 students attended elementary school at special education centers and 3,637 students with disabilities were enrolled in special secondary schools. In the same year, 14,470 elementary school students enrolled for continuous support in special classrooms, and 3,272 enrolled for after-school support. A total of 7,289 students with developmental disabilities, hearing disabilities, or multiple disabilities were enrolled in integrated classes.²⁸



*Entry to the Ministry of Education,
Costa Rica*

²⁷. Gerardo Monge, “La influencia de la Ley 7600 de Igualdad de Oportunidades para las Personas con Discapacidad en el Sistema Educativo Costarricense” [The Impact of Law 7600 on Equal Opportunities for Persons with Disabilities in the Costa Rican Educational System], (report presented to CNREE, 2002).

²⁸. *Ibid.*

Even though progress has been made in access to education for youth with disabilities, most schools are not readily accessible. The National Development Plan for 2002-2006 indicates that only 18% of all educational centers are minimally accessible. The numbers would be lower if only fully accessible centers were considered. Among the key features that are sometimes missing are appropriate ramps both at entrances and inside buildings and accessible toilets.²⁹

The need for continued effort is demonstrated by the number of complaints that have been filed with the Human Rights Ombudsman's Office regarding educational discrimination against people with disabilities. A full 30 percent of the complaints received by the Ombudsman's Office concern violations of the educational rights of persons with disabilities.³⁰ The Constitutional Chamber also hears summary actions against educational centers that violate the right to education of children with disabilities.³¹

School supervisors, who play an important role within the country's 20 educational regions, are often closed-minded about the enrollment of children and youth with disabilities in regular schools, even though regulations are clear in this area.³² Complaints by families describing how private and public educational centers deny a place to children with disabilities have been published in the media. There is also resistance towards inclusive education on the part of some special education teachers. Their training was based on models that focused on segregation, which presents a barrier to change.³³

Likewise, many primary and secondary school teachers tend to demean and discriminate against students with disabilities.³⁴ In an attempt to eliminate discriminatory attitudes, the MEP has begun efforts to train teachers on disability issues. The National Resource Center for Educational Inclusion (CNRIE) was established in April 2002 with this aim. The center provides information for educators, including special education teachers, parents and families with children that have disabilities, and institutions interested in inclusive education processes. The center also conducts research, supplies information on technical aids, and helps seek the resolution of educational disputes. The CNRIE is able to print materials in Braille upon request.³⁵

Finally, provision of technical aids for educational needs remains an issue. Although some progress has been made, demand continues to exceed supply, especially for poorer students.³⁶

²⁹ National Development Plan 2002-2006, ch. on education.

³⁰ José Manuel Echandi, "Avances y perspectivas de la ley No. 7600 en el contexto educativo" [Progress and Views on Law 7600 in the Field of Education], (presentation at the National Resource Center for Educational Inclusion, San José, 7 August 2003).

³¹ Otto Lepiz Ramos (civil officer of the Special Protection Unit, National Ombudsman Office), interviewed by author.

³² Gerardo Monge (Director of the Department of Special Education of the Ministry of Public Education), interviewed by author.

³³ *Ibid.*

³⁴ Comments made during a special training session at the National Autonomous University (UNA) that was attended by thirty educators in November 2001.

³⁵ National Resource Center for Inclusive Education (CNRIE), Department of Technical Assistance.

³⁶ *Ibid.*

Employment

No reliable official statistics are available concerning the number of unemployed persons with disabilities in Costa Rica. However, according to estimates provided by disability organizations, the unemployment rate is around 65 percent.³⁷

Section 23 of Law 7600 guarantees all persons with disabilities the right to work, and section 24 provides that "it shall be considered discrimination for an employer to use personnel selection criteria which are not adjusted to the conditions of any job applicant, to demand higher qualifications than those usually required for other applicants, and to refuse to hire an applicant who is an otherwise qualified individual, because of his or her disability."³⁸ These provisions have been difficult to enforce because of the challenges entailed in proving that discrimination has occurred when a person with disabilities applies for a job and is denied employment.³⁹

Before the creation of Law 7600, the Ministry of Labor and Social Security (MTSS) set up a special job placement service for persons with disabilities that was supported by the ILO. This service enabled an unspecified number of people to gain access to employment opportunities. Once Law 7600 was enacted in 1996, people with disabilities expected an increase in effort that would result in more job openings and more opportunities for gainful employment available to persons with disabilities. However, the job placement service became less effective, and eventually closed.

In its place, Law 7600 required the Ministry of Labor to create a service unit with qualified professionals that would provide advice on vocational rehabilitation, place and relocate persons with disabilities, and promote, to potential employers, the benefits of hiring persons with disabilities.⁴⁰ Even though the law came into force more than seven years ago, the Ministry of Labor has not created the service. The Ministry's National Director of Employment does act as an intermediary between job seekers with disabilities and outside businesses seeking to hire workers. Unfortunately, results of this process are poor with only 15 workers hired in 2002.⁴¹

³⁷. Panel discussion. Among the sources used to generate this estimate were the 1998 Household Survey, a study by the MTSS National Director of Employment indicating that on average, only 10 out of 100 job seekers with a disability find employment, and an ILO estimate that around 80% of persons with disabilities in the region are not employed.

³⁸. Law 7600, sec. 24, 15.

³⁹. Martha Hernandez (principal in charge of serving persons with disability seeking employment assistance, National Directorate of Employment of the Ministry of Labor and Social Security), interviewed by author.

⁴⁰. Law 7600, sec. 30, 17.

⁴¹. José Manuel Echandi, "Ponencia sobre cumplimiento de la ley 7600 en materia de empleo" [Compliance of Law 7600 in terms of Employment], (lecture, Forum on Employment and Disability, National Resource Center for Educational Inclusion, San José, 24 September 2003).

The problems faced in self-employment are similar to those in the competitive job market. There is an office in the MTSS in charge of promoting micro and small businesses. However, people with disabilities often cannot meet the loan requirements, so the efforts of this office have not resulted in substantially increased employment opportunities.

The CNREE, through its Rotating Fund, is the only organization that grants micro-loans to enterprises operated by people with disabilities, but available resources are extremely limited. The annual number of micro-enterprise loans does not exceed one hundred.⁴²

Lastly, there are 16 social and vocational workshops offering sheltered employment. Most of these workshops were established by associations of parents of children with disabilities, and most lack sufficient financial resources. The main source of support is provided by the Ministry of Public Education. The MEP provides teachers to assist people attending the workshops.⁴³

Health Services

Costa Rica has developed a good public health system in the past fifty years. The Costa Rican Social Security Fund (CCSS) provides a wide range of health services in hospitals, clinics, and more recently, by means of Basic Comprehensive Health Care Units (EBAIS), located in urban and rural areas across the country. Emphasis has typically been placed on health assistance, but in recent years preventive care has begun being offered as well.

Through the CCSS, all persons with disabilities are assured access to free medical care and rehabilitation, and all required health care support services, irrespective of their ability to contribute to the social security system. Persons with disabilities who require assistive devices and do not have the financial resources to purchase them, should have such aids provided by the CCSS. Unfortunately however, assistive devices are not being supplied as needed and most CCSS facilities are not accessible to people with disabilities.

Although all people with disabilities are eligible for extensive health care, rehabilitation services are not widely available across the country. A National Center for physical rehabilitation is located in the capital city. Although persons from the central area of the country are easily served by this center, those from more remote areas find it difficult to utilize the services offered. Coverage is increased somewhat through the CNREE Comprehensive Local Rehabilitation Services (SILOR). However, the scope of this program is limited as there are only six locations throughout the country and a small staff.

⁴² Luis Guzman (Administrative Director of CNREE), "Fondo Rotatorio" [The Rotary Loans Fund], (report presented to CNREE, Costa Rica, February, 2001).

⁴³ Panel discussion.

Children in need of physical rehabilitation are also affected by the scarcity of services. The services offered at the National Rehabilitation Center (CENARE) are intended for adults, and the National Children's Hospital (HNN) does not have specialized rehabilitation services. Likewise, women with disabilities are not assured adequate health care, especially in relation to reproductive health.⁴⁴

There are two national programs focusing on prevention and health care for infants and children with disabilities: the Child Health and Disability Screening and Prevention program, and the Registration Center for Congenital Diseases (CREC). The Child Health and Disability Screening and Prevention program focuses on the early detection of five diseases: congenital hypothyroidism, phenylketonuria, maple syrup urine disease, congenital adrenal hyperplasia, and galactosemia. They are treated with medications and specially prescribed diets. The program covers 95.1 % of the newborns in the country. The main goal of the CREC, on the other hand, is "to early identify and determine congenital defects at birth." CREC services cover 94 % of the country's population.⁴⁵ Fourteen congenital defects are included: Anencephaly, spina bifida, encephalocele, hydrocephaly, microtia, cleft palate, harelip, esophageal atresia, imperforated anus, hypospadias, limb reduction defects, diaphragmatic hernia, abdominal wall defect, and Down syndrome.⁴⁶

Finally, it should be noted that the country has little experience in Community-Based Rehabilitation (CBR). In 2003, the CCSS began to consider CBR as a rehabilitation alternative, and initiatives are now in their early stages.

Housing

By the end of the 1980s, the government had developed a policy to reduce the housing shortage in the country. The policy included subsidies to enable beneficiaries to build their own houses. Those who were eligible for this program had to first obtain a plot of land, and then the government would grant them resources to build their house. Because building costs are often higher for families that include persons with disabilities, it was agreed that these families should receive one and a half times the standard subsidy. This benefit is not yet guaranteed by law, but there is a proposal to amend the National Housing Finance System Act that would make it more permanent.⁴⁷

⁴⁴. Panel discussion.

⁴⁵. Dr. Manuel Saborío Rocafort (Director of the Early Detection of Disabilities Program, National Children's Hospital, Costa Rican Social Security Fund), interviewed by author, Costa Rica, 18 September 2003.

⁴⁶. Registration Center for Congenital Diseases and Costa Rican Research and Teaching Institute of Nutrition and Health, *Prevalencia de enfermedades congénitas por provincias y cantones de Costa Rica 1987-2.000* [Prevalence of Congenital Diseases by Provinces and Cantons of Costa Rica 1987-2000], (Impresos Cosan SRL, San José, 2002), 1.

⁴⁷. Federico Vargas Ulloa, Draft Amendment to Law 7950, "National Housing Finance System."

Institutionalization

There are two institutions that provide care for persons with psychiatric disabilities: the National Psychiatric Hospital and the Chacón Paut Hospital. At present, 991 persons are institutionalized in these two facilities. Patients are admitted through medical referrals that comply with strict procedures.

In the past six years, these hospitals have attempted to de-institutionalize many patients. Additional resources are necessary to provide adequate living accommodations for these people because the families of de-institutionalized patients are not always willing to accept them.

Patients rejected by their families have compelled hospitals to seek alternative solutions. The National Psychiatric Hospital for example, runs a "day care center", where persons who were institutionalized for long periods of time are given continuing care and training. They live with their families or in homes outside the hospital but spend their days at the institution.⁴⁸

Accessibility

The term established by Law 7600, for making public buildings and transportation accessible expired on 29 May 2003.⁴⁹

Prior to erecting new public facilities, builders must present construction drawings to the relevant authorities. Plans must incorporate features meeting accessibility requirements. However, building are often not constructed according to their plans and most facilities only partially meet these requirements, if at all. For example, ramps are sometimes included in the architectural drawings, but no ramps are actually constructed. The agencies responsible for enforcing the accessibility legislation provide little or no supervision of construction.

There has been little significant progress in making existing public buildings accessible. Some institutions have made alterations to building infrastructure, improving accessibility but not entirely solving accessibility problems. For example, access ramps are built to a building but obstacles to free movement within the building are still encountered, including steps, excessively heavy doors, and inaccessible toilets. Few ramps have been built along sidewalks in the country's main towns, including the capital, San José. Where ramps do exist, some were not constructed to appropriate technical specifications.

The legal penalties for non-compliance to accessibility guidelines in the transportation sector are weak, with the exceptions of those applying to buses. The Public Transportation Board (CTP) is responsible for assuring compliance by bus services. It has the authority, in the event of non-compliance, to cancel the licenses and permits of private bus companies. Unfortunately, although the deadline for compliance is past, only a few buses out of a fleet of 8,500 are accessible.

⁴⁸. Interview with members of the Institutional Committee on Disability of the National Psychiatric Hospital, Costa Rican Social Security Fund, Costa Rica, 18 November 2003.

⁴⁹. Law 7600, 21 & 47.

On the day the deadline passed, CTP issued an order extending the term for a three-month period.⁵⁰ Transportation companies challenged the order by means of a summary action presented before the Constitutional Chamber. The court dismissed the challenge. Subsequently, three companies filed separate lawsuits, on the same grounds, claiming that the order was unconstitutional. These suits are pending.

Law 7600 also provides that about 10 percent of taxi services must be accessible. In a recent invitation to submit applications for accessible taxi licenses, operators obtained 100 out of the 1,320 registered plates offered. Vehicles that fulfill accessibility requirements are more expensive than cars usually used to provide this service. Complaints about taxi driver discrimination against persons with disabilities are common. Taxi drivers often refuse to transport persons who are blind, alleging that their dogs might cause damage. Similarly, taxi drivers refuse or resist transporting passengers in wheelchairs, citing concerns relating to time. The Constitutional Chamber has decided several cases in favor of passengers with disabilities.⁵¹

Because of continued pressure from disability organizations demanding accessible transportation, and as a result of an agreement between the CNREE and the National Transport Forum, bus companies have agreed to a series of accessibility-related concessions relating to terminals and buses. They have committed to having 8% of all buses accessible by February 2004 as well as to having at least one fully accessible bus per route.⁵²

The national government plans to create a Commission on Accessible Transportation, that will include representatives of the Public Transportation Board, bus companies, the CNREE, and disability organizations. This Commission will be responsible for ensuring that sustained progress is made.⁵³ The Commission will implement two accessible bus transportation projects in the near future. One project involves creating a system using articulated buses along bus-only lanes, similar to Bogota's Transmilenio and a project in Curitiba, Brazil. In September 2003, the MOPT convened a consultative meeting with disability organizations of persons with disabilities to hear their views. The project, is scheduled to begin in 2005.⁵⁴

⁵⁰. *Order on bus transport accessibility*, Public Transportation Board, 29 May 2003.

⁵¹. Barbara Holst-Quiros.

⁵². CNREE, *National Transport Forum Agreement*, (Heredia, 28 August 2003).

⁵³. Ministry of Public Works and Transportation (MOPT), *Agreement between the Directing Body of CNREE and the National Forum on Transportation*, (October 2003).

⁵⁴. Document on agreements resulting from the negotiations of a Ten-Point Petition between the Government of the Republic and organizations for persons with disabilities, San José, 27 October 2003, 6.

The second project concerns intercity trains that would travel from the capital to major towns in the center of the country. "Pursuant to the provisions of Law 7600, these trains must include accessible facilities, terminals must be accessible, and moveable ramps must be in place for boarding and descending from the trains, to enable passengers to move safely and effectively in wheelchairs or when using other types of technical aids."⁵⁵ The responsible authorities have said that these trains will be fully accessible.



Accessible entry to the main post office in Costa Rica

Culture, Sports, and Recreation

Law 8306 requires that accessible areas are clearly defined at public shows and that ramps, toilets, and emergency exits are included as appropriate. However, access to most recreational activities is still limited for persons with disabilities. Some improvements have been made in museums, especially in the Gold Museum of the Central Bank of Costa Rica. However, most cinemas and theatres, including several that are newly built, are not accessible.⁵⁶

Stadiums and gyms, seaside resorts, and recreation centers in general also have accessibility problems. Active participation in sports is low for persons with disabilities because of these accessibility problems. Organizations with an interest in this area, such as the Costa Rican Association of Persons in Wheelchairs, work to promote sports activities for persons with disabilities, provide sports trainer assistance, and ensure sports equipment is in place.⁵⁷

⁵⁵. *Ibid.*

⁵⁶. Law 8306, *La Gaceta*, 29 September 2002.

⁵⁷. Panel discussion.

Efforts are being made to improve accessibility in national parks and conservation areas and are expected to become more widespread in the future. Thanks to the participation of the Earth Council Foundation and the Ministry of the Environment and Energy (MINAE), an Accessibility Protocol for this type of park setting addresses the type of changes that need to be made. The protocol is the first of its kind in the world.⁵⁸

Disability Action & Awareness

There are three public agencies concerned with disability issues. The country's most important disability agency is the National Council for Rehabilitation and Special Education (CNREE). The initial mandate of the CNREE put it "in charge of general policy-making on rehabilitation and special education...as well as planning, promoting, organizing, creating and supervising rehabilitation and special education programs and services for persons with physical or mental impairments, in all sectors of the country."⁵⁹ Its scope was further extended by Law 7600 to include all other policy sectors serving persons with disabilities. The CNREE Board of Directors consists of representatives from public institutions, private organizations, and civil society organizations. Twenty-five percent of the board members must belong to organizations of persons with disabilities.⁶⁰

Despite its mission, CNREE has not played a significant leadership role because it has continued to be responsible for the direct provision of services in fields like employment and health. The provision of such services is typically under the jurisdiction of other public agencies that have failed to fully implement the necessary programs. Consequently, although the country has modern legislation in the field of human rights for persons with disabilities, the CNREE has failed to rigorously control and supervise compliance.⁶¹ Less than five percent of the total staff of the council has been appointed to carry out such tasks.

Although the CNREE has not played the role envisioned for it, it has had two important successes. First, the CNREE produced an important set of policies called the "National Policies on Disability 2000-2010."⁶² In producing these policies, the CNREE organized a forum that brought together 185 officials from public agencies and 15 persons with disabilities.⁶³

⁵⁸. Luis Fernando Astorga, "Costa Rica Designs and Tests First Accessibility Protocol in Protected Wildlife Areas", *Disability World* 17, (January-March 2003).

⁵⁹. CNREE, Compendio de Normas Internacionales y Nacionales vigentes en materia de discapacidad/Compilación [Compendium of existing International and National Laws and Regulations on Disability/Compilation]; Law 5347, <http://www.cnree.go.cr/datos/datoscompendio/Ley%205347.htm>.

⁶⁰. Law 7600, sec. 12, 12.

⁶¹. Panel discussion.

⁶². CNREE, December 2001e

⁶³. In September, 1999, the Rapporteur on Disabilities of the UN, Dr. Bengt Lindquist, visited Costa Rica for a consultative forum organized by CNREE for the formation of public policies on disabilities. Dr. Lindquist voiced his impressions of the country's management of disability at a meeting comprised of representatives of organizations of persons with disabilities.

The CNREE handed the public policies document to the President of the Republic, Miguel Ángel Rodríguez Echeverría, at a special ceremony on 8 December 2000. He expressed a commitment to turn the policies into an Executive Order that would have been legally binding for the public institutions covered by the policies. Eventually, however, Echeverría adopted these policies as a Presidential Guideline.⁶⁴ These public policies have not, however, proved to be a guiding principle for the current administration (2002-2006), headed by Abel Pacheco de la Espriella.

Although the policies have not significantly contributed to achieving greater government compliance with the provisions of Law 7600, the guidelines resulted in the creation of 56 Institutional Commissions on Disability within government agencies. The commissions that are already in place and actively working are helping foster compliance; however, relatively few institutions have commissions that are functioning and producing concrete results.⁶⁵

The second important contribution of CNREE is the creation of a Register of Organizations related to disability issues.⁶⁶ This register includes duly incorporated associations and foundations of persons with disabilities, parents of children with disabilities, and persons connected with the disability field. As of 30 September 2003, a total of 132 disability organizations were registered with the CNREE.⁶⁷

In addition to the CNREE, the other two institutions in the disability field are the National Institute for the Protection of the Blind (PANACI), a leading organization concerning blindness and visual impairments, and the National Rehabilitation Institute (PANARE). Both institutions are affiliated with the Ministry of Health. They operate autonomously and very little cross-institutional coordination appears to exist.

The scope of PANACI is vast since, according to the 1998 Multi-Purpose Household Survey, a little over a quarter of the people with disabilities in the country are blind or have visual impairments. Like CNREE, the PANACI Board of Directors includes representatives from organizations of persons with disabilities. The PANARE was established in the 1970s as part of the country's response to the poliomyelitis epidemic at the time. Today the institution has a poorly defined role. Consequently, PANARE has very little impact on disability policy across the country.⁶⁸

Finally, local Commissions on Accessibility have been established in some of the country's 81 town governments. They have been making efforts to improve access to services for persons with disabilities, with greatest emphasis being placed on physical accessibility.

⁶⁴. Presidential Guideline 27, *La Gaceta*, (January 2001).

⁶⁵. Service Team of CNREE Institutions and Municipalities.

⁶⁶. Barbara Holst Quirós.

⁶⁷. Rodrigo Jimenez.

⁶⁸. National Institute for the Protection of the Blind, www.oit.or.cr/bidiped/pnc.

Unfortunately, there is still little coordination among disability organizations, and their impact on the political life of the country is minimal. In addition to physical accessibility and transportation issues, the organizations tend to focus on providing services rather than advocacy, making it harder for them to work together.

There are some recent exceptions. Cooperative efforts resulted in the organization of a public demonstration on 1 June 2001. The march for equality mobilized more than 2,000 persons. Additionally, from May to October of 2003, joint efforts by the Human Rights Forum for Persons with Disabilities and the Federation of Sheltered Workshops resulted in a series of agreements with the government. These agreements are expected to lead to improved compliance with Law 7600 in the areas of education and technical training, employment, transportation, and housing.⁶⁹

⁶⁹. Press release published by the Social Council on benefits for persons with disabilities, 29 October 2003.

Dominican Republic

Key Factors: The Dominican Republic shares the Caribbean island of Hispaniola with Haiti. Of the Dominican Republic's 8.5 million people, 66 percent live in urban areas.¹ High unemployment and the cost of health care create hardships for many poor, among whom people with disabilities and their families figure prominently.



Terminology

The Disability Act, enacted in June 2000, specified that: “As of the effective date of this law, the words “*invalido*”, [invalid] “*minusvalido*” [crippled] or “*inhabilitado*,” [handicapped] as used in any legal document to refer to people and their abilities, shall be replaced with “*personas con discapacidad*” [people with disabilities].”²

However, some disability-related publication use the word “*discapacitados*”, translated here as “disabled,” to refer to the disability community.³ Additionally, the most recent census asked about “*limitación*”, translated here as “impairment,” as well as “*sordo*” and “*mudo*” translated here as “deafness” and “muteness.”⁴ When directly quoting legal documents in this report, the original terminology has been preserved.

The country's radio and television media outlets have begun using appropriate words to refer to people with disabilities. This change is a result of a social awareness campaign that was carried out in 2000 by disability organizations.⁵

¹ United Nations Development Programme, *Human Development Report 2003: Millennium Development Goals: A compact among nations to end human poverty*, (Oxford University Press, New York, 2003).

² Law 42-2000, *Discapacidad en República Dominicana* [Disability Act], http://www.bvs.org.do/docs_en_html/conadis.htm.

³ Noemi Mendez, Booklet No. 3, “Derechos de los Excluidos” [Rights of the Excluded], (brochure Padre Juan Montalvo Social Studies Center, 2001).

⁴ National Statistics Office, *Census Taker Manual, 7th National Population and Housing Census, 2002*, <http://www.one.gov.do>.

⁵ “Pero le falta algo” [But something is missing], campaign sponsored by the Democratic Participation Project (PID), Pontificia Universidad Católica Madre y Maestra and the Dominican Rehabilitation Association.

Definition of Disability

With Law 42-2000, the Dominican Republic adopted a standardized definition of disability it states that: “For the purposes of this law, disabilities will be assessed based on the latest Spanish version of the International Classification of Impairments, Disabilities and Handicaps adopted by the World Health Organization (WHO), or any such classification accepted by this International Organization. Once a disability is detected, a referral must be made to a specialized care center, where disability will be assessed as appropriate and the required intervention measures will be determined.”⁶

In contrast, other concepts of disability within Dominican law focus primarily on impairments. For example, the “Rules for the Assessment and Rating of the Degree of Disability of Beneficiaries of the Dominican Pension System” define disability as “any restriction or lack resulting from an impairment of ability to perform an activity in a way or within the range considered normal for a human being, resulting in excess or impaired performance and behavior in a normal or routine activity. This may be temporary or permanent, reversible or irreversible, and progressive or regressive.”⁷ These rules are used to classify levels of disability when a request for a pension due to accident or illness is made.

The rules also specify the meaning of other terms including: “handicap” defined as “the physical or intellectual condition of an individual who has a disease or weak health condition causing a loss of his or her ability to perform work by 50%”; and “statutory impairment,” defined as “a disease or weakened physical and/or mental condition, the characteristics of which serve as a basis to assess the degree of handicap.”⁸

Disability Population

There are no available statistics on the number of people with disabilities in the Dominican Republic. The widely cited WHO estimate that an average of 10% percent of the world’s population consists of people with some kind of disability is used as a reference. Based on that rate and using figures from the latest Population and Housing Census, the number of people with some kind of disability in the Dominican Republic is estimated to be 850,000.⁹

⁶ Law 42-2000.

⁷ Resolution 78-02, *Normas para la Evaluación y Calificación del Grado de Discapacidad de los Afiliados al Sistema Dominicano de Pensiones* [Rules for the Assessment and Rating of the Degree of Disability of Beneficiaries of the Dominican Pension System], adopted by the National Council on Social Security, 7 August 2003.

⁸ *Ibid.*

⁹ *7th Population and Housing Census.*

The 2002 census included two questions on disability, however, the data on this population segment are not yet available.¹⁰ The results will be released in mid-2004. The first question asked "Do you have any of the following impairments?" Answers included "blindness in one eye/blindness in both eyes/deafness/muteness/loss or permanent limitation of arm movement/loss or permanent limitation of leg movement/mental retardation or deficiency/other limitation/no limitation."¹¹ Because of the limitations of this type of question, the census is not expected to accurately enumerate the disability population of the country. The follow-up question asked the cause of the disability including heredity, illness, accidents, and aging among the possible causes.¹²

Disability Rights & Legal Protections

Legal Protections

The first law to include specific provisions for the disability sector was Law 87-01, which established the Dominican Social Security System (SDSS).¹³ The first paragraph of the preamble expressly references people with disabilities, stating that "the Dominican State shall foster the progressive development of a Social Security system, so that every person can be adequately protected during unemployment, ill health, disability and old age." The preamble also states that one of the objectives of the law is "to effectively contribute to improve living standards, to reduce poverty and social inequalities, to protect the helpless and the disabled." The law came into force on 2 February 2003.

Law 42-2000 is another important piece of disability rights legislation. The law is a general anti-discrimination law that protects persons with disabilities "from every discriminatory act or process." It recognizes people with disabilities as "subjects with equal human, constitutional and civil rights and duties as those who do not find themselves in the same condition."¹⁴ The law also regulates institutions "the main purpose of which is the disability issue or is related to the disability issue".

¹⁰ Héctor Vargas (Head of the Census and Survey Department of the National Statistics Office ONE), interviewed by author, Dominican Republic, 15 September 2003. He said that the number of people with disabilities in the country will only be known when population segmentation data become available in 2004.

¹¹ *7th Population and Housing Census*.

¹² That question asked "What is the cause of the limitation(s)? [Born with it/Sickness/Violence or abuse/Motorcycle accident/Other automobile accident/Other non-work related accident/Work-related accident/Aging/Other cause/Unknown.]"

¹³ Secretary of State of Labor, *Sistema Dominicano de Seguridad Social* [Dominican Social Security System], (Santo Domingo, Dominican Republic, 10 June 2001).

¹⁴ Law 42-2000.

Despite the existence of these provisions, the Dominican Republic has a clear need for a specific organization to protect the rights of people with disabilities. There is no Ombudsman Office or other institution with which to file complaints regarding human rights violations.

Civic Participation

People with disabilities have the right to vote. The Constitution of the Dominican Republic provides that “Every Dominican citizen, in full exercise of his or her civil and political rights, upon reaching the age of 25, has the right to elect and to be elected.”¹⁵ As established in the Civil Code, there are no restrictions to these rights.¹⁶

The Central Electoral Board of the Dominican Republic has issued some provisions on accessibility of ballot boxes; however, those provisions do not address barriers to the built environment. In addition, ballots in Braille or other alternative formats are not required, so people who are blind must be accompanied by someone in order to exercise their right to vote.¹⁷

During the 2002 Elections, several disability organizations (the Dominican Rehabilitation Association, the Circle of Women with Disabilities, the Dominican Wheelchair Sports Club, and the Association of Persons with Physical/Mobility Disabilities) hosted a series of conferences and visited various polling stations to ascertain the level of accessibility.¹⁸ Fifteen members of the Wheelchair Sports Club participated in the election as monitors and as part of election security. The objective of all these activities was to increase the participation of persons with disabilities in the electoral processes of the country.¹⁹

Inclusion

Communication

Alternative format materials for persons who are blind are available from a variety of sources. The Dominican Foundation for the Blind tape records or prints in Braille any amendments or updates to the text of legal documents like the Constitution. The Educational Resource Center (formerly the National School for the Blind) provides educational texts in alternative formats. The center is associated with the Secretariat of Education.

¹⁵. Constitution of the Dominican Republic, art. 13, sec. II, para. 2.

¹⁶. *Código Civil* [Civil Code], title III, sec. II, art. 13 1-2.

¹⁷. Ricardo Gonzales Camacho, *Sistema Electoral, Reforma Política y Participación Ciudadana en Los Procesos Electorales* [The Electoral System, Political Reform, and Civic Participation in Electoral Processes], Social Center for Community Development, Inc., under the auspices of the project for Support for Democratic Initiatives.

¹⁸. The work was carried out within the framework of the Democratic Participation Project (PID). Conferences included “The Conscious Vote,” “Por el valor de mi voto” [For the value of my vote], and “Participation of persons with disabilities in Social Processes.”

¹⁹. Dominican Rehabilitation Association, *Rehabilitación en Marcha* [Rehabilitation in Action], vol. 28, no. 63, 14-18.

The "Cultural Services Unit for the Blind" of the National Library provides Braille documents and other alternative format information for people who are blind. Available documents include: the Disability Act, the UN Standard Rules, other UN Documents, educational brochures, a tape-recorded cultural magazine called "*Fono Revista Cultural Contacto*," and textbooks. Documents are updated as required rather than according to a specific schedule.²⁰ The National Library has a Braille printer donated by Sweden, which is out of order because no specialized technical service is available.²¹

Approximately 500 to 600 people who are blind are estimated to use the alternative format documents each year, as do a large number of people who are not blind. The service is only available at the National District Library.

Currently, the official television station (Radio Televisión Dominicana) broadcasts the evening news in sign language. However, there is no method for people with hearing impairments to communicate with authorities in case of natural disasters, civil emergency or criminal assault. Several schools and NGOs address the communication needs of people with hearing disabilities. These include audiological centers for diagnosis, education and job placement, and training programs for regular teachers. There are no government resources for alternative communication for people with multiple disabilities.

Education

There are no reliable data on the number of students with disabilities who are able to participate in the national education system.²² However the number is thought to be low.

Two major issues hindering people with disabilities from receiving appropriate education: physical barriers, and lack of adapted educational materials. The government has recently initiated programs to address both.

The State Secretariat of Education, through the School Building Division, recently started a national project to adapt classrooms and school buildings, in order to make them accessible to wheelchair users.²³ There is no information on the number of schools that have been adapted.

Although educational materials (in Braille or other alternative formats) are currently not available in state and private schools, Resolution 18-2001 designated the National School for the Blind as an "Audio-Visual Education Resource Center."²⁴ The center plans to conduct a survey in classrooms to detect blindness and/or visual impairments. The Center will then receive direct support from the Secretariat of Education to distribute Braille educational materials to schools with students who are blind students. The center will work through 17 regional

²⁰ Edgar Reyes (Head of the Cultural Services Unit for the Blind), interviewed by author, Dominican Republic, 14 November 2003.

²¹ *Ibid.*

²² Catalina Andujar Scheker (Director of the Special Education Office), interviewed by author, Dominican Republic, 28 July, 2003.

²³ *Ibid.*

²⁴ Director of Special Education, Secretary of State of Education, *Departmental Order 18-2001*, Dominican Republic, 2001.

branches located throughout the country.²⁵

Only a few courses on special education are included in the national teacher training curriculum. Felix Evaristo Morales, a public teacher training institute, offers special education studies with a focus on mental retardation in coordination with the Special Education School of the Dominican Rehabilitation Association. At present 20 students are studying in the program. Scholarships are often granted by non-governmental service providers.

Employment

The general unemployment rate is currently very high in the Dominican Republic, but there are no specific statistical data on the unemployment rate among people with disabilities.²⁶ Leaders of disability organizations report that the experience of the disability community is consistent with the national trend, and a majority of people with disabilities are unemployed.²⁷ In the face of high unemployment, the informal market plays a significant role in the Dominican Republic economy and provides a range of jobs such as street trading. However these jobs are largely inaccessible for people with disabilities.

A small scale study by the Circle of Women with Disabilities (CIMUDIS) found that of 102 members, 64 are currently unemployed 38 are employed. Of those employed, five work in the "informal sector" (i.e. were self-employed).²⁸

Lack of training and preexisting poverty often adversely affect the employment potential of people with disabilities, making them particularly vulnerable to unemployment.²⁹ Additionally, working conditions in many areas are not adapted for people with physical disabilities. For example, jobs may involve standing or working behind high counters.

²⁵. Anniuska Castillo (Head of the Integral Rehabilitation program at the Catholic University of Santo Domingo), interviewed by author, 13 November 2003.

²⁶. Secretary of State of Labor, *Estadísticas Laborales*, [Labor Statistics], Bulletin No. 6, 2001.

²⁷. Panel discussion with leaders of the disability community, discussion facilitated by author, Dominican Republic, 13 November 2003.

²⁸. The study was based on the review of information contained in the admission forms of 125 members of the organization living in the National District. The organization has about 350 members nationwide. The CIMUDIS admission forms include general information about members, such as age, type of disability, level of education, civil status, assistive devices used, employment, etc. The information on those admission forms was evaluated and direct phone contacts were made in order to find out how many of those members were currently employed.

²⁹. Diogenes Lantigua (Head of the Vocational Rehabilitation Department State Secretary of Public Health and Social Welfare), interviewed by author, 15 August 2003.



Street trading offers an informal market for people with disabilities during International Day of Women celebration.

Law 42-2000 addresses the issue of employment of people with disabilities, providing that:

The main purpose of the policy on social and economic integration of people with disabilities shall be their integration into the open labor market, or otherwise their inclusion in a system of sheltered or supported employment, to ensure people with disabilities the opportunity to obtain employment in the job market, following the spirit of Rule 7, paragraph 7, of the UN Standard Rules for the Equalization of Opportunities for People with Disabilities, and International Labor Organization (ILO) Convention 159 on Vocational Rehabilitation and Employment (Disabled Persons), Part VII, articles 32–35. Therefore, the coordinating body (CONADIS) shall ensure that the relevant public and private institutions take the measures necessary to achieve said purpose.

CONADIS is also responsible for monitoring social and economic integration programs.

In October 2003, the National Population and Family Council (CONAPOFA), released a research report describing the labor market experiences of people with disabilities.³⁰ The purpose of the largely qualitative study was to provide the necessary information for developing policies that foster labor insertion.

³⁰. Fausto Báez Jiménez, *Compendio de Investigación sobre la Inserción Laboral* [Research Compendium on Labor Market Insertion], National Population and Family Council, Dominican Republic, 2003.

The largest employer in the private sector, Central Romana, runs a fruit picking operation located, in the interior of the country. The company does not have a policy prohibiting discrimination against people with disabilities. The type of agricultural work performed by the company, does not favor the integration of people with disabilities, since fields and farms are largely inaccessible.³¹

The second largest company in the country, Banco Popular, which is located in the metropolitan area. Although it does not have a formal policy requiring employment of people with disabilities however, the company reports an informal agreement that applicants with disabilities should not be discriminated against and should be treated on an equal footing with all other applicants.³²

The Vocational Rehabilitation Program run by the Dominican Rehabilitation Association (ADR) provides technical training courses on computers and crafts such as confectionery and dressmaking. The program also contacts companies in order to facilitate placement of people with disabilities, once they have finished their training.³³

Health Services

Law 87-01, which established the Dominican Social Security System (SDSS), will provide healthcare coverage for people with disabilities, among others. This new law came into force in 2002 and it is being gradually implemented. The first stage has involved enrollment with benefit coverage scheduled to begin in 2004.

The SDSS Basic Health Plan provides: "health promotion and preventive medicine, according to the list of benefits as determined by the National Council on Social Security (CNSS)" "physiotherapy and rehabilitation services when prescribed by a specialist physician according to CNSS criteria" and "complementary benefits, including devices, medical prosthesis and technical assistance to disabled people, according to the CNSS list." Additionally, all "essential medication" is supplied at no cost to those covered by the subsidized program.

There are no health specialty centers devoted to people with disabilities. Persons with disabilities report that medical doctors, nurses, and specialists (including gynecologists) usually do not know how to provide adequate care to people with disabilities.

³¹. Washington Gonzáles (Managing Director of the State Secretary of Labor), telephone interview, 14 November 2003.

³². Interview with the head of the Interpersonal Relations at Banco Popular, 16 November 2003.

³³. Elsa Hernández (Director of the Professional Rehabilitation, Dominican Rehabilitation Association), interviewed by author, Dominican Republic, 23 July 2003.

A small number of health professionals have access to state-run training programs that focus on the provision of services to people with disabilities.³⁴ Non-governmental organizations, such as the Dominican Rehabilitation Association, offer a range of training activities for health professionals.³⁵ One private university (Santo Domingo Catholic University) has started a new program on Physical and Occupational Therapy. The program currently awards technical degrees but will eventually award bachelor's degrees.³⁶ There are three classes each year, with approximately 110 physiotherapy students and 32 education students. A course for Prosthetics Technicians has also been created.

There was a 6.3 percent reduction in the number of patients requiring rehabilitation between 2001 and 2002.³⁷ The Statistical Bulletin of the Dominican Rehabilitation Association shows that in 2001 there were 24,178 cases requiring hospital admission for rehabilitation, while in 2002 there were 23,436 cases. Among the potential causes cited for this decrease is the near complete eradication of polio, which had been one of the principal causes of permanent disability.³⁸

Housing

There is no adapted public housing system in the country. Regulations M-007, issued by the State Secretariat of Public Works, stipulate that a certain number of adapted dwelling units be built. However, to date no private or public initiative or project has been undertaken.

Leaders of the disability community report that most people with disabilities live with their families.³⁹ Currently, no government policy to provide housing to people with disabilities or their families has been implemented.

Institutionalization

One institution, Hogares Luby (Luby Homes), operates with the specific mission of providing long-term housing and care to children with disabilities. It is partially supported by the state. The main purpose of the homes is to provide care and shelter to people with severe disabilities, who generally live there permanently because they have been abandoned. People with severe disabilities may be declared legally incapable, losing both their civil rights and their ability to reject treatment. Hogares Luby has three locations: two in the National District and one in the interior of the country. Although the institution focuses on children, it occasionally admits elderly or adolescent people with severe disabilities.

³⁴. Interviews with doctors from the Public Health and Social Welfare Hospital and the Dr. Darío Contreras Hospital, a major medical center providing trauma services.

³⁵. Anniuska Castillo.

³⁶. No other private or public universities offer these courses to date.

³⁷. *Boletín Estadístico de la Asociación Dominicana de Rehabilitación* [Statistical Bulletin of the Dominican Rehabilitation Association], annual report, October 2003.

³⁸. *Ibid.*

³⁹. Panel discussion.

The institution currently provides housing to 140 people with the help of 15 staff members at each of its three facilities. At present, those housed in the facility include ten elderly people and six adolescents; the rest are girls and boys.⁴⁰

In 2000, there were reports of a case in which children with severe disabilities were abused in a rehabilitation home. Several complaints to the Dominican journalist Nuria Piera, resulted in a journalistic investigation that was broadcast on the Color Vision television channel's investigative television program, "Nuria en el 9". The program revealed abuses and mistreatment of children, who were kept under inhumane conditions, with some tied to their beds.⁴¹

The investigation eventually resulted in staff dismissals and cancellation of subsidies to the facility. Currently, the rehabilitation home is under the supervision of the State Secretariat of Public Health and Social Welfare (SESPAS).⁴²

Accessibility

Physical barriers in public and private places are hurdles to the social participation of people with disabilities. The lack of ramps, elevators, and appropriately sized doors hinders access to proper education.

At present, the Dominican Republic has a transportation system that is in generally poor condition and is inaccessible for persons with disabilities. The government has established two agencies to coordinate and organize public transportation: the Metropolitan Office of Bus Services (OMSA) and the Metropolitan Transportation Authority (AMET). Despite the creation of these agencies and efforts by disability organizations, the government has not developed policies designed to increase transportation accessibility for persons with disabilities.

⁴⁰. Mariluz Acosta (supervisor of Luby Homes), telephone interview.

⁴¹. During the months of August and September of 2000, Nuria en el 9, which is an investigative television program on Canal 9 Color Vision looked at the deteriorating condition of the rehabilitation center and the condition of the children living there.

⁴². Dr. Adalgisa Abreu (Undersecretary, SESPAS), interviewed by author, Dominican Republic, 19 July 2003. The Head of the Social Work Department in the Undersecretary's office now supervises the home.

Disability Action & Awareness

The National Council on Disability (CONADIS), was created by Law 42-2000. It is an autonomous state agency attached to the Presidency of the Republic, whose duties are to make, assess, and ensure compliance with disability-related policies. The CONADIS is also responsible for ensuring compliance with the law.

The Board of Directors is chaired by a representative of the Presidency. Other representatives are divided equally between government agencies, organizations of people with different kinds of disabilities, and institutions that provide services to people with disabilities. CONADIS is currently undergoing a restructuring process, during which new members will be appointed to the Board of Directors.



Participants in the celebration of the International Day of Disabled Person

Ecuador

Key Factors: Ecuador has a strong legal framework, recognized when the nation received in 2002 the Sixth Franklin Delano Roosevelt International Disability Award.¹ However, the country is in the midst of a severe economic crisis. Budgetary allocations prioritize the payment of the foreign debt, often at the expense of social expenditure. Few protections are implemented, and people with disabilities remain a severely vulnerable population.



Terminology

The 6th Population and 5th Housing Census, conducted by the National Statistics and Census Institute (INEC) in 2001, used the word “incapacidad,” which is translated to “incapacitated” or “incapacity.” Section 102 of the Civil Code, in describing certain restrictions, uses the term “los dementes, los ciegos, los sordos y los mudos” which, when directly translated, means “the insane, the blind, the deaf and the mute.” When quoting directly from these documents, the original terminology is retained.²

Definition of Disability

Chapter II of Executive Decree 3603, which provided regulations for and amended the Disability Act, contains the following definition:

For the purposes of the law and the regulations thereto, a “person with disabilities” is any individual who, as a result of one or more congenital or acquired physical, mental or sensory impairments, which can be expected to be permanent, is restricted in at least 30 percent of his or her ability to perform an activity within the range considered normal, limiting or preventing him or her from performing daily life functions or activities.³

The definition is based upon the World Health Organization's ICIDH-1 classification.⁴

¹ National Organization on Disability, <http://www.worldcommitteeondisability.org>.

² Comisión Andina de Juristas, *Personas con Discapacidad* [People with Disability], <http://www.cajpe.org.pe/RIJ/BASES/pcd/CUADRCIV.htm>.

³ Executive Decree 3603, *General de la Ley Reformatoria de la Ley de Discapacidades* [General Regulations of the Law amending the Disability Act].

⁴ World Health Organization Classification (WHO), ICIDH Geneva 1980.

Although this is the most significant legal definition of disability, other definitions are sometimes used by specific agencies. In the case of the census, for example, disability is labeled “permanent incapacity” and is defined in the Census Taker’s Manual as “a permanent difficulty to perform activities in the manner or within the range considered normal, as a consequence of irreversible effects of a congenital or acquired incurable disease.”⁵

Disability Population

The 6th Population and 5th Housing Census, conducted by the INEC in 2001, collected information on the number of people with disabilities in the country. At the time of the census, Ecuador had a total population of approximately 12 million people and people with disabilities accounted for 4.65% or approximately 558,000.⁶ The census question used to identify people with disabilities asked whether each person “has some permanent incapacity of a physical, sensorial or mental type.” The focus on “incapacity,” as well as the narrow definition of disability it implies, indicates that the INEC most likely missed significant numbers of people with disabilities. In addition to potential question wording problems, other methodological problems included lack of interviewer training and knowledge about disabilities and interviewer omission of disability-related questions.⁷ Moreover, this figure contrasts sharply with data from the “Study of the Current Disability Situation in Ecuador” (ESADE) published by the National Council on Disabilities (CONADIS), which found that people with disabilities number 13.2 percent of the population.⁸ The ESADE survey was conducted by a professionally trained team from the Central University of Ecuador. The definitions of disability used in that survey were provided by CIDDM, which uses classifications prepared by the WHO.

Among the causes of disabilities reported by national disability organizations, including the National Federation of Ecuadorians with Disability, the National Federation of the Blind of Ecuador, and the National Federation of the Deaf of Ecuador, are pollution from oil extraction and the harmful effects of chemicals used in flower crops and banana plantations.⁹

⁵ INEC, *Manual del Empadronador para VI Censo de Población y V de Vivienda* [Census Taker’s Manual for the 6th Population and 5th Housing Census], (Instituto Geográfico Militar, Quito, November 2001), 38, 39.

⁶ INEC, *Información del VI Censo de Población y V de Vivienda 2001, relacionada con población con Discapacidad en el Ecuador* [Information from the 6th Population and 5th Housing Census, 2001, related to the population with Disabilities in Ecuador], Communication 348-DIFU-SETEC, (D.M., Quito, 19 August 2003).

⁷ Dr. Ramiro Cesar Flores (executive Director of CONDADIS), interviewed by author, 15 August 2003; Xavier Torres (President of FENEDIF), interviewed by author, 23 August 2003; Quito Panel discussion, 23 August 2003; Riobamba Panel discussion, 27 September 2003.

⁸ CONADIS, “Resumen Ejecutivo de la Fase Epidemiológica del Proyecto ESADE” [Executive Summary of the Epidemiological Phase of Project ESADE] *Situación Actual de las Personas con Discapacidad en el Ecuador*, [Current situation of people with disabilities in Ecuador] (Imprenta y Offset Santa Rita, Quito, 2000), 1 – 85.

Legislation & Disability Rights

Legal Protections

Ecuador has signed several international instruments on disability and human rights. The ILO Convention 159 on vocational rehabilitation and employment for people with disabilities was ratified on 20 May 1988. Ecuador signed the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons With Disabilities and ratified it on 1 March 2004.⁹ The ratification document was deposited with the OAS General Secretariat on 18 March 2004. Ecuador has also signed the Salamanca Statement on Special Needs Education for Children and Youth; the Managua Declaration on Policies for Children and Youth with Disabilities; and the Cartagena Declaration.¹⁰

Nationally, early assistance for people with disabilities was based upon a charitable model, beginning in the 1950s as the initiative of parents and private organizations. The paradigm has gradually changed to one focused less on charity and more on rights.

In addition to these strides, several government agencies in the 1970s started taking responsibility for the education, health, and social welfare of people with disabilities, and in the 1980s Ecuador celebrated the “Decade of the Disabled Persons.” In the 1990s the government published the First National Disability Plan and created CONADIS. Since then, Ecuador has continued creating legal instruments that now contain provisions making up a body of both general and sectoral policies on health, education, labor, and social welfare that drive the action of the various parties involved. In general, Ecuador has created “pioneering legal instruments in Latin America, a fact that markedly contrasts with the general social and economic development of the country and confirms, again, what is stated by local legal experts: Ecuador has a progressive set of laws and protections, but effective enforcement mechanisms and resources are lacking.”¹¹

The Political Constitution of Ecuador specifically addresses the topic of disability rights. Section 53 of Chapter Two establishes the responsibility of the government to guarantee disability prevention efforts, comprehensive rehabilitation, “access to goods and services, particularly in the areas of health, education, training, employment and recreation,¹² and the elimination of communication, urban, architectural and transportation barriers. Ecuadorian Sign Language is officially recognized by the Constitution, as is Braille.

⁹ The convention was initially ratified in a Plenary Session of the Honorable National Congress, 21 May 2003.

¹⁰ The Salamanca Statement and Framework for Action on Special Needs Education (1994) http://www.unesco.org/education/pdf/SALAMA_E.PDF; Declaration of Managua (1993); Declaration and Place of Action of Cartagena de Indias (2002), http://scm.oas.org/doc_public/ENGLISH/HIST_02/CIDI01002E04.DOC.

¹¹ CONADIS, “Marco Normativo de las Discapacidades en el Ecuador” [Legal Framework on Disability in Ecuador], *Situación Actual de las Personas con Discapacidad en el Ecuador*, [Current situation of people with disabilities in Ecuador], (Imprenta y Offset Santa Rita, Quito, 2000), 82.

Additionally, people with disabilities are entitled to financial benefits including “[preferential consideration] for loans, tax cuts and exemptions.” Ultimately, the Constitution mandates that the government “together with society and the family, take responsibility for the social integration and the equalization of opportunities of people with disabilities.”¹²

The rights guaranteed by the Constitution are further described in subsequent legislation. The Disability Act contains provisions on the rights of people with disabilities, as well as procedures to impose penalties on those who do not comply with the law. The overall framework of the act prohibits discrimination against people with disabilities. It also establishes a national system for the prevention of disability and contains provisions on the organization and operation of CONADIS.¹³ Executive Decree 3603 provides the powers and duties of institutions and agencies responsible for the prevention, care, and social integration of people with disabilities. The Regulations on the Registration of People with Disabilities establish the process and requirements for obtaining a disability registration card.¹⁴ The Childhood and Adolescence Code identifies the rights of children and adolescents with disabilities.¹⁵

A variety of legislation also exists that is related to specific areas of service and support. The National Health System Act establishes priority services for people with disabilities.¹⁶ The Program of Scholarships for People with Disabilities establishes eligibility criteria and ensures equal distribution of resources in all provinces.¹⁷ The INEN Standards on Accessibility to the Built Environment contain detailed accessibility requirements and were designed jointly by the Ecuadorian Standardization Institute (INEN) and CONADIS.¹⁸ The General Regulations on Special Education reorganized the means of providing educational assistance to children and youth with special educational needs, whether these needs result from a disability or not.¹⁹

Other legal instruments that explicitly refer to people with disabilities include: Regulations on the New Urban Housing Incentive System, the Reform of Public Finance Act, the Compulsory Military Service in the National Armed Forces Act, regulations for the enforcement of the Compulsory Military Service in the National Armed Forces Act, and regulations for the enforcement of the Internal Tax System Act. The 2nd National Disability Plan is currently in the approval process. The plan was submitted to Congress on 9 July 2003 as Bill 24-137, “Law Amending and Updating the Labor Code to Promote the Inclusion of People With Disabilities into the Labor Force.”

¹² *Political Constitution of the Republic of Ecuador, Official Gazette 1*, 11 August 1998.

¹³ *Disability Act, Official Gazette 301*, 6 April 2001.

¹⁴ *Regulations on the Registration of People with Disabilities, Official Gazette 291*, 23 March 2001e

¹⁵ *Childhood and Adolescence Code, Official Gazette 737*, January 2003.

¹⁶ *National Health System Act, Official Gazette 670*, 25 September 2002.

¹⁷ Ministry Agreement 3332, *Program of Scholarships for People with Disabilities, Official Gazette 413*, 17 September 2001.

¹⁸ *INEN Standards on Accessibility to the Built Environment Teamwork.*, made mandatory by Ministry Agreement 2000127-A1, January 2000.

¹⁹ Ministry Agreement 4850, *Reglamento General de Educación Especial* [General Regulations on Special Education], *Official Gazette 496*, 17 January 2002.

Despite the current legal framework, rights violations against people with disabilities do occur in Ecuador. One particularly important case involved a petition filed in 1994 by the Ecumenical Commission of Human Rights (CEDHU) against Ecuador for violation of the American Convention of Human Rights. Mr. Víctor Rosario Congo, a person with a mental disability, was placed in detention without a sentence on 25 July 1990. He was then physically assaulted by a guard, stripped naked and placed in solitary confinement, and denied medical care. Rosario Congo died on 25 October 1990. The Inter-American Commission on Human Rights (IACHR) notified Ecuador of its recommendations on 10 March 1999 and received the Government's commitment to taking all appropriate measures on 8 April 1999.²⁰

Nevertheless some people with disabilities remain subject to physical, psychological, and sexual violence. Leaders of disability organizations report that in some instances, people with disabilities are forced to beg by their families. Cases of mistreatment in special education institutions, particularly against people with intellectual disabilities, are typically kept hidden.²¹ Most cases of rights violations are not officially documented, and there are no records on cases of abuse and death. Moreover, disability rights are not included in the Ecuador Human Rights Operational Plan, 2003–2006.²²

Legal Barriers

Some laws that contain discriminatory language and negatively impact the rights of people with disabilities are still in force. Among those laws not yet amended are the Civil Code and the Criminal Code. Section 102 of the Civil Code prevents “the insane, the blind, the deaf and the mute” from acting as witnesses to a marriage. The same population is excluded from witnessing the signing of a will.²³ Section 536 declares some persons with disabilities legally incapable of guardianship including “the blind, the mute or the insane, even if they have not been declared incapacitated by a court.”

Civic Participation

Voting is mandatory for all citizens in Ecuador, including people with disabilities. Citizens who fail to vote must pay a fine. However, absenteeism in public elections is reported to be high among people with disabilities although no statistical data are available. Among the causes of absenteeism is a lack of sufficient political information in alternative formats. Inaccessible transportation and voting facilities may often prevent people with disabilities from reaching polling stations and ballot boxes. Because of these barriers, the President of the

²⁰ Inter-American Commission on Human Rights, Organization of American States, *Report 63/99*, (Ecuador, 13 April 1999), <http://www.cidh.org/annualrep/98span/fondo/ecuador%2011.427.html>, <http://www.cidh.oas.org/countryrep/Ecuador-sp/Capitulo%206.html>.

²¹ Quito Panel Discussion, 14 August 2003 and Riobamba Panel Discussion, 27 September 2003.

²² Ecuador Ministry of Foreign Affairs, et. al., editors, *Ecuador Human Rights Operational Plans*, (2003-2006, Quito, 2003).

²³ <http://www.cajpe.org.pe/RIJ/BASES/pcd/CUADRCIV.htm>.

National Federation of Ecuadorians with Physical Disabilities (FENEDIF) was able to obtain an exemption for people with disabilities who do not vote. In some instances, people with disabilities who have been abandoned may have no identification card, which means they are not registered as citizens and thus do not have the right to vote.²⁴

Inclusion

Communication

Section 19 of the Disability Act guarantees accessibility to communication, but the government has not yet implemented plans in this area. The government does not communicate its activities in alternative formats. The news is not captioned for viewers who are hearing-impaired. Most libraries do not provide materials in alternative formats. Among the few libraries that do have alternative format information available are the US Embassy's Lincoln Center and the Center of Education and Vocational Training for the Blind (CEFOCLAC).

The publishing house of the Ecuador National Federation of the Blind (FENCE) publishes some books and other materials in Braille. Due to lack of resources, it is unable to produce enough materials to meet the information needs of its member branches. People who are not registered members of FENCE have no access to these materials.²⁵

There is no method or strategy for people with speech impediments or hearing impairments to communicate with authorities in case of natural disasters, civil emergency, or criminal assault. In emergency situations, people with disabilities need the assistance of others in order to inform or receive information from authorities, which ultimately restricts their possibilities for independent living.

New information and communication technologies are at an early stage of development in Ecuador. Very few people have access to technological resources; for example, in 2002, only 3.36% of all Ecuadorians had Internet access.²⁶

²⁴. Cezar Flores Ramiro, "Derechos y Discapacidad" [Rights and Disability], (PPL Impresores, Quito, 2003), 108-109.

²⁵. Dr. Julio Barba (President of the National Federation for the Blind of Ecuador), interviewed by author, Riobamba, 27 September 2003; Riobamba Panel Discussion, 27 September 2003.

²⁶. *El Comercio Newspaper*, "Las cuentas de Internet en Ecuador" [Internet Accounts in Ecuador], (Quito, 27 March 2002).

Education

In Ecuador, education for children with disabilities is available in both special schools and regular schools. The National Special Education Division of the Ministry of Education and Culture assists 34,656 students nationwide. However, this figure includes both students with and without disabilities. No figures are available that break out the services provided specifically to children with disabilities.²⁷

Among the facilities providing services are 19 Diagnosis and Psycho-pedagogical Counseling Centers and 289 Psycho-pedagogical Support Programs in regular schools. These support programs account for 60% of the students assisted by the Special Education Division, however less than 5% of the students enrolled in these programs (917) are people with disabilities.²⁸

The resources available through the Special Education Division also include 129 special education schools. Most of these schools are located in the Coastal Region and the Sierra region. Approximately 50% are state-funded institutions, and 31% are privately funded by foundations, international funds, or tuition. The remainder of schools are funded either by local governments or jointly by the state and private or religious institutions. The majority of special schools assist students with different types of disabilities. Of those serving students with a single type of disability, 25% assist children and youth with intellectual disabilities ; 9% assist children with hearing impairments; 6% assist children with mobility disabilities; and 5% assist children with visual impairments.²⁹



Inaccessible entry to the Ministry of Education, Ecuador

²⁷. Ministry of Education and Culture, National Special Education Division, *Diagnóstico de la Educación Especial en el Ecuador* [Diagnosis of the status of Special Education in Ecuador], Regulations on Special Education (AH – Editoriales, Quito, 2003), 23-30.

²⁸. *Ibid.*

²⁹. *Ibid.*

Students attending special schools make up only 14% of those assisted by the Special Education Division, making it appear as though students with disabilities are well-integrated into regular education. However, in 2003, the Ministry of Education found that only 23.8% of school aged children with disabilities were attending an educational institution of any sort. Of those who were in school, 6.1% received no support.³⁰ Ecuador has 18,014 primary schools of which 644 regular schools (3.57%) integrate 1,072 students with disabilities. Secondary schools integrate fewer students, with 112 schools out of 3,474 (3.22%) integrating only 145 students with disabilities. These are concentrated in Pichincha and Manabí.³¹

As table one demonstrates, many people with disabilities are excluded from education altogether.

Table 1: Level of Education of People with Disabilities³²

Highest level of education completed	Percent of disability population
None	39.7%
Pre- school	3%
Primary school	42.3%
Literacy Center	1.1%
Secondary school	10.5%
University	1.8%

Almost 40% of people with disabilities receive no education, and only 10.5% finish high school. The high school completion rate for the general population is 25.9%, more than twice the rate for people with disabilities. Although there are no statistics on the illiteracy rate among people with disabilities, the high number of people who receive no education suggests that illiteracy is far higher among the disability community than the 9.8% rate for the general population.³³

Accessible, adapted teaching materials are designed by individual educational institutions and not widely shared between institutions. Technical aids are extremely limited. Most institutions are reported to have accessibility problems, although no statistics are available. Overall, the available statistics on education suggest that people with disabilities are a severely marginalized population, with limited access to basic education.

³⁰. Ministry of Education, Culture, Sports and Recreation, Office of the Assistant Secretary of Education, National Office of Regular and Special Education, National Special Education Division, *Proyecto: Integración Escolar de alumnos-alumnas con necesidades educativas especiales asociadas a la discapacidad, a los centros de educación secundaria y ocupacional. Orientaciones básicas para la integración escolar al nivel secundario* [Project: School Integration of Students with Disability-Related Special Educational Needs into Secondary and Occupational Education Centers. Basic Guidelines for High-School Integration], (AH - Editoriales, Quito, 2003), 48.

³¹. *Diagnóstico de la Educación Especial en el Ecuador*.

³². *Situación Actual de las Personas con Discapacidad en el Ecuador*.

³³. *6th Population and 5th Housing Census*.

Teacher training in the fields of special education, pedagogy, and psychological rehabilitation do address methodologies for the provision of care to students with special educational needs.³⁴ However, there is little or no special education training in regular teacher training courses. In special education schools, 70% of teaching staff are professionals in the fields of psychology and technology.³⁵

There is no available information on the number of students with disabilities in higher education. Recently, however, the High Council of Universities and Polytechnic Schools (CONESUP) and CONADIS have initiated a project called "University for All." The goal of the project is to train leaders in charge of academic planning for institutions of higher education on the inclusion of the disability issue as a cross-cutting theme. The project encourages new courses in a variety of disciplines that include disability issues. Universities taking part in the pilot program include: the Equinoccial Technological University, the Army Polytechnic School, the State University in Guayaquil, and the Catholic University in Cuenca.

The Equinoccial Technological University presented the results of its "University for All" project on 27 November 2003.³⁶ Among the results are suggestions for awareness raising projects, educational technology needs, development of adapted teaching materials and assessments, and adaptations of the admission systems. The university also began designing materials for students with sensory disabilities in 2003.³⁷

Employment

Unemployment and underemployment are widespread in Ecuador, with more than half of the total population living below the poverty line. The employment situation of people with disabilities is even more difficult than that of the general population. Table two identifies the employment status of all people with disabilities in the country.³⁸

³⁴. <http://www.conesup.net>.

³⁵. CONADIS, "Servicios de Atención para las personas con Discapacidad en el Ecuador" [Assistance services for People with Disabilities in Ecuador], *Situación Actual de las Personas con Discapacidad en el Ecuador*, [Current situation of people with disabilities in Ecuador], (Imprenta y Offset Santa Rita, Quito, 2000), 20.

³⁶. José Carrera, et. al., *University for All*, (Quito, August 2003).

³⁷. General Ecuadorian Foundation, *Análisis Situacional del Sector de la Discapacidad en el Ecuador, Encuesta de Inclusión Interamericana* [Situation Analysis of the Disability Sector in Ecuador, Inter-American Inclusion Survey], (Quito 2003), 7.

³⁸. *Situación Actula de las Personas con Discapacidad en el Ecuador*.

Table 2: Employment Status for People with Disabilities

Employment Status	Percent of people with disabilities
Employed	18.2%
Unemployed	1.5%
Household work only	29.7%
Student	10.2%
Retired and/or pensioner	3%
Unable to work	29.1%
Unknown	8.6%

Although the official unemployment appears low, the actual rate of people with disabilities who are not gainfully employed may be as high as 70.4% for the working age population.³⁹ Slightly more people receive some form of financial support. However, this amounts to only 36.2% of people with disabilities.⁴⁰ The vast majority of people with disabilities are economically dependent on their families. Of the 18.2% of people with disabilities who are employed outside the home, 24.1% are women and the remaining 75.9% are men.⁴¹ Women with disabilities are primarily relegated to household work with 73.6% employed in this way. Table three details the types of jobs outside the household at which people with disabilities are employed.⁴²

Table 3: Employment Types for People with Disabilities⁴³

Professional/Technical	6.3
Employed by government or public organization	3.1
Administrative	0.8
Merchants (generally informal)	17
Service	12
Agricultural worker	31.1
Rural producer (ex., wine producer)	18.5
Unclassified	10.2

A leading company in efforts to employ people with disabilities is Snack América Latina S.A. The company provides not only employment and benefits but also on-going support including the encouragement of family participation. At the moment, there are three people with intellectual disabilities working at their plant.⁴⁴

³⁹. This includes people who are "ocupado" (occupied) but receive no financial remuneration for their efforts.

⁴⁰. This figure includes retirees.

⁴¹. National Organization on Disabilities.

⁴². *Situación Actual de las Personas con Discapacidad en el Ecuador*.

⁴³. *Ibid.*

⁴⁴. Nancy Zárate (industrial psychologist, Human Resources coordinator for Operations division, Snack América Latina S.A.), interviewed by author, Monday, 11 August 2003.

Leaders of disability organizations report that among the most significant challenges to employment for people with disabilities are inaccessible workplaces and transportation, a general lack of social awareness regarding the potential of people with disabilities, and a lack of education and job training. Approximately 93% of people with disabilities have not received any vocational training. Of the 7% who have received some training, 51.1% participated in publicly sponsored programs, 36.7% in private programs, and 12.2% in programs held by trade unions.⁴⁵ The available job training has typically focused on crafts or other types of manual labor that provide access to low-paying jobs.

Labor insertion programs launched by the Ecuadorian General Federation, DEKISTEL, and the Braille Publishing House are reported to have created about 170 jobs.⁴⁶ Other important training and job placement programs for people with disabilities are run by FASINARM and the Center for the Eradication of Goiter and Training of the Handicapped (CEBYCAM).⁴⁷ Additionally, the Ecuadorian Vocational Training Service (SECAP) reported that its courses have occasionally been attended by people with physical disabilities.⁴⁸ The Ministry of Education and Culture is currently planning programs in conjunctions with the ASENIR, SERLI, CEREPSI foundations.⁴⁹

Health Services

Spending on health care accounts for only 1.6% of Ecuador's budget.⁵⁰ Health, accident, and retirement insurance cover only 15.6% of people with disabilities. The remaining 84.4% have no insurance benefits, compared to 75% of the general population. Of those people with disabilities who have insurance, 43.9% are beneficiaries of the general social security insurance, 52.3% of insurance for agricultural workers, and 3.9% of private insurance.⁵¹ For those without insurance, the government provides rehabilitation services through State Health Centers under the National Health System.⁵² However, the quality of health services provided by the National Health System of Ecuador is poor. Inadequate funding is complicated by the lack of appropriate models of intervention and flaws in the delivery of services.⁵³

⁴⁵. *Situación Actual de las Personas con Discapacidad en el Ecuador*.

⁴⁶. Dr. Julio Barba. Barba was awarded the 2003 Valdivia Award, which is granted every year by Congress for distinguished achievements in favor of people with disabilities.

⁴⁷. Foundation for the Psycho-Pedagogical Assistance of Mentally Retarded Children, Adolescents and Adults <http://www.fasinarm.org/servicios.htm>.

⁴⁸. Sara Villacís (economist, SECAP official), interviewed by author, Quito, 14 July 2003.

⁴⁹. Ministry of Education and Culture, <http://mec.gov.ec>.

⁵⁰. Martha Moncayo, "Gasto Social: Ecuador no le da importancia" [Welfare Spending: Ecuador does not give it importance], (Quito, 14 February 2003; Danile Badillo (consultant), "El Gasto Social en la Proforma Presupuestaria 2004" [Welfare Spending in the Budgetary Platform 2004], (presentation at UNICEF, September 2004).

⁵¹. *Situación Actual de las Personas con Discapacidad en el Ecuador*.

⁵². Ministry of Public Health, National Health Council, *Marco General de la Reforma Estructural de la Salud en el Ecuador* [General Framework for the Structural Reform of the Health System in Ecuador], (Quito, October 2002).

⁵³. Mariana Naranjo Bonilla, *Informe Hacia la Cobertura Universal de los Servicios Sociales Básicos, 2003 – 2020* [Report Towards a Universal Coverage of Basic Social Services], Chart # 8, Ecuador, Basic Health Indicators.

With the decentralization of health services that took place during the 1990s, services are often duplicated, resulting in an uncoordinated and less efficient health care system.⁵⁴ All services are typically easier to access in Quito and Guayaquil than in the provinces.⁵⁵

Some additional public funds are available for health care and rehabilitation. Such funding is channeled through CONADIS. One program provides financial support for special medical examinations, medications, and technical aids for people with physical, hearing, visual, and mental disabilities. The CONADIS also oversees a program for those who cannot afford health care services that subsidizes the purchase of medications and medical supplies for people with disabilities resulting from spinal injury, epilepsy, or developmental disorders. The National Institute of Children and Families (INNFA), the Network for Macroeconomic Dialog (REDIMA), and the National Epilepsy Center participate in this program, with INNFA providing services through the Support Medical Action and Disabilities Program.⁵⁶ A third CONADIS program created an "Assistance Scholarship," which was created to allow children affected by the economic deterioration in Ecuador to continue their rehabilitation and/or education.

Other organizations providing publicly-funded rehabilitation services include the Hermano Miguel Foundation, the Ecuadoran Society for Rehabilitation of the Disabled (SERLI), and the Medicial Solidary and Disabilities Action Program (PAMSyD).⁵⁷ Services provided by PAMSyD are delivered through a variety of centers including: Medical Rehabilitation Centers, Centers for the Integration of Persons with Hearing Impairments, Social Medical Services, the Center of Education and Vocational Training for the Blind (CEFOCLAC), and nursing homes for the elderly. Social Security Institutes provide services to those who are entitled to social security benefits. These services are available through the Ecuadorian Social Security Institute (IESS), the Armed Forces Social Security Institute (ISSFA), and the Police Force Social Security Institute (ISPOL).⁵⁸

Training in the provision of services to people with disabilities is not part of medical school training although some seminars and workshops are available for practicing physicians. According to a PAHO report on Ecuador, most educational activities on health services are carried out by medical associations, professionals associations, and professional foundations.⁵⁹ These programs are not coordinated under any system and therefore often duplicative. Most services are carried out with the support of private enterprises. However, there is no record of the number or type of activities, or the number of participants. In response to the general lack of training, CONADIS and the council of Higher Education (CONESUP) have proposed the development of "University for All," which would incorporate disability issues into professional training.

⁵⁴ PAHO, "General Health Situation and Trends for Ecuador," *Health in the Americas*, 2002.

⁵⁵ CONADIS, <http://www.conadis.gov.cc>.

⁵⁶ INNFA, <http://www.innfa.org>.

⁵⁷ Hermano Miguel Foundation, <http://www.fundacionhermanomiguel.org/>.

⁵⁸ IESS, <http://www.iess.gov.ec>; <http://www.fuerzasarmadasecuador.org>.

⁵⁹ PAHO, *Health in the Americas II*, 1998.

Disability prevention services are also poor in Ecuador. Maternal and neonatal health services in Ecuador rated a 57/100 in the Maternal Health Study.⁶⁰ Efforts to train doctors in disability prevention are underway by PRENATAL and NAR.⁶¹

Some Community-Based Rehabilitation programs are currently in place. The Ministry of Health trains Health Promoters who promote health, sanitation, oral health, first aid, and more, throughout the country.⁶² The PRONEPE is a Ministry of Education program for children 4 to 6 years old, which provides alternative education and promotes the development of basic abilities of children.⁶³ The Growing with Our Children Program by INNFA is a new project for development of children under the age of 6 that works with families so that they may take part in activities that stimulate the development of their children. Lastly, the School Food Program provides food for low-income children aged 5-14, who attend basic education schools.⁶⁴ None of these programs have been assessed for effectiveness.

Housing

There are no independent living centers run by people with disabilities in Ecuador. However, culture may be a significant factor in this situation.⁶⁵ Although a level of independence is important, the cultural significance of family life in Ecuador is paramount, making family living typically a positive situation. Table four details living arrangements for people with disabilities.

Table 4: Living Situations of Persons with Disabilities⁶⁶

Relation to living companions	Percent of people with disabilities
Family	93.4%
Alone	4.3%
Non-family members	1.9%
Other	0.3%

Although the majority of people with disabilities live with their nuclear families, the ideals of the independent living process may still be implemented in such settings. Funds are available from the Ministry of Urban Development and Housing for both urban and rural housing as well as for home improvements.⁶⁷ People with disabilities must meet general requirements. They are entitled to extra points, which are used in determining eligibility, upon presentation of their

^{60.} Futures Group, *Maternal and Neonatal Program Effort Index: Ecuador*, <http://futuresgroup.com>.

^{61.} PreNatal, *Prevención de Discapacidades*, <http://www.prenatal.tv/ecuador/proyectos.htm>.

^{62.} Latin American and Caribbean Regional Health Sector Reform Initiative, <http://www.americas.health-sector-reform.org/sidorh/documentos/html3.html>.

^{63.} Ministry of Education and Culture, <http://www.mec.gov.ec>.

^{64.} Ministry of Education and Culture, www.pae.org.ec.

^{65.} Cazar Flores Ramiro (CONADIS Executive Director), interviewed by author, 15 August 2003.

^{66.} *Situación Actual de las Personas con Discapacidad en el Ecuador*.

^{67.} Ministry of Urban Development and Housing, <http://www.miduvi-siv.gov.ec>.

Institutionalization

There are no official records on the total number of people with disabilities who are institutionalized in Ecuador. People with disabilities may be housed in psychiatric hospitals, shelters, orphanages, or nursing homes for the elderly, but there are no records maintained.⁶⁸ Disability advocates report that placement in an institution usually cannot be refused, since poverty levels are extremely high and people have few choices. There is no supervision and monitoring agency to systematically collect data on the incidence of abuse and/or death.

With regard to children, there is only one institution that expressly provides long term housing and care for children with disabilities. The Jacinta y Francisco Foundation in Guayaquil houses young women with intellectual disabilities.⁶⁹ The country report presented at the 2nd International Conference on Children and Residential Care acknowledged the difficulty of finding adequate residential care for children with disabilities, especially those who have been abandoned. It states that of the children with disabilities who are under the age of 18, "less than 2% receive the care they require. The infrastructure of Ecuador's social care system is impaired in quality and quantity, and a large part of the population does not have access to social services. There is a lack of [specialized] institutions for children with special needs. The institutions for protection admit these children together with non-handicapped children. Others are cared for in psychiatric hospitals. The reason many families abandon their handicapped child is often the high cost of treatment and medicine."⁷⁰

Accessibility

All buildings intended for public use are required by the Disability Act to be accessible to people with disabilities. This includes privately-owned facilities such as hotels, restaurants, and recreational sites as well as all places of interest to tourists. According to the law all new construction must comply with INEN Standards on accessibility. Existing public buildings were provided a three year term within which to make all necessary adaptations. This term expired on 6 April 2004. Some municipal ordinances establish additional requirements regarding accessibility and the elimination of barriers.

⁶⁸. Rommel Artieda Maruri (Director of the "Julio Endara" Psychiatric Hospital), interviewed by author, 23 October 2003; Patricio Jácome (Acting Director of the National Mental Health Office), interviewed by author, 18 August 2003; *El Comercio*, "El Hospital del Adulto Mayor acoge a 55 ancianos," [The Hospital for Elderly Adults Takes In 55 Elderly People], (Quito, 14 September 2003), <http://www.elcomercio.com>.

⁶⁹. Jacinta y Francisco Foundation, http://www.fundjacintayfrancisco.com/quienes_rese.html.

⁷⁰. Children and Residential Care, "New Strategies for a New Millennium, 2nd," International Conference, (Stockholm, May 12-15, 2003), <http://www.children-strategies.org/spanish%20creports/Informe%20de%20pais%20Ecuador.pdf>.

Leaders of disability organizations estimate that only 20% of public buildings are accessible for people with mobility disabilities. Public offices, except for those of CONADIS, are inaccessible. Access to the ground floor of buildings is also often limited by the presence of obstacles including curbs, cement blocks placed on sidewalks to prevent the parking of cars, advertising signs, and wastebaskets, among others.



Inaccessible Exterior and Interior design of the Ministry of Social Affairs Building, Ecuador

Transportation is also required by law to be accessible. Although some forms of transportation are partially accessible, no public transportation system fully meets the needs of people with disabilities. In Quito, the municipal transportation system, which is known as the Trolleybus, has accessible vehicles and stops. However, the condition of streets and sidewalks and the existence of curbs often prevent wheelchairs users from reaching bus stops easily and without help. Similarly, the vehicles of the Ecovía system, also municipally-run, are accessible. The gap between access ramps and the cars, however, makes boarding difficult. Adaptations to this system have been made in an effort to improve accessibility. The Disability Act grants people with disabilities who are able to access transportation a 50% discount on the rate of all ground transportation. Those who can afford private transportation typically travel by private cars or taxis. Rates for international air travel are established according to conventions signed by Ecuador.



An accessible Trolleybus in Quito, Ecuador

The two main obstacles to improving accessibility are the lack of trained professionals and financial constraints. With regard to the former, professionals are not given regular opportunities to learn about universal design. Courses are sporadic, and there are no data on the number of participants. Lastly, implementing the legislation on accessibility would require an investment that disability advocates recognize is currently difficult to commit. Even without the necessary expenditures on accessibility required by the Disability Act, the 2004 budget has an estimated deficit of approximately 1.221 million dollars.⁷¹

Disability Action & Awareness

The National Disability Council (CONADIS) is the government agency responsible for developing and coordinating disability policy. Disability organizations officially participate in CONADIS through a series of national disability federations. The federations include:

- Ecuadorian Federation for the Assistance of People with Mental Impairments, Autism, Cerebral Palsy and Down Syndrome (FEPAPDEM), which maintains three regional offices, several provincial coordination centers, and a documentation center;
- Ecuador National Federation of the Blind (FENCE), which consists of 30 affiliates and provides services to 900 persons who are blind or visually-impaired;
- National Federation of Ecuadorians with Physical Disabilities (FENEDIF), which consists of 30 organizations and 2400 members;
- Ecuador National Federation of the Deaf (FENASEC), which consists of 350 members and provides services to approximately 1200 persons who are deaf or hearing-impaired; and
- Federation of Non-Governmental Organizations Working in the Disability Field, which previously consisted of 59 organizations although it is reported to be defunct.⁷²

⁷¹ Fiscal Policy Observatory #1, *Finanzas Públicas en la Democracia. Aumentos de sueldos públicos, graves consecuencias*, [Public Finance and Democracy. Raises in public salaries, serious consequences], (Quito, September 2003), <http://www.pnud.org.ec/Pobreza.php>.

⁷² CONADIS, *2nd National Disability Plan*, technical proposal submitted for consideration, (draft provided by Jorge Luna Maldonado, President of the Federation of Non-Governmental Organizations Working in the Area of Disabilities), (Quito, November 2003).

The democratically elected presidents of the federations are voting members of the CONADIS Board of Directors. They participate in disability-related policy-making and planning at the national level such as creation of the Strategic Plan for the Disability Sector, 2002–2006, the 2nd National Disability Plan.⁷³ The federations played a key role in the inclusion of amendments to the Political Constitution that included explicit language on people with disabilities and disability rights. They were also important participants in the amending of the Disability Act in 2001, the design of the General Regulations on Special Education, and the content of the Childhood and Adolescence Code

As demonstrated by the inclusion of representatives from disability organizations in CONADIS, discussions bringing together various stakeholders are widely used in the development of disability policy. This process ensures that all parties are given the opportunity to express their views on proposed policies.⁷⁴ One result has been the creation of advocacy networks such as the Disability Rights Advocacy Network.⁷⁵ Another example is the Network for the Advancement of Rights and Mental Health, created in April 2001.⁷⁶ Despite these efforts at including stakeholders in the policy process, however, many individual people with disabilities remain unaware of their rights and the mechanisms in place to demand their enforcement.

The 1st National Disability Plan, currently in force, was released in 1991. The 2nd National Disability Plan for Ecuador, which will lay out an action plan for the next decade, is currently in the process of approval. The proposal developed by CONADIS was submitted to provincial representatives of CONADIS, presidents of national disability federations, governmental representatives of the relevant Ministries (Economy, Human Development, Health, Education, and Housing), and non-governmental representatives related to the disability field. The Final Consensus Workshop for the 2nd National Disability Plan took place in Quito in 5-7 November 2003.⁷⁷ The budget has not been presented for approval yet. The plan must now be approved by the CONADIS Board of Directors and the President of the Republic.

The plan addresses both general strategic guidelines and specific strategies for action. It focuses on three main topics: disability prevention, care for people with disabilities, and social integration. For each area, the document identifies the most important problems, programs that can address those problems, and the organization or institution responsible for implementation. The 1st National Disability Plan was important in the creation of the current legal framework protecting disability rights, so this instrument is also expected to be important in directing action in the future.

⁷³. *Ibid.*

⁷⁴. Government of the Province of Pichincha, *Plan General de Desarrollo Provincial 2002 – 2022* [General Provincial Development Plan 2002–2022], (Consultation Meeting for People with Disabilities, AH / editorial, Quito, 2002).

⁷⁵. Pilar Samaniego de García (President), interviewed by author.

⁷⁶. Hernán Chávez (Director of the National Mental Health Office, Ecuador Ministry of Public Health), interviewed by author.

⁷⁷. The workshop was sponsored by CONADIS.



El Salvador

Key Factors: During the 1980's, El Salvador endured a bloody civil war, which ended in 1992 after claiming the lives of an estimated 80,000 people. Post-conflict El Salvador faces social crises including continued violence and high unemployment. Although some legal protections for people with disabilities exist in El Salvador, weak implementation and poor enforcement of the law, along with the general social instability and widespread poverty are significant barriers to the full inclusion of people with disabilities in the Salvadoran society.

Definition of Disability

The definition of disability contained in the Equal Opportunities Law establishes that disability is "any temporary or permanent restriction of a psychological, physiological or anatomical function resulting from an organic impairment."² Because the definition focuses on impairment rather than the social context of disability, the law focuses on a welfare and medical perspective rather than on non-discrimination and civil rights.

Disability Population

Currently, there are no available statistics on the disability population in El Salvador that are considered reliable.

From April to November 2003, the General Bureau of Census and Statistics and the National Council for the Comprehensive Care of Persons with Disabilities (CONAIPD), a regulatory entity that deals with disability-related issues, fielded the Multiple Purpose Household Survey that aimed in part at identifying the disability population of El Salvador. The results of the survey were not yet available as of February 2004.

¹ The IDRM researchers for El Salvador's field trial stage were Eileen Giron Batres, Director of the Association of the Independent Group for Total Rehabilitation (ACOGIPRI) and Julio Canzales of the National Association of the Blind.

² Legislative Decree 888, *Official Gazette* 347, no. 95, 24 May 2000.

The 1992 census is the most recent source of data concerning disability. That census reported only 81,721 people with disabilities, less than 1.3% of the total population of 6,048,257.³ Leaders of disability organizations do not find this figure valid, and a recent statement by Jorge Isidoro Nieto, the Minister of Labor, suggests that it is also not widely accepted by government officials.⁴

Other estimates of the disability population include the Pan American Health Organization (PAHO) estimate that people with disabilities on average account for 10% of the region's population. Additionally, organizations of people whose disabilities were caused by El Salvador's civil war estimate that people with disabilities account for 13% of the population.

Legislation & Disability Rights

Legal Protections

El Salvador's legal and regulatory framework comprises a variety of protections for people with disabilities. These protections include: the Constitution, the Equal Opportunities Law, a policy on Equal Opportunities, the implementing guidelines for regulations, and the Technical Guidelines for Urban, Architectural, Transportation and Communications Accessibility.

The Constitution of the Republic of El Salvador states that all individuals are equal before the law and enjoy the same rights regardless of race, gender or religion.⁵ People with disabilities have the right to migrate and/or seek asylum, to form associations, and, with the exception of people with intellectual disabilities, they have the right to adopt children. Families with children with disabilities have the right to keep and raise their children.

The Equal Opportunities Law also establishes that the rights of people with disabilities be respected and the principle of equal opportunity be implemented. It applies to governmental actors (governmental agencies, the military, etc.), individuals, and businesses and corporations.

The gap between the legally-defined protections and the reality of the every-day life of people with disabilities in the country remains substantial. In some cases, there have also been steps backward regarding legal protections. For example, the pensions of people whose disabilities resulted from armed conflicts have been canceled or diminished because some of these people are considered "to be rehabilitated."⁶

³ General Bureau of Statistics and Censuses, *Population Census*, 1992.

⁴ Jorge Isidoro Nieto, "Discapacitados serán atendidos" [The Disabled will receive Attention] *El Diario de Hoy*, (22 October 2003).

⁵ Constitution of the Republic of El Salvador, <http://www.georgetown.edu/pdba/Constitutions/EISal/EISal83.html>.

⁶ Jesus Avalos (member of the Association of War Veterans of El Salvador (ALGES)), interviewed by author, (18 January, 2004).

There is no institution in the country specifically addressing human rights violations against people with disabilities. El Salvador has an Ombudsman Office of Human Rights, which is in charge of protecting the general population from the violation of their rights. However, this office does not have a division focused on disability. The IDRM research team found that the Ombudsman offices are not wheelchair accessible.

The Ministry of Labor, the Ministry of Education, the Ombudsman Office of Human Rights, CONAIPD, and associations of people with disabilities report receiving complaints of human rights violations from people with disabilities. They also report efforts to help these people within the framework of their respective areas. However, none of these organizations maintain records indicating whether the person reporting the violation has some disability, so it is difficult to ascertain the extent and frequency of these types of complaints.

Legal Barriers

Blatant discrimination provisions are found in the Electoral Code and the Municipal Code. Both codes prohibit persons who are blind, deaf, or have intellectual impairments from standing for election as members of Municipal Councils.⁷



A public service announcement urging equal rights for people with disabilities

⁷ Decree 417, *Código Electoral* [Electoral Code], <http://www.georgetown.edu/pdba/Electoral/EISal/code92.html>; Decree 1133, *Código Municipio* [Municipal Code], (originally enacted in 1986 and reformed in January 2003).

Civic Participation

People with disabilities have the right to vote in El Salvador, but the lack of accessibility to voting places presents barriers to exercising this right.



Members of the Association of the Independent Group for Total Rehabilitation (ACO-GIPRI) at the opening of their new center in 2004.

Inclusion

Communication

The government does not provide a Braille version of the Constitution. The national library does have some materials in Braille, but these are outdated. The government last purchased alternative format books in 1992. Since then, 20 alternative format books have been donated by other sources.⁸

National news is not generally captioned for hearing-impaired viewers. In the most recent presidential election campaign, held in March 2004, information from the Supreme Electoral Court was broadcast for the first time in Salvadoran Sign Language, and people with physical disabilities were included in television advertising.

⁸. Juan Mariano Velazques Coronado.

Education

A survey conducted by the World Health Organization found that 7.1 percent of Salvadoran children aged 0 to 5 years and 14.2 percent of children aged six to sixteen years have some kind of disability.⁹ For these children, like many others in the disability community, educational levels are very low. According to the Ministry of Labor, among the disability population “only 23% has completed first to third grades, 15% fourth to six grades, 8% seventh to ninth grades and 5 % completes its high school studies, only 3% attends university courses and 0.6% receives technical training.”¹⁰

Special education services are concentrated in major cities or in departmental capitals. The Ministry of Education runs a Child Welfare Center in San Salvador, which is in charge of detecting and diagnosing disease or disabilities in children. In addition, the Ministry of Health runs a children’s health program that includes early detection of disabilities and provides referral services for children.

Other special education services include a rehabilitation center and a day school that teaches Braille for people who are blind. The Ministry of Education runs a school for children who are deaf (grades 1st to 9th), at which teachers use the Salvadoran sign language in their lessons.

Some examples of inclusive education also exist. There are “educational support classrooms” where teachers assist children with learning disabilities in an integrated classroom environment. As of January 2004, the Ministry of Education will implement the systematic assistance program for children who are blind or visually impaired. In other cases, people with disabilities may attend regular schools even though no particular measures have been taken to ensure their full participation.

The Regulations on Architectural, Urban and Communications Accessibility address the need for curricular adjustments in order to facilitate the integration of people with disabilities into regular schools.¹¹ However, schools do not fully comply with these laws. Additionally, only a small group of regular teachers have been trained on the education of people with disabilities.

The Special Education Foundation (FUNPRES) has released the results of a research on physical abuse in the Special Education system conducted in 2002.

⁹. CONAIPD, *Política nacional de equiparación de oportunidades para las personas con discapacidad* [The National Policy on Disability], 2000.

¹⁰. Jorge Isidoro Nieto, interviewed by author, *El Diario de Hoy*, (22 October 2003), 64.

¹¹. CONAIPD, *Regulations on Architectural, Urban and Communications Accessibility*, (February 2003).

Employment

There is no data on the unemployment rate among people with disabilities, but unemployment is a serious problem in El Salvador. The working age population in El Salvador comprises 4,492,837 people, or close to 75% of the total population. Only 53.48% of the population, however, are among the economically active, and of these, 61% are male. The unemployment rate among the economically active is 22.10%.¹²

The Constitution of El Salvador protects the right to work for all people. It maintains that:

Work is a social function protected by the State and is not considered a commodity.

The State will use all resources available to provide employment to both manual and non-manual workers, and to ensure economic conditions for a dignified living to him or her and his or her family. Likewise, the State will promote the employment and placement of persons with physical, mental or social impairments or disabilities.¹³

In addition to the Constitution, the Equal Opportunities Law provides employment protections to people with disabilities. That law requires employers to hire one person with a disability for every 25 employees.¹⁴ Anecdotal evidence suggests that the definition of disability allows for a range of interpretations, especially of a legal nature, and that the policy is not consistently enforced.

In El Salvador, the sector that most frequently employs persons with disabilities is the maquila industry, which consists of the assembly of a range of products or items. There is no employment policy specifically addressing the sector.

¹² Fusades, Quarterly Economic Report, (September 2003).

¹³ Constitution of the Republic of El Salvador, sec. 37.

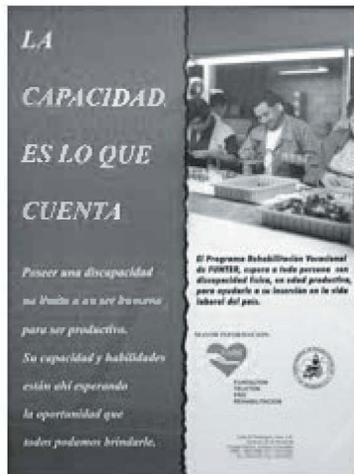
¹⁴ Legislative Decree 888, sec. 24.

There are some training and employment placement programs financed through the Salvadoran Institute of Vocational Training. Recently, the Foundation for the Americas financed a training program on technology. The Foundation for Solidarity, along with the Blind People in Latin America (FOAL-ONCE) have supported other vocational projects. Several organizations of people with disabilities run work centers and vocational training programs without official certification. These centers are self-financed and often staffed by volunteers.

Most of the jobs secured through these programs do not offer fringe or social security benefits. However, some of the training programs have been quite successful in starting to raise awareness in the Government and private sector on the productive capacity of people with disabilities.



Advertisements for vocational training programs for people with disabilities in El Salvador



Health Services

Legislative Decree 888, the Equal Opportunities Law, makes little reference to general access to health services. A relatively new Health Code mentions people with disabilities, but only in reference to the Salvadoran Institute for the Rehabilitation of Disabled Persons, which was established as a regulatory entity on physical rehabilitation issues.¹⁵

In general, people with disabilities receive medical care through the medical infrastructure used by the general population. There are some specialized services available, such as a geriatric clinic within the Salvadoran Institute for the Rehabilitation of Disabled Persons, which renders services to individuals with disabilities living in close proximity to the Institute.

Such rehabilitation services are financed by the government within the national hospital system. The user pays a small fee for therapy sessions. However, that fee in addition to costs of transportation may prevent people from seeking treatment.

A three-year Community-Based Rehabilitation program sponsored by the Pan American Health Organization was implemented in February 2003. However, as of February 2004, results of the program were not publicly available.

The Social Security Institute trains physicians on the provision of services for people with disabilities, within the context of different medical specialties. Training has occurred within the fields of ophthalmology and orthopedics, among others. El Salvador currently has a physical medicine and rehabilitation program, but the training is not focused on disabilities. Also, rural health promoters receive training in serving people with disabilities.

Housing

Although people with disabilities are eligible for public housing, the housing provided consists of very small houses built on an identical, inaccessible design. The Social Housing Fund, a governmental entity, reports that no accessible housing is available.¹⁶

The IDRM research team found few institutions providing housing services to people with disabilities in El Salvador. The most suitably equipped institutions are run by non-governmental organizations. A housing association in San Salvador has developed a self-sustaining housing program focused on people with disabilities. The building is accessible, and each resident pays his or her rent.

¹⁵ Decree 955, Health Code, http://www.mspas.gob.sv/ley_salud8.htm.

¹⁶ Interview with a representative from the Social Housing Fund.

No independent living centers were identified. The activities of disability organizations generally consist of support services rather than peer counseling and referrals. Leaders of such organizations reported that the lack of a programmatic approach results from low levels of funding and little training in project design and management. These institutions work with no government support and entirely rely on the volunteer work of their members.

Institutionalization

Four institutions in the country operate with the specific and exclusive mission of providing long-term housing and care to people with disabilities. Table one provides details about these institutions.

Table 1: Long-term housing and care facilities in El Salvador

Organization/Institution	Number of Residents	Services
Padre Vito Guaratto's Home	134	Psychological counseling, education/training
Roberto Callejas Montalvo Home for Cerebral Palsy	145	Psychological counseling, rehabilitation services, education/training
National Psychiatric Hospital	336	Psychological and psychiatric counseling, education/training
Villas Infantiles Home	112	Psychological counseling, rehabilitation services, educational counseling, acute care services, education/training

People with disabilities are admitted to these institutions under various circumstances.

In some cases, people with disabilities are placed in these institutions against their will. This may occur, for example, when an individual is arrested and a Family Court commits him or her to the institution. In other cases, family members may take the individual to the institution because he or she is considered dangerous to the rest of family. In every case, a psychiatrist is required to perform an individual assessment for admission purposes.

Other admission criteria pertain to children who are orphaned or abandoned by their family. In the case of Callejas Montalvo Home, for example, most of the children are from low-income families who live far from downtown. Children are often admitted because their families find it easier for them to stay at the home during the week.¹⁷

There is no mechanism for reporting incidences of abuse or death in such institutions.

¹⁷ Betida Menjivar (Callejas Montalvo Home), interviewed by author.

Accessibility

In February 2003, the government approved technical guidelines on accessibility of architecture, infrastructure, and communications.¹⁸ These guidelines supplement the provisions of the Equal Opportunities Law. However, the guidelines are not retroactive and apply only to new buildings. Under these mandates, the Ministry of Education, for example, is not required to make existing schools accessible to people with disabilities, and so they remain unadapted. In addition, enforcement is not effective. The research team found that at least some schools built after the approval of this policy were not fully accessible.

Currently, universities in El Salvador do not offer any courses on accessibility engineering, and the concept of universal design is not employed. The research team found that most facilities on university campuses are inaccessible to people with disabilities. Some universities, moreover, have been reported to show a lack of interest in adapting their facilities. One source cited the example of a Pan American University student who uses a wheelchair whose request for a specific course be located on the ground floor was refused.¹⁹

In regard to public transportation, the system is inaccessible to wheelchair users, and, in general, its service quality is poor. The central government has tried to regulate transportation to make it more efficient, but these efforts have been unsuccessful.

El Salvador's urban design is likewise difficult for wheelchair users and others with mobility disabilities to traverse. The major avenues in the city have obstacles; pedestrian bridges are inaccessible; and in the downtown area, peddlers use sidewalks to sell their merchandise, blocking access to people with mobility disabilities.

Disability Action & Awareness

Since a large number of individuals were wounded and affected by the armed conflict that occurred in El Salvador, the disability rights movement started to gain ground following the signature of the Peace Agreements in 1992. Participants in the Peace Agreements included the government, international observers, and members of the former Salvadoran guerrilla organizations. The Peace Agreements established a fund for war veterans and provided for pension rights, labor reinsertion, health care services, and prosthetic/orthotics support for amputees.²⁰ Less than 40% of the members of the governing body of this fund are people with disabilities. Even though the social protections offered to war veterans have not been extended to the disability community as a whole, the inclusion of people with disabilities caused by war in the Peace Agreements contributed to the visibility of disability issues.

¹⁸ Regulations on Architectural, Urban and Communications Accessibility, February 2003.

¹⁹ Ana Elia Sánchez (student of special education at the UCA), interviewed by author, 17 March 2004.

²⁰ Peace Agreements, <http://www.casapres.gob.sv/acuer8.htm>.

Later in the 1990s, under the framework of international treaties and conventions including the United Nations Standard Rules, a Central American Council was created for the purpose of addressing issues affecting children with disabilities. Through the initiative of the First Lady of El Salvador, the council became known as National Council for the Comprehensive Care of Persons with Disabilities (CONAIPD).²¹

This national coordinating organization is in charge of developing disability policy. The CONAIPD is involved in the following areas: disability prevention, access to health and rehabilitation services, job placement, access and integration of people with disabilities into the educational system, and social integration and independent living. It is based upon three fundamental principles:

- Integration of people with disabilities,
- Promotion of equal opportunities, and
- Promotion of self-reliance and active involvement of people with disabilities.²²

The CONAIPD is composed of 16 councilors, of which four are people with disabilities. Members hold regular monthly meetings where they discuss the progress of the four-year working plan. They also try to solve issues raised by disability organizations. The council addresses primarily public regulatory matters. It has several working committees, which are served by representatives of various organizations.

²¹. Executive Decree 111, *Official Gazette* 321, No. 226, 6 December 1993.

²². *Ibid.*



Guatemala

Key Factors: The signing of the Peace Agreements in December 1996 brought more than three decades of internal armed conflict to an end. One of the Peace Agreements obligates the government to provide priority assistance to persons with disabilities caused by the armed conflict. This agreement resulted in the mobilization of people with disabilities who had been in the Army and increased the visibility of the disability population. However, discrimination is still a

major factor hindering the access of people with disabilities to employment, health care, and education, leading to marginalization and social exclusion.

Terminology

The Political Constitution of Guatemala uses the term “minusválidos.” When directly quoting that term within this report, it has been translated as “handicapped.”

Definition of Disability

Broadly speaking, the best known and most widely used definitions of “disability,” as found in white papers, censuses, and national policies, stem from the World Health Organization ICFD classification. The following definitions are taken from several of the most significant documents referenced in this report:

A disability is any congenital or acquired physical, mental or sensory impairment substantially limiting the execution of one or more of the activities considered normal for an individual. (Legislative Decree 135-96 of the Congress of the Republic. Protection of Persons with Disabilities Act: Section 3. Guatemala. Published on 9 January 1997 in *Diario de Centroamérica*.)

Disability: Any physical, mental or sensory impairment, either permanent or temporary, limiting the ability to perform one or more essential activities of daily life, which can be caused or worsened by the physical, economic or social environment. (Policy and Rules on Access to Education for Individuals with Special Education Needs. Ministry of Education. Forthcoming.)

DISABILITY: Difficulty that some people have to hear, see, speak, learn or move as the others, which may be present from birth or acquired as a result of a disease or an accident. (National Institute of Statistics. 11th National Population Census and 6th National Housing Census. Guatemala, 2002.)

In the case of the Guatemalan Social Security Institute (IGSS), two of its programs use different definitions of disability. The IGSS Disability, Old Age, and Survival Program (IVS) defines disability solely in terms of impairment and uses monetary units to conceptualize disability. Human beings are appraised in terms of the value of various body segments. Based on this appraisal, a calculation of “lost” body segments is made in order to determine a pension benefit.¹

In contrast, the IGSS Rehabilitation Unit assesses disability from a functional standpoint. Although belonging to the same institution, the Rehabilitation Unit supports comprehensive rehabilitation of people with disabilities. Consequently, the Rehabilitation Unit uses different criteria to assess disability than the IVS program.²

Overall, a medical model of disability focused on rehabilitation continues to prevail in Guatemala. As a result, laws, policies, and programs are still designed for the purpose of meeting the needs of people with disabilities in a segregated and special manner.

Disability Population

Little effort has been made to reliably identify people with disabilities in Guatemala. Although the disability community has been included one way or the other in the last three national censuses, the information collected has been varied and highly inconsistent.

The 1994 National Population Census identified a total of 8,331,874 people, 59,841, or 0.72%, of whom had some kind of disability.³ The latest national census, conducted in November 2002, indicates a total population of 11,237,426 with 53.9% living in rural areas.⁴ It included one question in the “household” section aimed at determining whether at least one person with a disability lived in a household. The census surveyed a total of 2,200,608 households, 135,482 of which—6.2% of the total—reported at least one person with a disability. Of households reporting a person with a disability, 53.8% were located in rural areas. The disabilities identified in the various households are sorted on a reported-case basis as follows: visual, hearing, lower limb, upper limb, mental, and others.

¹ Juan Carlos Lorenti (Deputy Director of the IGSS Rehabilitation Unit and IGSS alternate member to CONADI’s Council of Delegates), interviewed by author, Guatemala, 4 September 2003.

² *Ibid.*

³ National Institute of Statistics, *Censo Nacional de Población*, [National Institute of Statistics. National Population Census], Guatemala, 1994.

⁴ National Institute of Statistics, *Censo Nacional XI de Población y VI de Habitación*. [National Institute of Statistics. 11th National Population Census and 6th National Housing Census], Guatemala, 2002.

The census data, however, does not provide enough information to accurately quantify the disability population in the country. Because the incidence of disability in each household may vary, the percentage of households cannot be projected to the percentage of people with some kind of disability.

Rather than using the estimates derived from the Guatemalan census, some national institutions use the estimates based on those of the World Health Organization (WHO) and the Inter-American Development Bank (IADB). The National Disability Council (CONADI), for instance, states that around 12% of the total population in Guatemala have some kind of disability.⁵ The IGSS uses the WHO estimate that, on average, 10% of the world's population consists of people with disabilities.⁶

Despite the lack of good quantitative data on Guatemala's disability population, there is a general consensus among those consulted by the IDRM that there has been an increase in the last five years of the number of people with disabilities. The causes of the increase cited include increasing violence at all levels including violent crime and domestic violence, increased early identification and detection of impairments, the lack and poor quality of maternal health care services, and poverty. Although not contributing to recent increases, injuries sustained during the internal armed conflict are another major source of Guatemala's disability population.

In addition, the IGSS Rehabilitation Unit reported a change in the major causes of trauma-induced disability. There has been an increased incidence of disability due to violent trauma. In contrast, ten years ago, many instances of disability were attributed to accidents related to farming.⁷

Legislation & Disability Rights

Legal Protections

Disability rights are guaranteed by a number of international treaties and conventions adhered to by Guatemala including: the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities, the Managua Declaration, and the Convention on the Rights of the Child. Guatemala ratified the Vocational Rehabilitation and Employment (Disabled Persons) Convention (Convention 159) of the International Labor Organization (ILO) on 5 April 1994.⁸

⁵ Carlos Pérez (Chairman of CONADI's Board of Directors), interviewed by author, Guatemala, 19 August 2003; Aníbal Robles (CONADI Director General), interviewed by author, Guatemala, 19 August 2003. In formulating an estimate of the number of people with disabilities, CONADI did not choose either the WHO or the IADB estimate (17% of the population in Latin America). Instead, they use a percentage somewhere in between the other estimates.

⁶ Juan Carlos Lorenti.

⁷ *Ibid.*

⁸ International Labor Organization, Convention 159, *Vocational Rehabilitation and Employment (Disabled Persons) Convention*, (1983), <http://www.ilo.org/ilolex/english/convdisp1.htm>.

On 8 August 2002, Guatemala ratified the Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities, and it deposited the instrument on 28 January 2003.⁹ Guatemala has also ratified the Protocol of San Salvador, which focuses on economic, social, and cultural rights and has a specific chapter on disability rights. The ratification instrument was deposited on 5 October 2000.¹⁰ No official announcement endorsing the development of an international convention protecting disability rights has been made by the government.

Although the government of Guatemala supports and signs all international instruments protecting human rights, it has not yet moved towards effective enforcement.

Guatemala also has a number of national legal instruments to protect the rights of people with disabilities. Section 53 of the Political Constitution of the Republic provides that “the state guarantees the protection of the handicapped and of individuals with physical, psychiatric, or sensory limitations.”¹¹ It also declares that it is in the national interest to provide health and social care to people with disabilities as is the promotion of policies and services that enable rehabilitation and social integration.

Legislative Decree 135-96, also known as the Protection of Persons with Disabilities Act was passed by the Congress in 1996.¹² The act was passed and enacted during the signing of the Peace Agreements. It expands on the guarantees of the Constitution and provides the disability community with guarantees for exercising their economic, social, and cultural rights. The Protection of Persons with Disabilities Act covers areas such as health, education, employment, accessibility to the physical environment and transportation, access to information and communication, culture, and sports. The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities served as a model in the drafting of the decree.

Legislative Decree 135-96 does not contain any penalties for non-compliance. There have been several initiatives to amend it in order to bridge this legal gap, but none have been successful so far. Furthermore, the act does not yet have regulations, which are essential to enforcing the law. Although the law came into force several years prior to this report, regulation drafting and adoption are still in process. Overall, few people are aware of the contents of this law, and there is little to no compliance.

Other national legislation includes the Social Insurance Act and the Comprehensive Protection of Children and Youth Act which includes a specific chapter on children and youth with disabilities¹³. The latter serves as a basis for Guatemala’s public policy on the protection of children and youth.

⁹ Luis Fernando Astorga Gatjens, “14 Countries Ratified Inter-American Convention on Discrimination” *Disability World* 19 (2003), http://www.disabilityworld.org/06-08_03/gov/interamerican.shtml.

¹⁰ Signatories of the Protocol of San Salvador, <http://www.cidh.oas.org/Basicos/basic6.htm>.

¹¹ The Political Constitution of the Republic of Guatemala currently in force was drafted and issued in 1985.

¹² Legislative Decree 135-96, *Diario de Centroamérica*, (9 January 1997).

¹³ Decree 295, *Ley Orgánica del Instituto Guatemalteco de Seguridad Social* [Social Insurance Act], *Diario de Centroamérica*, (Guatemala, 30 October, 1946); Decree 27-2003, *Diario de Centroamérica*, 18 July 2003.

Rather than adhering to a rights-based approach, the government's institutional stand toward the disability community has been very traditional, characterized by welfare assistance programs and a charitable approach. The various programs undertaken by ministries and presidential secretariats have been designed following this model.

There are still serious violations of the human rights of people with disabilities, mainly related to marginalization, exclusion, and discrimination. Human rights protection and advocacy institutions that do not focus on disability rights provide inadequate support to this sector of the population.

The creation of offices specifically devoted to protecting disability rights illustrates the challenges facing general human rights organizations. For instance, a special Ombudsman's Office for People with Disabilities was created in June 2003 within the Ombudsman's Office for Human Rights to serve as a working unit specifically devoted to promoting and protecting disability rights. Similarly, the Center for Legal Action in Human Rights (CALDH), a non-governmental organization that has spent almost a decade filing claims for serious human rights violations committed against the people of Guatemala, has added a Disability Rights Program to its working units. This program has been following up specific disability rights violation cases for the last few years. It has played a key role in the development and strengthening of organizations of people with disabilities and in influencing policy-making.

There are only a few documented cases of claims made on the grounds of disability rights violation that resulted in positive outcomes.¹⁴

Legal Barriers

The national legislation contains barriers that limit or hinder the opportunities of people with disabilities to participate in different activities on an equal footing with the rest of the society. One major barrier is found in Section 13 of the Civil Code, which provides that any individual who is congenitally blind or deaf or acquired his or her disability during childhood can be declared legally incapable, which means they are deprived of exercising their civil and legal rights.¹⁵ For example, any individual declared legally incapable is forbidden to act as a notary. Other rights denied by this provision are the right to vote, the right to elect, the right to be elected, and the right to freedom of association. These rights are otherwise guaranteed by the Political Constitution. In addition, people with sensory disabilities are not allowed to act as witnesses of certain acts or to make a will on their own behalf.¹⁶

¹⁴. CALDH, *Un dolor silencioso* [A Quiet Pain], Guatemala, 2002.

¹⁵. Decree-Law 106, *Codigo Civil* [Civil Code], *Diario de Centroamérica*, (14 September 1963).

¹⁶. Helen de Bonilla (Director of the Guatemalan Foundation for Blind and Deaf Children Alex), interviewed by author, Guatemala, 5 August 2003.

The legal procedure to declare an individual incapable is used to appoint, even against an individual's will, a representative. The Civil Code provides that legal representation may be vested in the father, mother, representatives, or guardians. The official representative will be then authorized by the court to perform judicial acts on behalf of the person declared incapable. Once a person with disabilities has been declared "incapable", he or she will be subject to the acts performed by his or her representative.

In theory, legal representatives are appointed to safeguard the rights of the persons under their representation. However, such legal representation hinders them from exercising their rights on their own behalf.

Many people with psychiatric disabilities and individuals with severe mental/intellectual disabilities are placed in institutions after having been abandoned and institutionalized on the basis of a court decision. They are declared legally incapable and are often subjected to medical treatment, and in some cases to psychiatric therapy, having no right to refuse treatment. Additionally, some of these institutions—particularly mental health institutions—do not offer adequate physical and sanitary conditions nor do they have enough qualified staff to provide proper and decent care.¹⁷

Civic Participation

No legal prohibitions other than those set forth in the Civil Code prevent persons with disabilities from voting. However, there are serious limitations in the practical ability of people with disabilities to exercise their civil rights.

First, there is no accessible information on the electoral process or the candidates and their platforms. Campaign messages broadcast on television are neither captioned nor interpreted in sign language. Second, none of the information published by print media is made available in alternative formats for people with visual or reading disabilities.

Physical accessibility of polling stations presents another challenge. Although there is no official data in this regard, an informal survey of the polling stations in the last general elections held in Guatemala showed that accessibility was a significant barrier in the voting process.¹⁸

¹⁷ Interview with a member of the Human Rights Commission of the National Mental Health Hospital, Guatemala, 18 September 2003.

¹⁸ Guatemala held general elections on 9 November 2003. CONADI, through its Civic Participation Committee, maintained communication with the authorities of the Supreme Electoral Court regarding the physical accessibility requirements in polling stations necessary to enable the participation of persons with disabilities. Although an agreement was reached to ensure minimum accessibility conditions for people with disabilities, the experience of that day showed that the agreement was not fulfilled.

Inclusion

Communication

Legislative Decree 135-96 mandates access for people with disabilities to information and communication in four different areas: the provision in alternative formats of disability-related information released by governmental agencies, the captioning or sign language interpretation of television news programs, accessibility of both public and private telephone services, and the provision of accessible information in libraries.

Nevertheless, there is neither a national information system nor a specific communication network available to people with disabilities. All official information is released to the mass media without considering the need of disseminating it in any alternative formats.¹⁹

Alternative information formats, such as Braille materials, tape-recorded texts, electronic formats, sign language interpretation, and captioning on television, among others, are virtually non-existent. There are a few available resources, which are provided by private charitable institutions. The Braille Library Unit of the National Library, for example, is funded by the Committee in Support of Blind and Deaf People of Guatemala, a private institution that is the only institution in Guatemala that renders services to persons with sensory disabilities. It is also the only institution providing computer access for the blind. Since it is private, coverage is limited and restricted mainly to the capital city.²⁰

In general, people with disabilities who require accessible communication and information must attempt to obtain services on their own. People who are blind that need informational material—students and professionals, for instance—often resort to private support organizations to obtain it and they generally have to pay for the services they use. Likewise, people who are deaf must typically look for a private sign language interpreter. Not even institutional leaders in the field of disability have a sign language interpreter available for people who are deaf and require this type of assistance.

¹⁹ Interview with the General Attorney on Human Rights (Office of the Ombudsman for People with Disabilities), General Attorney on Human Rights, September 2003.

²⁰ *Ibid.*

Education

There are no records or data on the number of children with disabilities in the educational system. The official records of the Ministry of Education do not include the disability population.

The educational offerings for persons with disabilities in Guatemala fall into two large categories: public schools in the national education system, and private educational institutions.

Education for people with disabilities is predominantly provided in a private segregated educational system. At a local level, "special education" institutions prevail for children with physical, visual, and hearing disabilities, and especially for children with intellectual disabilities. Only a few children have been integrated into the mainstream educational system, and this has been the result of individual efforts.²¹

Within the national education system, the Ministry of Education has a special education unit called the Special Education Office. Its main goal is to promote the Policy and Rules on Access to Education for People with Special Education Needs.²² The policy has not yet been published, but it establishes norms for the accessibility conditions required for persons with special education needs to be able to integrate into inclusive and mainstream education. While the Policy and Rules on Access to Education for People with Special Education Needs provides for accessibility in every other aspect, schools and educational centers belonging to the national education system are not required to be physically accessible. The national education system does not have enough human, technical, and material resources to comply with these rules.

The national education system has around ten schools working on the integration of children with intellectual disabilities. Teachers who have some level of training in special education have been an important source of support for this project. There are no programs in the national education system aimed at early detection of disabilities.

The national teachers training curriculum does not include training in special education. For teachers to become certified in special education, they need to obtain a technical university degree or a diploma from a private institution, like the Association for Training and Technical Assistance in Education and Disability (ASCATED), one of the main providers of such training.²³

²¹ Gabriela de Búrbano (Director of ASCATED), interviewed by author, Guatemala, 22 August 2003.

²² Silvia de DeLeón (Director of the Special Education Office), interviewed by author, Guatemala, 17 September 2003. She provided information about the Policy and Rules on Access to Education for Persons with Special Education Needs. This policy has neither been approved nor published yet, although she said that it is already being implemented.

²³ Gabriela de Búrbano.

Teachers can also obtain a specialized university degree in other disciplines such as speech therapy, occupational therapy, physical therapy, education for children who are deaf or hearing-impaired, and education for children with learning problems.²⁴

Courses given at middle and higher education centers do not include topics related to disability policies or disability rights. At present, discussions are taking place with a view to including the disability issue in the curriculum of a master's program on human rights taught by one of the private universities in Guatemala.²⁵

Employment

Chapter Five of Legislative Decree 135-96 provides for the right to a decent job under equal conditions. The act covers non-discrimination during the application process as well as workplace accommodation and provision of technical aids. Because there are no penalties for non-compliance, however, the actual employment situation for persons with disabilities is still precarious.

There is no reliable data on the number of persons with disabilities currently employed. All national censuses and surveys conducted to date have lacked data on employment. According to the director of CONADI, the percentage of persons with disabilities who currently have jobs is very low, possibly as low as 2%.²⁶ Most of those who are employed are likely to be working at informal jobs.

Broadly speaking, people with disabilities must deal with a variety of hurdles in order to obtain a job: social rejection, discrimination by employers, the lack of accessible transportation, inaccessible workplaces, the lack of training and education, the absence of job placement programs, and few vocational adaptation programs providing technical aids.

One important employment barrier that people with disabilities often encounter is lack of vocational training. Although some private institutions offer vocational training programs, there is no government policy or regulation dealing with the need for training and education of people with disabilities. The number of people who actually receive training is minimal, and most of the time they are trained in manual trades only.²⁷

Moreover, there are no effective job opportunity programs for people with disabilities. There are some job placement efforts, but these are sporadic, individual placements and do not account for an actual job placement program run by state institutions or private organizations. Additionally, these efforts are based mainly in the capital city.²⁸

²⁴ Ronald Solís (Secretary of the School of Psychology of the San Carlos University of Guatemala and alternate member on behalf of that institution to CONADI's Council of Delegates), interviewed by author, Guatemala, 27 September 2003.

²⁵ Ada Melgar.

²⁶ Aníbal Robles.

²⁷ *Ibid.*

²⁸ Gabriela de Búrbano.

The Ministry of Labor and Retirement Security has created a Workers with Disabilities Employment Unit that has mainly focused on micro-lending for micro-business development. The lending takes place through a revolving fund set up by the Spanish Agency for International Cooperation.²⁹ Originally, the purpose of this unit was to assist persons with disabilities caused by the armed conflict. However, the program has been expanded and now assists people with disabilities stemming from a variety of causes.

Health Services

As with education, health services can be classified into two large categories: governmental and private. Most rehabilitation services and other specialized services for persons with disabilities are usually provided by private institutions. Specialties such as ophthalmology, otorhinolaryngology, neurology and psychiatry are available to people with disabilities in private centers.

There are three specialized centers within the health care system run by the Ministry of Health and Social Welfare: the Children's Infectology Center, the Jorge von Ann Orthopedics and Rehabilitation Hospital, and the Roosevelt Hospital Rehabilitation Unit. The Ministry of Health also runs a program, DISPAM/PRADIS, which is funded by the Presidential Secretariat for Peace and which was created following the signing of the Peace Agreements.³⁰ The DISPAM/PRADIS program is specifically intended for people with disabilities caused by the armed conflict, and has several program areas: health care, rehabilitation, and entry into the labor market by micro-enterprise.

The health care system run by the Guatemalan Social Security Institute (IGSS) also has a rehabilitation unit. Services include physical therapy, psychiatry, and occupational therapy. As part of its services, the IGSS also provides assistive devices to its members, including wheelchairs, prostheses and orthotics, standing frames, and crutches.³¹ Because the Social Security system only covers those who are employed, the IGSS rehabilitation unit only assists economically active workers who become physically disabled. Thus, the Rehabilitation unit of IGSS covers approximately only 20% of the demand for assistive devices.³²

Other institutions providing assistive devices are the Committee for the Advancement of Blind and Deaf Persons and the Foundation for the Welfare of the Disabled (FUNDABIEM). The Secretariat of Social Welfare of the First Lady (SOSEP) has previously donated wheelchairs. Other programs have been run in conjunction with the Red Cross and other private institutions.³³

²⁹ Estuardo Aldana (Head of the Workers with Disabilities Employment Unit of the Ministry of Labor and Retirement Security), interviewed by author, Guatemala, 26 August 2003.

³⁰ Gabriela de Búrban.

³¹ Estuardo Aldana.

³² Interview with an official at IGSS who asked to remain unidentified.

³³ Juan Carlos Lorenti.

Most of the institutions providing health care for people with disabilities are located in the capital city with only a few located in other major cities. People who require health care services and live in rural areas have to travel long distances, usually to the capital city, to receive assistance.

Health care professionals can be trained in certain specialty fields related to the care of persons with disabilities. The IGSS Rehabilitation Unit offers specialty training in physiatry, while the national university offers specialty training in ophthalmology, physical therapy, speech therapy, and occupational therapy.³⁴

The education and training of health care professionals in the provision of services to people with disabilities does not focus on the social needs of people with disabilities. Instead, physicians are trained with a strong emphasis on biological/medical aspects. Although several attempts have been made to shift the focus away from the physiological side, many persons with disabilities claim that they are not yet satisfied with health care professionals because professional barriers limit their participation in the comprehensive rehabilitation process.

Housing

There is a shortage of programs that provide housing for people with disabilities in Guatemala. Besides a Center for Independent Living, there are no housing units specially designed for people with disabilities or any systems in place to design or provide special housing units for persons with disabilities. Most people live in isolation, with their families or with their caregivers.³⁵

An agreement, which established that 5% of all affordable houses built would be allocated to people who are blind or deaf, was signed in 1989 between the former National Housing Bank and the Committee for the Advancement of Blind and Deaf Persons of Guatemala.³⁶ Only 18 blind persons eventually benefited from it.³⁷

There are a limited number of specialized shelters for homeless people with disabilities. These are usually overcrowded since the number of persons with mental and severe disabilities abandoned is alarmingly high. These shelters include the National Mental Health Hospital and a psychiatric center called "*Centro Experimental Psiquiátrico Pedagógico*" for abandoned children and youth with mental impairments and psychiatric disorders.³⁸

³⁴ *Ibid.*

³⁵ Ada Melgar and Gustavo Muñoz (Disability Rights Program, Center for Legal Action in Human Rights), interviewed by author, Guatemala, 19 August 2003.

³⁶ The National Housing Bank ceased operation in 1994. Copies of the original agreement were requested by IDRM, but the Committee for the Advancement of Blind and Deaf Persons of Guatemala did not respond.

³⁷ Sebastián Toledo.

³⁸ Gabriela de Burbano; Office of the Ombudsman for People with Disabilities, General Attorney on Human Rights.

Institutionalization

Many people with psychiatric disabilities and individuals with severe mental/intellectual disabilities are placed in institutions after having been abandoned and institutionalized on the basis of a court decision. They are declared legally incapable and are often subjected to medical treatment, and in some cases to psychiatric therapy, having no right to refuse treatment. Additionally, some of these institutions—particularly mental health institutions—do not offer adequate physical and sanitary conditions nor do they have enough qualified staff to provide proper and decent care.³⁹

Accessibility

Chapter Seven of Legislative Decree 135-96 obligates city governments to regulate both the construction and adaptation of buildings and public transportation in order to make them accessible for people with disabilities. However, the Political Constitution of the Republic guarantees the autonomy of local governments, which has been interpreted by some jurists and municipal authorities to mean that municipalities are not bound by the decree.⁴⁰ Thus, although this law came into force in 1997, municipalities have not complied with it.

The design and construction of public accommodations and facilities are regulated by city governments through construction standards. These standards do not contain any provisions for accessibility of people with disabilities. Even governmental buildings are not typically accessible.⁴¹

Transportation infrastructure that would enable the free movement of people with disabilities is also largely absent. In Guatemala, the public bus system is run by Empresa Metropolitana de Tránsito (EMETRA), registered with the Municipality of Guatemala City. In 1999, some organizations of people with disabilities made an attempt to reach an agreement with EMETRA in order to make urban transportation accessible. The agreement did not materialize, and there have been no further initiatives to allow people with physical disabilities to freely use public transportation.⁴²

Institutions that render services to or work with people with disabilities also do not provide any kind of accessible transportation. People with disabilities must look for other alternatives that are often much more expensive than public transportation. Those who cannot afford private transportation, like taxis, are deprived of freedom of movement.⁴³

³⁹ Office of the Ombudsman for People with Disabilities, General Attorney on Human Rights.

⁴⁰ Constitución Política de la República de Guatemala [Political Constitution], Guatemala, 1985.

⁴¹ Álvaro Véliz (Consultant to the Department of the Historical Center of the Municipality of Guatemala City and Lead Consultant to the Management Program for the Historical Center of Guatemala City), interviewed by author, Guatemala, 25 August 2003.

⁴² *Ibid.*

⁴³ *Ibid.*

The topic of accessibility and universal design is not part of the curriculum of university courses in architecture or engineering. Although CONADI has supported some training courses on this issue intended for design and construction professionals, efforts in this area have been sporadic and isolated and have had minimal impact.

As noted earlier, general elections were held recently in Guatemala. CONADI, through some disability organizations, approached the mayoral candidates in different municipalities. Their goal was to obtain the candidates' commitments to include accessibility requirements in construction standards and to progressively adapt public transportation units. The experience was reported to be positive, as candidates pledged themselves to meeting these requirements.⁴⁴

Disability Action & Awareness

The National Disability Council (CONADI) was created pursuant to Article 22 of Legislative Decree 135-96. CONADI role is to coordinate, advise on, and promote general policies on disability. The Council of Delegates is the body with maximum authority within CONADI's, and it is composed of representatives of both the public sector and civil society.

Public sector membership includes delegates from: the Ministry of Labor and Retirement Security; the Ministry of Education; the Ministry of Public Health and Social Welfare; the Guatemalan Social Security Institute; the Presidential Secretariat for Social Welfare; the Ombudsman's Office for Human Rights; and San Carlos University of Guatemala. Delegates from civil society include representatives of organizations of and working for people with disabilities.

Although CONADI's main objectives are related to the design of general policies on disability, there is still no nation-wide program. The social movement of people with disabilities is still politically weak and has failed to have a significant influence on the design and implementation of such a program.

CONADI has included some specific actions in its strategic internal plan mainly aimed at raising awareness in Guatemalan society. It has established working committees of Council delegates and others from the represented organizations. Committees have been established in the following areas: strengthening disability organizations, women with disabilities, civic participation, and, more recently, human rights. The goal of the Committee on Human Rights is to provide human rights training to Council delegates and disability organizations as well as to lobby and advocate for laws, policies, and programs on disability at a local, national, and international level. Special emphasis has been placed on promoting the International Convention on Disability Rights sponsored by the United Nations Organization.⁴⁵

⁴⁴ Office of the Ombudsman for People with Disabilities, General Attorney on Human Rights.

⁴⁵ *Ibid.*

At a national level, 23 organizations of persons with disabilities have been identified. Only three of them have a membership made up of persons with different types of disabilities. There has been increasing coordination and cohesion among organizations in recent years, probably as a result of the creation of CONADI since the various sub-sectors have had to coordinate CONADI's actions at some level.



Guyana

Key Factors: Data pertaining to persons with disabilities are largely non-existent in Guyana. The situation confronting most people with disabilities is one of limited opportunities, lack of programs, and negative social treatment. Services and facilities are typically inadequate, non-existent, or provided on an ad hoc basis.

Definition of Disability

There is no official definition of disability in Guyana.

Disability Population

An exact number of persons with disabilities in Guyana is not yet available. The census conducted in late 2003 was the first to include specific questions about disability. At the time of this writing, results had not been made public.

The most recent data regarding the number of persons with disabilities living in Guyana was published by Pan American Health Organization in 1993 and revised in February 1994. The estimated number of persons with disabilities in Guyana at that time was 71,800.¹ Based on the 1991 census estimate of the country's population, which was close to 800,000, the percentage of the population living with disabilities was then 9%. The current population of the country is approximately 740,000.

Legislation & Disability Rights

Legal Protections

The government of Guyana is not a signatory of the OAS Inter-American Convention of the Elimination of Discrimination Against People with Disabilities. The United Nations Standard Rules served as a guiding framework for Guyana's National Policy on Rights of People with Disabilities, but the government has not responded to the United Nations Standard Rules on the Equalization of Opportunities for people with Disabilities (UNSRPEOP) questionnaire.

¹ Pan American Health Organization (PAHO), *Situation Analysis of Disability and Rehabilitation in the English Speaking Caribbean*, 1993, revised 16 February 1994.

The Constitution was recently amended by Bill 9 of 2003 which declared discrimination against people with disabilities unconstitutional. The amendment process began in 1998 with the consultation of individuals and representatives of civil and political groups. There were both oral and written presentations at the consultations and included those by disability groups. At the conclusion of the exercise, a committee was established with representatives from both civil and political groups. No representatives from disability organizations were invited to participate in this committee. The committee's task was to review the submissions and determine which recommendations would be acceptable as constitutional amendments. These recommendations were then reviewed by a special parliamentary oversight committee and after months of deliberation several Constitutional Amendment Bills, including the Bill 9 of 2003, were tabled in Parliament and passed.²

No other laws have been passed that specifically protect the rights of persons with disabilities. Guyana's disability policy is established by the National Policy on Rights of People with Disabilities.³ However, the policy lacks legal standing and would need to be passed into law before it would be enforceable.

The Guyana Police Force and the Probation Department of the Ministry of Human Services are in charge of maintaining records of reported abuse or violence against people with disabilities. The National Commission on Disability and the Guyana Human Rights Association keep records of cases of discrimination against persons with disability in regard to employment, housing, education, and transportation.

Legal Barriers

People with certain types of disabilities may be prevented from election to Parliament. Article 55 of the Constitution, for example, states that, "No person shall be qualified for election as a member of the National Assembly who...(b) is a person certified to be insane or otherwise adjudged to be of unsound mind under any law in force in Guyana." Article 159, section (3) adds that, "No person shall be qualified to be so registered who on the qualifying date is a person certified to be insane or otherwise adjudged to be of unsound mind under any law in force in Guyana." Article 53, establishes that, "a person shall be qualified for election as a member of the National Assembly if, and shall not be so qualified unless, he...(b) is able to speak and, unless incapacitated by blindness or other physical cause, to read the English language with a degree of proficiency sufficient to enable him to take an active part in the proceedings of the Assembly."⁴

² Mike McCormic (Co-President, Guyana Human Rights Association), interviewed by author, 8 October 2003.

³ National Policy on Rights of People with Disabilities, March 1997. The document was obtained from the Clerk of Parliament on 30 October 2003.

⁴ Constitution, updated in 1996.

Civic Participation

People with disabilities have the right to vote in Guyana. There are no permanent polling centers in Guyana. When an election takes place, schools, community centers, and even private residences are used as polling places. Many individuals with disabilities are unable to enter polling centers, due to their inaccessibility. No alternative forms of communication, such as Braille or large print, are available.

Because of these obstacles, provisions have been put in place to allow persons with disabilities to participate in general elections. There are three options provided by law. First, a person with a disability who is unable to cast his or her vote independently can delegate a friend or family member to fill out his or her ballot, after both individuals have taken an oath. Any such designated individual can represent only one person with disabilities and must be a voter at the same polling station. Second the law also provides that a person with a disability may apply to have their ballot cast by proxy. In this case the person is not required to be present at the polling station, and their delegate appears for them. Lastly, a Presiding Officer at the polling center can mark the ballot as requested by a person with a disability. Representation by a delegate or by proxy must be recorded in polling center record books.⁵

Information about the election process is generally made available to the public and specifically to persons with disabilities. Mass media, community discussions, and visits by personnel from the Elections Commission to disability organizations are the most common strategies for communicating information. The Constitution does not prohibit people with disabilities from running for or being elected to public office.

Inclusion

Communication

Access to information for persons who are blind or hearing impaired is not readily available in Guyana, and the cost of purchasing assistive devices overseas is prohibitively high. Thus official and public information remains extremely difficult to access.

The Guyana Society for the Blind and the Attorney General's Office provide a Braille version of the Constitution, but Braille or audio editions of most public documents are largely nonexistent. The National Library provides some access to information for persons who are blind or visually impaired through a limited Braille and audio cassette service. This is a recently established service which began in early 2003, and is only available at the Central Georgetown location of the National Library.

⁵ *Representation of the People*, ch. 1:03.

The national television news is not captioned for persons who are deaf. Contacting the police or fire department in the case of a crime or an emergency is a significant problem. Public officers cannot interpret even the basic signs, and TTY facilities are unavailable. If an incident occurs, persons who are deaf have to rely on their ability to lip read or seek an interpreter. Sign Language interpreters, who are mainly teachers, are few in number, and therefore are not easy to access.

There are three special education schools for the deaf, and the sign language taught by each differs slightly. All use American sign language as the base, but make adaptations to suit the local context, for example in signs used for local flora and fauna.

Education

The National Policy on the Rights of People with Disability states that it should be the responsibility of the State to “recognize the principles of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings.”⁶ However, the policy statement is not accompanied by any established laws that enforce or encourage compliance.

The number of children with disabilities in Guyana and by extension the number in the public school system could not be ascertained. Nevertheless, the Ministry of Education reports having made significant efforts to integrate children with disabilities into the mainstream school system, although education opportunities typically depend on the type and degree of disability. Children who are blind or have a mild physical disability are often placed in local schools through a rather unstructured process.⁷

Many children with disabilities are either kept out of school by their families, or are excluded by the inaccessibility of the school system's buildings and information. A national policy is not in place to facilitate access to school buildings, although some international donor agencies stipulate that schools built with their funds be accessible. The high cost of speech programs and related resources, the lack of Braille teachers, and the fact that teachers are not taught to deal with multiple disabilities also contribute to the difficulty encountered in accessing education.

Other children with disabilities attend special schools. There are seven public primary schools in Guyana that provide education for children with disabilities, the majority are located on the coast. There are no public secondary schools for students with disabilities. One recently established private institution in Georgetown, the Open Door Centre, offers vocational training for persons aged 17 to 45 who have physical or mild intellectual disabilities. It provides basic training in Information Technology and Electronics and a remedial English and Math course.

⁶ National Policy on the Rights of People with Disability.

⁷ Interview with an official from the Ministry of Education, 18 July 2003.

At present there is no program available to detect disability in early childhood.⁸ However, early detection measures are included in the National Commission on Disability's three year development plan for the period of 2003 to 2005. Funding for implementation is currently being sought.⁹

Training for teaching children with disabilities was introduced into the national teachers training curriculum at the Cyril Potter College of Education in September 2003. Prior to that time, it was not a required part of teacher training.¹⁰ Models for the new curriculum were prepared with the assistance of VSO, which is a British-based volunteer organization similar to the United States Peace Corps. It was introduced in September of 2003, following extensive consultation with disability organizations, the Ministry of Education, special education teachers, parents of people with disabilities, and other interested persons. The new curriculum includes a required course on special education, and students have the option to continue their study in more depth in their second year.

Resources available to families and caregivers of persons with disabilities are very limited. Although parents and family members of children with disabilities have expressed the need, there is no public program that aims to integrate families into the rehabilitation and education of people with severe, profound or multiple disabilities.

Employment

According to the National Policy on the Rights of People with Disabilities, the right to gainful employment in the public and private sectors should be reflected in national legislation. Aside from the Constitutional Amendment forbidding discrimination, there are no laws requiring the employment of people with disabilities by either the government or the private sector. There are some people with disabilities employed by the government, but only a few occupy mid-level positions. The largest private sector employer, which requested to have its name withheld, reported that there is no written policy concerning employment of persons with disabilities. No one with a disability currently works there and no one with a disability has applied for a position in recent years. There are no statistics on the unemployment rate among people with disabilities.

Among the strategies recommended by the National Policy on the Rights of People with Disabilities for promoting the employment of people with disabilities are tax concessions for employers who provide adaptations for employees with disabilities, an employment register, training, micro-loans, and awareness raising campaigns. The National Commission on Disability is currently using the policy document as a basis for developing its own internal action plan.

⁸ *Ibid.*

⁹ Interview with the Commissioner on the National Commission on Disabilities, 14 October 2003.

¹⁰ The only special education class available prior to the introduction of this curriculum was offered in the 1980s and discontinued when the course coordinator resigned and was not replaced.

While no nationally coordinated training program exists for people with disabilities, local training is conducted by some organizations of disabled persons. These courses are intended to prepare their members to create or pursue job opportunities. Training is usually ad hoc and can address self-employment, small business management, advocacy, leadership skills, and self-esteem. Self-employment workshops address and encourage self-employment in a variety of areas such as cosmetology, food, floral decoration, cake making, and handicrafts.

Leaders of disability organizations report that barriers to employment include: inaccessible workplaces, limited training and educational opportunities, high transportation costs, and cultural barriers. As a result of these barriers, most persons do not even consider applying for many jobs even if they have the appropriate qualifications.

Health Services

The Ministry of Health provides funding specifically for the promotion of the health and rehabilitation of persons with disabilities, and maintains a specific rehabilitation section that offers nurses instruction on providing rehabilitative services to trauma patients. Additionally, the Polio Rehabilitation Centre was established in 1967, following an outbreak of the disease in Guyana. Its purpose was to treat affected children by providing physical therapy and other rehabilitation services. In 1985 the name was changed to Ptolemy Reid Rehabilitation Centre, after the Prime Minister at the time, Dr. Ptolemy Reid. The Centre is now a nongovernmental organization. This name change reflected a shift of the center's primary focus from Polio, which has been eradicated from the country, to the provision of services for children who have physical disabilities. Nevertheless, lack of rehabilitation services remains a major problem for persons who acquire a disability later in life.¹¹

The Ministry of Human and Social Services maintains a program that provides limited assistance to persons with disabilities in obtaining certain types of auxiliary materials and technical aids such as prosthetics or eyeglasses. Other resources are available from non-profit organizations such as the Lions Club and the Rotary Club. For example, the Lions Club provides glasses for low-income individuals. Both organizations occasionally provide wheelchairs or other assistive devices. They also assist patients who require corrective treatment, such as heart surgery or eye operations.

¹¹. National Development Strategy.

Community based rehabilitation has not been implemented by the National Health Service, however, CBR services are available through the independently funded Guyana Community Based Rehabilitation Programme.

Most health professionals have not received training in this field. There are currently no professional training programs for personnel in a variety of specialized fields including physical therapy, occupational therapy, speech therapy, physiatry, or prosthetics and orthotics. In order for a health professional to receive such training, they must attend institutions abroad in the Caribbean, North America, or Great Britain.

Housing

Leaders of disability organizations report that most people with disabilities live with their families or close relatives. The high rate of unemployment of persons with disability, unaffordable rents, and their inability to qualify for mortgage approval create a situation in which many persons with disabilities are dependent on their families. For the small number of people who are employed and able to afford rent, prejudices and cultural norms become the obstacle. One individual recounted a situation she encountered at home:

“...one day I was cooking on my one burner kerosene oil stove and it fell off the table and the flames caught the kitchen blinds. Luckily my father and an aunt were at home and they put out the fire before it spread. Everyone quarreled with me for going to the stove. I knew I was tired and should not have attempted to cook in that state. But cooking for me is not a problem...I sell things like fried channa, plantain chips, sugar cake, cassava balls, etc. (these are all local fried foods) in front of my home...these are prepared by me...what I do however is ask someone to see if the raw ingredients such as vegetables were washed clean. But I do the frying myself. I use my sense of smell a lot to determine if cooking is complete. I had to fight for my independence, or my loved ones would have taken it from me...”

Ideas about independent living are not well-established in Guyana.

There is a public housing program, and three commercial banks provide mortgage lending services. Although these services are technically available to persons with disabilities, they must meet the same requirements as persons without disabilities. Additionally, the government provides some land for construction of housing. According to the National Development Strategy of Guyana, (Chapter 26), “Criteria for the allocation of housing lots will be revised to accommodate the poor ... and people with disabilities.”

A member of the disability community reported that efforts have been made to encourage the government to implement a quota system in its housing programme or set aside plots of land exclusively for persons with disabilities. Even so changes have not been made to the current program. Applications for land submitted by persons with disabilities are managed on an ad hoc basis. An assessment is made of the person's physical and mental disability in order to determine their suitability and where they may be placed. Some lots have very rugged terrain and might be difficult for a person with physical disability to access.¹² Once a lot is obtained, construction on the land must be individually financed by the person with disability. Therefore, obtaining a housing lot is just the first of several obstacles that are encountered by persons with disabilities.

Institutionalization

There is one long-term residential institution, the Shesta Home, located outside of the capitol city. Currently, eleven males and nine females live in this long-term institution. The Ptolemy Reid Center provides short-term rehabilitation services to children and offers long-term care for some residents until adulthood. At present, the center has 25 residents and provides classes and outpatient treatment to an additional 45 persons, mostly children. Most persons are placed in these institutions because they have been abandoned.

The Ministry of Health monitors the conditions of such institutions, as well as any incidence of death and abuse. Although there is no law prohibiting institutional abuse, there is no indication of such resident abuse.

Accessibility

The importance of constructing an accessible environment has been discussed in several public documents. The National Development Strategy of Guyana states that, "all buildings for public use will be immediately required (in the case of publicly owned buildings) or strongly urged (in the case of privately owned buildings) to provide affordable accessibility to people with disabilities, e.g. ramps." According to the National Policy on the Rights of Persons with Disabilities, the state should "develop standards and guidelines and enact legislation providing for accessibility to be required in new facilities such as buildings, parks, pavements, buses, and be gradually introduced into existing facilities." Based on the economic investment required to provide an accessible environment, the policy suggests that the government should actively foster collaboration among all sectors to design, implement and monitor a ten year program for establishing such accessibility.

¹² Interview with a senior Housing official.

The recently drafted Guyana Building Code prepared by the Bureau of Standards stipulates that all public buildings must meet accessibility requirements including easy internal circulation and expeditious evacuation by persons in wheelchairs. Such requirements are relevant to "all...areas used by the general public, employees, persons visiting or on the premises for any reason, and shall apply to all occupancy except R-3 Houses, and occupancy T-temporary."

The Building Code sets standards for a variety of architectural elements, including recommended widths of passageways, the need for accessible toilets, and the maximum gradient for ramps. The maximum height for light switches, fire alarms, and public telephones is set at 1.25m above floor level. In addition, buildings and facilities must make at least one primary ground floor entrance accessible from a parking lot or the nearest walking path that is uninterrupted by steps. Parking lots should provide reserved parking spaces for persons with disabilities that are visibly identified and close to entrances.

However, Section 2 of the code provides that, "where it can be demonstrated that one or more of the following provisions is not applicable to the proposed use and occupancy, modification may be sought and a dispensation obtained from the building authority." Thus, the standards may not be universally applied. Furthermore, the building code is not enforceable because there is no legislation to make it binding.

Although it is difficult to determine the percentage of public buildings that are accessible because there are no data available, the figure is likely to be below five percent. In some cases where a service is provided on an upper floor or in an inaccessible building, special arrangements are made to accommodate the persons with mobility disabilities on the ground floor or in a suitable environment. There are no specific courses in accessibility engineering available to engineering students. However, lectures on building design and environment in the regular courses do mention the need to design structures that are accessible to persons with disabilities, the elderly, and pregnant women.¹³

Transportation for persons with disabilities depends on the resources available to them and their capacity to make individual arrangements. If an individual must rely on public transportation, the situation can become very expensive and burdensome. The public mini buses, which are an economical mode of transportation, are not wheelchair accessible. If an individual requires public transportation and cannot access the bus, he or she must use a taxi service. Taxis are not only more expensive, but also entail the disassembly of the wheelchair for storage, and sometimes the need for physical assistance from others.

¹³. Interview with a senior lecturer at the University of Guyana's Faculty of Technology, Building Design and Architecture.

Culture, Sports, and Recreation

It is the responsibility of the Ministry of Sports to manage the planning and support of sports activities for the disability community. The government has cooperated with several disability organizations by hosting workshops and training courses to encourage physical education teachers and various sports coaches to include persons with disabilities in their teams and programs. With ministry assistance, some persons with disabilities, especially children and youths, are able to participate in the Special Olympics. Dominoes games and athletic competitions are also organized for persons with physical disabilities.

Disability Action & Awareness

The National Policy on Rights of People with Disabilities was drafted through a consultative process that consisted of a series of workshops conducted between November 1994 and July 1996. The workshops were organized by a Steering Committee coordinated by the Director of the Ptolemy Reid Centre. Representatives from the national government, the Guyana Trades Union Congress, employers, and disability organizations participated.

Among the policy's objectives are "the development of a sense of self worth among persons with disabilities which will enable them to demand their rights as equal citizens", the integration of people with disabilities into "the economic, social, cultural and recreational life of their communities," and disability prevention. The policy recommends the creation of new legislation to prevent discrimination and promote the equalization of opportunities for persons with disabilities.

The Policy also provided for the establishment of a National Commission on Disability. The Commission is comprised of a Chairman and 13 Commissioners. Commissioners are drawn from disability organizations, the government, the private sector, trade unions, and the media. They are appointed by the President of Guyana or his chosen representative, who has been the Minister of Health for the last four years. Commissioners serve a two year term and may be reappointed. Two of the current commissioners are people with disabilities. At present the Commission's sole funding is from the Ministry of Health, but efforts are underway to procure funding from other agencies and Ministries, as well as internal and external donors.¹⁴

The National Commission should be the focal point for disability policy and planning at the national level. The Commission's primary functions are to develop and implement programs to ensure the equalization of opportunities within the framework of the National Policy; advise the government on all issues relating to people with disabilities; and monitor the implementation of the policy.

¹⁴. Mike McCormic.

It does not, however, have the means to enforce or protect the rights of people with disabilities. It collaborates with the 22 existing disability organisations in Guyana as well as the Ministries of Health, Education, and Labour, Human Services and Social Security, which should lead in the promotion of the rights of persons with disabilities. It also networks with international disability organizations, the private sector, and the Labour Movement. At present the Commission is developing a national database of persons with disabilities in Guyana. It is also crafting a five-year action plan for its work.

With regard to disability organizations, resources are limited and advocates report the need for increased collaboration. Currently, most organizations compete for members and power within the community. Moreover, most organizations are led by people without disabilities. Advocates suggest that organizations of and for people with disabilities, while not necessarily forming an umbrella body, need to find common ground in order to become more effective. Although the community of disabled people is numerous, the demand to satisfy it is weak because of its failure to unite or adequately articulate its demands.

Strategies for improving the protection of rights of people with disabilities should include raising awareness, the creation of legal protections, and targeted lawsuits to ensure the implementation of any legislation that is passed.¹⁵ Advocates also feel that increased media involvement is a strategy that could also be effective. Overall media coverage of people with disabilities is lacking although there is one radio program hosted by a person with a disability. In addition, driver awareness campaigns have incorporated people with disabilities. Finally, Guyana has recently approved the creation of a Human Rights Commission, which should act as an important resource for disability advocates once it becomes functional.¹⁶

¹⁵. Guyana Human Rights Association.

¹⁶. Panel discussion with leaders of disability organizations.

Honduras

Key Factors: Honduras is the third poorest country in the region and one of the least developed in the world, ranking 116th out of 173 countries in the 2002 UN Human Development Index. People with disabilities constitute one of the most disadvantaged sectors of Honduran society. Government officials are often unaware of disability issues, but there is a clear interest in human rights on the part of some government officials and NGO leaders.



Terminology

There is general agreement in Honduras regarding the most appropriate disability related terminology. “Personas con discapacidad”, translated as “person with disabilities” is the term of choice because it focuses on the person and does not define him or her through disability. Other terms are occasionally used but generally considered inadequate. These include terms like “discapacitado”, translated as “disabled” “lisiado”, translated as “crippled” “limitado”, translated as “limited”; “minusválido”, translated as “handicapped”; or “personas con necesidades o retos especiales” translated as “person with special needs or specially challenged” When quoting official documents within this report, the original terms have been preserved and translated as noted here.

Definition of Disability

The recent document entitled the “Social Policies for Disability Prevention, Comprehensive Care and Rehabilitation of Disabilities, and the Promotion and Protection of the Rights and Duties of People with Disabilities” conforms to the accepted terminology. The policies, which are still pending approval, define a person with a disability as “any person suffering or that will suffer for more than 6 months from a physical or mental health condition that restricts their activities.”²

¹ United Nations Development Programme, *Human Development Report 2002: Deepening democracy in a fragmented world*, (Oxford University Press, New York 2002).

² Ministry of Health, “Social Policies For Disability Prevention, Comprehensive Care And Rehabilitation Of Disabilities, And The Promotion And Protection Of The Rights And Duties Of People With Disabilities,” 4 May 2004.

This definition acknowledges that while a particular impairment may be an individual problem, disabilities and disadvantages are social problems. Once approved, this definition will be officially used by all areas of the government.

The definition provided by an earlier disability law is currently still in use. That law, which is currently under review, stated that: “a handicapped person is a human being who, due to congenital or acquired causes, suffers from a reduction in his or her mental or physical abilities, which affects his or her potential for self-sufficiency, learning or working to become an active member of society.”³

Disability Population

The last Multi-Purpose Household Survey, conducted by the National Statistics Institute (INE) in September 2002, included a disability module that collected important information, such as the number of people with disabilities and their employment condition. According to the household survey, the total population of Honduras is estimated to be 6,697,916 people. Of that, approximately 2.6 percent of the population, or 177,516 individuals, are people with disabilities. This number includes 97,867 men and 79,649 women.⁴

Disability organizations do not rely on this survey, due to concerns over the definition of disability adopted by the INE. They prefer to use the World Health Organization (WHO) or Pan American Health Organization (PAHO) estimates, both of which are based on a much wider definition of disability. The WHO estimates that people with disabilities average 10% of the population, while PAHO puts that number at 14% for Honduras.⁵ Based upon these figures, there would be approximately 600,000 people with disabilities in Honduras.

Legislation & Disability Rights

The Honduran government has not yet issued any statement in support of the creation of a United Nations Convention for the protection of the rights of people with disabilities, and it has not signed the Inter-American Convention on the Elimination of All forms of Discrimination Against People with Disabilities.⁶ Honduras did ratify the ILO Discrimination (Employment and Occupation) Convention 111 on 20 June 1960 with Decree 209.⁷ It has not, however, ratified ILO Convention 159 on Vocational Rehabilitation and Employment (Disabled Persons).

³ Congressional Decree 184-87, (22 December 1987).

⁴ National Statistics Institute, *Encuesta de Hogares* [Household Survey], September 2002. The sample included 21,935 households.

⁵ World Health Organization, “International Day of Disabled Persons: 3 December 2002”, (Press release, 3 December 2002), <http://www.who.int/mediacentre/notes/np9/en/>; http://www.ops.org.ni/opsnil/tematicas/rehabilita/resumen_americas.htm#cifras_discapacidad.

⁶ Oscar Salomon Núñez (General Director of Special Matters, Ministry of Foreign Affairs), interviewed by author, 21 October, 2003.

⁷ *Comisionado de los derechos Humanos de Honduras*, [Honduras Human Rights Commission] *Informe sobre los derechos de las personas con discapacidad en Honduras* [Report on the rights of people with disabilities in Honduras], October 2003. Information about ratification also available at <http://www.ilo.org/ilolex/english/convdisp1.htm>.

In Honduras, the needs of vulnerable groups have traditionally been addressed through a charitable approach rather than a human rights approach. Thus, the disability rights framework is not yet well-established in Honduran law. There is no central agency to deal with reports on human rights violations against people with disabilities.

Honduras has several national laws that specifically protect or benefit people with disabilities. Legislation includes:

Military Junta's Decree 962, dated 7 May 1980, which created the National Council on Comprehensive Rehabilitation to coordinate and supervise disability services.

Legislative Decree 86-45, dated 11 April 1984, which proclaimed the last Friday of April as the "Day of Solidarity Toward the Handicapped", to be observed every year.

Legislative Decree 184-87, also known as the "Training and Rehabilitation of the Handicapped Person Act", dated 22 December 1987, which guaranteed equal rights for people with disabilities and mandated the provision of comprehensive rehabilitation services for the social integration of people with disabilities.

Legislative Decree 17-91, also known as the "Promotion of Employment for People with Disabilities Act", dated 26 February 1991, which encouraged the integration of people with disabilities into the open labor market or other appropriate occupational alternatives.

Agreement 1662-EP91 between the President of the Republic and the Ministry of Public Education, dated June 1991, which established the Policies on Special Education of the Ministry of Public Education.

Executive Agreement STSS-116-01, dated 30 May 2001, which approved the Safety and Occupational Health Regulations for underwater fishing, aimed at preventing disabilities by establishing minimum health and safety requirements.

Members of the disability community note that compliance with these laws is often low. For example, despite its legal creation, the National Council on Comprehensive Rehabilitation was never an actively working entity. There are no penalties for noncompliance, and few people are aware of the full extent of the existing laws.

Inclusion

Communication

There are extensive limitations to communication for people with disabilities in Honduras. The Constitution of the Republic is not available in Braille, and no arrangements have been made by the responsible government agencies to obtain a Braille printer.⁸

The National Library offers no information access facilities for people with visual disabilities, nor does it offer new technologies.⁹

Of the more than 12 television channels broadcasting in Honduras, there is only one television channel that broadcasts the news with captions for hearing-impaired viewers.¹⁰

Sign language interpreters are scarce in Honduras. Over the past year, the National Association of the Deaf has been developing a Honduran Sign Language dictionary.

No strategies are in place to help people with speech or hearing impairments to communicate with the authorities in case of natural disasters, civil emergencies, or crimes.¹¹

⁸ Armando Sanchez Padilla (General Coordinator of the National Federation of Organizations of People with Disabilities), interviewed by author, 21 October 2003.

⁹ National Library, interviewed by author, 9 July 2003.

¹⁰ Channel 48, the Catholic television channel, broadcasts many of its programs captioned for people who are deaf.

¹¹ Orguidea Centeno (Executive Director, National Association of the Deaf), interviewed by author, 20 October 2003.

Education

Broadly speaking, children with mild to moderate intellectual disabilities are integrated into the mainstream educational system. Youth with severe disabilities are trained separately in private or semi-private specialized centers and work at sheltered or occupational workshops run by those centers.¹² Table one provides a summary of how many students with disabilities are being taught in each type of educational setting.

Table 1: School Attendance¹³

Educational setting	Number of students with disabilities	Percentage of total
Public sector (regular classroom)	10,442	84%
Public sector (support classroom)	466	4%
Private sector	760	6%
Special education center	449	4%
Distance learning	77	1%
Informal education	54	0%
Other	97	1%
Don't know	77	1%
Total	12,421	100%

As with the full population of people with disabilities, there is no valid data available on the number of children with disabilities. However, based upon the low number of students with disabilities identified in table one, there are most likely a large number of children excluded from the educational system. There are 17 Special Education Centers, mostly located in Tegucigalpa, the capital city, and San Pedro Sula, the second most important city in the country. Most centers were established by NGOs and private initiatives. Of the centers in San Pedro Sula, two are run by the Honduran Institute for Children (IHNFA), and one is run by the San Pedro Sula municipality.¹⁴

Most of these centers work with pre-school and elementary-school children, and aim to integrate these children into the mainstream educational system. The centers also sometimes provide vocational training for adolescents who have been unable to integrate into the regular system.¹⁵

¹² Yolanda de Coello (Executive Director, FUHRIL), interviewed by author, 20 October 2003.

¹³ INE, *26th Survey of the National Statistics Institute*, September 2003.

¹⁴ Yolanda de Coello. Information was also obtained from Handicap Honduras.

¹⁵ Marien de Romero (Executive Director, Juana Leclerc Psychopedagogical Institute), interviewed by author, 15 October 2003.

The Teletón Foundation runs a school integration program aimed at including children from their rehabilitation centers into the public education system. The National Autonomous University of Honduras (UNAH) has developed a support program which benefits about 100 students with disabilities annually.¹⁶ In Honduras, the national teachers training curriculum includes one course on special education.¹⁷ The National Pedagogical University also offers a five-year course on special education.¹⁸

Employment

The 2002 INE Household survey collected employment data for people with disabilities. Unemployment is higher among people with disabilities than it is for the general population. According to the survey, 68% of people with disabilities of working age are not in the active labor force compared to 49% of the total population of Honduras. Table two provides a summary of the employment status of those people with disabilities who are in the active labor force.

Table 2 Employment statistics for people with disabilities¹⁹

Employed	49,150
Gainfully employed	13,206
Self-employed	30,077
Unemployed	1,155
Active labor force	50,304
Open Unemployment rate	2.3%
Underemployment rate	5.0%
Visible underemployment rate	31.8%

Among those people with disabilities who are employed, 73% are either self-employed or working for no pay. Among the general population, this number is 51%. Moreover, self-employment is the only type of employment for which the overall percentage of people with disabilities in the sector is roughly the same as the larger population. In general, even among those people with disabilities who have managed to find work, underemployment remains a problem.

In 1987, the Training and Rehabilitation of People with Disabilities Act was passed by the legislature. Implementation of its provisions became the responsibility of the Institute for the Habilitation and Rehabilitation of People with Disabilities. However, this institute was closed for budgetary reasons, and so the goals contained in the legislation remain largely unfulfilled.

¹⁶ Nery Madrid (Director of the SED Program, UNAH); Rina Lobo (former Director of Teletón Foundation), interviewed by author, 4 November 2003.

¹⁷ Carlos Avila (Minister of Education, Ministry of Public Education, interviewed by author, 9 July 2003.

¹⁸ Carlos Avila (Minister of Education).

¹⁹ *Encuesta de Hogares*. "Underemployment" refers to those people working 36 hours or more a week who are not earning a basic minimum wage. "Visible underemployment" refers to those who are employed but who are working less than full time. "Open unemployment" refers to those people seeking employment who are not employed.

Section 2 of the Promotion of Employment for People with Disabilities Act, obligates Public Administration Agencies and private businesses to hire a certain number of people with disabilities. Under the current Administration a greater number of people with disabilities have been hired at all levels, including high-ranking positions. Examples are Vice-Minister of the Presidency, President of the UNAH, Legal Counsel for the Ministry of Finance, Coordinator of the SED program for the UNAH, and General Employment Director in the Ministry of Labor.²⁰

Health

The Ministry of Health provides funding of approximately two million lempiras (US\$12,000) to at least four health care organizations working for people with disabilities. Additionally, the government currently provides funding of approximately 12 million lempiras (US\$676,000) to the disability sector, through the Ministry of Governance and Justice.²¹ The funds are used for a variety of projects including personnel and infrastructure as well as orthopedic appliances and comprehensive rehabilitation programs.

Rehabilitation centers are located in major cities and strategic regional locations. These include Danli, Comayagua, Ceiba, Choluteca, San Pedro Sula, Copan, Santa Bárbara, La Esperanza, Olanchito, Catacamas, and Juticalapa.²² Area hospitals and the country's two general hospitals also provide medical rehabilitation services.

People with disabilities can obtain auxiliary materials such as technical aids from the Physical Medicine and Rehabilitation Department of the San Felipe Hospital, a publicly funded hospital. There are also private institutions, such as Teleton and FUHRIL, where people with disabilities can obtain technical aids.

There is no training on the provision of care to people with disabilities available for physicians, either before or after they acquire a medical degree in Honduras. However, some opportunities to study abroad do exist. Training in Functional Therapy is offered as well as training for auxiliary nurses in the field of Physical Therapy.²³

²⁰. Armando Sanchez Padilla.

²¹. Dr. Maria del Carmen Sevilla (Chief of the comprehensive care of persons with disabilities, Ministry of Health), interviewed by author, 10 July 2003; Miguel Calix (Assistant of the Vice Minister of Governance and Justice, Ministry of Governance and Justice), interviewed by author, 21 October 2003.

²². Research data provided by FUHRIL and Handicap Honduras.

²³. Nery Madrid.

Housing

There is no state-run housing project for people with disabilities, nor are there any credits or aid for them to purchase a house.²⁴

A housing project called "Ciudad España" was implemented after Hurricane Mitch tore through Honduras. At first, this project targeted flood victims. Later, efforts were made by the National Union of Honduran Blind Persons, the Honduras Association of Physically Impaired People, and the Christian Fraternity of People with Disabilities to secure a portion of the housing units (200 units), which could then be granted to people with disabilities. This project is sponsored and conducted by the Honduran Red Cross and the Spanish Red Cross.²⁵

Independent living centers are reported to be operating in Santa Bárbara and Danli, supported by FUHRIL.²⁶

Institutionalization

There are several institutions in Honduras that provide housing and long-term care for people with disabilities. They include Pilar Salinas School for the Blind, Home for the Handicapped, Bencalet Home, SOS Villages, and Casa de Ángeles. Most people in these types of homes or shelters have been abandoned by their families or are orphaned.²⁷ There is no mechanism to report the incidence of death or abuse in those institutions.

Accessibility

In addition to economic hardship, movement and transportation problems are among the most significant challenges experienced by people with disabilities. Most public buildings and transportation remain inaccessible even in urban areas.

To date there are no regulations on accessibility. The National Federation of Organizations of People with Disabilities (FENOPDIH), the National Association of the Deaf (ANSH), the Honduras Association of Physically Impaired People (ALFH), the National Association of the Disabled (ANADISH), and the Honduran Foundation for the Rehabilitation and Integration of the Handicapped (FUHRIL) are working together on a proposal for national regulations that would require all public buildings and facilities to be made accessible for people with disabilities.²⁸

²⁴. Fausto Ramirez Garcia (Executive Director, Social Housing Fund), interviewed by author, 5 November 2003.

²⁵. Armando Sanchez Padilla. The person in charge of this project is Meneka Mencia.

²⁶. Yolanda de Coello.

²⁷. Armando Sanchez Padilla; Yolanda de Coello.

²⁸. Manual de Accesibilidad elaborado por el Grupo solidario para la Accesibilidad en Honduras. The manual was compiled from accessibility publications of other countries.

Currently, most public buildings are not accessible to people with mobility disabilities. The central post office in the capital city is not accessible since there are stairs at the main entrance. The buildings of the Ministry of Education, the Ministry of Finance, and the Ministry of Health are also not accessible.

Infrastructure, in general, is far from optimal. For people with disabilities it can be difficult to simply use the streets without the risk of accidents. There is no proper signaling at intersections, there are open sewers and potholes in roads and sidewalks; there are no handrails on walls; there are no ramps or elevators; and there are no public toilets that are accessible for people with mobility disabilities.²⁹

Public transportation is not accessible for people with physical disabilities, hindering their freedom of movement. Public buses are not adapted to people with mobility disabilities. Very few people with disabilities can afford an adapted vehicle of their own. Thus, it is almost impossible for people with mobility disabilities to participate in social events, access education, or travel to a workplace.³⁰

Disability Action & Awareness

The agency that was previously in charge of planning disability policy was the Institute for the Habilitation and Rehabilitation of People with Disabilities, which has been closed. Thus, there is currently no national disability action plan. The planning role has been taken up temporarily by the Ministry of Health which developed the Social Policies. These policies were jointly designed by representatives of government agencies and private disability organizations.³¹ The Social Policies will be the starting point for a future national plan. The plan will be prepared with all the parties involved in the earlier discussions, especially people with disabilities.³²

In addition, government agencies and organizations from civil society are working together to draft a revised Disability Law. Two workshops will be held to collect feedback from the disability community regarding the proposed reforms. The draft is expected to be completed in 2004 and will be sent to Congress after approval by representatives from the disability sector. Among those disability organizations that are participating in the process are FENOPDIH, the Coordinator of Rehabilitation Institutions and Associations (CIARH), FUHRIL, and Handicap Honduras.

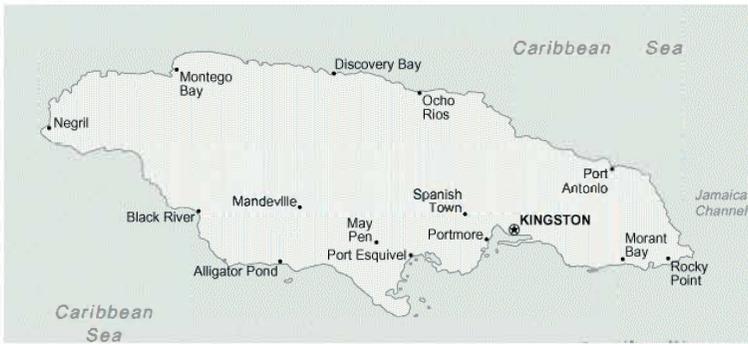
²⁹. Maricela Turcios (Cordinator of the Accessibility Commission of the Tegucigalpa City Hall), interviewed by author, 12 January 2004.

³⁰. Panel discussion with leaders of disability organizations, 9 September 2003.

³¹. Dr. Maria Del Carmen Sevilla (Chief, Department of Attention for Persons with Disabilities of the Ministry of Health), interviewed by author, 10 July 2003.

³². Armando Sanchez Padilla.

In July 2001, in an unprecedented effort, various organizations of persons with disabilities nationwide joined the efforts of the National Association of the Disabled of Honduras to create the National Federation of Organizations of Persons with Disabilities of Honduras. Like the National Association of the Disabled of Honduras, which is made up of individuals with a variety of different disabilities, the National Federation is a cross-disability organization. Its main objective is to advocate for social recognition of people with disabilities and to influence the political and social policies that affect them. The group participates in high-level meetings and takes part in decision-making processes.



Jamaica

Key Factors: Government involvement in disability issues has led to considerable improvements in the conditions for people with disabilities. Improved access to special education and training, housing, transportation, and some parts of the built environment has resulted in greater participation and inclusion for persons with disabilities. These advances, however, are concentrated in urban areas. Moreover, the national policy on disability is not enforceable, so there is no obligation to continue implementing change.

Terminology

In the Constitution, the terms “insane” and “of unsound mind” are used to refer to some people with mental disabilities. When directly quoting this document, the original terminology is retained.

Definition of Disability

Various definitions of disability are used in Jamaica depending on the policy or purpose for which disability is being defined. The National Policy for Persons with Disabilities and the Population Census of Jamaica use the same definition. In both these documents a disability is defined as “any restriction or lack of ability to perform an activity in the manner or the range considered normal for a human being. Such restriction or lack of ability must be as a result of an impairment.”¹

Another definition is used in the National Survey of Living Conditions. Here, disability is defined as when “an individual whose prospects of securing and retaining suitable employment are substantially reduced by physical and/or mental impairment.”² This definition focuses more on a person’s ability to work than his or her medical condition.

¹ Statistical Institute of Jamaica, *Population Census 2001*, Jamaica 1, 2001; Ministry of Labour and Social Security, *National Policy on Disability for Persons with Disabilities*, 1999.

² Statistical Institute of Jamaica, *Jamaica Survey of Living Conditions*, (The Planning Institute of Jamaica), 2001e

Disability Population

Identifying the total population of people with a disability is a major point of interest for people with disabilities and policy-makers alike. The 2001 Census of Population of Jamaica recorded a total population of 2,607,633. The census taken in 1991 recorded a population of 2,380,667. Each of the last two censuses attempted to identify the number of people with disabilities. In 2001, the census recorded 162,860 persons with disabilities, comprising 6.2% of the population. In comparison, the 1991 census recorded a total of 111,114 persons with disabilities, comprising 4.7% of the population.³ Table one illustrates the composition of the disability population in Jamaica.

Table 1: Population Totals in 1991 and 2001

	Total Population 1991	Population with Disabilities 1991	% of total	Total Population 2001	Population with Disabilities 2001	% of total
Total	2,380,667	111,114	4.7%	2,607,633	162,860	6.2%
Males	1,167,496	50,966	4.4%	1,283,547	80,004	6.2%
Females	1,213,171	60,148	5.0%	1,324,085	82,856	6.3%

Policy-makers and disability advocates both reported that the census figures understate the actual population figures for people with disabilities. Instead, they tend to use the World Health Organization's estimate that an average of 10% of the world's population is comprised of people with disabilities.

Another source which identifies the population with disabilities is the annual Survey of Living Conditions. The survey is conducted jointly by the Statistical Institute of Jamaica and the Planning Institute of Jamaica. Questions about disabilities are included in the health module, which has been included in two of the surveys conducted since 2000. The module aims to determine if individuals have either physical and/or mental disabilities and how long they have had those disabilities. The results have never been published because the number of persons identified in the sample is too small to allow for meaningful analysis.⁴

The registrations of various agencies for persons with disabilities indicate that the percentage of people with disabilities has not changed significantly over the past five years. However, as shown in table one, there has been a steady increase in the numbers of people with disabilities. This gradual increase is likely due to better reporting and public awareness. Also there have been noticeable changes in the nature of some disabilities. For instance, in the case of the

³ Statistical Institute of Jamaica, *Population Census 2001*.

⁴ Kristen Fox, interviewed by author, August 2003; Huber Serrard, interviewed by author, September 2003.

Jamaica Association for the Deaf in the 1960s and 1970s, there were more persons with severe to profound hearing disabilities whereas today more persons have mild to moderate hearing disabilities.⁵

Legislation & Disability Rights

Legal Protections

Jamaica has signed and ratified several international human rights agreements including, the Convention on the Rights of the Child (1989), the International Covenant on Civil and Political Rights (1966), the Universal Declaration on Human Rights (1948), and the International Covenant on Economic, Social and Cultural Rights (1966). Jamaica is also signatory to the 'Bill of Electoral Rights for People with Disabilities,' a project of the International Foundation for Election Systems (IFES).⁶

Jamaica supports the creation of a Convention for the Protection of the Rights of Persons with Disabilities. Jamaica voted in favor of such a convention when it was initially proposed by Mexico in 2001. It also participated actively in the United Nations Ad Hoc committee meetings in 2001 and 2002.⁷

National policy regarding people with disabilities is composed of the Constitution, the National Policy on Disability, and various specific legal provisions. The Jamaican Constitution guarantees certain basic rights for all persons in society, although it does not specifically mention people with disabilities. In 1999, Parliament convened a committee to make recommendations on the amendment of the Jamaican Constitution. Senator Floyd Morris, who is visually impaired, advocated for the inclusion of constitutional protections for people with disabilities. The committee did not, however, include disability rights among its recommendations for the Charter of Rights.⁸

The National Policy on Disability in Jamaica was passed by Parliament in November 1999. It was crafted based on the requirements of the U.N. Standard Rules. This policy provides guidelines for cooperation between government and civil society in addressing the equalization of opportunities for persons with disabilities. The National Policy on Disabilities, however, is not enforceable as it lacks legal sanctions.

Much work has been done to try to pass additional legal rights for people with disabilities. At present the government is in the process of developing a National Disability Act, which was initially scheduled for completion during the 2003 legislative year. A statement by the Prime Minister recently endorsed the National Disability Act.

⁵ Thelma Tweedle Hearing and Assessment Clinic, Jamaica Association for the Deaf; Ministry of Health, *Jamaica Annual Report 2001*.

⁶ *Bill of Electoral Rights for Citizens with Disabilities*, (Sigtuna, Sweden, 16 September 2002), http://www.electionaccess.org/rs/Bill_English.htm.

⁷ Faith Innerarity, interviewed by author, 2001e

⁸ *Report of the Joint Select Committee on its Deliberations on the Bill Entitled "An Act to Amend the Constitution of Jamaica to Provide for a Charter of Rights and for Connected Matters*.

In addition to the National Policy for Persons with Disabilities, there are several laws that protect people with disabilities. For example, persons with disabilities are recognized and protected under the social protection system. In 1992, income tax concessions were introduced for persons with disabilities. However few people are able to benefit due to the fact that many are not employed or fall below the income tax threshold. Additional provisions include education policies, health policies, and reduced bus fares.

There are no restrictions to immigration, however, some persons with disabilities might not be eligible for asylum in Jamaica. Asylum is granted based on the UN guidelines, however, careful consideration is given to accepting persons who are not able to work. There are no restrictions against the adoption of children by persons with disabilities.

In cases of violations of their rights, the primary mechanisms for recourse for persons with disabilities are civil lawsuits, criminal prosecutions, and intervention from an independent human rights organization.

Legal Barriers

Legal exclusions remain for some people with mental disabilities. The Constitution states that people who are “certified to be insane or otherwise adjudged to be of unsound mind” are declared “incapable of being registered as electors and disqualified from voting at an election and shall not be so registered or vote at an election.”⁹ The electoral section of the Constitution similarly restricts such persons from being “appointed as a Senator or elected as a member of the House of Representatives.”¹⁰

Section 15 of the Constitution specifies that a person who is “reasonably suspected to be of unsound mind,” may be deprived of personal liberty. While Section 20 allows for the provision of a court interpreter for those who do not understand English, it does not specify whether the assistance of an interpreter is required if the accused is a person with a speech or hearing impairment.

Civic Participation

Under the Constitution of Jamaica, all citizens have the right to vote. The law also provides for a voter who is blind to be assisted in casting his or her ballot, either by an acquaintance of his or her choosing or by the presiding officer at the polling station.

The Electoral Office is responsible for establishing polling stations. Although consideration is taken for the elderly and people with mobility limitations, there is no actual guarantee that access will be provided to all citizens.

⁹ Constitution, sec. 5, subsec. 3.

¹⁰ Constitution, sec. 40, subsec. 2.

According to the Public Information Officer at the Electoral Office, polling stations are established at ground level whenever possible, though no ramps are provided when there are stairs present. Polling workers are provided with information on assisting people who are blind or have other physical disabilities. However, alternative formats such as Braille and sign language are not provided should a voter require additional information.¹¹

Inclusion

Communication

The National Library has an audio-visual section that is updated regularly through donations and purchases. It is not specifically intended for persons with hearing or visual impairments persons, but special accommodations can be made upon request. None of the libraries had material in Braille nor do they provide an interpreter service for persons who are deaf or hearing impaired.

The government does not communicate its activities in alternative formats. However, sign language interpretation can be provided for major national events. One local television station—CVM TV—is developing a captioning system for its primary newscast. Television Jamaica (TVJ) used to provide some on-screen sign language interpretation however the service was discontinued as a result of lack of sponsorship.

Sign language interpreters are available in the courts for victims of abuse and other criminal acts. The Jamaica Association for the Deaf (JAD) provides the interpreters as part of their Social Services Program. With only one staff member coordinating services and assigning personnel to the courts, the extent of the program is limited. In conjunction with JAD, the court offers sign language training at the Justice Training Institute for staff members who are interested. The JAD also offers additional, independent courses in sign language interpretation and is looking at building partnerships with churches and other NGO's to offer training courses.¹²

Education

There are no data available from the Ministry of Education regarding the number of school aged children with disabilities. Based on British and American standards, the Ministry works from the assumption that approximately 25% of the population requires special education.¹³ There has been considerable development in the area of special education in the last 30 years. Special education was largely provided by private voluntary organizations until 1974.

¹¹ Neville Graham (Public Information Officer, Electoral Office of Jamaica), interviewed by author, October 2003.

¹² Iris Soutar (Executive Director, Jamaica Association for the Deaf), interviewed by author, August 2003.

¹³ Hickswell Douglas (Education Officer, Ministry of Education), interviewed by author, August 2003.

At that time, the government took responsibility for all on-going operating costs. Despite the lack of statistics on children with disabilities, the Ministry of Education, Youth, and Culture reports that since coming under the control of the government, more children with disabilities have gained access to school-based special education programs. Home and community-based education programs have also improved the education opportunities for children with disabilities. Nevertheless, opportunities are limited for children with mental disabilities. Some vocational training is available at the School of Hope and the Abilities Foundation.¹⁴

Currently 2,202 students are enrolled in government-owned or government-aided special schools and special education facilities. These programs employ 307 teachers. There are forty eight government-aided schools across the island. The School of Hope is the main provider of special education for children with disabilities, comprising twenty-nine facilities attached to regular schools. Only one school provides integrated education. In addition to government-supported schools, approximately 300 students with various learning and other disabilities are enrolled in privately run schools. According to a Ministry of Education, Youth and Culture report, "despite these initiatives and the increase in coverage and quality, the Special Education programme continues to suffer from the lack of sufficient numbers of trained teachers, inadequate facilities and equipment and irregularity in student attendance."¹⁵ There is a notable difference between both rural and urban personnel and facilities. New facilities are required to be furnished with accessible classrooms.

All teachers must complete training on "exceptionalities" during their certification. In addition, two teachers' training colleges offer special education programs for those who wish to specialize in the subject. Teachers are also provided in-service training for working with students with disabilities at their school of employment, and at the post-graduate level courses are offered through the University of the West Indies and Nova University offshore.¹⁶

Early detection and stimulation programs exist under the framework of the Early Stimulation Project, a unit of the Jamaica Council of Persons with Disabilities, which is an agency under the Ministry of Labour and Welfare. Programs are predominantly carried out through community-bases and are administered by several non-governmental organizations that receive funding from the Ministry of Labour and Welfare. In addition to the Early Stimulation Project there is the 3D Project, Rural Services for Children with Disabilities (RSCD), and the Clarendon Group for the Disabled.¹⁷ Table two shows the number of children with disabilities identified through the various intervention programs.

¹⁴. The Way Upward, Green Paper of the Ministry of Education, Youth, and Culture, 1999, <http://www.moec.gov.jm/policies/whitepaper.htm>.

¹⁵. *Ibid.*

¹⁶. Kickswell Douglas (Education Officer, Ministry of Education, Youth, and Culture), interviewed by author, 27 August 2003.

¹⁷. Pamphlets from the Early Stimulation Project, Jamaica Council of Persons with Disabilities, Ministry of Labour and Welfare.

Table 2: Number of Children With Disabilities Identified through Early intervention, 2001¹⁸

Agency	No. Of Offices	No. Of Children
Early Stimulation Project Kingston	1	155
3D Projects (4 parishes)	6	300
Clarendon Group for the Disabled	1	202
Private Organization Ltd (6 parishes)	No independent offices, services through health centres	650
McCam Centre Kingston	1	7
Total	9	1304

In order to provide widespread services, agencies cover different areas of the country. Previously, most services were centred in Kingston, resulting in a large number of rural children who were not being served. Programs offered by the agencies provide on-going training for rural health workers and in-home training for parents. The RSCD, Clarendon Group for the Disabled, and the 3D Project also have early detection programs implemented through clinics. All programs teach parents how to help with mobility training and their child's development. Parents are monitored closely to ensure proper care.¹⁹ Strong parent support groups have evolved through this process.

Teachers and parents may refer children to the Mico Teachers' College CARE Centre, the School of Hope, or the Jamaica Association for Children with Learning Disabilities (JAICLD) for testing. Some detection is also provided in grade school, though these tests are intended to evaluate education competency and disability detection is largely incidental.²⁰

Employment

The majority of people with disabilities in Jamaica are unable to find gainful employment. Factors that prohibit their inclusion in the workforce are discrimination, inaccessible workplaces, and the low levels of experience and training available to most people with disabilities. The government is the top employer of people with disabilities, however it fails to meet the National Policy on Disabilities' recommendation that a minimum of five percent of government jobs should be filled by people with disabilities.

¹⁸. Thorburn Samms-Vaughn, *Draft Situational Analysis*, 6th draft, Ministry of Health and UNICEF.

¹⁹. Sandra Long-White (Rural services for Children with Disabilities PVO Ltd.), interviewed by author, August 2003.

²⁰. The Way Upward.

Some vocational training and job placement programs are offered by the government through the Abilities Foundation, the JCPD, and various NGOs. The JCPD offers a placement service designed to help persons with disabilities find suitable jobs. According to the JCPD, "the training is effective, however the socio-economic conditions in Jamaica makes it difficult to obtain jobs for the disabled clientele, also the negative attitude of employers towards disability". Some employers accept applicants with disabilities reluctantly and will only offer temporary employment. The JCPD also provides grants to assist persons with disabilities in establishing and managing viable businesses.

Health Services

Health care for people with disabilities is funded by the Ministry of Health. Rehabilitation services are provided by the Ministry of Health at the Sir John Golding Rehabilitation Centre, which offers long-term rehabilitation services, and eleven public hospitals that provide acute care.²¹

Assistive devices are available at the Sir John Golding Rehabilitation Centre on a subsidized basis. These can also be obtained from NGO's such as Jamaica Society for the Blind, Jamaica Society for the Deaf, and Paradof, as well as commercial entities such as Rehab Plus.

Primary care physicians, nurses, physician assistants, and rural health workers have access to training programs that focus on the provisions of services to people with disabilities. The Ministry of Health was unable to provide information on the percentage of health professionals that have received training to provide services to people with disabilities.

Housing

The National Housing Trust (NHT), a government-funded agency, has a special benefit program to assist people with disabilities in purchasing or building homes. Mortgage loans are offered to people with disabilities at two percent below the market interest rate. A percentage of all houses built by the NHT are reserved for persons with disabilities. Eligibility is dependent on a person's ability to meet the required income criteria and finance the mortgage. Once a house is assigned to a person with a mobility disability, NHT adapts the home to accommodate him or her. The housing units available through this program are moderately priced, as the target market is a low/middle income consumer.

²¹. Nicholas Ford (Coordinator Physiotherapy Services, Kingston Public Hospital), telephone interview, October 2003.

Institutionalization

There are various institutions, which provide long and short-term care for people with disabilities. Persons with disabilities are typically admitted in situations of risk; when they are abandoned; or when their families are unable to care for them. Institutions for people with disabilities offer counselling and rehabilitation. Individuals have the right to refuse treatment. In cases when the individual is deemed unable to decide for his or herself, medical officers are responsible for deciding the length of stay and appropriate type of institution for the person's treatment. The legal framework for this process is stated in the Mental Health Act September 1999 Section 6.

The Jamaicans for Justice and the Independent Jamaican Council for Human Rights (IJCHR) monitor cases of abuse in institutions, including an investigation into the treatment of children with disabilities who live in institutions while awaiting adoption. That investigation was the result of the case of a child whose behaviour showed signs of being abused while institutionalized prior to adoption. The Jamaica Council for Persons with Disabilities also investigates reported cases of abuse. The Council does not keep records of past cases so no information was available for this report.

Additionally, the IJCHR actively monitors the treatment of people with mental disabilities who are incarcerated in prison without being convicted of a criminal offense. After being deemed unfit to plead to the charges against them, they cannot advocate for themselves and become lost in the prison system, sometimes for many years. One case publicized by the IJCHR included a man who, after having broken a window, was never tried but remained imprisoned for 29 years. Through the advocacy of the IJCHR some persons have been released and reunited with their families, while provisions were made to care for others through compensation from the State.²²

Accessibility

The National Building Code was amended to address access for persons with disabilities.²³ The amendment's guidelines are part of a policy rather than a law and, thus, are not enforceable. The revised building code is consulted for new building projects, but is rarely used to modify existing buildings. The Government of Jamaica Employees Occupational Safety and Health Policy and Guidelines 2002 addressed the issue of access to government buildings.²⁴ The guidelines discuss the provision and maintenance of ramps for the entry into the buildings but do not extend to the access of other facilities within the building.

²² Yvonne Barnett-Russell, "The Mentally Ill In Prison Project," *Human Rights Link* 6, no. 2, 2002.

²³ Standing Review Committee on the Building Code Ministry of Finance, *The National Building Code of Jamaica*, 2nd Edition, 1992

²⁴ *The Government of Jamaica Employees Occupational Safety and Health Policy and Guidelines*, 2002.

Leaders of disability organizations estimate that around ten percent of all public buildings are at least partially accessible to people with mobility disabilities. Some buildings that have entrance ramps lack interior design features to allow accessibility beyond the ground floor.²⁵ Although the main post office is accessible to persons who use wheelchairs, there are no curb cuts to gain entry to the sidewalk. In Kingston many post offices are fully accessible, but accessibility to post offices in other parts of the nation is limited. At this time, there are no courses in universal design available to architects in Jamaica.

The regular bus system in the capital city, Kingston, is not wheelchair accessible. However, four buses were designated by the Jamaica Urban Transit Company (JUTC) specifically for people with disabilities and the elderly. These buses run routes heavily travelled by its intended users and connect places such as hospitals, schools, the main shopping areas, and local residential communities. In October, two additional buses were added to the fleet. The JUTC acts in collaboration with the Jamaica Council for Persons with Disabilities and the Combined Disabilities Association to train the drivers and conductors who operate the service. The Montego Transit Company provides a similar service in Montego Bay. Reduced fares are offered to elderly and people with disabilities travelling on public transportation.

Culture, Sports, and Recreation

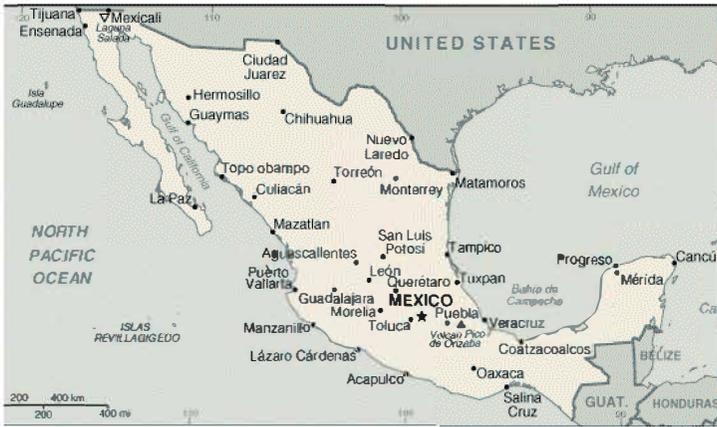
Some recreational facilities have been modified to provide access for persons with disabilities. For example, the National Stadium and some cinemas in the capital are accessible.

Disability Action & Awareness

The disability movement began in Jamaica in 1981 with the formation of the Combined Disabilities Association, a cross-disability organization. The Jamaica Society for the Blind advocated for representation on the Board of the Combined Disability Association, which was originally comprised of non-disabled persons. The main role of the association, both then and now, is to advocate for persons with disabilities. Many of the policy changes are a result of their lobbying efforts.

Despite these efforts, a lack of coordination between government and civil society remains. Moreover, there is continued need for more public education on the policies and programs directed towards inclusion and the protection of the rights of persons with disabilities. Information about disability rights is fragmented and, often, people with disabilities are unaware of the possibilities available for them.

²⁵ Informal survey conducted by researcher.



Mexico

Key Factors: The legal standing of disability rights in Mexico is contradictory. A Federal Act for Persons with Disabilities is currently under legislative consideration, and Mexico has been very active in United Nations attempts to create a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. However, much current legislation lacks regulations, and compliance is a problem. Moreover, awareness of disability rights is low among both people with and without disabilities.

Terminology

In discussions of disability, the preferred term in Mexico is “personas con discapacidad” (people with disabilities). The Persons with Disabilities Act of the State of Mexico uses the phrase, “personas con capacidades diferentes,” which directly translated means, “people with different abilities.” Mexico does not recognize mental or psychiatric disabilities, so other relevant terms include “deficiencia mental” and “desorden mental”, translated as “mental deficiency” and “mental disorder,” respectively. When quoting official documents within this report, original terminology has been retained.

Definition of Disability

Broadly speaking, the definitions of disability used in official and legislative documents refer to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the World Program of Action concerning Disabled Persons.¹

¹ “México (república)” [Mexico (Republic)], *Enciclopedia® Microsoft® Encarta 2001*; UN General Assembly, *Fourth Eight Session, Official Records, Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, 20 December 1993, <http://www.un.org/esa/socdev/enable/dissres0.htm>; UN General Assembly, *Resolution 37/52, World Program of Action concerning Disabled Persons*, 3 December 1982, <http://www.un.org/esa/socdev/enable/diswpa01.htm#Definition>.

Both the Program of Action for Disability Prevention and Rehabilitation (PreveR-Dis) and the Program for the Labor Integration of Persons with Disabilities make reference to the International Classification of Functioning, Disability and Health (ICF or ICIDH-2), which purports to change the traditional approach to disability by integrating medical and social models.² However, the ICF is currently undergoing a thorough review prior to implementation, so it has not yet impacted definitions of disability in Mexican law. The following are representative of the definitions written into official documents:

Disability. "Restriction or lack, resulting from a physical or mental impairment, of ability to perform an activity in the manner or within the range considered normal for a human being." (12th General Population and Housing Census)³

Disability. "Lack, restriction or loss of the ability to perform an activity in the manner or within the range considered normal for a human being." (Official Mexican Standard (NOM-173-SSA1-1998) for the Comprehensive Assistance of Persons with Disabilities.)⁴

Person with disabilities. "Any human being with a temporary or permanent restriction, loss or reduction of his/her physical, intellectual or sensory abilities to perform the activities that are inherent thereto." (Decree enacting the Federal Act for Persons with Disabilities)⁵

From a review of 13 official definitions, some patterns can be observed. Terms such as "suffers from" or "endures" recur frequently entailing the idea that people with disabilities are ill and restricted by life-long diseases. The word "normal" is used often, implying that any disability-related issue or activity is abnormal. This type of language can prevent disability from simply being considered a living condition.

² Secretary of Health in collaboration with the Presidential Office for the Advancement and Social Integration of Person with Disabilities, *Programa de Integración Laboral para Personas con Discapacidad* 2001e2006 [2001-2006 Program for the Labor Integration of Persons with Disabilities, Contents I Disability: Concept Approach], 2001, 7; Secretary of Health in collaboration with the Presidential Office for the Advancement and Social Integration of Persons with Disabilities, 2001e2006 *Programa de Acción para la Prevención y Rehabilitación de Discapacidades (PreveR-Dis)* [Program of Action for Disability Prevention and Rehabilitation (PreveR-Dis)], 2001, 13.

³ INEGI, *12th General Population and Housing Census*, "Tabulados de la Muestra Censal, Cuestionario Ampliado" [Tables of the Census Sample Extended Questionnaire], Glossary, 2000, 321e

⁴ Secretary of Health, Mexican Official Standard NOM-173-SSA1-1998, *Para la Atención Integral a Personas con Discapacidad, Definiciones* [For the Comprehensive Assistance of Persons with Disabilities, Definitions], 1998, 3.

⁵ *Decreto por el que se expide La Ley Federal para las Personas con Discapacidad* [Decree enacting the Federal Act for Persons with Disabilities], ch. 1, sec. 4, 2003.

The introduction of “People with Different Abilities” and “Different Abilities” in the Persons with Disabilities Act of the State of Mexico is worthy of special mention. The definition states that “People with Different Abilities are those persons suffering from a loss, impairment or reduction of an organ or physical, sensory or intellectual function, which restricts daily life activities and prevents their individual and social development.” In this context, “Different Abilities” means “a restriction an individual has to perform on his or her own the activities that are necessary for his or her physical, mental, social, occupational and economic development resulting from a loss, impairment or reduction of an organ or physical, sensory or intellectual function.”⁶ No explanation of this terminology change has been given. Some non-governmental organizations consider this change detrimental in its influence on media and government action.⁷

In conclusion, most definitions tend to closely follow internationally-established models. However, the current status of the ICF has meant that newer concepts of disability are not yet well known.

Disability Population

In Mexico, census data regarding disabilities can be traced back to 1900 when the issue was included for the first time. Collection of disability statistics continued until 1940, after which it was discontinued. The National Institute of Statistics, Geography and Information Technology (INEGI), a decentralized organization of the federal government, was founded in January 1983. The INEGI is in charge of producing national statistical data and has been involved with the renewed collection of disability statistics in Mexico.⁸

In February of 1997, the first Workshop of Census Users was held in preparation for the 2000 census. At this workshop, non-governmental organizations and agencies of the Federal Public Administration proposed that the INEGI include the disability issue in the census questionnaire, as recommended by the United Nations. Once the proposal was approved, an INEGI document, “The Presence of the Disability Issue in Statistical Information: Theoretical and Methodological Framework,” provided the basis for conducting research on the issue.⁹

⁶ *Código Administrativo* [Administrative Code], Book Eleven, Title 1, ch. 1, sec. 11.1, 13 December 2001.

⁷ Center for International Rehabilitation in coordination with Civil Association Libre Acceso, *The Rights of People with Disabilities in Mexico* (panel discussion with leaders of disability organizations, Mexico, F.D., 28 October 2003.)

⁸ INEGI, *12th General Population and Housing Census*, “Resultados Definitivos” [Final Results] (power point presentation, 2000), 29.

⁹ INEGI, *Presencia del Tema de Discapacidad en la Información Estadística, Marco Teórico-Metodológico* [Presence of the Disability Issue in Statistical Information, Theoretical and Methodological Framework], 2001, www.inegi.gob.mx.

The 12th General Housing and Population Census was conducted from 7-18 February 2000. Basic and extended versions of the questionnaire were used. The extended version was administered to a sample of 2.2 million households, while all others received the basic questionnaire.¹⁰ The basic version of the census found that a total population of 97,483,412 people in Mexico.¹¹ Of these, approximately 1.8 million, or 1.84%, have some kind of permanent or long-term disability. However, the disability item had substantial nonresponse. Approximately 2.2 million people did not answer the disability question, suggesting that persons with disabilities may have been undercounted due to methodological issues.¹² Tables One and Two present findings from the basic version of the census form.

Table 1: Distribution by disability status ¹³

DISABILITY STATUS			
Total Population	Without disabilities	With disabilities	Non-specified
97,483,412	93,463,833	1,795,300	2,224,279

Table 2: Distribution by type of disability¹⁴

Disability	Males	Females	Population	% of Disabilities
	943,717	851,583	1,795,300	
MOBILITY	418,690	395,177	813,867	45.33
HEARING	155,814	125,979	281,793	15.70
SPEECH	46,506	40,942	87,448	4.87
VISUAL	230,862	236,178	467,040	26.01
MENTAL	161,409	128,103	289,512	16.13
OTHER	7,450	5,617	13,067	0.73
NON-SPECIFIED	4,414	2,705	7,119	0.40

The sum of the different kinds of disabilities may be higher than the total number due to some individuals with multiple disabilities.

¹⁰ INEGI, *12th General Population and Housing Census*, "Cuadros con Datos Básicos, Cuadro 22 Distribución Porcentual de la Población por Entidad Federativa Según Condición de Discapacidad y Tipo de Discapacidad" [Basic Data Charts, Chart 22 Percentage Distribution by Federal Entity by Disability Status and Type], 2000, 105.

¹¹ INEGI, *Información Geográfica, Datos Generales* [Geographic Information, General Data], <http://mapserver.inegi.gob.mx/geografia/espanol/datosgeogra/basicos/estados/tabla-poblacion.cfm>.

¹² *Resultados Definitivos*.

¹³ INEGI, *12th General Population and Housing Census*, "Población Total por Entidad Federativa, Sexo y Grupos Quinquenales de Edad y su Distribución y Tipo de Discapacidad" [Total Population per Federal Entity, Sex and Five-Year Age Groups and their Distribution and Type of Disability], 2000.

¹⁴ Cuadros con Datos Básicos, Cuadro 22 Distribución Porcentual de la Población por Entidad Federativa Según Condición de Discapacidad y Tipo de Discapacidad.

In contrast, the extended version of the questionnaire reported a slightly higher number of people with disabilities. It estimated the rate of people with disabilities at 2.31% of the country's total population. The distribution among types of disabilities was similar to that found by the basic questionnaire with the exception of hearing and mental disabilities. In basic form responses, hearing disabilities were reported slightly less often than mental disabilities, while on the extended form they were reported slightly more often than mental disabilities. The extended form also included a question about causes of disability. Table Three shows that illness is reported to be the largest cause of disability in Mexico.

Table 3: Distribution of cause of disability by gender¹⁵

	Birth	Illness	Accident	Old Age	Other Cause	Non-Specified
Total	19.41%	31.59%	17.68%	22.66%	1.93%	6.73%
Males	20.02%	29.40%	23.29%	18.60%	1.96%	6.73%
Females	18.74%	33.99%	11.52%	27.11%	1.91%	6.73%

Although the census figures are the official national disability statistics, other sources of data on the number of persons with disabilities in Mexico suggest much higher counts. The 2001-2006 National Health Program estimates that there are about 267,000 new cases of disability each year. Table four displays the number and estimated causes for new disabilities.

Table 4: Estimate of New Disability Cases Each Year¹⁶

Serious Fractures	125,000
Congenital Malformations	67,000
Consequences of Stroke	43,000
Consequences of Cranio-Encephalic Trauma	20,000
Cases of Child Cerebral Palsy	12,000
Total	267,000

¹⁵. INEGI, *12th General Population and Housing Census*, "Tabulados de la Muestra Censal, Cuestionario Ampliado."

¹⁶. Secretary of Health, "En Dónde Estamos. La Salud y los Servicios de Salud en México" [Where are we? Health and Health-Care Services in Mexico], 2001-2006 National Health Program, 2001, 35.

The PreveR-Dis has developed disability projections based upon population trends in Mexico. Because disability tends to progressively increase in developing countries, the projections indicate that by 2050 Mexico's total population will be approximately 145 million people with a disability population of 22 million (15.17%).¹⁷ Lastly, some information is available from the Mexican Social Security Institute's (IMSS) 2000 National Health Survey (ENSA 2000).¹⁸

The official Mexican disability statistics released by the Census of 2000 are now starting to be used as a reference for the design of programs aimed at the disability community. However, civil society and some public institutions still find them highly unreliable, and many refer to the WHO estimate of a 10% rate of people with disabilities. Under these circumstances, there is a risk of underestimating the dimension of the disability problem and of creating action plans and allocating resources based on the interpretation of highly uncertain figures. Currently, attempts are underway to determine question wording that will allow for more accurate identification of people with disabilities in the next population census.

Legislation & Disability Rights

Legal Protections

Mexico became a Member State of the United Nations on 7 November 1945, and since that time it has, in general, voted in favor of treaties related to people with disabilities.¹⁹ The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities were formally adopted by Mexico in 1995 with the creation of the National Program for the Welfare and Development of People with Disabilities (CONVIVE).²⁰ Additionally, the Standard Rules have helped define the direction of disability policies and regulations in Mexico. For example, the state-level Persons with Disabilities Acts are based on these standards.

The Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities was ratified by Mexico on 6 December 2000, and the ratification document was deposited on 25 January 2001. The law ratifying the convention was officially published in Mexico on 12 March 2001. The Convention is currently in force.²¹ The Inter-American Convention contributed specific disability-related provisions to the Federal Act to Prevent and Eliminate Discrimination, which was recently implemented on 11 June 2003.²²

¹⁷ 2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades PreveR-Dis, 16.

¹⁸ IMSS, *La discapacidad en los derechohabientes del IMSS, Resultados de la Encuesta Nacional de Salud 2000* [Disability in persons entitled to the IMSS, Results of the 2000 National Health Survey], January 2003.

¹⁹ UN, *List of Member States of the United Nations*, <http://www.un.org/spanish/aboutun/unmember.htm>.

²⁰ Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

²¹ 2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades, 13.

²² *Ley Federal para Prevenir y Eliminar la Discriminación* [Federal Act to Prevent and Eliminate Discrimination], sec. 6-8, (new act passed on 11 August 2003).

Mexico has also signed ILO Convention 159 on the Vocational Rehabilitation and Employment of Disabled Persons. This convention was ratified by Mexico on 5 April 2001 and was officially published on 22 April 2002.²³

At the 56th session of the United Nations General Assembly, Mexico submitted a proposal aimed at developing a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities. The proposal was adopted through resolution 56/168.²⁴

An Expert Group Meeting on the United Nations Convention for Persons with Disabilities was held in the Mexico City, from 11-14 June 2002.²⁵ During the subsequent Ad Hoc Committee meeting, held in New York from 29 July to 9 August 2002, Mexico submitted a draft convention.²⁶ As a result, the report of the first session of the Ad Hoc Committee recommended convening a second session of the Committee in June, 2003.²⁷

With regard to national legislation, people with disabilities were not initially mentioned in the Political Constitution of the United Mexican States. In August 2001, Section 1 of the Constitution was amended to specifically include people with disabilities.²⁷ It should be noted that the word “disability” does not appear as such in this section, but that the phrase “different abilities” is used instead.

²³. Secretary of Foreign Affairs, *Ratificación de la Convención Interamericana para la Eliminación de Todas las Formas de Discriminación contra las Personas con Discapacidad* [Ratification of the Vocational Rehabilitation and Employment], (Disabled Persons) Convention (Convention 159), Treaties Signed by Mexico, Multilateral Treaties, <http://tratados.sre.gob.mx/BusquedaIndice.htm>.

²⁴. *UN General Assembly, Resolution on the Report of the Third Committee (A/56/583/Add.2). 56/168, Comprehensive and Integral International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities*, <http://www.un.org/esa/socdev/enable/disA56168s1e.htm>.

²⁵. Secretary of Foreign Affairs, Expert Group Meeting on the Comprehensive and Integral International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities, <http://www.sre.gob.mx/discapacidad/>.

²⁶. UN, Ad Hoc Committee on a Comprehensive and Integral Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/AC.265/WP.1, *Working Paper submitted by Mexico*, <http://www.un.org/esa/socdev/enable/rights/adhocmeetaac265w1s.htm>.

²⁷. UN, Ad Hoc Committee on a Comprehensive and Integral Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/57/357, *Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, <http://www.un.org/esa/socdev/enable/rights/adhoca57357s.htm>.

²⁸. Decree approving the amendment which adds paragraphs two and three to section 4, and paragraph six to section 18, and a last paragraph to the third item of section 115 of the Political Constitution of the United Mexican States, sec. 1, *Official Gazette of the Federation*, 14 August 2001, 2.

Section 1, paragraph 3, provides that: "Any discrimination by reason of ethnic or national origin, gender, ages, different abilities, social status, health conditions, religion, opinion, preferences, marital status or any other reason, which may constitute a violation against human dignity and be intended to curtail or impair people's rights and freedoms is hereby forbidden."²⁹

Recently, several state and federal laws have incorporated disability issues as have numerous codes, plans, agreements, programs, standards and guidelines. All are aimed at fostering respect for the rights of people with disabilities. As of this writing, however, Mexico does not yet have a specific federal law protecting people with disabilities. Such a law has been drafted and is currently awaiting the approval of the Senate. On 30 April 2003, the House of Representatives released an Opinion Approving the Draft Decree enacting the Federal Act for Persons with Disabilities.³⁰ As of January 2004, this bill had not yet been signed into law, but it is expected to become an important national tool for the advancement and protection of the rights of people with disabilities.

Until the passage of the bill, the only existing statutes specifically aimed at promoting and protecting the rights of people with disabilities are those of the 31 states and the Federal District. Most statutes include provisions regarding monitoring, penalties for violations, and appeal procedures. The penalties provided by these statutes are typically monetary in nature. The effective application of such penalties is still deemed limited, as more than 80% of such statutes have not yet been regulated. Regulations are needed to attain significant benefits for people with disabilities.³¹

There are a number of other federal laws that contain some provisions pertaining to people with disabilities. Table five summarizes those statutes. Lastly, the Federal Criminal Code and the Code of Criminal Procedures contain punishments for crimes committed against people with disabilities who have been declared "legally incapable." Further information about state provisions and national guidelines is available on the IDRM web site.

²⁹. *Constitución Política de los Estados Unidos Mexicanos* [Political Constitution of the United Mexican States], (last amended on 12 November 2002).

³⁰. House of Representatives, Committee on Vulnerable Groups Assistance, *Dictamen de la Comisión de Atención a Grupos Vulnerables, con proyecto de decreto por el que se expide la Ley Federal para las personas con Discapacidad* [Opinion of the Committee on Vulnerable Groups Assistance with draft decree enacting the Federal Act for Persons with Disabilities], 2003.

³¹. The Rights of People with Disabilities in Mexico.

Table 5: Mexico Federal Legislation³²

Name	Sections
Federal Civil Code	Several
Federal Code on Electoral Institutions and Procedures	149, 218
Customs Act	61
Airports Act	36
Civil Aviation Act	33
Sustainable Rural Development Act	15, 154, 162
Reading and Book Promotion Act	10
National Commission on Human Rights Act	25
Rights of Senior Citizens Act	6
Public Works and Related Services Act	21
Income Tax Act	222
Institute of the National Housing Fund for Workers Act	51
National Women Institute Act	3
Social Security Act	Several
Career Professional Service of the Federal Public	21
Administration Act	
Federal Rights Act	186, 198, 198-A, 238-B, 238-C, 288
Federal Consumer Protection Act	7, 58
Federal Tourism Act	2, 9, 11, 16, 19, 28, 30, 32
Federal Labor Act	Several
Federal Act to Prevent and Eliminate Discrimination	4, 5, 11, 13
General Human Settlement Act	3, 33, 51
General Physical Culture and Sports Act	2, 29, 47, 80, 90
General Education Act	41
General Health Act	Several
Federal Public Administration Organic Act	39
General Congress of the United Mexican States Organic Act	3, Temporary
Girl, Boy and Adolescent Rights Protection Act	3, 16, 28, 29, 30, 31
Railway Service Regulatory Act	43
National Social Welfare System Act	4, 12, 15, 17, 44, 45, 46
Federation Expenditure Budget for Fiscal Year 2003	55, 16o Temporary

³². These provisions were in place as of 23 July 2003. Revised and complete texts at <http://www.cddhcu.gob.mx/leyinfo/>.

There is no organization that specifically protects the human or civil rights of people with disabilities in Mexico. The National Commission on Human Rights and the State Commissions on Human Rights, which are in charge of protecting human and civil rights, assist both people with and without disabilities. Their main duty is to receive, hear, and investigate all complaints regarding alleged human rights violations by public servants. With respect to cases of discrimination against people with disabilities, the National Council to Prevent Discrimination, established on 17 September 2003 by mandate of the Federal Act to Prevent and Eliminate Discrimination, will be in charge of receiving and recording discrimination complaints. This activity is scheduled to begin in January 2004.³³

Over the past 10 years, policy-making bodies have shown great interest in the social integration of persons with disabilities. As a result, an increasing number of laws include disability provisions. However, people with disabilities and the organizations serving them, had no say in the process of designing or reforming such laws. Thus, the multiple special needs or characteristics of each type of disability were not taken into account, and the social impact of these laws has been lessened. Although there are many legal protections for people with disabilities, noncompliance remains an issue. In general, then, "the national legal framework does not restrict, but rather emphasizes both the equality of people with disabilities in the labor context and non-discrimination in all aspects of social life. However, in practice there is no disability culture making society feel that this social group is part of it and that it should be accepted with all its characteristics."³⁴ Civil society organizations have had an increasingly active and vital role in the formulation of social development policies, which may improve this situation in the future.

Civic Participation

People with disabilities have the right to vote and to be elected to public office with no restrictions.³⁵ However, pursuant to the provisions of Sections 450 and 2585 of the Federal Civil Code, a person with disabilities who is considered "naturally or legally incapable" is not allowed to hold public office or act as an attorney in court proceedings.³⁶

³³ Doctor Amalia Gamio Ríos (National Council to Prevent Discrimination), e-mail response, 26 November 2003.

³⁴ Programa de Integración Laboral para Personas con Discapacidad 2001-2006, 12-13, Código Federal de Instituciones y Procedimientos Electorales [Federal Code of Electoral Institutions and Procedures], sec. 4, (last amended on 24 June 2002); Ley Federal para Prevenir y Eliminar la Discriminación [Federal Act to Prevent and Eliminate Discrimination], sec. 9, (new act passed on 11 May 2003).

³⁵ Código Federal de Instituciones y Procedimientos Electorales [Federal Code of Electoral Institutions and Procedures], sec. 4, (last amended on 24 June 2002); Ley Federal para Prevenir y Eliminar la Discriminación [Federal Act to Prevent and Eliminate Discrimination], sec. 9, (new act passed on 11 May 2003).

³⁶ Código Civil Federal, [Federal Civil Code], sec. 450 and 2585, (last amended on 20 May 2000).

Significant progress was made in the 2003 elections with respect to accessibility. Changes include ballot boxes of an appropriate height and some Braille materials, but the lack of accessible polling places remains a major obstacle. Leaders of disability organizations estimate that only 20% of polling stations were physically accessible facilities. The Federal Electoral Institute has committed to encouraging and gradually facilitating the vote of people with disabilities. Among the initiatives announced are training strategies for election officials that consider disability issues and accessible information on electoral processes for citizens with disabilities.³⁷

Inclusion

Communication

In general, few communication resources are available for persons with disabilities. The government does not typically use alternative formats such as Braille to provide information on its activities, with the exception of those few items specifically aimed at people with visual disabilities.³⁸ The Braille version of the Political Constitution of the Mexican United States is made available through a civil organization rather than through the government. The International Committee for the Blind (private assistance institution) offers various publications in Braille including an outdated version of the Political Constitution from 1998. These publications are not free of charge.

³⁷. Federal Electoral Institute "National Coordination of Social Communication," (press release No. 107, 11 June 1997); Federal Electoral Institute, *Estrategia de Capacitación Electoral e Integración de Mesas Directivas de Casilla para el Proceso Electoral Federal 2002-2003* [Electoral Training Strategies and Appointment of Polling Station Officials for the 2002-2003 Federal Electoral Process], November 2002, 46, <http://deceyec.ife.org.mx/>; Federal Electoral Institute, *Catálogo de Preguntas para Orientar a los Ciudadanos Sobre el Proceso Electoral Federal 2002-2003* [Catalog of Questions to Guide Citizens on the 2002-2003 Federal Electoral Process], 37-38, <http://deceyec.ife.org.mx/>.

³⁸. Telephone interview with a representative of the International Committee for the Blind I.A.P., 21 October 2003.

The Mexican National Library, run by the National Autonomous University of Mexico, has a Special Typhology Room that provides the following services to persons who are visually impaired:

- Special document scanning
- Automated reading and recording
- Editing of printed material (Screen Reader, Open Book and Jaws software)
- Character enlargement
- Braille to text characters conversion and vice versa
- Training workshops on how to use PCs

Given the type of collection that the library has, the materials do not require constant updating. Instead, they are updated gradually based on user's requirements. These services are primarily educational in nature, and some require the user to pay a fee or provide their own materials. In addition, the delivery time can be very long. Individuals or private institutions requiring Braille to text conversion for personal use must hire such service on their own or seek assistance from specialized non-government organizations.

Closed captioning is not standard practice in Mexico television programming, and no closed captioning is used in nationwide television news broadcasts. Simultaneous sign language interpreting for people with hearing disabilities is, however, used for special television programs or events. Only *Noticiero with Lolita Ayala*, a *Noticiero* Televisa news broadcast aired Monday through Friday from 2:30 p.m. to 3:00 p.m., includes a news summary translated into sign language for viewers with hearing impairments.

The most recent accessible communication initiative is the 1998 Federal Radio and Television Broadcasting Act reform, which as of October 2003 had not been approved by the necessary Congressional Committee.³⁹

The Attorney General's Office does not provide any way for people with hearing or speech disabilities to communicate with the relevant authorities in the event of a natural disaster, civil emergency, or criminal assault. If an individual with such disabilities wishes to file a complaint with the agencies reporting to the Attorney General's Office, officials may request the expert assistance of a sign language interpreter. Interpreters are not provided on a regular basis but as a special service.⁴⁰

Education

The 12th Census reports that among children with disabilities, there are 44,629 under the age of 4; 191,340 aged 5 to 14; and 91,396 aged 15 to 19.⁴¹

³⁹. *Diario de Debates, Año II, Iniciativa de Reformas y Adiciones a la Ley Federal Radio y Televisión* [Congressional Record, Year II, Federal Radio and Television Broadcasting Act Reform Initiative], 57th Legislature, 25 November 1998.

⁴⁰. Telephone interview with an official from the Deputy Attorney General's Office for Human Rights and Assistance to Victims and Community Services of the Attorney General's Office, 22 October 2003.

⁴¹. *Población Total por Entidad Federativa, Sexo y Grupos Quinquenales de Edad y su Distribución y Tipo de Discapacidad*.

Table Six shows several estimates of the number of students with disabilities who are participating in special education programs and the percentage receiving education in regular versus special schools.

Table 6: Students with disabilities by Type of Educational Setting

Document	Inclusive Education (USAER)	Special Education (CAM)	Total Population of Students with Disabilities	Date
National Special Education and Educational Integration Strengthening Program. ⁴²	31%	69%	103,237	Start of 2001-2002 school year
Basic Statistics of the National Educational System. ⁴³	28%	72%	99,952	Start of 2001-2002 school year
Mexican Educational System. 2002–2003 School Year. ⁴⁴	28%	72%	106,733	Start of 2001-2002 and 2002-2003 school years. ⁴⁵
Preliminary Results of the Fact Sheet on Special Education for Students with Disabilities ⁴⁵	31%	69%	96,210	Start of 2002-2003 school year. Note that this document contains preliminary figures.

⁴² Secretary of Public Education in coordination with the Presidential Office for the Advancement and Social Integration of Persons with Disabilities, "Current Situation of Special Education Services and the Educational Integration Process: "Service Coverage and Performance, Assisted Population," part of the *Programa Nacional de Fortalecimiento de la Educación Especial y de la Integración Educativa* [National Special Education and Educational Integration Strengthening Program], 2002, 15-16.

⁴³ Secretary of Public Education, *Estadística Básica del Sistema Educativo Nacional, Inicio de cursos 2001-2002* [Basic Statistics of the National Educational System. 2001-2002 School Year], <http://www.sep.gob.mx/work/apps/site/pubbas01/index.htm>.

⁴⁴ Secretary of Public Education, *Sistema Educativo de los Estados Unidos Mexicanos, Principales Cifras Ciclo Escolar 2002-2003, VI Otros Servicios, Educación Especial* [Mexican Educational System, Key Figures, 2002-2003 School Year, VI Other Services, Special Education], 84, http://www.sep.gob.mx/wb2/sep/sep_Principales_Cifras_Ciclo_Escolar_20022003.

⁴⁵ As a result of a new special education structure implemented in 1998, people with behavioral, learning, and speech problems or autism and early intervention are not included among the population with disabilities. Percentage estimated on the basis of an increase in the number of students and services as compared to the previous school year.

⁴⁶ Secretary of Health, National Advisory Committee of Health Promotion and Regulation Standardization, Mexican Official Standard NOM-197-SSA1-2000, *Que establece los requisitos mínimos de infraestructura y equipamiento de hospitales y consultorios de atención médica especializada* [Providing the minimum infrastructure and equipment requirements to be complied with by specialized health care hospitals and clinics], 2000, 13-14, 23; *Sistema Educativo de los Estados Unidos Mexicanos, Principales Cifras Ciclo Escolar 2002-2003, VI Otros Servicios, Educación Especial*.

According to the largest estimate, children with disabilities accounted for only about 0.52% of the 20,517,261 children enrolled in the national education system during 2002. The majority of children with disabilities who participate in educational service programs are those with mental disabilities (approximately 70%), followed by hearing disabilities (13%), mobility disabilities (12%), and visual disabilities (4.5%).⁴⁷

Special Education is available for students with disabilities in major cities and in many large and small towns, but coverage is not nationwide.⁴⁸ Students with disabilities attending regular schools usually require the support of Regular Education Support Service Units (USAER). However, these are limited in number and distribution. The main goal of special education programs is to integrate children with disabilities into regular classrooms.

The educational integration process has gained some momentum through Section 41 of the General Education Act which reads:

Special education is designed for individuals with either temporary or permanent disabilities as well as for individuals with exceptional abilities. It shall cater to students in a manner suitable to their own capabilities thereby ensuring social equity. Since it deals with children with disabilities, special education shall promote their integration into mainstream basic education structures by applying specific methods, techniques and materials. For those individuals who do not become successfully integrated, special education shall aim at meeting their basic learning needs so that they can have an autonomous social and productive life, and to this end, it shall develop the necessary programs and teaching aids. Special education encompasses guidance to parents or guardians as well as to teachers and staff of elementary and high schools integrating students with special education needs.⁴⁹

The creation of this act along with the signing of the National Basic Education Modernization Agreement and the amendment of section 3 of the Constitution has resulted in a process of "reorienting and reorganizing special education services, focusing primarily on changing the prevailing conception of the role of special education services, promoting the integration of children with disabilities into regular schools and restructuring the existing services."⁵⁰

⁴⁷. Secretary of Public Education, *Sistema Educativo de los Estados Unidos Mexicanos, Principales Cifras Ciclo Escolar 2002 - 2003, Vi Otros Servicios, Educación Especial*. http://www.sep.gob.mx/wb2/sep/sep_Principales_Cifras_Ciclo_Escolar_20022003

⁴⁸. María del Carmen Escandón Minutti (Coordinator of the National Special Education and Educational Integration Strengthening Program of the Secretary of Public Education), interviewed by author, Mexico, F.D., 6 October 2003.

⁴⁹. *Ley General de Educación* [General Education Act], sec. 41, (last amended on 13 March 2003).

⁵⁰. *Programa Nacional de Fortalecimiento de la Educación Especial y de la Integración Educativa, 1 Situación actual de los servicios de educación especial y del proceso de integración educativa*, 13-16.

There is no national policy requiring public or private schools to be accessible to people with disabilities.⁵¹ Approval is being sought to officially extend a Mexican Official Standard regarding accessibility to include schools. Schools are not specifically mentioned in the current document. However, the standard refers to all buildings providing a public service, and as such, schools are implicitly included.⁵² The education system also often lacks accessible communication for students with sensory disabilities. Government efforts to provide free Braille textbooks for primary education encountered a number of distribution problems. The headquarters of the Secretary of Public Education are located in the Federal District and are wheelchair-accessible. The Secretariat participates in the National Program on Public Buildings Accessibility; therefore, its five administrative facilities in Mexico City are scheduled to be made accessible by 2006.⁵³

Teachers are trained in Teacher Training Schools under the authority of the Secretary of Public Education (SEP). Schools offer undergraduate degrees in Preschool Education, Elementary Education, High School Education, Physical Education, Artistic Education, and Special Education.⁵⁴ In view of the need of all teaching staff to be trained on how to meet the needs of a diversified student population, the SEP has added "Special Education Needs" to the curricula of undergraduate programs in Preschool Education, Elementary Education, and Physical Education.⁵⁵ Training in educational integration in elementary schools was also incorporated into the curricula of regular teacher training for the 2002-2003 and 2003-2004 school years. The course was conducted in 25 out of 31 Mexican states. Three national courses on educational integration aimed at teachers working in regular preschool, elementary and high schools were scheduled to take place during the 2003-2004 school year.⁵⁶

Of the 52 schools around the country providing special education training, most only offer an undergraduate degree in Learning Problems. Other undergraduate specialty programs include Mental Deficiencies, Blindness and Visual Impairments, Hearing and Speech, Neuromotor Disorders, Learning Problems, Social Misconduct and Maladjustment. The Specialization Teacher Training School of the Federal District offers undergraduate degrees in all specialties and also runs two postgraduate programs and a Master's degree program.⁵⁷

⁵¹. María del Carmen Escandón Minutti.

⁵². Taide Buenfil Garza (architect and Director for Urban Projects of the Presidential Office for the Advancement and Social Integration of Persons with Disabilities), interviewed by author, Mexico, F.D., 28 November 2003.

⁵³. *Ibid.*

⁵⁴. María del Carmen Escandón Minutti.

⁵⁵ Secretary of Public Education, "Syllabus and Supporting Material for Studying," *Necesidades Educativas Especiales, Licenciatura en Educación Preescolar* [Special Education Needs, Undergraduate Preschool Education Program], Fourth Semester, 2nd ed. (Mexico, F.D., 2001); Secretary of Public Education, "Syllabus and Supporting Material for Studying," *Necesidades Educativas Especiales, Licenciatura en Educación Primaria* [Special Education Needs, Undergraduate Elementary Education Program], Third Semester, 3rd ed., (Mexico, F.D., 2000).

⁵⁶. María del Carmen Escandón Minutti.

⁵⁷. Secretary of Public Education, Specialization Teacher Training School of the Federal District, curriculum.

The postgraduate programs include behavioral problems in basic education, speech problems, prevention and assistance in the classroom, and the master's degree in special education. Table Seven shows the number of schools providing specialized training in the various fields that make up special education in Mexico.

Table 7: Teacher Training Schools by Training Area in Mexico⁵⁸

Area	Number of teacher training schools
Learning Problems	48
Hearing and Speech	23
Mental Deficiencies	8
Neuromotor Disorders	2
Blindness and Visual Impairments	2
Social Misconduct and Maladjustment	1
Undergraduate degree in Special Education	5

Source: Information provided by PTFAEN officials and confirmed by telephone.

The curriculum of the 2004-2005 Undergraduate Special Education Program will accommodate the need to train teachers in the assistance of children with disabilities rather than with learning problems only.⁵⁹

Family integration into the education of people with severe, profound or multiple disabilities is a complex problem. The public school system does not offer counseling to parents or programming designed to include families in the education of people with disabilities. The minimal level of assistance provided to children with multiple or severe disabilities has been an obstacle to the creation of such programs. There is not enough accurate information on the type of assistance provided to these children at Multiple Assistance Centers (CAM).⁶⁰ Some NGO's offer guidance to parents, but there are no formal programs. According to one advocate, "the absence of this kind of support is considered to be one of the main causes of family disintegration in Mexico, [yet] there is no research."⁶¹

⁵⁸. Secretary of Public Education, Program for the Academic Change and Strengthening of Teacher Training Schools (PTAEN), *Informe Cuantitativo, Ciclo Escolar 2002-2003, Escuelas Normales que imparten la Licenciatura en Educación Especial en México. 2003* [Quantitative Report, 2002-2003 School Year, Teacher Training Schools Offering Undergraduate Degrees in Special Education in Mexico], 2003.

⁵⁹. *Ibid.*

⁶⁰. María del Carmen Escandón Minutti.

⁶¹. Elizabeth Montes Aguilar (representative of Adelante Niño Down A.C.), e-mail response, 22 December 2003.

The National Special Education and Educational Integration Strengthening Program and the National Advisory Council for the Social Integration of People with Disabilities Subcommittee on Education Integration are considering proposals to address this issue. A working group is being created to promote family integration and education. Because NGOs are the source of most efforts to involve parents of children with disabilities in the educational process, they will play an important role in the working group.⁶²

The Secretary of Public Education does not have a disability detection program in place. However, the National System for the Comprehensive Development of the Family (National DIF)—the social welfare institution with the largest infrastructure in the country— runs an early detection program in all its rehabilitation centers and basic care units.⁶³ In line with the goals of the Federal Government's 2001-2006 National Development Plan, early detection should also be available through PreveR-Dis.⁶⁴ Both programs will cover the four major groups of disabilities: neuromotor, visual, hearing and intellectual. Mental or psychiatric "disorders" are not included because they are not yet considered disabilities in Mexico.⁶⁵ Upon early detection of a disability, the National DIF program refers people to a rehabilitation center, while PreveR-Dis refers people to other second or third-level care institutions. If the type of disability does not fall into any of the existing categories, preventive measures such as early stimulation programs are adopted.⁶⁶

People with intellectual disabilities who are over the age of 20 have almost no social integration or development opportunities since very few institutions provide such services. According to a representative of one disability organization, "the public educational system provides educational services to people with disabilities until they reach the age of 20 through the Occupational Multiple Assistance Centers (CAM) Then, it is up to the parents to provide their

⁶². María del Carmen Escandón Minutti.

⁶³. Doctor Luis Rosales Pérez (Occupational Therapist) and Rita Solís Moreno (Assistant Director of Rehabilitation and Head of the Department of Community-based Programs of the National DIF), interviewed by author, Mexico, F.D., 16 December 2003.

⁶⁴. *2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades, Goals, Description of Subprograms*, 26, 36-37.; Blanca Bernal Acosta (Head of the Medical Units Department of the National Rehabilitation Center), e-mail interview, 26 December 2003.

⁶⁵. Doctor Luis Rosales Pérez and Rita Solís Moreno.

⁶⁶. *Ibid.*

children with some kind of educational, occupational or housing support by their own means. However, parents usually do not know what to do with their children and in most cases, young people and adults who once attended school or took part in a rehabilitation program stay at home.”⁶⁷

With regard to higher education, the La Salle University of Mexico offers various disability-related courses through the Social and Community Development Coordination Office. There are courses available on Braille system, the Mexican Sign Language, and a Workshop on Disability given by the PROACCESO Program. The PROACCESO Program was begun in coordination with Libre Acceso in July 2001 with the goal of removing social, cultural, and physical barriers within educational institutions. Likewise, the Morelia La Salle University offers a diploma on “Alternative Communication: Sign Language and the Braille System.” Approximately 100 students enroll in the courses annually.⁶⁸

Significant efforts have been made in the field of special education and educational integration in Mexico. However, children with disabilities have long been subject to abandonment and neglect. Children with disabilities continue to be deprived of education, whether special or regular, even though the necessary physical and service infrastructure is already partially in place.

Employment

The economically inactive rate in Mexico is very high. The National Urban Employment Survey (ENEU) conducted by the INEGI found an overall unemployment rate of 3.25% for 2003.⁶⁹ However, the survey also reports that only 55.58% of the total population is economically active.⁷⁰ The ENEU does not provide any information about people with disabilities. According to the 2000 census, only 25% of the total population with disabilities is economically active. The remaining 75% are economically inactive.⁷¹ Not only is there a substantial difference between the likelihood of people with and without disabilities to be

⁶⁷. Elizabeth Montes Aguilar.

⁶⁸. Héctor Figueroa Solano (President of Proaccesso ULSA Mexico) and Juan Medina Salgado (President of Proaccesso ULSA Morelia), e-mail response, 27 December 2003.

⁶⁹. INEGI, “General Unemployment Rate,” *Encuesta Nacional de Empleo Urbano (ENEU)*, [National Urban Employment Survey (ENEU)], <http://www.inegi.gob.mx/est/default.asp?c=1801>.

⁷⁰. INEGI, “Economically Active Population,” *Encuesta Nacional de Empleo Urbano (ENEU)*, <http://www.inegi.gob.mx/est/default.asp?c=1801>.

⁷¹. INEGI, *Tasa de participación económica y de participación no económica de la población con discapacidad por entidad federativa según sexo* [Percentage of the economically active and non economically active disabled population by federal entity according to sex], 2000, <http://www.inegi.gob.mx/est/default.asp?c=2406>.

economically inactive, there is also a difference between the inactive status of the two groups. Economically inactive people without disabilities are more likely to be students, retired or doing housework (92.37%) than economically inactive people with disabilities (51.45%).⁷² The 1996 National Household Income and Expenses Survey found similar results.⁷³ Table eight shows the status of those people with disabilities within each of the activity categories.

Table 8: Activity by employment status

Economically Inactive		76%
	Student	6%
	Staying home	26%
	Practicing sports	8%
	Would like to work	60%
Economically Active		24%
	Working	85%
	Looking for work	15%

Those people with disabilities who are employed often earn relatively little. Almost 14% earn no money, and 22.6% earn less than one minimum wage.⁷⁴ Among the most common occupations for people with disabilities are: farmers (23.4%), craftsmen and manual workers (17.1%), and merchants and self-employed (13%).⁷⁵

Given the large number of people with disabilities who are not working, the government passed antidiscrimination employment legislation. The Federal Act to Prevent and Eliminate Discrimination says that people with disabilities should not be discriminated against by reason of their disabilities when applying for a job.⁷⁶ Also, the right of every

⁷² INEGI, "Non Economically Active Population by Inactive Status," *Encuesta Nacional de Empleo Urbano* (ENEU), Población no económicamente activa por condición, [Non Economically Active Population by Inactive Status], 2003, <http://www.inegi.gob.mx/est/default.asp?c=1801>; Población Total por Entidad Federativa, Sexo y Grupos Quinquenales de Edad y su Distribución y Tipo de Discapacidad.

⁷³ *Partido Revolucionario Institucional, Committee on Disability Sigues, "Iniciativa de Reformas a la Ley Federal del Trabajo"* [Federal Labor Act Reform Initiative], 2003-2006 Legislative Agenda for Persons with Disabilities, 72.

⁷⁴ This includes people whose primary tasks are housekeeping within their own residence and others who are not occupied outside of the home. In Mexico, one minimum wage is considered to be the income of the poorest sector of the population

⁷⁵ INEGI, *Distribución porcentual de la población ocupada con discapacidad por ocupación principal para cada sexo* [Percent Distribution of the Employed Disabled Population by Income Level per Main Occupation for each sex], 2000, <http://www.inegi.gob.mx/est/default.asp?c=2406>.

⁷⁶ Resolution adopted by the General Assembly on the Report of the Third Committee (A/56/583/Add.2) 56/168, *Comprehensive and Integral International Convention to Protect and Promote*.

⁷⁷ *Ley Federal para Prevenir y Eliminar la Discriminación*, sec. 1, 3, 4, 9.

person to work is recognized as an individual guarantee in the Political Constitution and the Federal Labor Act.⁷⁸ Disability-related labor policy is further elaborated in the 2001-2006 Program for the Labor Integration of Persons with Disabilities, which seeks to successfully integrate or reintegrate people with disabilities into productive employment.⁷⁹

The "Opening Spaces" Program run by the Secretary of Labor and Social Security (STPS), handles training and job placement opportunities and provides support to people with disabilities and senior citizens who are looking for a job. The "Opening Spaces" Program encompasses disability assessment centers, the Occupational Training System (SICAT), the Labor Exchange (CHAMBA-PAR), a special Liaison Network for persons with disabilities and a program entitled "Inclusive Companies: Towards a New Labor Culture."⁸⁰ Applicants have their skills assessed and then contact agencies that help locate job vacancies requiring the skills identified in that assessment. Agencies include the National DIF's Labor Integration Agencies, the National Employment Service's labor exchanges, and a variety of NGOs.

At present, the STPS program is operating in Aguascalientes, Veracruz, Toluca, and the Federal District.⁸¹ The CHAMBA-PAR reports that in 2002 it served a total of 2,367 people with disabilities, 433 of whom were placed in a job. Between January and September 2003, 2,891 people received assistance, and 533 obtained a job.⁸²

Despite the fact that the Federal Government is not required to hire persons with disabilities, positions sometimes are made available to them. There are no data on the number and position of these individuals, but they appear at different government levels. The Office for the Advancement and Social Integration of Persons with Disabilities (ORPISPCD) is headed by a person with disabilities.

One private company that is working to end disability discrimination is Fomento Económico Mexicano, S.A. de C.V. (FEMSA). The FEMSA is one of the country's largest companies in the private sector, and it runs a national program entitled the Program for the Integration of People with Disabilities. The company takes the position that "disability is not a limitation to perform different occupational activities; on the contrary, this can be a booster for improved professional performance."⁸³

⁷⁸. *Constitución Política de los Estados Unidos Mexicanos*, sec. 1, 5, 123, *Ley Federal del Trabajo* [Federal Labor Act], sec. 1-4, (last amended on 23 January 1998).

⁷⁹. *Programa de Integración Laboral para Personas con Discapacidad 2001e2006*, 21.

⁸⁰. "¿Cómo queremos lograrlo?" [How Can We Achieve This?], *Programa de Integración Laboral para Personas con Discapacidad 2001-2006*, 2002, 26-33.

⁸¹. Secretary of Labor and Social Security, *Opening Spaces Program*, http://www.gob.mx/wb2/egobierno/egob_Chambapa.

⁸². Secretary of Labor and Social Security, *Reporte De Chambapar al Mes de Diciembre del 2002* [Chambapar's Report as of December 2002], 2002.

⁸³. *Fomento Económico Mexicano, S.A. de C.V. (FEMSA)*, *Program for the Integration of People with Disabilities*, <http://www.femsa.com/index.asp>.

Despite some efforts, employment remains a problem for people with disabilities. Although there are no figures on the unemployment level in the disability community, the rate is estimated to be much higher than that of people without disabilities. Training and labor integration programs have not made a significant contribution to the solution of this problem. Many people with disabilities still resort to self-employment or underemployment as a way to meet their immediate employment needs.

Health Services

Disability is acknowledged as an increasingly important public health problem in Mexico.⁸⁴ Consequently, the Secretary of Health, as a member of the National Advisory Council for the Social Integration of People with Disabilities (CODIS), developed the PreveR-Dis for inclusion within the 2001-2006 National Health Program.⁸⁵ As of December 2003, PreveR-Dis was operating in 3 out of the 31 Mexican states. It will gradually be implemented in the other states.

The resources needed for the implementation of PreveR-Dis are still being determined, so they have not yet been budgeted by the Secretary of Health. Specific funding has already been obtained for providing financial aid to people with disabilities and their families. The Secretary is looking into the possibility of also obtaining specific funding for health care and rehabilitation services for people with disabilities.

Rehabilitation services are provided throughout the country. Institutions that make up the health care sector include: Secretariat of Health (SSA), Mexican Social Insurance Institute (IMSS), Social Services and Security Institute for State Employees (ISSSTE), National System for the Comprehensive Development of the Family (National DIF), Secretariat of Defense (SDN), Secretariat of the Navy, and Petróleos Mexicanos (PEMEX). The National DIF has the country's largest rehabilitation services network, which consists of 63 large Rehabilitation Centers and 775 Basic Rehabilitation Units (UBR). The aim is to achieve full coverage by means of an expansion program (called "White Flag"), that will ensure the operation of one UBR in each municipality. Services are financed by federal, state and municipal governments.

Fideprótesis is an investment and management trust fund created to help pensioners and retirees of the IMSS and the ISSSTE obtain assistive devices. This trust fund was set up with contributions from the IMSS, the ISSSTE, and a grant from the Secretariat of Social Development (SEDESOL). The fund can provide the following technical aids: glasses, dental prosthesis, hearing aids, lower limb prosthetics, orthotics, wheelchairs, crutches, walkers, support girdles, walking canes, and intraocular lenses. Moreover, *Fideprótesis Popular* provides

⁸⁴. Secretary of Health, *Programa Nacional de Salud 2001-2006* [2001-2006 National Health Program], 2001, 108.

⁸⁵. *Discapacinet Portal, Fideprótesis*, http://www.emexico.gob.mx/wb2/eMex/eMex_Fideprotesis.

financial assistance to people with disabilities who have no insurance and need help purchasing necessary prosthetics, orthotics, orthopedic products, or technical aids.⁸⁶

Health care for persons with disabilities faces several challenges in part derived from inadequate training for medical professionals. Instruction at medical schools and colleges concerning disability causes, prevention and rehabilitation methods is poor.⁸⁷ The PreveR-Dis will work to improve the training that is available, ensuring that future medical, paramedical and related staff will be properly trained. Currently, training in physical therapy, occupational therapy, physiatry for nurses and other health professionals, prosthetics and orthotics, and speech therapy is widely available throughout the health care sector. Likewise, basic training on the provision of services to people with disabilities is available to professionals such as primary health care physicians, obstetricians and gynecologists, pediatricians, nurses, medical assistants and health aides (rural health advocates). There are no data on the number of healthcare professionals who receive such training.⁸⁸ Some non-governmental organizations are also working with educational institutions to train specialized professionals. For example, the Teletón Foundation operates an Institute of Higher Studies in Rehabilitation, and two undergraduate programs (Physical Therapy and Occupational Therapy) are held in collaboration with the Autonomous University of the State of Mexico.⁸⁹

In 2003, the Secretariat of Health implemented the Community-Based Rehabilitation (CBR) pilot project in the State of Tlaxcala. In addition, the National DIF has been implementing this strategy for about 15 years. The National DIF pioneered the use of CBR in Mexico and was the driving force behind the formal creation of the Basic Rehabilitation Units (UBR). Since National DIF's Rehabilitation Centers can only serve 200,000 people each year, the Basic Rehabilitation Units play a major role in assisting the remaining population and providing services based on CBR strategies. As a result of its CBR strategy, National DIF now has the largest rehabilitation infrastructure in the country; it has enough capacity to serve approximately 1.2 million people each year. CBR is thus a primary health care service and is promoted within the communities around the country.

^{86.} *2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades*, 19.

^{87.} *2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades*, 21.

^{88.} Blanca Bernal Acosta.

^{89.} Teletón Foundation, Teletón Institute of Higher Studies in Rehabilitation, <http://www.teleton.org.mx/crit.html>; Autonomous University of the State of Mexico. <http://www.uaemex.mx/pestud/licenciaturas/home.html>.

Housing

Independent Living Centers are not available in Mexico, but the philosophy of Independent Living is promoted by one non-governmental organization. Intensive courses have been gradually delivered in a variety of states throughout the Republic.⁹⁰

Housing subsidies and/or assistance for people with disabilities have only very recently come into existence. The Office for the Advancement and Social Integration of Persons with Disabilities signed the "Collaboration and Coordination Agreement for Promoting and Implementing Actions in Housing that will Contribute to the Social Integration of People with Disabilities" on 16 October 2002. Among other commitments, the agreement establishes that 1% of dwellings in new developments must meet specific accessibility standards or must include adaptable facilities. These homes must be allocated to both people with disabilities and individuals who have a dependent with a disability. The operating rules for this agreement were expected to be published in December 2003.⁹¹ This agreement establishes the groundwork for collaboration and coordination that are hoped will contribute to the social integration of people with disabilities. Among those party to the agreement are the main national housing bodies: the National Commission for Housing Promotion (CONAFOVI), the Institute of the National Housing Fund for Workers (INFONAVIT), the Institute of Social Services and Security for State Employees through the Housing Fund (FOVISSSTE), the Federal Mortgage Corporation S.N.C (SHF), the National Trust Fund for Affordable Housing (FONHAPO), the Mexican Chamber of the Construction Industry (CMIC) and the National Chamber of the Housing Development and Promotion Industry (CANADEVI).⁹²

For the most part, people with disabilities are still deprived of fully exercising their right to adequate housing, but the future holds promise since many actions are being taken to promote physical and financial accessibility.

⁹⁰. International Independent Living Organization, <http://www.vidaIndependiente.com/indexExplorer.htm>.

⁹¹. Francisco Cisneros Rivero (Director of Institutional Programs of the Presidential Office for the Advancement and Social Integration of People with Disabilities), interviewed by author, Mexico, F.D., 4 November 2003.

⁹². Secretary of Social Development, *Convenio de Colaboración y Concertación para Promover y Aplicar Acciones en Materia de Vivienda que Contribuyan en la Integración Social de las Personas con Discapacidad* [Collaboration and Coordination Agreement for Promoting and Implementing Actions in Housing that will Contribute to the Social Integration of People with Disabilities], (Mexico City, Federal District, 16 October 2002).

Institutionalization

Public institutions in Mexico are not run with the specific mission of providing long-term housing and care to people with disabilities. Institutions offering this service generally assist third-age and homeless people, some of whom may have some kind of disability.⁹³ The National DIF also does not provide long-term housing and care to people with disabilities. No information is available with respect to private institutions offering such services.⁹⁴

Some alternatives to public accommodation are available through the National DIF and various non-governmental organizations. Services may be provided on either a permanent or temporary basis, primarily to street children, indigent persons, and neglected elderly people. There are no data regarding the number of people with disabilities residing in such centers.⁹⁵

The permission of the family or guardian is required before institutionalization at any facility. Some institutions may request placement when they are authorized to provide guardianship services. Persons with disabilities have the right to refuse treatment, except for those persons who have been declared legally incapable by a court. In these cases, the guardian or representative of a person with disabilities may place him or her at an institution, provided it has been proved to be an emergency measure.

Organizations in Mexico that may provide long-term housing and care exclusively to people with disabilities are not registered, so there are no formal mechanisms for reporting or monitoring incidences of death, abuse or violence against people with disabilities at any such institutions. The Secretary of Health has some mechanisms in place for reporting violence at public and private health-care institutions including the Report of Assistance for Family Violence. However, none of these systems reports the disability status of those involved in an incident.⁹⁶

In 2003, the National DIF piloted the Federal, State and Municipal Information System (SIFEM), the purpose of which is to collect data related to victims and aggressors in incidents of family violence. In the trial stage, system operation was monitored in the State of Southern Baja California. Even though the system is designed for the population at large, once implemented, it will include disability characteristics for both the victim and the aggressor in reported incidents.

⁹³. América Larrainzar Pérez (Assistant Director of Citizen Assistance of the Presidential Office for the Advancement and Social Integration of Persons with Disabilities), telephone interview, 4 November 2003.

⁹⁴. Doctor Luis Rosales Pérez and Rita Solís Moreno.

⁹⁵. *Ibid.*

⁹⁶. Secretary of Health. National Advisory Committee of Health Promotion and Regulation Standardization. Mexican Official Standard NOM-190-SSA1-1999, *Prestación de servicios de salud, Criterios para la atención médica de la violencia familiar* [Presentation of health-care services, Criteria for health care in cases of family violence], 1999, 4, 9-10.

Ultimately, the system will create a database of statistical data regarding disability and violence. Although the program will initially address violence within families, it will also be used to track violence in institutions.

Accessibility

Accessibility to federal government buildings and facilities is promoted by the National Program on Public Buildings Accessibility. The first diagnostic assessment of accessibility to federal premises is being conducted with 48 government offices participating. As of December 2003, 5,604 premises had been assessed, of which 26.5% already met appropriate accessibility requirements. The diagnostic assessment for the remaining facilities is expected to be completed by 2006.⁹⁷

Public buildings are also the focus of the Agreement Establishing Guidelines on Accessibility of Federal Buildings and Facilities to People with Disabilities. The agreement, published in January 2004, was drawn up by the Commission for Valuation of National Assets (CABIN), a decentralized body of the Secretariat of Public Services.⁹⁸ It obligates the removal of physical, architectural, and urban barriers in public premises under the responsibility of the federal government. Approximately 14,000 state-owned buildings will be gradually adapted as a result. Moreover, proposals are under review in order to cover rented facilities.

No national regulations require private buildings to be accessible for people with disabilities. Since accessible facilities are only provided on the initiative of building owners, significant progress in this direction has not been made. A Mexican Official Standard entitled "Accessibility for People with Disabilities to Public Service Premises and Safety Specifications" has been drafted and is in the process of being approved. The document will establish accessibility requirements for all areas or premises rendering public services such as streets, parks, and shopping malls. Private facilities will also be required to comply with this standard. Official publication is expected by mid-2004.

Concepts regarding accessibility and universal design are sporadically included in courses and lectures, but they are not a formal part of most engineering and architecture degree courses. One exception is the Master's course in Architectural Design, a graduate course in the School of Architecture at the UNAM, which offers a course on "Architecture for People with Disabilities," that covers the concepts and principles of universal design.

⁹⁷. Taide Buenfil Garza.

⁹⁸. *Acuerdo por el que se Establecen los Lineamientos para la Accesibilidad de las Personas con Discapacidad a Inmuebles Federales* [Agreement Establishing Guidelines on Accessibility of Federal Buildings and Facilities to People with Disabilities], *Official Gazette of the Federation*, sec. 1, (12 January 2004), 27.

With respect to transportation, given the size of Mexico City and the number of services and units involved in the Public Transportation System, the system is largely inaccessible. The Metro System has 175 operating stations, but only 5 stations are wheelchair accessible. Guide rails, Braille signs, step treads, and large print logos have been installed in 30 stations.⁹⁹ Additionally, the Passenger Transportation Network (RTP) has a vehicle pool of 1,400 units, of which only 50 are wheelchair accessible.¹⁰⁰ Because only a small percentage of the total vehicle fleet is wheelchair accessible, public transportation is primarily a secondary support for people with disabilities rather than an inclusive, fully accessible transportation system.

Disability Action & Awareness

Two government agencies are largely responsible for the major policies regarding the rights of people with disabilities in Mexico: the Presidential Office for the Advancement and Social Integration of Persons with Disabilities (ORPISPCD) and the National Advisory Council for the Social Integration of Persons with Disabilities.

The development of disability policies in Mexico is supported by the ORPISPCD. The office is attached to the Executive Office of the Presidency of the Republic and was created by a Presidential Agreement on 4 December 2000.¹⁰¹ The head of this office represents the President of the Republic in disability-related matters. The main objective of ORPISPCD is to promote the integration of people with disabilities into social life on an equal footing with all others. Its main duties are:

Promoting the necessary adjustments to the legal framework at the three levels of government in order to improve the wellbeing of people with disabilities.

Fostering cross-organizational coordination to improve and extend the coverage of programs for people with disabilities, focusing primarily on rural areas.

Promoting the development of projects with national and international financial support and technical cooperation to improve the quality of life of people with disabilities.¹⁰²

⁹⁹. Federal District Secretary of Transportation and Road Administration. <http://www.stc.df.gob>.

¹⁰⁰. Federal District Secretary of Transportation and Road Administration; Numeralia, *Red de Transporte de Pasajeros* [Numeralia, Passenger Transportation Network], <http://www.setravi.df.gob.mx/numeralia/index.html>.

¹⁰¹. Francisco Cisneros Rivero.

¹⁰². Office for the Advancement and Social Integration of Persons with Disabilities, "About Us, Objectives and Roles," <http://discapacidad.presidencia.gob.mx/?P=12>.

The ORPISPCD develops institutional programs, citizen projects, and the legal framework surrounding disability rights. Through these three basic approaches, it attempts to address all aspects of the daily life of people with disabilities. However, due to budgetary constraints, the office has only four staff members.

To support its work, the ORPISPCD created the National Advisory Council for the Social Integration of People with Disabilities. Specifically, the Council was established to coordinate disability-related policies, strategies, and actions with both government and civil society organizations.¹⁰³ The ORPISPCD has also been influential in the creation of a number of programs on social rights, which are designed to promote the social integration of people with disabilities and their inclusion in social development. Table nine lists the various programs currently in existence.

Table 9: National Programs on Social Rights

Program Name
2001-2006 Program for the Integration of People with Disabilities ¹⁰⁴
National Special Education and Educational Integration Strengthening Program ¹⁰⁵
National Program on Public Buildings Accessibility ¹⁰⁶
Program of Action for Disability Prevention and Rehabilitation ¹⁰⁷
National Quality Health Care for People with Disabilities Program ¹⁰⁸
Support for People with Disabilities in Rural Areas Program ¹⁰⁹
Program for the Assistance of People with Disabilities (National DIF) Technical Guide ¹¹⁰

¹⁰³. *Acuerdo por el que se crea el Consejo Nacional Consultivo para la Integración de las Personas con Discapacidad* [Agreement creating the National Advisory Council for the Integration of People with Disabilities], *Official Gazette of the Federation*, sec. 1 (13 February 2001), 2.

¹⁰⁴. *Programa de Integración Laboral para Personas con Discapacidad 2001-2006*.

¹⁰⁵. *Programa Nacional de Fortalecimiento de la Educación Especial y de la Integración Educativa*.

¹⁰⁶. Secretary of Communications and Transportation in coordination with the Presidential Office for the Advancement and Social Integration of Persons with Disabilities. *Programa Nacional de Accesibilidad a Inmuebles Públicos* [National Program on Public Buildings Accessibility].

¹⁰⁷. *2001 - 2006 Programa de Acción para la Prevención y Rehabilitación de Discapacidades (PreveR-Dis)*.

¹⁰⁸. Secretary of Communications and Transportation in coordination with the Presidential Office for the Advancement and Social Integration of Persons with Disabilities, *Programa Nacional de Atención con Calidad para Personas con Discapacidad* [National Quality Health Care for People with Disabilities Program], 2001.

¹⁰⁹. Secretary of Agriculture, Livestock, Rural Development, Fisheries and Food in coordination with the Presidential Office for the Advancement and Social Integration of Persons with Disabilities, *Programa de Apoyo a Personas con Discapacidad en el Medio Rural* [Support for People with Disabilities in Rural Areas Program], 2003.

¹¹⁰. National DIF, *Programa de Atención a Personas con Discapacidad, Guía Técnica*. [Program for the Assistance of People with Disabilities, Technical Guide], <http://www.dif.gob.mx/grupos/discapacitados/guiatecnica/guiatecnicaprogramadiscapacitadfos.html>.

Of these programs on social rights, the 2001-2006 National Program for the Assistance of People with Disabilities (PRONADIS) is particularly important. It contains the programs, actions, and guidelines that set the direction for disability issues in Mexico until at least 2006. The program seeks to achieve social integration of persons with disabilities by establishing plans that include all areas of the daily life of people with disabilities including: accessibility, arts and culture, sports, education, economics, family and social development, legislation and human rights, labor integration, health and social security.

As of November 2003, the implementation of the PRONADIS was not enforced by law. Thus, implementation is still subject to the discretion of the parties involved (i.e. the legislative branch and federal government). The PRONADIS in itself does not have and does not require a budget allocation. The authorities responsible for implementing the programs and their actions must allocate the appropriate resources. To date, the amount allocated to operating the various programs cannot be determined or quantified because there is no formal financial monitoring instrument. The ORPISPCD, however, monitors the actual implementation of the programs and the responsible entities.

Disability action in Mexico is also the work of numerous civil society organizations. The National Directory of Associations of and Working for People with Disabilities contains basic information regarding the 932 disability organizations that were registered through the year 2000. Table 10 shows that of registered organizations, the greatest number served people with mobility and/or intellectual disabilities.

Table 10: Disability Associations by Type of Disability Assisted¹¹¹

Type of disability assisted	Associations
Visual	337
Hearing	342
Speech	391
Mobility	543
Intellectual	522
Other	116

Note: An association may assist various types of disabilities.

¹¹¹ INEGI, *Directorio Nacional de Asociaciones de y para Personas con Discapacidad 2000, Anexo Estadístico, Cuadro 5 Asociaciones de Personas con Discapacidad según Tipo de Discapacidad que Atienden* [National Directory of Associations of and working for People with Disabilities 2000, Statistical Annex, Chart 5 Disability Associations by Type of Disability Assisted], 407, <http://www.inegi.gob.mx/est/default.asp?c=136>.

Funding for these organizations is obtained almost entirely in the form of donations or contribution fees. Some funding of specific projects is available from national and international groups. Direct support from the government is very limited and may be channeled through a government department. In the past few years, sources of government funding for projects have primarily consisted of social co-investment funds granted by the National Institute for Social Development (INDESOL) and by some agencies. Greater direct government support is needed. Leaders of some organizations argue that it is also important for organizations to refine their own mechanisms for attracting support in order to have a greater impact on society.¹¹²

In general, civil organizations both provide assistance to and promote the rights of people with disabilities. Table 11 shows the number of organizations that provide various types of services.

Table 11: Disability Associations by Type of Service Provided¹¹³

Service	Number of Associations Providing the Service
Health Care	215
Physical Rehabilitation	510
Special Education	545
Psychological Counseling	474
Occupational Training	512
Sports and Recreational	592
Artistic and Cultural	448
Other	263

Note: An association may provide various types of services.

Non-governmental organizations are the driving force in the protection and promotion of disability rights. They collaborate with one another in a friendly atmosphere but they lack the necessary coordination to develop networks and strengthen their social capital. Among those organizations that are very active in promoting the rights of people with disabilities in Mexico are APAC, I. A. P. APIH, A. C.; CONFE, A. C. the Mexican Confederation of the Deaf; Free Access; and the Mexican Union of Associations of the Blind. In the past few years, there has been increased collaboration between the government and disability organizations. The government has invited disability organizations to take part in subcommittees of the National Advisory Council for the Social Integration of People with Disabilities. Their participation is expected to become a right when the new General Social Development Act is enacted.

¹¹² Enrique Garrido (Research Director, APAC Association for People with Cerebral Palsy I. A. P.), e-mail response, 28 December 2003.

¹¹³ IGNEGI, *Directorio Nacional de Asociaciones de y para Personas con Discapacidad 2000, Anexo Estadístico, Cuadro 5 Asociaciones de Personas con Discapacidad según Tipo de Discapacidad que Atienden.*

Since disability rights are now in the process of being recognized and accepted, effective dissemination strategies are needed to make all individuals, both with and without disabilities, aware of the existence of these rights. Many people with disabilities do not know what their rights are. The National Commission on Human Rights has engaged in some awareness-raising activities. In its 2000 report, the Commission reported the publication of 12 booklets regarding the rights of vulnerable groups. Nine of these booklets make reference to the rights of people with different types of disabilities.¹¹⁴ The interactive compact disc known as *Nuestros Derechos Versión 1.1* [Our Rights Version 1.1] also includes the rights of people with disabilities.

The report also notes that out of 3,918 complaints of alleged rights violations, only eight came from persons with disabilities. This small number further suggests a lack of rights awareness on the part of persons with disabilities.

In conclusion, the establishment of the Office for the Advancement and Social Integration of Persons with Disabilities has led to increased action and enhanced awareness regarding disabilities in Mexico. However, lack of commitment to disability rights beyond 2006 and the lack of legislative instruments have created uncertainty regarding the continuation of the recently created programs and bodies, thereby jeopardizing progress and posing a risk to social inclusion and the equalization of opportunities for persons with disabilities.



Constitution of the Workers with Disabilities Union in Mexico City Sep 22, 2001

¹¹⁴ National Commission on Human Rights, *Report From January 1 to 31 December 2002*, February 2003, http://www.cndh.org.mx/Principal/document/la_cndh/activid/fr_activi.htm.



Nicaragua

Key Factors: From 1960 to 1990, the interior regions of Nicaragua were the site of prolonged and violent political revolution. The conflicts resulted in an increased number of persons with disabilities throughout the country. Currently, disability rights are protected by Law 202; however, this law is largely unknown by many governmental offices.

Terminology

The Constitution of Nicaragua uses the phrase “invalidez,” which has been translated as “disabled.” In addition, the election law refers to “personas que tuvieron impedimentos físicos,” which has been translated as “individuals with physical impairments.” Whenever quoting these documents, the original language is retained.

Definition of Disability

Definitions of disability differ between organizations. For example, the Ministry of Health defines disability as “a deviation from the biomedical normalcy of the body-mind structure and function as a consequence of an illness, trauma or injury, and which calls for therapeutic or compensatory measures, generally on an individual basis.”¹ The National Institute of Statistics and Census (INEC) defines disability as “a problem of a physical-mental nature affecting a person.”²

Although there is no single, prevailing definition, most are consistent with the ideas established by Law 202 on the “Prevention, Rehabilitation and Equal Opportunities for Persons with Disabilities,”³ as well as with international laws. Law 202 defines disability as “any restriction or impairment in the execution of an activity, caused by some deficiency in the manner or within the sphere of action that limits or prevents the fulfillment of a function that is normal for that person for his or her age, gender, and cultural factors.”³

¹ Interview with Héctor Collado (National Director of Rehabilitation of the Ministry of Health), interviewed by author, February 2003.

² Interview with Domingo Primante Furlan (Research Consultant of the National Institute of Statistics and Census), interviewed by author, Managua, February 2003.

³ Law 202, “Prevention, Rehabilitation, and Equal Opportunities for Persons with Disabilities Act,” ch. 7, sec. 26, subsec. 47, 23 August 1995, <http://legislacion.asamblea.gob.ni/Normaweb.nsf/>.

Disability Population

According to the National Institute of Statistics and Census (INEC), as of April 2004 the population of Nicaragua is 5,400,000, and 12.5%, approximately 675,000 people, have some kind of disability.⁴ However, these figures are disputed by some experts. Oscar Cano, the Coordinator of Rehabilitation for the National Technological Institute (INATEC) stated that "...the disability population amounts to 15%, based on my personal visits to nine departments, and I know there is more population than the country's organizations know about."⁵

The growth rate of the disability population is 2.7% annually, according to data provided by the Ministry of Health (MINSAs), the National Institute of Statistics and Census (INEC), and the Nicaraguan Federation of Organizations for Rehabilitation and Integration (FECONORI).⁶ Among the continued causes of disability are poverty, automobile accidents, civil unrest, natural disasters, and the presence of antipersonnel landmines scattered randomly across the country by the Hurricane Mitch floods of 1998.

Legislation & Disability Rights

Legal Protections

Nicaragua ratified the Organization of American States (OAS) Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities on 15 July 2002. The instrument was deposited with the General Secretariat of the OAS on 25 November 2002. Additionally, Nicaragua signed the Universal Declaration of Human Rights, the United Nations Convention on the Rights of the Child, and International Labor Organization (ILO) Convention 111, which establishes non-discrimination in employment. Nicaragua has not ratified the ILO Convention 159 that specifically deals with employment policies regarding persons with disabilities.⁷

In June 2003 in New York, the Nicaraguan government delivered a statement before the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. According to that statement, the position of the government is that "a binding treaty or convention should be formalized, which should take into consideration the existing instruments on Human Rights, in order for persons with physical and/or mental disabilities to effectively enjoy civil, political, economic, social and cultural rights as well as their fundamental freedoms on an equal footing."⁸

⁴ Domingo Primante Furlan (Research Consultant of the National Institute of Statistics and Census), interviewed by author, April 2004.

⁵ Oscar Cano (Coordinator of Rehabilitation for the National Technological Institute), interviewed by author, February 2003.

⁶ Domingo Primante Furlan.

⁷ ILO Convention 111, "Discrimination in Respect of Employment and Occupation," <http://webfusion.ilo.org/public/db/standards/normes/appl/appl-displayConv.cfm?conv=C111&hdoff=1%E2%8C%A9=EN>; ILO Convention 159, <http://www.ilo.org/ilolex/english/subjlst.htm>.

⁸ Statement delivered by Ambassador Mario H. Castellón (Alternate Representative of Nicaragua

In regard to national legislation, disability-related laws have been based on international human rights documents, including the UN Standard Rules, to which Nicaragua adheres. The Constitution of the Republic addresses the rights of persons with disabilities, as do a number of other codes and laws.⁹ The Constitution establishes that “the State shall seek to establish programs in the best interest of the disabled for their psychosocial and vocational rehabilitation, for their occupational placement.”¹⁰ The “Prevention, Rehabilitation and Equal Opportunities for Persons with Disabilities Act,” Law 202, promotes disability rights and covers all disabilities.¹¹ It was enacted on 23 August 1995. The regulations of the law were elaborated and published in Decree 50-90 of 25 August 1997. Although disability rights are officially protected by Law 202, the contents of this law are not well-known.

These policies and laws must apply to government, private corporations and society at large. The primary mechanisms of recourse for persons with disabilities regarding the defense of their rights are civil lawsuits, criminal prosecutions, mediation, and intervention from an independent human rights organization. While anyone with disabilities in Nicaragua has the opportunity to make use of these legal instruments, the IDRM research team concluded that many refrain from doing so for three fundamental reasons: a lack of financial resources; the slowness of the judicial process; and a lack of awareness about the laws providing protections.

At the national level, no public or private institutions keep records of discrimination against persons with disabilities in the areas of housing, employment, education or transportation. The Ombudsman’s Office of Human Rights is the government agency responsible for promoting respect for human rights.¹² However, the Ombudsman’s Office has no special disability-related unit or strategy in place.

Legal Barriers

Although the Parent-Child Relationship Act, enacted in 1982, contains no special restrictions for the adoption of children by persons with disabilities, there are limitations for those people who have psychiatric disabilities and no family. There are also restrictions for those who do not earn an adequate living to support their family, which due to lack of employment opportunities, may include numerous people with disabilities.¹³

⁹ National Assembly of the Republic of Nicaragua, [http://legislacion.asamblea.gob.ni/Normaweb.nsf/\\$\\$\\$Search?OpenForm&Seq=1](http://legislacion.asamblea.gob.ni/Normaweb.nsf/$$$Search?OpenForm&Seq=1); Law 185 <http://legislacion.asamblea.gob.ni/Normaweb.nsf/164aa15ba012e567062568a2005b564b/8157a2761151db9c06256afd006369a4?OpenDocument&Highlight=2,discapacidad>; Parent-Child Relationship Act, 1982, [http://legislacion.asamblea.gob.ni/Normaweb.nsf/\\$\\$\\$Search?OpenForm&Seq=1](http://legislacion.asamblea.gob.ni/Normaweb.nsf/$$$Search?OpenForm&Seq=1).

¹⁰ Political Constitution of Nicaragua, art. 62.

¹¹ Law 202.

¹² Jenny Palacios (person in charge of the Complaint Office, Ombudsman’s Office of Human Rights), interviewed by author, Managua, February 2003.

¹³ Parent-Child Relationship Act, sec. 1, enacted in 1982.

Civic Participation

In Nicaragua, all persons with disabilities have the right to vote, pursuant to Law 331 on elections. That law also provides procedures for allowing persons with disabilities to vote, stating that “any individual with physical impairments may be accompanied by a person he or she trusts in order to exercise his or her right to vote. This will be attested in the respective record. Where the physical impairment affects the upper limbs the fingerprint will be replaced by a permanent ink print taken from any other visible part of the body, which will also be attested in the respective record.”¹⁴

Persons with disabilities find it extremely difficult to exercise their right to vote because of the barriers that hinder access to polling stations. Polling stations are not typically accessible to wheelchair users, and neither sign-language interpreters for persons who are deaf nor alternative format ballots for persons who are blind or visually-impaired are available. Leaders of disability organizations estimate that only 40% of polling stations are accessible.¹⁵

The Election Act contains no restrictions preventing persons with disabilities from holding public office. In 2004, two persons with mobility disabilities are in high-level positions in the government: the President of the National Lottery, and a congressman.

Inclusion

Communication

The National Library of Nicaragua does not contain Braille materials, and official documents are not translated into Braille. One small library, financially supported by the Ministry of Culture, does contain some Braille materials although the collection does not include public documents. No other alternative format texts are readily available for persons who are blind. People with visual disabilities can request material from NGO's serving this sector, but requests are not always granted.

Nicaragua's mass media are inaccessible to persons with hearing and/or visual disabilities. News broadcasts do not include sign-language interpreting or close-ups for viewers with hearing impairments.

At present, there is no established method for persons with hearing or speech impairments to communicate with the authorities in the event of a natural disaster, emergency or criminal assault. The Nicaraguan Association of the Deaf (ANSNIC), working in coordination with the regional courts, provides sign-language interpreting services to victims of abuse and other criminal acts. At the national level, human resources dedicated to this end are scarce.

¹⁴. Law 331, “Election Act,” sec. 119, *La Gaceta* [Official Gazette], 24 January 2002.

¹⁵. Panel discussion with leaders of disability organizations, panel facilitated by author.

Education

According to data from the Ministry of Education, Culture and Sports (MECD) and the Ministry of Health, 12% of children aged 0-16 have some kind of disability. However, only 3.5% of children aged 6-16 are enrolled in Special Education programs.¹⁶ Within the elementary education system, 98% of all students with disabilities are enrolled in inclusive education programs or special classes in regular schools. The remaining 2% are enrolled in government-subsidized programs that may consist of special or home education programs. At local schools, willingness to provide education to students with some kind of disability generally exists, although only 27 schools nationwide offer Special Education programs.¹⁷ These programs are located primarily in the major cities. Many children with disabilities in Nicaragua do not have access to education because they live in rural or isolated areas.

Access to high school education is more restricted and depends on the type of disability. Of those youth with disabilities who are enrolled in inclusive high school programs, about 95% have visual and/or physical-mobility disabilities. A pilot project including students who are deaf is scheduled to begin in 2004.

The two-story building of the Ministry of Education, Culture and Sports, headquartered in Managua, is not accessible to wheelchair users. No national regulations require schools to be accessible, but some schools accessible for persons with mobility disabilities have been designed based on individual initiatives.

Training on teaching children with disabilities is available. The general curriculum includes courses in special education for teachers who wish to focus in this area.¹⁸ The National Autonomous University of Nicaragua, UNAN, offers specific courses in Pedagogy with an emphasis on special education. These courses are available both to teachers and other graduate students who wish to specialize in special education. Also found at the college level are courses on disability-related subjects including public policy, the rights of persons with disabilities, and physiotherapy with an emphasis on special education.



*Center of Early Education in Managua
Nicaragua - Los Pipitos*

¹⁶. Hector Collado; Domingo Primante Furlan; Noel Ortega (Assistant to the Executive Secretary of FECONORI), interviewed by author, Managua, February 2003.

¹⁷. Elizabeth Baltodano (Director of Special Education-MECD), interviewed by author, Managua, February 2003.

¹⁸. Governance & Legislation: U.S. Agency for International Development Issues Progress Report on Disability Policy Disabilityworld, vol 2, April/May 2000, <http://www.disabilityworld.org/April-May2000/Governance/USAID.htm>.

With regard to early detection, both the MECD and the Ministry of Health run disability detection programs. The MECD deploys community-based strategies. These programs cover hearing, speech, visual, intellectual, and psychological disabilities. Children whose disabilities are detected through these programs are referred for treatment to the appropriate institutions run by the Ministry of Health, or, in some cases, to private specialist centers or practitioners.¹⁹ Over 50% of mainstream schools throughout the country, in addition to the 27 special education schools, participate in these programs.

Some educational opportunities exist for adolescents with mild intellectual disabilities over the age of 18, however, the number of persons who actually take advantage of these opportunities is low. The Special Education Office, together with groups of parents, coordinates occupational training activities aimed at persons with disabilities and their families. "Los Pipitos," a non-governmental organization for persons with disabilities, conducts similar activities. Care for persons with severe and/or multiple disabilities is provided based on parents' initiatives.

Employment

The unemployment rate for persons with disabilities is unknown, however, it is assumed to be extremely high. Although some employment protections are available for people with disabilities in Law 185, in Law 202, and in the Constitution of the Republic, Nicaragua has no national norms or policies that specifically state that a person with disabilities cannot be discriminated against in employment on the basis of his or her disability.²⁰

Anecdotal evidence suggests that these laws are not supported by adequate policies and are largely ignored by or unknown to public and private employers. For example, Law 185 sets a quota, specifying that for every 50 employees, an employer must hire one person with disabilities. Yet less than 1% of workers hired by the government have some kind of disability.²¹

Among those organizations found to have no policies proscribing employment discrimination against persons with disabilities were the following: the Ministry of Labor (MITRAB), the Superior Council of the Private Enterprise (COSEP), the Ministry of Transportation and Infrastructure (MTI), and the National Technological Institute (INATEC).

The major barriers to employment include inaccessible work environment, ineligibility for social security benefits, lack of transportation, and lack of training. Persons with disabilities who have received job training are better positioned for employment. Training programs are funded by the central government, religious and non-religious non-governmental organizations, and an international development agency that is attached to the United Nations. These programs are run throughout the country, however, the greatest number of them are offered in the capital city. Although these programs provide job skills to persons with disabilities, there are no job placement programs to help secure employment after training.

¹⁹ Héctor Collado.

²⁰ Law 185, sec. 198 – 201e Political Constitution of Nicaragua, art. 80-87.

²¹ Hector COLLADO; Dominga Primante Furlan; Noel Ortega.

The number of persons with disabilities who are placed in jobs is very low, with a rate of about one placement each year.

Health Services

The Ministry of Health (MINSa) provides rehabilitation services for persons with disabilities nationwide. Services are available through hospitals that are located in the main cities of geographical departments around the country.²² Users are reportedly satisfied with these services.²³ Although the government does not provide technical aids for persons with disabilities, some national organizations that are linked to international NGOs do provide such items. The “Aldo Chavarría” National Rehabilitation Hospital in Managua is funded by the Ministry of Health while the “Oscar Danilo Rosales” Hospital in León is primarily supported by donations from international contributors.²⁴

The MINSa coordinates community-based rehabilitation strategies at the national level. The actual programs have not yet been assessed.²⁵

The Ministry of Health provides training on the provision of care to people with disabilities for both medical students and public health physicians who work in related fields.²⁶ The following programs exist: physical therapy, occupational therapy, psychiatry training for nurses and other health professionals, prosthetics and orthotics, and speech therapy. Physical therapy and psychiatry training are considered priorities.²⁷ The UNAN, located in Managua, and the “Oscar Danilo Rosales” Teaching Hospital, located in León, offer training courses on the provision of care to persons with disabilities.²⁸

Although disability-related training is available to all health professionals, the number of professionals who have had such training varies by field. Approximately 10% of all physicians from the MINSa take advantage of these courses. This figure includes those who specialize in disability-related fields. Among general doctors, approximately 3% have received some training on the provision of services to people with disabilities, as have approximately 20% of rural health promoters and 50 percent of nurses and medical assistants.²⁹

Housing

The Nicaraguan Institute for Urban and Rural Housing does not currently have any programs for providing housing for persons with disabilities. Similarly, there are no subsidies available for assistance with housing costs for persons with disabilities.³⁰

²² U.S. Department of State, “Nicaragua: Country Reports on Human Rights Practices - 1999,” 23 February 2000, <http://www.state.gov/g/drl/rls/hrrpt/1999/39.htm>.

²³ Panel discussion.

²⁴ Gustavo R. Siles (Academic Vice-Rector, UNAN), interviewed by author, Managua, February 2003; Héctor Collado.

²⁵ <http://fs1.ops.org.ni/opsnic/tematicas/rehabilita/logros.htm>.

²⁶ Héctor Collado.

²⁷ Héctor Collado; Gustavo R. Siles; Rosa Eva Orellana (Medical Doctor, Head of Rehabilitation of the “Oscar Danilo Rosales” Teaching Hospital), interviewed by author, León, February 2003.

²⁸ Gustavo R. Siles; Rosa Eva Orellana.

²⁹ Héctor Collado.

³⁰ Francisco García, Engineer (Head of Staff of the Institute for Urban and Rural Housing), interviewed by author, Managua, February 2003.

Senior citizens with disabilities often live in nursing homes, which are located across about half of the country. The remainder are not eligible for public housing.

There are no Independent Living Centers in Nicaragua. Disability advocates report that the vast majority of persons with disabilities live with their families because they do not have access to independent housing.

Institutionalization

With regard to long-term hospitalization, there are two major state-run centers that provide short and long-term services, accommodation, and care for persons with disabilities. The Psychiatric or Mental Health Hospital, located in the capital city provides psychological and psychiatric counseling, mental rehabilitation, and acute care for 200 - 250 patients.³¹ The "Aldo Chavarria" Physical Rehabilitation Hospital provides accommodation for periods shorter than 6 months.³² However, when a person is abandoned by his or her family, he or she may remain hospitalized for longer periods.

There are other government-subsidized treatment centers that provide similar services for periods shorter than one year. These centers are listed in Table One.

Table 1: Government Subsidized Homes

Center	Location	Capacity
Pajarito Azul Home	Managua	75 persons/year
Niños Ángeles Home	León	50 persons/year
Santa Lucía Home	León	20 persons/year
Ciudad Darío Home	Matagalpa	30-130/year

A medical prescription is required for patient admission to the hospital facilities. In contrast, admission to a home is based on the family's decision or upon suggestion of a non-governmental organization. Organizations may recommend admission when a person with disabilities is considered to be in a situation of risk, work exploitation, sexual exploitation (primarily in the case of children), or when he or she has been abandoned by his or her family. In addition, the Ministry of the Family refers street children to these homes as a protective measure, even though these children may have no disabilities.³³

³¹. Aura Martínez (Director of the National Psychiatric Hospital), interviewed by author, Managua, February 2003.

³². Raúl Jarquín (Director of the "Aldo Chavarria" Rehabilitation Hospital), interviewed by author, Managua, February 2003.

³³. Berna Castillo (Director of Rehabilitation of the Ministry of the Family), interviewed by author, Managua, February 2003

These institutions or centers are regularly monitored by the Ministry of Health, the Ombudsman's Office of Human Rights, the Ministry of the Family, and the Ministry of Education, Culture and Sports. However, there is no official mechanism for reporting incidences of abuse or death in these institutions. In the past few years no abuse or death has been reported in these centers.³⁴

Accessibility

A joint committee made up of the Ministry of Transportation and Infrastructure (MTI), disability organizations, and the National University of Engineering (UNI), along with representatives from other institutions is in charge of drafting accessibility standards for public and private buildings. As of April 2004, the committee had not completed the standards. A member of the committee reported that the standards "will be a major technical tool to build constructions that are accessible... parks, cinemas, restaurants, urban developments, churches, shopping malls, entertainment centers, streets, train platforms, stairs, steps, ramps, banks, supermarkets, public buildings, schools, hospitals, airports, etc."³⁵ Currently, however, most buildings are not yet accessible. For example, the post offices in Managua, León, and Matagalpa are not accessible to wheelchair users.³⁶

The National University of Engineering (UNI), which trains a large number of the engineers in the country, does not currently have any courses focusing on accessibility. However, the University does offer specific courses on accessibility for the public at large. A universal design course is included in the curriculum of basic architecture of the UNI.

Local public transportation in Managua, León, and Matagalpa is not accessible to wheelchair users, nor is any other adapted or special transportation. Wheelchair users must typically travel by taxi or private vans.

Culture, Sports, and Recreation

The Institute of Youth and Sports (INJUDE) spends 1% of its budget (US\$5,400) on adapted sports including: goalball, chess, basketball, soccer, volleyball, and weightlifting.³⁷ However, these limited actions are considered insufficient. Most of the existing recreational centers in the country are not accessible to persons with disabilities. There are no cultural programs for persons with disabilities.

³⁴ Francisco García, Engineer.

³⁵ Roberto López (Architect, delegate of the Office of Building Standards and Urban Development of the Ministry of Transportation and Infrastructure in charge of drafting accessibility standards), interviewed by author, Managua, April 2004.

³⁶ Yader Valle (press consultant of the Ministry of Transportation and Infrastructure), interviewed by author, February 2003; Leonardo Icaza (Architect, Head of the Office of Urban Development), interviewed by author, City Hall of Managua, February 2003.

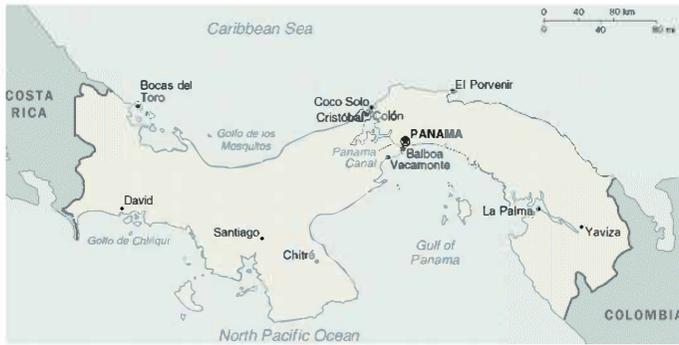
³⁷ Dionisio Zeledón (Director, Nicaraguan Institute of Youth and Sports), interviewed by author.

Disability Action & Awareness

In Nicaragua, the National Council for Rehabilitation (CNR), run jointly by the Ministry of Health and the Ministry of Education, coordinates the cross-institutional efforts and develops rehabilitation policies for persons with disabilities. As of April 2004 no such policies have been made known to the public.³⁸ With no National Disability Action Plan, each government office or entity applies its own policies independently.

There is no cross-disability organization in Nicaragua. Thus, disability organizations develop disability-specific plans of action. The cooperation among disability non-governmental organizations appears to be increasing as a result of their participation in the National Council of Rehabilitation and the drafting of standards on accessibility coordinated by the MTI. Currently, the largest organization in this sector is the Nicaraguan Federation of Organizations for Rehabilitation and Integration (FECONORI), which is made up of organizations that represent persons with multiple disabilities. FENOCORI has three major goals: social integration, accessibility, and human rights protections. Among the obstacles to achieving more effective disability action are noncompliance with Law 202, ineffective operation of the CNR, the lack of coordination in the disability sector, and the lack of financial resources. In order to advance the rights of persons with disabilities, more unified disability organizations at the governmental and non-governmental levels are necessary.

³⁸. <http://www.grupoese.com.ni/2001/bn/02/01/bg1MN0201.htm>.



Panama

Key Factors: The passage of the Equalization of Opportunities for People with Disabilities Act, Law 42 of 1999, created a legal framework for the protection of the rights of people with disabilities in Panama.

Terminology

The official terminology used to refer to disability has shifted over time. Historically, the word “impedido”, translated here as “handicapped,” was used in the context of disability. The most recent national law specifically focused on disability issues, however, abandoned that language. Law 42 on the Equalization of Opportunities for People with Disabilities, which was enacted on 27 August 1999, makes specific reference to disability rights and the protection thereof.¹

Terms like “físicamente imposibilitados” and “impedidos físicos” are found in other Panamanian legal documents.² When directly quoting these documents within this report, these phrases have been translated as “physically impaired.” The phrase “niños y jóvenes con necesidades educativas especiales” has been translated as “children and youth with special education needs.”³

1. Law 42, *Equalization of Opportunities for People with Disabilities Act*, Official Gazette 23876, 1996.

2. *Código Electoral de Panamá*, Official Gazette 24748, 22 February 2003.

3. Law 34, 1995.

Definition of Disability

There is not a single definition of disability that forms the basis for all legislation on disability rights issues. The following table details the various definitions of disability contained within Panamanian law.

Table 1: Definitions of Disability in Panamanian Law

Document	Date	Definition
Law 1 Protection of Hearing-impaired Persons	28 January 1992	Disabled Person: Any individual suffering from a permanent or temporary, total or partial functional disorder, whether physical, sensory, emotional or intellectual, which restricts the effective execution of activities regarding familial, social, educational or occupational integration.
Law 3 Family Code	17 May 1994 Amended in 1995	'Disabled Person' means any individual suffering from any limitation or restriction, resulting from an impairment, of ability to perform an activity in the manner or within the range considered normal for a human being. The State shall put in place a multi-sector and inter-institutional coordination program to guarantee his or her comprehensive development and his or her social insertion.
Law 2 Equalization of Opportunities for People with Dis- abilities	27 August 1999	Permanent or temporary, total or partial functional disorder, whether physical, sensory or intellectual, which restricts an individual's ability to perform an activity in the manner or within the range considered normal for a human being.
Executive Order 46 Rules for the Care of Persons with Disabilities	28 December 1998	Permanent or temporary functional disorder, either physical or mental that limits an individual's ability to maintain an adequate integration at the familial, social, educational or occupational levels.

Other official documents such as the Procedural Guide for the Regulation of Executive Order 1 and the "Diagnosis on the Quality of Life of Persons with Disabilities in the Province of Panama" are based upon similar, but slightly varied definitions. Overall, these definitions emphasize the physical or sensory impairment of an individual. However, by also including within the definition the concept of restrictions on activities and life roles, these definitions represent an improvement over the medical model of disability.

Most of the laws include within their purview people with physical, sensory, or mental disabilities. Only Law 1 and the Family Code include people with psychiatric disabilities.

Disability Population

Panama conducts a national population census every ten years to determine the size of the population. Both the 1990 and 2000 censuses included questions to measure the number of people with disabilities within Panama. According to the most recent census in 2000, the total population of Panama was 2,984,331. Of that, the census found 52,197 persons with disabilities, comprising 1.8% of the total population. In 1990, there were 31,111 persons with disabilities, comprising 1.33% of the total population.

These numbers are likely very poor estimates of the actual number of people with disabilities in Panama. There are three main factors that contributed to the depressed numbers reported in official reports. First, the question in the 2000 census that assessed the presence of a disability used the word “handicapped.” Despite its negative connotation, it was thought to be better understood by people at large than a more complex definition of disability.⁴ However, the use of such a narrow and problematic term likely excluded many people from the final count.

Second, cultural patterns and stereotypes hinder data collection. Parents may hide their children with disabilities, and people with disabilities also may not report their disability, leading to inaccurate numbers.⁵ Lastly, the census does not cover all geographical regions of the country. The neglected areas tend to be primarily indigenous and have higher rates of poverty. Sanitation and nutrition conditions are typically worse in these areas than in the rest of the country, making it likely that there is a higher proportion of the population that is disabled. In districts that are classified at the level of severe poverty, 70.5% of dwellings do not have access to clean drinking water or sanitation.⁶

Legislation & Disability Rights

Legal Protections

Panama signed the Organizations of American States (OAS) Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities in June 1999. It ratified the convention on 24 January 2001 and deposited the ratification instrument on 16 February 2001.⁷ The convention entered into force on 14 September 2001. Panama is not currently complying with the submission requirements of the convention.⁸

⁴ General Auditing Authority of the Republic of Panama, *National Housing and Population Census*, 14 May 2000.

⁵ Panel discussion with leaders of disability organizations, discussion conducted by author, Patronato Luz del Ciego, 27 August 2003.

⁶ Ministerio de la Juventud, la Mujer, la Niñez y la Familia, *II Informe Nacional “Clara González”, Situación de la Mujer en Panamá* [2nd “Clara González” National Report - Women’s Status in Panama], 1999.

⁷ Luis Fernando Astorga Gatjens, “14 Countries Ratified Inter-American Convention on Discrimination,” *Disability World*, (8 June 2003), www.disabilityworld.org.

⁸ Interview with an Official from Ombudsman’s Office, Panama, October, 2003.

Panama issued a statement in support of the creation of a UN Convention on the Rights of Persons with Disabilities. The government has also sent a note to the UN Standing Panamanian Representative to support the UN International Convention on Disability Human Rights proposed by Mexico.⁸

The country has a variety of national laws and agreements in place that are intended to protect the rights of people with disabilities. In addition, other laws such as Law 4, the Equality of Opportunities for Women Act, contain sections regarding disability issues.⁹ The laws impose obligations upon government officials, municipalities, businesses, the media, public and private transportation groups, and individuals.

The most important of these laws is Law 42, which covers a broad range of topics within a rights framework. Section 54 establishes that “any individual or entity incurring any form of discrimination against an individual by reason of his or her disabilities, or limiting his or her access to health services, education, employment, information, communication, transportation, recreation, sports and other rights enjoyed by the rest of the population, will be sanctioned according to damage caused by such discrimination, under current legislation in force, notwithstanding the civil and criminal penalties that may apply.” Additionally, the law provides for the participation of people with disabilities in the policy-making process. Regulations for Law 42 were created by Order 88 on 12 November 2002.¹⁰

Leaders of disability organizations within Panama report that overall compliance with the laws is very low.¹² Although there is no central agency recording rights abuses, violence or discrimination against people with disabilities, the Ombudsman’s Office and the National Disability Office are able to handle complaints.¹³

Civic Participation

All persons with disabilities have the right to vote. The Electoral Code of Panama contains two provisions that specifically pertain to persons with disabilities. First, it provides that “the vote is secret. Those known to be blind and the physically impaired may be accompanied by a person they trust when entering the ballot booth.”¹⁴ It also states that “voters will queue outside the voting booth and will vote one at a time. The voting authority at each polling station shall take the steps necessary for candidates, pregnant women, sick people or persons with mobility disabilities to vote immediately without having to queue ...provided they have the right to vote.”¹⁵

⁹ Fausto Perez (Director of the National Disability Office, Ministry of Youth, Women, Childhood and Family), interviewed by author, Panama, 24 June 2003.

¹⁰ Law 4, *Equality of Opportunities for Women Act*, Chapter XII, Title VII, sec. 28, *Official Gazette* 23729.

¹¹ Order 88. *Official Gazette* 24682.

¹² Panel discussion.

¹³ The National Disability Office is under the Ministry of Youth, Women, Childhood and Family and was created by Law 42, 19 November 1997.

¹⁴ *Electoral Code of Panama*, Panamanian Election Court, sec. 265, *Official Gazette* 24748, 22 February 2003.

¹⁵ *Electoral Code of Panama*, sec. 266.

Law 42 on the Equalization of Opportunities states that “the Election Court shall take the steps necessary for persons with disabilities to freely exercise their right to vote. For that purpose, the Court will make available voting stations, centers and places.”¹⁶ Notwithstanding these statutory provisions, less than 20% of voting stations are reported to be accessible.¹⁷ Braille-formatted documentation for persons who are blind or visually-impaired is non-existent. The Election Court has initiated an effort to create a registry of people with disabilities in order to allow them to vote in accessible voting stations.

Persons with disabilities also have the right to be elected to public office. The National Disability Office, which is considered the ultimate authority in disability matters, is headed by a visually-impaired person.

Inclusion

Communication

The Government does not provide a Braille version of the Constitution, and no other official documents are published in alternative formats. National television news programs are not captioned for viewers who are hearing-impaired. There are no initiatives in progress intended to create accessible communication networks.

The National Library does not provide materials in alternative formats. However, the Simón Bolívar Library of the University of Panama has a special Braille and talking book section managed by the Visually-Impaired College Graduates Association. In addition, the Patronato Luz del Ciego organization provides talking books and JAWS-based Internet access.

At the Hellen Keller School of the Panamanian Institute for Special Habilitation (IPHE), teachers specialized in services for people who are deaf and blind are implementing a program intended for this segment of the population. The program provides some alternative means of communication for both teachers and parents of children with multiple disabilities.¹⁸ There are no resources or support services for other multiple disabilities.

No method or strategy is in place for people with hearing or speech impediments to contact authorities in the event of a natural disaster, civil emergency, or criminal assault. In January 2000, the Technical Advisory Commission for Municipal Agreement 19 held two meetings with top executives of the Telephone Company Cable & Wireless to put in place the TTY system for persons who are hearing-impaired. To date, however, the TTY system is not yet operating.¹⁹

¹⁶ Law 42, sec. 10, 1999.

¹⁷ Panel discussion.

¹⁸ Interview with teaching staff at the Panamanian Institute for Special Habilitation, Panama, 5 September 2003.

¹⁹ Interview with officers from the telecommunications company Cable and Wireless and from the Municipal Works and Construction Office, Panama, 2000.

Education

The Ministry of Education does not have a program to detect disabilities among school-aged children (6-16 years old), and there are no records available on the percentage of students enrolled in special education programs. Since 1951, the Panamanian Institute for Special Habilitation (IPHE) has been in charge of special education, but there is no effective coordination with the Ministry of Education to make sure all children are receiving education.

The IPHE has a national program for the early detection of visual and hearing impairments and is developing a program for the prevention of these impairments. However, it does not cover other disabilities, nor does it cover all geographical areas within Panama.²⁰ The IPHE also runs a program for parents of children with disabilities based on a comprehensive care model that includes education, legal counseling, training, and psychological support.

Law 34 enacted in 1995 and Executive Order 1 of 2000 both provide a framework for requiring inclusive education. IPHE officials report that “a program intended to promote inclusive education is beginning to be implemented in an attempt to move away from the segregated approach.”²¹ Sixty percent of school-aged children with disabilities are reportedly undergoing an integration process. This information cannot yet be verified since there are no records in this regard.²² Institutions with special education programs tend to be located in major cities only.²³ In rural areas, education opportunities are minimal due to poverty levels.

Law 42 requires that all schools must be accessible for persons with disabilities in terms of infrastructure, communication, teachers’ training, and alternative format educational materials. The percentage of schools complying with these policies is reported to be less than 20% in both urban and suburban areas of the country. Moreover, the building which houses the Ministry of Education is not accessible to wheelchair users.



The Ministry of Education building is not accessible to persons with mobility disabilities.

²⁰. Interview with an official from the Technical and Medical Services Department of the Panamanian Institute for Special Habilitation, Panama, 5 September 2003.

²¹. *Ibid.*

²². *Ibid.*

²³. Interview with an official from the National Special Education Office of the Ministry of Education, Panama, 12 September 2003.

Teacher training in special education can be obtained from three facilities: the Advanced Training Institute of the State University of Panama, the Santa María La Antigua University, and the Americas' Specialized University (UDELAS).²⁴

Employment

According to the latest household survey, unemployment in Panama is 12.8% for the entire population and 18% for persons with disabilities. However, a large percentage of the disability population was considered economically inactive and thus was not included in the unemployment calculations. According to research conducted by the National Disability Office, unemployment among the disability population hovers near 40%.²⁵

Laws concerning employment for people with disabilities include Executive Order 88 of 1993, which provides benefits for employers of people with disabilities, and several sections of Law 42, which prohibits discrimination against people with disabilities. Section 41 establishes that "where an individual with disabilities applies for a job on equal qualifications, he or she shall be entitled to preferential consideration to fill the vacant position."²⁶ This law eliminated Subsection 5 of Section 213 of the Labor Code, which authorized employers to dismiss personnel on the grounds of disability.²⁷ Section 44 requires that the staff of all employers with 50 or more employees must be composed of at least 2% people with disabilities. It also establishes that the national government must employ persons with disabilities in all its ministries, agencies, and institutions.²⁸

The federal government funds some training and placement programs for people with disabilities. These are concentrated in the capital city, so their scope is limited. As of this writing, the government had appointed only one official for these selective placement programs. Training and placement programs are also conducted by Industrias de Buena Voluntad, a non-religious NGO. These programs, however, are restricted to people with particular disabilities, and so are not available to all members of the disability community.²⁹

Health Services

The Ministry of Health provides funding for health care and rehabilitation programs for persons with disabilities, but the funding and services are limited. The National Institute of Physical Medicine and Rehabilitation provides physical therapy, rehabilitation, health care, and speech therapy for children and adolescents with cerebral palsy or mobility disabilities up to the age of 22. For those persons who become disabled at a later stage in life, comprehensive rehabilitation

²⁴. The Santa María La Antigua University is a private entity that has offered teacher training courses, and the Americas' Specialized University (UDELAS) is a semi-public teacher training center.

²⁵. Fausto Pérez.

²⁶. Law 42, sec. 41, 1999.

²⁷. Código de Trabajo, <http://www.legalinfo-panama.com/legislacion/laboral/codtrabA6.pdf>.

²⁸. Law 42, sec. 44, 1999.

²⁹. Participants in IBV programs are typically people with intellectual or motor disabilities as well as some persons who are deaf.

services are not available. Most of the rehabilitation institutions are located in the capital city.

The Panamanian National Health Service has not implemented a strategy of Community-Based Rehabilitation (CBR).³⁰ However, the National Disability Office services are based on this approach and help rural and indigenous parents with children with cerebral palsy by providing them with training in home therapies and the design of technical aids for functional development.³¹

The social security system does not provide access to technical aids for people with disabilities. A limited number of aids are available from some publicly and privately funded organizations including: the First Lady's office, the National Lottery, the National Disability Office, the Pro-Disabled Foundation, the Lions' Club, and the Rotary Club.³²

The School of Medicine does not train students on the provision of care to people with disabilities either before or after obtaining the medical degree. However, Panama does have some special education training in physical therapy, occupational therapy, and speech therapy.³³

No measures have been taken regarding discrimination against people with disabilities in connection with health insurance coverage.

Housing

There is currently a serious housing shortage in Panama. The Ministry of Housing estimates that at present the shortage comprises approximately 200,000 housing units and is particularly acute in the province of Panama, which is the most densely populated area of the country. The high cost of land and construction restricts supply, and social housing programs fall short of meeting demand.³⁴

It is especially difficult for the disability community to freely choose where to live. Adapted, accessible housing is not available. No housing subsidies are available for persons with disabilities, nor are they eligible for public housing. It is estimated that 70% of persons with disabilities reside with their families; 10% reside in public institutions; 15% reside in charitable institutions operated by religious orders, private institutions, or nursing homes for elderly people; and 5% are homeless.

³⁰. Interview with an official from the National Office for the Promotion of Health of the Ministry of Health, Panama, 1 September 2003.

³¹. Fausto Pérez.

³². President of Panama, <http://www.presidencia.gob.pa/dpd/index.htm>; National Lottery, http://www.loterianacional.com.pa/dirección_de_desarrollo_social_y.htm; Fausto Pérez; US Panamanian Embassy, "Wheelchair Donation By Fundacion Pro-Impedidos," (press release, 2003, <http://usembassy.state.gov/panama/press0903.html>); Lions' Club, <http://www.leonesparquelefevre.8m.com/actividades.html>; Wheelchair Foundation, http://www.wheelchairfoundation.org/news/newsletter_list.cfm.

³³. Fausto Pérez.

³⁴. Bleixen Caballero, "Miles de Panameños no Tienen Viviendas Dignas" [Thousands of Panamanians Lack Dignified Housing], *El Panamá América*, 26 October 2003, sec. C, 9.

Institutionalization

Table two lists many of the institutions offering long-term lodging and care for persons with disabilities.

Table 2: Institutions in Panama

Name of institution	Disability population served	Funding type
Rayos de Luz Home	Persons over the age of 18 with mental retardation, Down Syndrome and autism	Private
Larga Estancia Hospital	Persons with sensory and mobility disabilities	Ministry of Health
Esperanza Residence	Persons with mobility disabilities	Social Security Fund
San José de Calcuta Residence	Persons with disabilities who have been abandoned	Religious
Bolivar Home	Elderly adults with disabilities	Religious
Nueva Vida Residence	Elderly adults with disabilities	Religious
San José de Malambo Home	Persons with AIDS, sensory and mobility disabilities who have been abandoned	Religious
National Union of Blind Persons	Persons who are blind or visually-impaired	Subsidized by the Ministry of Youth, Women, Childhood and Family
Colon Club of the Blind	Persons who are blind or visually-impaired	Subsidized by the Ministry of Youth, Women, Childhood and Family

Accessibility

Law 42 establishes that both new and existing buildings must be made accessible to people with disabilities. This requirement applies to both public and private facilities. However, disability advocates estimate that only 5 percent of public buildings meet accessibility standards.³⁵ For example, there are 72 post office branches in the capital city of Panama, yet very few of them meet accessibility requirements. The main post office building is inaccessible.

³⁵. Panel discussion.



Inaccessible Post Office in Zone One



Accessible Post Office in the El Dorado Unit

Courses in universal design are not typically available in the country. However, two basic courses on accessibility to the built environment were organized by the Christian Fraternity of Ill and Disabled Persons (a disability NGO) and the National Federation of Persons with Disabilities. These courses were aided financially by Spain's Real Patronato and the Pan-American Health Organization, and jointly coordinated with the National Disability Office, the Architects' Association, and the Municipal Works and Construction Office. Seventy construction-related professionals, including engineers and architects, were trained on universal design through these courses.³⁶

Organizations of people with disabilities participate in ongoing meetings with the Technical Advisory Commission of the Municipal Works and Construction Office regarding the removal of architectural barriers.

Public transportation in Panama is of generally poor quality. Neither the capital city nor the provincial capitals have adapted bus systems for wheelchair users. People with mobility disabilities must travel by their own car or by taxi.

Both Law 42 and Executive Order 88 establish tax benefits for the import or adaptation of special vehicles and contain specific provisions intended to have adapted vehicles available by 2004. They also include rules related to air and railway transportation. However, few transportation organizations appear to be complying with these rules.

Culture, Sports, and Recreation

Leaders of disability organizations report that government impact in facilitating the access of persons with disabilities to sports, recreation, and cultural activities is extremely low.³⁷ The National Institute of Sports (INDE) is responsible for policies and actions related to sports at the national level. The INDE supports very few activities for people with disabilities because there are few programs in place and a restricted budget. Organizations contributing to the

³⁶. Elementary Course on Accessibility and Safety to the Built Environment, offered at Patronato Luz del Ciego, Panama, 30-31 May 2000 and Santa María la Antigua University, Panama, 5-6 August 2002.

³⁷. Panel discussion.

participation of persons with disabilities in such activities include: the National Lottery, the Americas University, which established a master program in Physical Education aimed at training teachers who assist students with special education needs; and the Special Olympic Games, a private organization devoted to persons with intellectual disabilities.

Disability Action & Awareness

Disability rights action is primarily taken by a limited number of government agencies and by organizations of and for people with disabilities. Human rights organizations more generally have not yet included the systematic protection and promotion of disability rights in their agendas. An informal poll conducted among seven organizations that advocate for human rights revealed a lack of knowledge and awareness regarding the vulnerability of the disability sector and the need for promoting the human rights of people with disabilities.³⁸ Although disability issues are not among their priorities, these organizations have shown a willingness to engage with disability as a human rights issue.³⁹

The National Disability Office is among the most active government agencies. The office organized several disability awareness raising seminars, which were targeted at the population in general, representatives of NGOs, and representatives of governmental agencies responsible for the enforcement of disability laws and regulations.⁴⁰

Additionally, the National Disability Office helped create a National Disability Action Plan in coordination with disability NGOs. The goals of the plan are to improve the quality of life of persons with disabilities in Panama. It was based on data gathered in the National Census 2000 and examined ten intervention areas: prevention, disability detection, access to services, quality of rehabilitation services, quality of education services, vocational training and job placement, sports, leisure and recreation, community awareness, accessibility, and transportation. The cost of implementing the plan has not yet been quantified, but it implies short-, medium- and long-term budget disbursements by numerous institutions. Government ministries and the National Federation of Persons with Disabilities are responsible for the implementation of the plan.

³⁸. Demetrio Solís (Commission for Justice and Peace), interviewed by author, Panama, 18 Sept. 2003.

³⁹. Maribel Jaén (Executive Director of the Commission for Justice and Peace), interviewed by author, 30 Oct. 2003.

⁴⁰. Fausto Pérez.

The National Federation of Persons with Disabilities (FENAPEDI) is a coordinating organization that has been developing disability policies since 2000. It consists of 14 organizations of persons with disabilities. Among the goals of FENAPEDI are: monitoring participation in all discussions of disability policies and rules; monitoring compliance with the law to ensure the inclusion of disability representatives; and supporting disability awareness raising campaigns targeted at the population in general and at the government. It has not yet assumed a significant role in coordinating and leading advocacy efforts.

Other important organizations include the IPHE, which acts as a policy and planning forum for disability issues, and the Christian Fraternity for Ill and Disabled Persons, which is an international NGO headed by persons with disabilities. In addition to various advocacy efforts, activities of the Christian Fraternity for Ill and Disabled Persons include: awareness-raising and training activities through weekly radio programs and national television programs; organization of annual commemoration of the International Day of Disabled Persons; and implementation of leadership training programs. This institution's programs are funded by means of donations and self-sustaining activities.⁴¹

Some financial support for national organizations of people with disabilities comes from the Ministry of Youth, Women, Childhood, and Family.⁴² Other groups receive financial support from international organizations and international NGOs or develop self-sustaining activities.

Leaders of disability organizations point to the following goals as the most significant for the advancement of disability rights in Panama: raising awareness of disability rights among key government decision-makers; promoting the organizational development of advocacy groups and institutions; raising awareness among the general population regarding Law and incorporating inclusive education into national education plans.⁴³

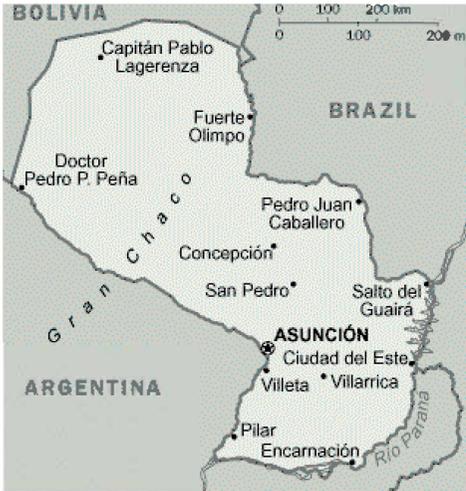


Disability Action Group in Panama

⁴¹. Juan Bello (National Coordinator, Christian Fraternity for Ill and Disabled Persons), interviewed by author, Panama, 2 October 2003.

⁴². Fausto Pérez;

⁴³. Panel discussion.



Paraguay

Key Factors: Since 1998 Paraguay has been in financial crisis, and the need to reduce the national deficit has resulted in the postponement of government investment in social policy and programs in health care, education, and infrastructure. Social and economic surveys reveal poor quality and coverage of social services. Thus, although Paraguay has enacted a series of laws and created institutions intended for the protection of disability rights, the

country has not made the changes necessary to secure equal opportunities for people with disabilities.

Terminology

A number of terms are used in Paraguay to refer to persons with disabilities. Although associations of persons with disabilities use “personas con discapacidad,” translated as “persons with disabilities,” other terms are often used in official contexts. For example, the 2002 Central Department survey of people with disabilities used the phrase “personas con capacidades diferentes,” which has been translated in this report as “person with different abilities.” Other legal documents, including the Constitution, refer to “personas excepcionales,” translated as “exceptional person,” or “personas con impedimentos,” translated as “impaired person.” The Electoral Code, Section 210, uses “misusválidos,” translated as “handicapped.” Several legal documents and the National Census, use the broad term “impedimentos,” translated as “impediments,” and include designations such as “mudos,” translated as “mute.” When directly quoting original documents, the original terminology has been preserved.

Definition of Disability

Most definitions of disability used within the country focus on the characteristics of the individual who has a disability rather than on the environment or the barriers that determine the impact on the individual. The 1979 law that created the National Institute for the Protection of Exceptional People (INPRO), for example, defined a person with a disability as “any individual that suffers from any reduction, caused by a congenital or an acquired condition, of his or her mental or physical ability that affects his or her possibilities of self-reliance, learning or working.”¹

The definition of “different abilities” adopted by the Central Department survey is “a permanent restriction, resulting from a mobility, sensory or mental impairment, of ability to perform daily life activities in the manner or within the range considered normal for a human being.”²

Disability Population

According to the most recent, 2002 National Census the total population of Paraguay is 5,183,080 people.³ The census included a disability-related question intended to identify the number of people with disabilities in the country. The question asked “Is there any person in this home who has a permanent physical or mental impediment?”⁴ The results have not yet been tabulated. Leaders of the disability community do not expect the forthcoming census data to be fully reliable. According to the reports received by disability associations, census interviewers in some areas might not have been adequately trained and, in some cases, questions about disability were not asked.⁵

¹ Law 780/79, 30 November 1979, <http://www.iin.oas.org/badaj/docs/I780py79.htm>.

² National Census, *Encuestas a personas con Capacidades Diferentes del Departamento Central* [Central Department Survey of Persons with Different Abilities], August 2002, 9, http://www.dgeec.gov.py/Publicaciones/biblioteca/capacidades_diferentes/capacidades_diferentes.pdf.

³ National Census, *Principales Resultados Del Censo 2.002 Vivienda Y Población* [Results of the 2002 Housing and Population Census], 2002.

⁴ *Encuestas a personas con Capacidades Diferentes del Departamento Central*. The survey includes the following list of possible “impediments”: “Paralysis or diminished strength of the legs or arms; missing body part; completely deaf; does not hear well, needs, or uses appliance to hear; mute (does not speak); speaks with great difficulty; blind in both eyes (does not see at all); blind in one eye; seeing difficulty (even with eyeglasses); down syndrome; mental retardation; dementia.” Lastly, the census provides the following list as possible causes of disability: “born with impediment; illness; accident; product of aging; another cause.”

⁵ Panel discussion with leaders of disability organizations, discussion facilitated by author, Asunción, 11 September 2003.

Without a reliable and valid count of the number of people with disabilities in the country, some officials base their estimates on the World Health Organization's finding that people with disabilities average about 10% of the worldwide population. This estimate suggests that the disability population in Paraguay would be approximately 500,000 persons.⁶

Although there are no national figures yet available, between June and July 2002 the Secretary of Health of the Central Department government conducted a survey among "persons with different abilities" living in that department. This work was supported by Deutsche Gesellschaft Fur Technische Zusammenarbeit (GTZ), the National Institute for the Protection of Exceptional People (INPRO), and the Network for the Comprehensive Care of Persons with Different Abilities.⁷ The sample comprised a total of 8,000 households from the 19 districts of the Central Department. Table one details the results.

Table 1: Distribution of "Impairments" Among People in the Central Department⁸

Seeing difficulties	18,532
Hearing difficulties	7,273
Speaking difficulties	5,347
Do not speak	2,288
Walking, climbing stairs, standing, etc.	9,901
Gripping, holding or carrying objects	5,788
Mental retardation	5,370
Seizures or convulsions	5,207
Others	10,969
Total	70,675

Legislation & Disability Rights

Legal Protections

Paraguay adheres to the OAS Inter-American Convention on the Elimination on all Forms of Discrimination Against Persons with Disabilities. It signed the convention on 8 June 1999, ratified it on 28 June 2002, and deposited the ratification document on 22 October 2002.¹⁰ The country ratified ILO Convention 159 on 2 May 1991.¹¹

The president of Paraguay along with the other heads of state of the Southern Common Market (Mercosur) also signed the Mercosur Social and Labor

⁶ Gloria González (Information Center of the General Statistics Office), interviewed by author, 2 August 2003.

⁷ *Encuestas a personas con Capacidades Diferentes del Departamento Central*.

⁸ *ibid.*

⁹ CINTERFOR/ILO, *Centro Interamericano de Investigación y Documentación sobre Formación Profesional*, <http://www.cinterfor.org.uy/public/spanish/region/ampro/cinterfor/temas/worker/doc/otros/iii/>.

Declaration as part of the Treaty of Asunción. Section Two of the declaration states that “individuals with intellectual or sensory disabilities shall be treated with dignity and shall not be discriminated against. Their social and labor insertion shall be favored.”⁸

Finally, Paraguay attended the first meeting of the Ad Hoc Committee that is considering proposals for a UN Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. No representatives were present at the second Ad Hoc Committee meeting.¹²

The 1992 National Constitution of Paraguay contains two sections regarding people with disabilities. Chapter IV explicitly acknowledges the right of people with disabilities to health care, education, recreation, and vocational training. Section 58 holds that “the government shall put in place a prevention, treatment, rehabilitation and integration policy regarding persons with physical, intellectual and sensory disabilities to provide them with the special care needed. They will enjoy all the rights granted by this Constitution to all inhabitants, on the basis of equal opportunities, so as to compensate for their disadvantages.”¹³

The Constitution also contains a section on employment rights that includes a non-discrimination clause. Section 88 reads that “no form of discrimination shall be admitted among employees on the grounds of ethnic origin, sex, age, religion, social status, or political or trade union preferences. Additionally, the work of persons with impairments or disabilities, whether intellectual or physical, shall be especially protected.”¹⁴

Several other laws also focus on people with disabilities. One of the first was Law 780/79, passed in 1979, which created INPRO, “to protect Exceptional People in a comprehensive way so as to counter the disadvantages caused by their impairments and be given the opportunity, based on their own efforts, to perform a role within the community equivalent to that performed by normal people.”¹⁵ Although several other national laws were drafted prior to the UN Standard Rules, they address some of the same points. Law 122/90 establishes disability rights and privileges in health care, employment, public transportation, education, vocational training, and priority service in public places.¹⁶ Law 1098/98 created rules on accessibility.¹⁷ Finally, the Labor Code, Law 213, which refers specifically to people with disabilities, establishes that “the State shall be in charge of providing vocational and technical training to employees so as to enhance their skills for the purposes of earning better income and attaining greater performance.”¹⁸

No human rights organization in the country is active on issues pertaining to disability rights.

¹⁰. Law 1925.

¹¹. Law 36/90.

¹². UN Document, A/AC.265/2003/ Inf./ 1.

¹³. National Constitution of Paraguay, 11.

¹⁴. National Constitution of Paraguay, ch. VIII, Title I, 14.

¹⁵. Law 780/79.

¹⁶. Law 122/90, <http://www.iin.oas.org/badaj/docs/ldispy90.htm>.

¹⁷. Law 1098/98, *Gazeta oficial de la Republica del Paraguay* 228, 27 November 1998, 4.

Legal Barriers

Section 36 of the Paraguayan Civil Code provides that “legal capacity consists of the ability of a person to exercise his or her rights on his or her own.” In some circumstances, people with certain disabilities can be declared legally incapable. According to Section 37, these include “mentally-ill persons” and “deaf-mute persons that cannot make themselves understood either in writing or in any other way.”¹⁸ In addition, Section 153 of the Constitution states that the exercise of citizenship rights will cease “should there be a court decision declaring the citizen legally incapable because he or she cannot make free and informed decisions.”²⁰ People with disabilities who are declared legally incapable lose all legal rights including the right to vote.

Civic Participation

People with disabilities have the right to vote in Paraguay. The National Constitution states that “Paraguayan citizens over eighteen years old residing in the national territory have, without any distinction, the right to elect authorities.” Additionally, they “have the right to elect and be elected to public office without further restrictions than those herein established.”²¹

The Electoral Code establishes some accommodations to be made for people with disabilities at the time of voting. People with disabilities who “are restricted from marking the voting card and placing it into the ballot box may be helped by any person who they trust.”²² Section 210 states that:

- Voters will queue outside the voting booths and will vote one at a time. The voting authorities at each polling station will give priority to:
- a. pregnant women and handicapped individuals;
 - b. sick individuals
 - c. voters exceeding the age of 75; and
 - d. election authorities and candidates.

¹⁸. Law 213, *Labor Code*, ch. II, sec. 16. ·

¹⁹. *Ibid.*

²⁰. National Constitution of Paraguay, ch. III, 22.

²¹. National Constitution of Paraguay, ch. X, 18.

²². Law 01/90, *Electoral Code*, 39.

The factors that make it difficult for persons with disabilities to exercise their right to vote include social barriers and the lack of accessible facilities. Ballot boxes are typically not located on the ground floor, creating problems for persons with mobility disabilities. Disability leaders report that elections generally take place in public schools, which are often old buildings with steps. They estimate that only 20% to 40% of voting booths in the country are accessible.²³

Lack of accessible communication is also a problem. Braille voting cards are not available for persons who are blind or visually impaired, and persons who are deaf typically lack access to information on candidates' proposals. Inaccessible communication presents barriers to making an informed choice. People with intellectual disabilities or mental retardation experience some of the most severe discrimination.²⁴

Leaders of disability organizations report that many people from the disability community are not registered to vote because they are unable to reach the registration center. They relayed that this problem is especially prevalent in the interior of the country.²⁵ After the last election the International Foundation for Elections Systems recommended that the government provide more information to electors about the location of their polling places on voting lists and ensure greater access to the polling places for citizens with disabilities.²⁶

Inclusion

Communication

Neither the government nor the National Library provides a Braille version of the Constitution for persons who are blind or visually-impaired, nor are there any other materials available in alternative formats. When persons who are blind need information on a specific issue, they must go to the library accompanied by another person or ask for assistance from librarians.

The national news is not captioned and there are no sign-language interpreters for viewers who are hearing-impaired.²⁷

²³. Panel discussion.

²⁴. Civic and Electoral Research Center, Electoral Justice Paraguay, *El Derecho al Sufragio de la Persona Con Discapacidad* [The Right to Vote of Persons with Disabilities], (Paraguay, 2002).

²⁵. Panel discussion.

²⁶. Law 01/90, http://www.ifes.org/pressroom/Press%20Releases/04_28_2003_paraguay_elections2.pdf.

²⁷. Selva Recalde (Vice-president, Paraguayan Association of Blind Persons), interviewed by author, 9 September 2003; Francisco Garay Soto (National Library Director), telephone interview, 10 February 2004; Emilio Pineda (Coordinator of the Paraguayan Association of Deaf-Mute Persons), interviewed by author, 2 September 2003.

Education

According to Paraguay law, persons with disabilities have the same right to education as other members of society. There are no data, however, on the percentage of elementary students with disabilities.

The Ministry of Education and Culture has a special education office, but has not yet developed a clear policy enabling the integration of persons with disabilities into the regular schooling system in a way that will provide equal educational opportunities. There is no national program for the early detection of disabilities.²⁸

In general, children with disabilities who are attending school receive their education in special classes within regular schools, special day schools, or separate residential schools. The country has 1 inclusive school, 5 schools with special classes, 480 schools with support classes, 21 special day schools, 17 special education schools, 3 special education and rehabilitation centers, 4 comprehensive centers, and 5 separate residential schools. Special education schools are located only in major cities.²⁹ High-school students with physical, visual, or hearing impairments are usually taught at regular schools.

Many children are referred to support classes without proper evaluation and sometimes with a mistaken diagnosis. Schools with support classes do not admit children with multiple disabilities or severe mental retardation since teachers are not adequately trained to meet their needs.³⁰

Several teachers consulted by IDRM reported that there may be a large number of children with disabilities who have never attended school since no special education schools exist in some areas of the country and special classes are often non-existent. In small cities or villages, children with disabilities attend school only by consent of the teacher. Since the teachers do not have a special syllabus to offer, most students in these circumstances attend school for the sake of integration rather than education.³¹ People with intellectual disabilities over the age of 18, especially those living in the capital city, can attend occupational workshops.

Training on teaching children with disabilities is not included in the national teacher curriculum. Teachers who wish to obtain special education training must acquire it abroad or on their own. There are some very general courses addressing disability in certain areas such as psychology, pedagogy, and sociology.³²

²⁸. UNESCO, *Educación Especial- Paraguay* [Special Education – Paraguay], 2000.

²⁹. Sonia Ferreira, (Ministry of Education and Culture, Special Education Office), interviewed by author, 28 August 2003; *Educación Especial 2003* [Special Education 2003], September 2003.

³⁰. *Ibid.*

³¹. Myriam Aguilar (Special Education Statistics Office, Ministry of Education and Culture), interviewed by author, 19 September 2003.

³². Myriam Melgarejo (Psychologist, Special Education Institution N° 1 Máximo Arellano), interviewed by author, 23 September 2003.

Employment

Although there are no national data on the employment rates of people with disabilities, Paraguay has a high overall unemployment rate and is currently experiencing a severe recession. In urban areas only 71.3 percent of men are employed as are 44.5 percent of women.³³ In rural areas, 74.1 percent of men and only 19 percent of rural women are employed.³⁴

The Central Department survey from 2002 contains information about the employment of people with disabilities in the region, which is presented below in tables two and three.

Table 2: Employment Status of People with Disabilities in the Central Department³⁵

	Men	Women	Total
# of persons	18,698	19,467	38,164
Employment Status			
Employed (occupied)	39.5%	23.6%	31.4%
Unemployed	5.7%	5.2%	5.5%
Inactive	53.9%	70.1%	62.2%
Not Available	0.9%	1.1%	1.0%

Table 3: Employment Type of People with Disabilities in the Central Department³⁶

	Men	Women	Total
# of persons	7,379	4,603	11,982
Employment Category			
Public Employee	8.2%	9.8%	8.8%
Private Employee	38.9%	15.5%	29.9%
Self-Employed	49.2%	46.3%	48.1%
Non-Remunerated Family Worker	3.2%	0.7%	2.2%
Domestic Employee	0.5%	26.9%	10.7%
Not Available	-	0.8%	0.3%

³³. Encuesta de hogares. Principales Resultados EPH 2002. Direccion General de Estadisticas, Encuestas y Censos, Asunción, July 2003.

³⁴. *Ibid.*

³⁵. *Encuestas a personas con Capacidades Diferentes del Departamento Central*, 18.

³⁶. *Ibid.*, 20.

Employment statistics for the Central Department cannot be used to extrapolate the employment rate for people with disabilities in the rest of the country. In combination with the overall employment data, however, they strongly suggest that unemployment and underemployment are widespread among people with disabilities.

At the time this report was written, one chamber of Congress had approved a bill obliging governmental agencies to fill 2% of their workforce with people with disabilities.³⁷

Leaders of the disability community report that the greatest obstacles to disability employment are the lack of training, inaccessible work environments, the lack of adequate public transportation, and cultural barriers.³⁸

The Paraguayan Physical Disability Rehabilitation Association (ARIFA) is the only association that has implemented an employment training program. ARIFA has entered into an agreement with the Catholic University and the Rotary Club of Paraguay, which pays the tuition fees for ten people with disabilities to attend an Information Technology Course at the University.³⁹

There is no national job placement program. The Ministry of Education and Culture runs a training center, and INPRO funds an occupational workshop.⁴⁰ Other organizations that run occupational or sheltered workshops, include the APADEM-TELETON Foundation, the APAPEX Community Center, the Association of Parents and Friends of Persons with Disabilities of Alto Paraná (APAMAP), and the Association of Parents and Friends of Exceptional People of Quiindy (APAQUIPEX). Some of these operate at the local level.⁴¹

Some organizations make efforts to place their members in private or public employment. For example, the Paraguayan Association of Blind Persons is building small shops for interested members with the support of Spain's O.N.C.E. Foundation. However, placements are reportedly limited in scope.⁴²

³⁷. Note sent by the Senate to the President of Paraguay submitting the Bill for consideration, (photocopy provided by the Secretary of the Senate), 16 October 2003, .

³⁸. Panel discussion.

³⁹. Rotary Club Asuncion, http://www.quanta.net.py/rotaryasuncion/Programas_del_Club/Programas_Permanentes/rotaryqprogramas_permanentes.html.

⁴⁰. Ruth Irala de Kurz, "Civil and Political Rights" in *Derechos Humanos en Paraguay 1997*, (Nizkor 1997).

⁴¹. Ashoka Foundation, <http://www.ashoka.org/fellows/viewprofile.cfm?PersonID=1474>; Global Giving, <http://www.globalgiving.com/proj59p.html>.

⁴². ONCE Foundation, <http://foal.once.org/FOAL/Castellano/Asi+somos/Origen+y+Trayectoria/OrigenYTrayec-2.htm>.

Health Services

Although there is no protection against the discrimination by private health insurers against persons with disabilities, national Worker's Social Security is available. The Institute for Social Services was created by Executive Order 17071/18/02/1943 and applied by Executive Order No. 1860/1/12/1950. The laws that regulate social security and disabilities include Law 98, passed in December of 1992, which states that the social insurance system covers all employed persons.⁴³ There are special systems for railroad employees, bank employees, elected parliamentary representatives, and public-sector employees. Benefits include general and specialist care, hospitalization, laboratory services, medicines, prosthetics, dental care, and maternity care. Dependents under this system include spouses, unmarried children under age 16, children with disabilities, and dependent parents over age 60. Medical services are provided directly to patients at the facilities of the Social Insurance Institute facilities. Benefits for any one illness last 26 weeks and may be extended to 52 weeks in special cases.

Since rehabilitation services are not part of the general health services in Paraguay, their provision is minimal. Clínicas Hospital, Itaguá National Hospital, and Medical Emergencies Hospital are the only three publicly funded hospitals that have physical therapy services.⁴⁴

One government agency, INPRO, provides people with disabilities with diagnosis and treatment, professional training, sports and recreation, X-ray services, and blood and urine tests. The INPRO has a multidisciplinary medical team that covers various areas such as: psychology, family-oriented therapy, psycho-pedagogy, occupational therapy, speech therapy, early stimulation, physical therapy, and musical therapy among others. This is the only institution providing such services, and it is located in the city of Fernando de la Mora.

In addition, INPRO has a pharmacy where patients can buy medicines prescribed by relevant specialists, and it covers costs for specialized studies and some surgeries. One other government supported organization, the Charity and Social Aid Office (DIBEN), provides some support to people with disabilities who have financial needs.

⁴³. *Social Security Administration, Social Security Programs Throughout the World: The Americas*, 2003, (March 2004), <http://www.ssa.gov/policy/docs/progdesc/ssptw/2002-2003/americas/paraguay.html>.

⁴⁴. Palmira Soto (Coordinator of the Third Age and Disability Social Welfare Office, Ministry of Public Health and Social Welfare), interviewed by author, 28 October 2003.

There are two rehabilitation centers located in Asunción: the APADEM-TELETON Foundation and the Center for the Rehabilitation of Children with Physical Disabilities (CERENIF). There are an additional five rehabilitation institutions throughout the country.

Some privately-funded organizations, like the Rotary Club and the Lions' Club, also help persons with disabilities meet their needs and achieve greater independence. For example, the Lions' Club donates medicines, wheelchairs, eyeglasses, and other items. Some religious associations help church-goers in economic distress.

The National Health Service has not yet implemented any Community-Based Rehabilitation (CBR) strategy. From 1995 to 1998, INPRO had a CBR program in place, but the organization abandoned the program due to lack of assessment data, inconsistent operation, and administration changes.⁴⁵ The Social Welfare Office is currently initiating a trial plan with the collaboration of INPRO, and training is underway.

In Paraguay, little specialized training is currently available for medical doctors on the provision of services to people with disabilities. On 10 October 2003, the School of Medicine of the National University of Asunción and INPRO signed an agreement to begin training graduate medical doctors on "Basic Rehabilitation."⁴⁷ In 2000 The National University of Asunción and the Paraguayan Physical Therapy Association created the Physical Therapy Study Plan. One private university offers similar courses in physical therapy. There is no other training available in the rehabilitation related fields of occupational therapy, physiatry, speech therapy, prosthetics, and orthotics. Professionals who are working in these fields have studied or become specialized abroad.⁴⁶ This general lack of available training is a significant factor in the scarcity of disability professionals.

Housing

At this time, there are no adapted housing programs or subsidies for people with disabilities to purchase their own houses. There is also no independent living center that provides peer counseling and referral services to people with disabilities. Leaders of the disability community report that most people with disabilities live with their families. Only people with disabilities who work and are self-reliant or who have decided to start a family will live separately.

^{45.} *Ibid.*

^{46.} *Ibid.*

^{47.} Lourdes de Ratti (Technical Office Head, INPRO), interviewed by author, 20 October 2003. The agreement is a result of Resolution HCD 423/03.

Institutionalization

Paraguay has very few institutions providing housing and long-term care to people with disabilities. The Psychiatric Hospital, located in the city of Asunción is the only government supported facility specifically focused on people with disabilities. The hospital, which is supported by the Ministry of Public Health and Social Welfare, cares for 450 people. Serious human rights violations have been documented. Mental Disability Rights International (MDRI) and the Center for Justice and International Law (CEJIL) appealed to the OAS Human Rights Commission (IACHR) to “prevent conditions threatening the lives, liberty, and personal security of two boys, ages 17 and 18, and 458 others detained in the Neuro-Psychiatric Hospital of Paraguay.” The two boys had been left in isolation for more than four years with no clothing and in squalid conditions. The IACHR has since ordered Paraguay to end abuses in national psychiatric facilities.⁴⁸

There are three additional institutions providing housing to persons with disabilities who have been abandoned, are orphans, or are members of extremely poor families. The Albino Luis Home has 15 residents and is located in Asunción. The Pequeño Cotelengo Home is run by the Guanelian religious organization and has 35 residents. It is located in the city of Mariano Roque Alonso. The Norma Home, which depends on a Swedish religious foundation, has 25 residents and is located in the city of Ypacarai. There are also some homes for the elderly that are subsidized by the Ministry of Public Health through the Social Welfare Office.⁴⁹

Patients with disabilities, whether they are minors or adults, are typically taken to these institutions by a family member or neighbor, or as a result of a judicial order if they are found on the streets.⁵⁰

Accessibility

National regulations on the “Elimination of Architectural Barriers and the Promotion of Accessibility to the Built Environment for all Persons with Mobility or Sensory Disabilities and Elderly People” provide that: “all constructions, extensions and alteration works of public buildings and facilities must be performed in such a way so as to ensure they are accessible to all persons with mobility or sensory disabilities and to elderly persons.”⁵¹ This order was endorsed by the Ministry of Education and Culture.⁵²

⁴⁸ Mental Disability Rights International, “OAS Human Rights Commission orders Paraguay to end horrendous abuses in national psychiatric facility” (press release, 18 December 2003), <http://www.mdri.org/projects/americas/paraguay/pressrelease.htm>.

⁴⁹ Maria Gloria Zapattini (Construction Office, Housing National Commission), interviewed by author, 25 November 2003.

⁵⁰ Miryan Azuaga, (Head of the Psychology Department, Psychiatric Hospital, Albino Luis Home) interviewed by author; Gustavo Sostoa, MD (Pequeño Cotelengo Home), interviewed by author, 18 December 2003; Brother Omar Berteá (Director Norma Home), telephone interview, 18 August 2003; César Cubillas MD, telephone interview, 19 August 2003.

⁵¹ Executive Order 1098/98, sec. 1, *Gazeta Oficial de la Republica del Paraguay* 228, Asunción, 27 November 1998.

⁵² *Ibid.*

The only public buildings accessible to people with disabilities are the Post Office Building, the new Parliament Building, INPRO, and the Ministry of Public Works and Communications. The Municipality of Asunción has a ramp, but the ramp is steeper than regulations recommend, making it difficult to use. The ESAP office (Paraguayan Sanitary Services Company S.A.), the Ministry of Education and Culture, the Ministry of Health and Social Welfare, the Ministry of National Defense, the Ministry of Justice and Labor, the Palace of Justice, the Ministry of Economy, the Ministry of Foreign Relations, and the telephone company (COPACO) among others, are all inaccessible. Inaccessible public buildings outnumber those that are accessible.

There are no national regulations mandating the accessibility of private buildings. There are, however, municipal regulations on adaptation of buildings and constructions in the city of Asunción.

Courses on universal design are not available to architects or engineers in the country.⁵³

Paraguay does not have an adapted public transportation system for people with disabilities. Even in the capital city, existing buses are not adapted to be accessible to wheelchair users.⁵⁴

Disability Action & Awareness

The agency that currently coordinates disability policy is the National Institute for the protection of Exceptional People (INPRO). Since 1995, INPRO has coordinated the activity of all government and non-government agencies serving people with disabilities.⁵⁵ Despite the organization's extensive network, national policy is regarded as inefficient and inadequate.

The Social Welfare Institute of the Ministry of Public Health and Social Welfare has a disability policy aimed at promoting community-based rehabilitation actions as part of a national plan for comprehensive rehabilitation. The policy also envisions various disability awareness activities.

Representatives of disability non-governmental organizations have created a disability coordinating unit aimed at developing an adequate disability policy. However, this group has not yet had a significant impact.

⁵³. Amado Franco Navon (Dean, School of Architecture, National University of Asunción), telephone interview, 20 November 2003; Andrés Cubilla (INPRO Construction Office Head), interviewed by author, 25 September 2003.

⁵⁴. Panel discussion.

⁵⁵. Pan American Health Organization, *Paraguay General Studies and Trends*, 1998, www.paho.org/english/HIA1998/Paraguay.pdf.

The National Federation of Persons with Disabilities (FENADIS) has brought together organizations of people with disabilities and associations of parents of children with intellectual disabilities in an effort to establish a coordinated approach. The FENADIS does not have any facilities of its own, but instead moves its operations to the organization of the presiding leader, who is elected every two years. Membership consists of organizations from the capital city and other parts of the country. FENADIS is financially supported through member organizations' contributions.

Organizations of persons with disabilities typically collaborate well with each other, especially in the capital city where major disability organizations carry out joint activities in order to advocate for disability rights. There are combined social activities such as the commemoration of the International Day of Disabled Persons. The organizations also sponsor meetings with presidential candidates during election campaigns. In general, leaders of these organizations feel that further improved coordination is critical for bringing disability rights to the agenda of politicians.



Peru

Key Factors: In the past two decades, terrorism in Peru has caused heavy loss of life and traumatic injuries, thereby enlarging the number of persons with disabilities in the country. The Committee on Truth and Reconciliation disclosed that “Peru lived through an internal armed conflict between 1980 and 2000, which was the most extensive and prolonged episode of violence in all the history of the Republic. About 69,280 persons were victims of violence.”⁴

Terminology

The terminology used to refer to people with disabilities varies throughout Peru. Most often, the phrase “personas con discapacidades”, translated as “people with disabilities,” is used. There are still several other phrases that are also used to refer to people with disabilities, though. The word “minusválidos,” translated as “handicapped” continues to be used. Additionally, some legal documents use outdated language in reference to persons with mental disabilities. The Peruvian Civil Code uses the terms “retardados mentales,” and “deterioro mental” which have been translated as “mentally retarded people” and “mentally impaired individuals” respectively. Other outdated terminology in the Peruvian Civil Code makes reference to “sordomudos,” “ciegosordos,” and “ciegomudos,” translated to “deaf/mute,” “blind/deaf,” and “blind/mute” respectively. Also the Judiciary Act refers to “mudos” or “mutes.” When directly quoting from legal documents and interviews, the original terminology has been retained.

Definition of Disability

The People with Disabilities Act contains the following, most frequently used, definition:

A person with disabilities is an individual with one or more impairments as evidenced by a substantial loss of any physical, mental, or sensory function, resulting in a reduction or lack of ability to perform an activity

¹ Committee on Truth and Reconciliation, *Informe Final* [Final Report], 28 August 2003, <http://www.cverdad.org.pe>.

in the manner or within the range considered normal, that limits or prevents the fulfillment of a role, the performance of life activities, and the enjoyment of opportunities to participate on an equal footing in society.²

A second definition, proposed by the National Council for the Integration of People with Disabilities (CONADIS) in the Equal Opportunities Plan for People with Disabilities, is less commonly used. The plan defines disability as “a condition...that affects individuals regardless of age, gender, race, social and economic status, or origin. Any person may face disabling conditions in any stage of his or her life cycle.”³

Disability Population

At present, there is no reliable data on the number of people with disabilities in Peru. The National Institute of Statistics and Information Technology (INEI) estimates that Peru currently has a population of approximately 27,148,000 people.⁴ There are no published estimates of the disability population. According to the last census conducted by the INEI, in 1993 Peru had a total population of 22,639,443. Of that number, the census reported 288,526 persons with severe impairments and determined that 1.3% of the population had some kind of physical impairment.⁵

However, the INEI also makes use of data reported by the Pan American Health Organization (PAHO), according to which the population of persons with disabilities represents approximately 13% of the population, that is, about 2,943,125 people.⁶

According to the Specialized Rehabilitation Institute, 31% of the Peruvian population has some kind of disability, defined according to the ICIDH-1 developed by the World Health Organization (WHO).⁷

². CONADIS, Plan de Igualdad de Oportunidades para las personas con Discapacidad (PIO) 2003 – 2007 [Equal Opportunities Plan for People with Disabilities (PIO) 2003 - 2007], 2003.

³. *Ibid.*

⁴. National Institute of Statistics, *Peru: Estimaciones y Proyecciones de Población, 1950-2050; Urbana-Rural 1970-2025*, [Peru: Estimations and Projections of the Population 1950 -2050; Urban-Rural 1970 - 2025], Demographic Analysis Bulletin 35, Lima, August 2001, <http://www.inei.gob.pe>.

⁵. National Institute of Statistics and Information Technology, *Censo Nacional de Vivienda y Población*, [Population and Housing Census], 1993 <http://www.inei.gob.pe>.

⁶. Farid Matuk (Head of the National Institute of Statistics and Information Technology), Communication 120-2003-INEI/DTDIS.

⁷. Rómulo Alcalá Ramírez (Managing Director of the Specialized Rehabilitation Institute), Communication 774-DG-INR-2003, September 2003.

In 1993, the National Rehabilitation Institute conducted a survey to identify the “prevalence of impairments, disabilities and handicaps in Peru.” The survey found that the prevalence of disabilities was largest in the coastal area of the country with 39% of the population consisting of persons with disabilities. Of the population of the forest area, 37% have a disability, as do 28% of those in the Sierra region.⁸

Data on the number of persons with disabilities has not been obtained for some areas in Amazonia and the Andean regions, raising concerns about the abuse of human rights of people with disabilities in those areas. The former Minister of Health confirmed this situation at a presentation made before the Ad Hoc Disability Study Committee of the National Congress. He asserted that “in the native Amazonian world, there are communities that adopt a very peculiar attitude in this sense. They have their own ‘Mount Taygetos’, which they call ‘canoe capsizing’. From my experience after many years of work in the Amazonia, when a handicapped child is born, he or she is eliminated by capsizing the canoe. The canoe is turned over and the child falls into the river. This practice may be the cause of distortions in actual disability figures.”⁹

Most people with disabilities in Peru live in the poorest areas of the country and belong to the lower income strata.¹⁰ Notwithstanding this situation, in recent years some services and programs for people with disabilities have been implemented, primarily in the capital city and, to a much lesser extent, in the provinces.

Despite the lack of reliable disability statistics, experts estimate that the number of persons with disabilities has increased more than 10% during the past five years. Causes of the suspected increase include lingering effects of the armed internal conflict and the border conflict with Ecuador, continued political unrest, occupational accidents, environmental pollution, the lack of an effective prevention policy, and poverty and malnutrition.¹¹

Traffic accidents are another important source of the increase in the disability population. As reported by the former Minister of Health before the Ad Hoc Disability Study Committee, the number of fatal traffic accidents in Peru increased from 2,000 to over 4,000 within a two-year period. In that same period, amputations, paralysis, and physical disability caused by traffic accidents increased from 20,000 to 40,000.¹²

⁸ *ibid.*

⁹ Fernando Carbone Campoverde (Minister of Health), (presentation, 3 February 2003), <http://www.congreso.gob.pe/discapacidad.htm>.

¹⁰ J.M. Cosar Camacho, “Derechos Humanos y Protección Jurídicas de las Personas con Discapacidad en el Perú” [Human Rights and Legal Protection of the People with Disabilities in Peru], (master’s thesis, Universidad Privada de San Martín de Porres, 2002).

¹¹ International Campaign to Ban Landmines, *Landmine Monitor Report 2003: Toward a Mine-Free World*, 2003.

¹² *Exposición Ministro de Salud* [Presentation of the Ministry of Health], (transcription of the presentation made by the Minister of Health before the Ad Hoc Study Committee, Lima Department of Transcription, 3 February 2003), www.congreso.gob.pe/discapacidad.htm.

Legislation & Disability Rights

Legal Protections

Peru ratified the International Labor Organization's (ILO) Convention 159 Concerning Vocational Rehabilitation and Employment (Disabled Persons) on 16 June 1986 with Law 24509.¹³ On 10 July 2001, Peru ratified the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities of the Organization of American States with Legislative Order 27484 of the Peruvian Congress.¹⁴ The ratification document was deposited on 30 August 2001.¹⁵

A review of the national legislation in Peru reveals a variety of laws mandating priority treatment, care, and benefits, and provisions for the social inclusion for persons with disabilities. Much of the legislation was inspired by the Standard Rules on the Equalization of Opportunities for Persons with Disabilities of the United Nations.¹⁶

Through the years, Peru has incorporated into its Political Constitutions rules for the protection and recognition of the social, economic, and political rights of persons with physical, intellectual, or sensorial impairments and of persons who are "mentally ill." This is especially true of the last two Constitutions, adopted in 1979 and 1993, respectively.

The current Constitution, adopted in 1993, provides broader coverage and specifically addresses the areas of social security, health, education, and employment. Section 7 of the Constitution establishes the general right to dignity for persons with disabilities. This section closely follows the first part of section 19 of the 1979 Constitution. However, it repealed part of the earlier provisions that provided tax exemptions in favor of entities or persons that rendered services to people with disabilities.¹⁷

Section 16 of the 1993 Constitution establishes the duty of the government to guarantee "adequate education" for people with disabilities, and Section 23 obligates the government to protect employment rights. Section 59 also addresses the right to work and the right to engage in business, trade, and industry. It establishes that "The state shall support sectors that suffer any kind of inequality in overcoming disadvantages; accordingly, it shall promote the organization of small businesses."¹⁸

¹³ ILO, Convention 159, <http://www.ilo.org/ilolex/english/convdisp1.htm>.

¹⁴ Luis Fernando Astorga Gatjens, "14 Countries Ratified Inter-American Convention on Discrimination" *Disability World* 19, (June-August 2003), http://www.disabilityworld.org/06-08_03/gov/interamerican.shtml.

¹⁵ OAS, *Inter-American Convention for the Elimination of all Forms of Discrimination Against Persons with Disabilities*, <http://www.oas.org/main/main.asp?sLang=E&sLink=http://www.oas.org/OASpage/humanrights.htm>.

¹⁶ Carlos Manuel Román Heredia (Human Rights Director), Communication RE(DHU) 0-4-A/323.

¹⁷ *Constitución Política del Perú* [Political Constitution of Peru], 1993, <http://www.georgetown.edu/pdba/Constitutions/Peru/per93.html>.

¹⁸ *Constitución Política del Perú*, art. 23.

A series of additional laws, decree-laws, legislative decrees, executive orders, and municipal orders have been passed for implementation purposes. On 18 December 2002, Congress created the Ad Hoc Disability Study Committee to analyze, diagnose, and expose problems faced by people with disabilities and to make legislative proposals.¹⁹ Other actions include the People with Disabilities Act, (Law 27050) and Executive Order 001-2003-PCM, which declared 2003 the “Year of Disability Rights” and established the commemoration of the centennial of the birth of Jorge Basadre Grohmann. The People with Disabilities Act, which amended Law 23241, established that people with disabilities have the same basic rights as all others in the society. The Act declared 16 October as the “National Day of the Disabled Person”, in memory of 16 October 1980, when people with disabilities staged a national protest before Congress. The People with Disabilities Act also created the National Council for the Integration of People with Disabilities (CONADIS), the Municipal Office for the Assistance of People with Disabilities (OMADEP), and a disability unit at the Ombudsman’s Office.

Many of these laws are primarily statements of rights, as they are not mandatory in nature. Most laws fail to provide penalties for non-compliance, making it difficult to enforce them. The People with Disabilities Act does not provide any penalties for failure to comply with provisions granting benefits from institution to people with disabilities. For example, the National Institute of Culture is required to make all national heritage monuments accessible by providing entrances, facilities, and signs usable by people with disabilities. This statute was passed in 1998. Five and a half years after coming into effect, access of people with disabilities to museums and other cultural heritage institutions still had not been facilitated.

Legal Barriers

Pursuant to the Peruvian Civil Code, a guardian is appointed to an adult individual with disabilities who does not have the legal capacity to exercise his or her rights.²⁰ Once a person with disabilities is declared legally incapable by a court, his or her civil rights are exercised by legal representatives who are appointed in accordance with the provisions on custody and guardianship.

Section 564 of the Peruvian Civil Code specifies those persons with disabilities who can be declared legally incapable:

Those who lack the capacity to make informed judgments.

The deaf/mute, the blind/deaf, and the blind/mute who cannot express their will undoubtedly.

Mentally retarded people.

Mentally impaired individuals who cannot express their free will.²¹

¹⁹. Ad Hoc Disability Study Committee, <http://www.congreso.gob.pe/comisiones/2002/discapacidad/c-principios.htm>.

²⁰. *Comisión Especial de Estudio Sobre Discapacidad*, (transcription of the presentation made by the Minister of Education, 29 January 2003), 3, www.congreso.gob.pe/discapacidad.htm

²¹. Law 295, sec. 564; Alicia Rodríguez Berrocal (Justice of the Peace of the Molina District), interviewed by author, Lima, 25 October 2003.

Civic Participation

People with disabilities have the right to vote in Peru. Law 26859 on Elections protects the right of any person to be elected and freely elect his or her representatives.²²

There are some restrictions, however, on civic participation in a professional context. For example, the requirement outlined in Section 177 of the Judiciary Act²³ restricts persons with disability from becoming a judge stating that candidates are required "not to be blind, deaf or mute, and not to suffer from any mental disorder or permanent physical disability that may prevent the performance of duties with due diligence."²⁴

People with disabilities are also restricted from the foreign service in accordance with the guidelines of the medical, psycho-technical, and psychological tests taken at the Foreign Service College of Peru.²⁵

Inclusion

Communication

The Library of Congress and the National Library have Braille versions of the Peruvian Constitution. However, they have no other government documents in Braille or any other alternative format for people who are blind or visually impaired.²⁶

By law, educational and informative cultural programs broadcast by the Radio and Television Institute of Peru (IRTP) are required to incorporate visual means of communication such as captioning or sign language for persons with hearing impairments. Regulations issued by Executive Order 011-2003-MTC, on 5 March 2003, require IRTP to offer alternative means of visual communication in at least one of the daily news programs produced in the country.²⁷ Inclusion of these alternative means by other air and cable television stations is optional.²⁸

²². Law 26859, *Ley Organica de Elecciones* [Law on Elections], *Diario Oficial El Peruano*, October 1997; Luz Elena Foronta Merino (Planning Manager of the National Office of Election Processes), Communication 174-2003-GP/ONPE.

²³. Law 767, *Ley Orgánica del Poder Judicial* [Judiciary Act], *Diario Oficial El Peruano*, 29 November 1991.

²⁴. Mario Alvarez Quispe (Head of the Office of the Secretary General of the National Council of the Judiciary), Communication 1320-2003-SG-CNM.

²⁵. Ministerial Resolution 0516-RE, December 21, 1984, files of the Human Rights Office, Ministry of Foreign Affairs.

²⁶. Segundo Soto Coronel (Director of the Congress Library), Communication 221-2003-DIRGPI/CR; Margarita Ordinola Martínez (Executive Director of Public Library Services), Communication issued without number.

²⁷. Law 27471, *Diario Oficial El Peruano*, 5 June 2001; Carlos Valdez Velásquez (Communications Secretary of the Ministry of Transportation and Communications), Communication 965-2003-MTC/03.01e

²⁸. Law 27471e

Despite these legal requirements, most television news programs, including those broadcast by IRTP, only caption headlines, and only one network (RED GLOBAL) uses captions to provide a summary of each news story.

Education

There are no national data on the percentage of the student community between the ages of 6 and 16 that have some kind of disability, however, many children with disabilities are reportedly excluded from the educational system.²⁹ The former Vice Minister of Teaching Management stated at a presentation made in January 2003 before the Ad Hoc Disability Study Committee of the National Congress:

According to statistical estimates, 13% of the Peruvian population, which is equivalent to over 3 million people, have some kind of “disability” or differentiated abilities.

During 2002, only 30,000 students attended public and private educational centers. This, as compared to the universe of persons with disabilities, means that only 1.1% had access to education. This is a fact that speaks for itself. There is a long way to go to develop this education policy.³⁰

The former Vice Minister went on to say, “there is a sector of the disability population that suffers complete abandonment and neglect.”³¹ A survey conducted by the Ann Sullivan Association, with the participation of technical experts from the Ministry of Education, concluded that “at present, there are segments of the population that receive no assistance from the Peruvian Government. Such is the case of persons with severe mental retardation, autism and cerebral palsy. These are areas we have to cover because there are omissions, complete gaps in this territory.”³²

Special education was first established in Peru in 1971 and incorporated into the structure of the Ministry of Education as a Special Office. Currently, special education is handled by the Special Education Unit, part of the National Office of Initial and Primary Education.³³

²⁹ Sonia Ascue Bravo (Head of the Special Education Unit), Communication 157-UEE-2003.

³⁰ *Comisión Especial de Estudio Sobre Discapacidad*.

³¹ *Ibid.*

³² *Ibid.*

³³ Ministry of Education, National Office of Initial and Primary Education, Special Education Unit, http://www.minedu.gob.pe/gestion_pedagogica/dir_edu_inicial_primaria/unidades/dir.php?obj=educa_especial.htm.

The newly enacted Education Act maintains that children with disabilities should be educated in inclusive, mainstream classrooms.

Section 39 – Basic Special Education

Basic Special Education has an inclusive approach and is intended for persons with special educational needs in order to achieve their integration into community life and their participation in society. It is aimed at:

- a) Persons who have some kind of disability which hampers regular learning.
- b) Children and youth who are highly-gifted or have special talents.

In both cases, education is given with a view to the inclusion of those students in regular classrooms, notwithstanding the supplementary and personalized care they may need.

Students shall pass from grade to grade on the basis of their capabilities and chronological age, respecting the principle of educational and social integration.³⁴

Section 23 of the People with Disabilities Act establishes that Peru should work toward the educational integration and inclusion of children with disabilities, and that accordingly, public and private educational centers may not deny access to persons with disabilities. Section 22 defines the modifications that must be made in school curricula in order to offer an educational alternative that meets the needs of a wide range of students, including children and youth with special educational needs.

Despite the existence of such legislation, agencies of the Ministry of Education do not comply with the provisions of the law. Education policies in favor of people with disabilities are not implemented due partially to limited budget funding.

Typically, children and youth with hearing, visual, and mental disabilities attend segregated special education schools. Special education is intended for individuals from birth to 20 years old. Programs such as the Early Intervention Program (PRITE), classrooms for pre-school and primary education, and vocational training make up the special education curriculum.³⁵

³⁴. Law 28044, *Ley General De Educacion* [Education Act], *Diario Oficial El Peruano*, 28 July 2003.

³⁵. Sonia Ascue Bravo.

According to a report issued by the Ombudsman's Office, entitled "The Situation of Special Education in Peru: Towards Quality Education", there are 397 special education centers. Of these centers, 92% are located in urban areas, while the remaining 8% are located in rural areas. Of these centers, 79% are state run, and 21% are run by non-governmental organizations.³⁶

Special education in Peru is going through a period of neglect. Special education teachers are not adequately compensated for their dedicated work, so recruiting and encouraging the training of teachers in this area is more difficult.³⁷ Javier Diez Canseco, Congressman and Chairman of the Ad Hoc Disability Study Committee, has stated:

There are no equal opportunities for persons with disabilities. Facilities are not fit. Special education teachers have not been assigned to schools.

It is dramatic but the Higher Teaching Institute of Special Education known as "*María Madre*" which belongs to the Government, has no school for its students to do their teacher practice.³⁸

Teachers in the regular education system are not given specialized training on working with students with disabilities.

Employment

There are no current statistics on the unemployment rate of people with disabilities. The last survey conducted by the National Rehabilitation Institute in 1993 revealed that 64% of people with disabilities were unemployed, and of those employed, 45% worked on a freelance basis, and 19% worked for their families with no compensation. The small number of people with disabilities engaged in gainful activity performed jobs that could be performed without accommodations.³⁹

Section 23 of the Peruvian Constitution guarantees government protection of the right to employment of people with disabilities. In agreement with this provision, the People with Disabilities Act, Chapter VI on Promotion and Employment, provides that people with disabilities should participate in and be integrated into the economic life of the country. They are entitled to all the rights and benefits of workers under labor law, and discrimination against people with disabilities in any aspect of employment is prohibited.

³⁶. Ombudsman's Office, *La situación de la educación especial en Perú: Hacia La Educación De la Calidad* [The Situation of Special Education in Peru: Towards Quality Education], Lima, December 2003.

³⁷. *Comisión Especial de Estudios sobre Discapacidad*.

³⁸. *Ibid.*

³⁹. *Comisión Especial de Estudios sobre Discapacidad*, "Trabajo y Desarrollo: hacia una vida independiente" [Work and Development: towards an independent life], 11 July, 2003, <http://www.congreso.gob.pe/comisiones/2002/discapacidad/discapacidad01.htm>.

In addition, the law proposes certain benefits for people with disabilities and organizations who employ them. In the competitive selection processes conducted to hire personnel for vacant positions in the public sector, people with disabilities are awarded a certain amount of bonus points. These points are included in the process of evaluating applicant merits.

Micro and small businesses run by people with disabilities are eligible for priority loans or financing from national and international finance institutions. Public companies and institutions are required to give preference to products manufactured and services rendered by those businesses.

Likewise, public and private entities can realize financial benefits by hiring people with disabilities. Institutions may deduct from their gross income a percentage of the wages and salaries paid to people with disabilities. The additional amount deducted is determined by the Ministry of the Economy.

Despite these legal provisions, the unemployment rate in Peru remains high for people with disabilities. Very few people with disabilities are employed by the government. Specific employment information was requested from CONADIS, but no reply was given.

As reported by the Director of the Occupational Rehabilitation Center (CERP – ESSALUD) some training and employment programs for people with disabilities exist in Peru. They are free services, whose program and staffing costs are covered by ESSALUD funds.⁴⁰

The Ministry of Labor and Employment Promotion (MTPE) also administers several employment programs that provide services to people with disabilities. According to guidelines, at least 10% of the participants in specialist courses taught at Occupational Training Centers run by the MTPE should be people with disabilities. Some of the centers that provide training include: the Professional Rehabilitation Center of Lima and Callao, the National Institute of Rehabilitation, the National Union of the Blind (MASAJES), and the Lima Center for Blind Rehabilitation. Table one reflects the effectiveness of MTPE programs in assisting people with disabilities in attaining employment.

Table 1: Participation of People with Disabilities in MTPE Employment Programs (Ministry of Labor Programs 2002)

Program	Total Number of Beneficiaries	Persons with disabilities
PROJOVEN	4,500	104
Temporary Jobs	5,000	244
PROEMPLEO	18,000	11
BONOPYME	7,961	119

⁴⁰. José Fariás Aseng (Director of the Occupational Rehabilitation Center, letter 1417-CERP-LV-GDLI-Essalud-2003).

Under the PROJOVEN program, institutions that train young people with disabilities and succeed in securing them traineeships in companies are given a bonus. Another program, the CIL-Pro-Empleo Network, works to enhance the employability of people who have difficulties in getting a job by linking companies requiring personnel with workers who are unemployed or underemployed.⁴¹ This network primarily serves vulnerable sectors of the population, such as like people with disabilities. Finally, the BONOPYME program provides grants to small businesses so they can hire various training services and technical assistance. Although it does aid some people with disabilities, BONOPYME does not serve them exclusively.

As shown in table one, the number of people with disabilities who obtain training and employment services is low. Inaccessibility of workplace facilities creates another significant barrier to employment, as does lack of public transportation to the workplace. In Lima, many facilities lack ramps, bathrooms, and infrastructure appropriate for persons with disabilities. In the provinces, such infrastructure is almost non-existent.⁴²

Health Services

There are 73 institutions in the country that offer physical medicine and rehabilitation services, of which 38 are run by the Ministry of Health, 26 by ESSALUD, 7 by the armed and police forces, and 2 by private institutions. The infrastructure of many of these services is insufficient.⁴³

Section 18 of the People with Disabilities Act “establishes that prostheses, orthopedic devices, medication, drugs and any compensatory aid for the physical rehabilitation of persons with disabilities, shall be furnished by the physical medicine services of [the Ministry of Health] with the support of and in coordination with CONADIS.”⁴⁴ The legislation, however, is not implemented.⁴⁵

The scarce budget funding of the National Rehabilitation Institute (INR), now called Specialized Rehabilitation Institute of the Ministry of Health, is the main inhibitor. The budget projected by INR for 2003 was the of \$19,072,894, and the funding it actually received was \$17,348,025, less than 1% of the total budget for the Ministry of Health.⁴⁶

The National Rehabilitation Institute has been working for the past ten years on a Community-Based Rehabilitation strategy, and to date has signed agreements with more than 70 health care centers of the Ministry of Health (MINSA). In practice, the strategy has only been working as a pilot plan because it has not yet been included in the health programs offered by the government and, therefore, lacks its own budget.⁴⁷

41. Leonardo Ojeda Zañartu (Managing Director of the Administration Office of the Ministry of Labor), Letter 051-2003-MTPE/SG/OA.

42. Panel discussion with leaders of disability organizations, discussion facilitated by author.

43. Rómulo Alcalá Ramírez. It is believed the number of privately run institutions has been underreported.

44. *Exposición Ministro de Salud.*

45. Javier Diez Canseco (Chairman of the Ad Hoc Disability Study Committee).

46. *Exposición Ministro de Salud.*

47. Rómulo Alcalá Ramírez.

Funding is a serious problem for the provision of health care services to people with disabilities in Peru. In addition to the low levels of funding for rehabilitation, there is inadequate funding for prevention programs. Despite the fact that 87% of disabilities in Peru are acquired, there has been little interest shown in making investments in such programs.⁴⁸

Regarding health care coverage, the Statistics and Information Technology Office of the Ministry of Health states “the health care coverage of patients with impairments and disabilities is offered primarily at facilities under the Ministry of Health, which cover 62% of the needs, followed by ESSALUD (33%). The health care offered by the private sub-sector is still scarce.”⁴⁹

Peru has Comprehensive Health Insurance (SIS) for low income people, including people with disabilities, the main eligibility criteria being lack of alternative health insurance and not belonging to ESSALUD. SIS does not cover congenital diseases or prosthetic aids.⁵⁰

As reported by the Dean of the School of Human Medicine of the San Martín de Porres Private University, the academic curricula of medical schools at Peruvian Universities include a course on physical medicine and rehabilitation. This course covers treatment and physical rehabilitation of patients with disabilities, as well as occupational therapy. There is also a course on human psychology, focused mainly on psychotherapy for patients with disabilities. These courses are taken by all medical students as an introductory module at the undergraduate level. They can also be taken at the post-graduate level.⁵¹

On the percentage of medical doctors who benefit from this rehabilitation training, there are no overall figures because each university handles its own statistics. This information was requested from the Ministry of Health, which was unable to furnish the information requested.

Housing

In Peru there is no long-term official housing for people with disabilities in the strict sense of the term. Persons with intellectual and/or multiple disabilities generally reside with their families.⁵² No housing units that are technically accessible for people with disabilities have been built, nor are there any plans to do so. There are no residencies, such as respite homes, where parents can leave their children with disabilities if, for example, they need to travel for a short period of time.⁵³

⁴⁸ Lima Health Commission, *Comisión Especial de Estudios Sobre Discapacidad. Revertir la falta de inversión para mejorar la condición de las personas con discapacidad* [To revert the lack of investment to improve the condition of the people with discapacidad], 2003.

⁴⁹ Office of Statistics and Information Technology, *Reporte Estadístico de la Discapacidad en el Perú 1999 – 2000* [Statistical Report on Disability in Peru 1999-2000] Ministry of Health, 2000, 25.

⁵⁰ *Exposición Ministro de Salud.*

⁵¹ Dr. Frank Lizaraso Caparó (Dean of the School of Human Medicine, San Martín de Porres Private University), Communication 296-03-D-FMH.

⁵² Panel discussion.

⁵³ Celia Orpella (President of Peruvian Association Of Parents Of Children With Disabilities), interviewed by author, 3 September 2003.

However, the Peruvian Government, through the Ministry of Housing, Construction and Sanitation, set up a national housing plan, known as "Housing for All". This plan led to the creation of the "My Own House" program, which caters to the needs of low-income earners by providing them with housing units at a very low cost. The government grants a Housing Family Certificate (BFH) which offers a portion of the total value of the house. In order to obtain this certificate, eligibility requirements must be met. All applicants to this certificate program who are responsible for a person with disabilities receive between 10 and 20 additional points, which are awarded based on different criteria and considered in eligibility scoring.⁵⁴

Institutionalization

Abandoned children and youth with disabilities are taken to shelters of the National Institute for Family Welfare (INABIF). Persons with mental disabilities who are abandoned by their families are taken to psychiatric hospitals. Abandoned elderly people with disabilities are sheltered in homes of the Lima Public Benevolent Society.⁵⁵

Accessibility

National Construction Regulations in Peru were approved by a Ministerial Resolution in 1978. These mandatory regulations are made up of Technical Building Standards U-190 and U-060, known respectively as "Urban Adaptations for the Physically Impaired" and "Architectural Adaptations for the Physically Impaired." All construction should be designed pursuant to these regulations.⁵⁶

Additional legal provisions on accessibility have subsequently been approved as part of the People with Disabilities Act. Section 43 establishes that the Ministry of Housing, Construction, and Sanitation, as well as the municipalities should coordinate the progressive adaptation of cities, making alterations and installing modern technical elements as appropriate to make facilities readily accessible to and usable by people with disabilities.

According to Section 44, "public accommodations operated by governmental or private entities, and built after the enactment of this law, shall have entrances, rooms, corridors, and facilities which are appropriate for use by people with disabilities."⁵⁷ In addition, the law establishes that all venues where public activities and/or shows are held must make accommodations for appropriate signaling and accessible entrances and areas in order to allow for the free movement of people with disabilities.

⁵⁴ Ministry of Housing, Construction, and Sanitation, "My Own House' Program," <http://www.techopropio.gob.pe>.

⁵⁵ The National Institute of Family Welfare, [Management of Comprehensive Protection, Psychology], August 2003.

⁵⁶ Patrick P. Allemant, (General Office of Land Traffic of the Ministry of Transportation and Communications), Communication 2692-2003-MTC/15.

⁵⁷ Law 27050.

Law 27920, which was published on 14 January 2003, extended this deadline for six months from the day after its publication. It also established that, upon expiration of the term, municipalities should forbid public use of structures that had not been properly adapted until such structures were in compliance with the law. Section 4 establishes penalties for non-compliance which consist of fines ranging between 5% and 10% of the value of the building under construction.⁵⁸

Municipalities are the enforcement authority responsible for imposing penalties and allocating fines. The amount of any fines collected should be allocated to programs to ensure compliance with the law, as well as local projects and programs for persons with disabilities. The regulatory authority is the National Council for the Integration of People with Disabilities (CONADIS), the entity which is responsible for reporting violations to the appropriate municipal authorities for enforcement.⁵⁹

The term expired in June 2003, but very few buildings in Peru have been fully adapted, and no fines have been imposed by Peruvian municipalities. For public institutions, adaptations are generally limited to the addition of ramps and public telephones in the entrance areas of some buildings.

With regard to public transportation, many people with disabilities, especially those who use wheelchairs, cannot use public transportation. Patrick P. Allemant, Director of the General Office of Land Traffic of the Ministry of Transportation and Communications, stated that "there is no rule whatsoever to govern the access conditions of wheelchair users to the land public transportation system, or to allow for the incorporation of special vehicles for people with disabilities into the public transportation system, because there are neither specially conditioned vehicles in the domestic market nor the conditions to allow for such incorporation."⁶⁰

Architectural barriers are among the main obstacles faced by persons with disabilities, preventing them from freely exercising their rights, such as the right to vote and the right to work. This, in turn, hinders the exercise of basic human rights, such as studying, working in an accessible environment, enjoying recreational activities, attending health care centers, and participating in sports and culture.⁶¹

Disability Action & Awareness

In Peru, CONADIS is the coordinating agency in charge of developing national policies on disability, however, few people with disabilities hold important positions in this organization. The CONADIS recently appointed a new president, who has a disability. However, two other employees with disabilities were fired, so only two people with disabilities are currently employed by the agency.

⁵⁸. Law 27920, *Diario Oficial El Peruano*, January 2003.

⁵⁹. *Ibid.*

⁶⁰. Patrick P. Allemant.

⁶¹. Panel discussion.

A national plan, entitled the Equal Opportunity Plan for Persons with Disabilities (PIO), was approved in 2003 with Executive Order 009-2003-MINDES. The plan was the result of the coordinated efforts of several ministries.⁶²

The purpose of the PIO is to improve the quality of life of persons with disabilities. It focuses on prevention, priority care, anti-discrimination, and the strengthening and enhancement of existing services. The plan is intended to serve as an executive management and action instrument in assisting all national and local authorities in efforts to incorporate disability issues into all development plans.

The plan incorporates specific goals for health care, education, employment, housing, transportation and communications, and social integration.

With regard to civil society action on disability rights, organizations of people with disabilities are privately funded and receive no government assistance. Their funding sources include individual contributions, donations, and bequests. Very few receive foreign funding, either from foreign governments or other foreign private institutions. There is no collaboration among disability organizations due to the lack of resources. Lack of ties between organizations and poor relationships with some organization leaders create further difficulties for collaboration. Organizations work together only under very exceptional circumstances or in cases of special requests from the government.

Leaders of disability organizations concluded that the most effective strategies to address cases of human rights violations and discrimination against persons with disabilities are: the creation an anti-discrimination law; campaigns to raise social awareness; the strengthening of trade unions; the dissemination, through the media, of information about disability rights; and enforcement of constitutional guarantees through summary proceedings or other legal actions as appropriate.⁶³



The National Cross Disability Organization of Peru (COFENADIP) visited the Congress in Lima Peru July 2003.

⁶². *Plan de Igualdad de Oportunidades para las personas con Discapacidad (PIO)*.

⁶³. Panel discussion.

Suriname

Key Factors: Disability rights are not high on the political agenda in Suriname. The development of services for people with disabilities has stagnated. The government lacks policy initiatives regarding this group and expresses limited support for initiatives by NGOs.



Suriname's border is currently under dispute.

Definition of Disability

There is one primary definition of disability that is used by Suriname's Ministry of Social Affairs and the national government in general. According to this definition, a disability is "any limitation in capacity a person experiences when implementing an activity that can be considered "normal" in the community he/she belongs to. These can be limitations in learning, speaking, hearing, seeing, walking, and other daily activities."¹

Disability Population

The government of Suriname conducted a national census in 2003². However, much of the data may have been lost in a fire at the Census Bureau. Consequently, no recent national level data on the number of persons with a disability in Suriname is currently available. Previously, the 1980 Census found that 2.7 percent of the general population was made up of persons with disabilities.³ Six years later, in 1986, the Ministry of Social Affairs and Public Housing conducted a national registration of persons with disabilities in Suriname. A statistical projection based on the results of the registration also resulted in a disability rate of 2.7 percent, with an estimated 10,693 persons with disabilities. If the rate of people with disabilities has remained consistent since the 1980s, given the current population of 435,449, there are approximately 11,757 people with disabilities in Suriname.³

¹ Ministry of Social Affairs and Public Housing, *Policy Document 2001-2005*, (2001); Ministry of Social Affairs and Public Housing, *Folder Disability Care Division*; General Bureau for Statistics, *Census 2003 Questionnaire*, 2003.

² University of Suriname, Office of the 5th General Census, "People with disabilities in Suriname," (Paramaribo, 1981), 40.

³ CIAWorld Factbook, <http://www.cia.gov/cia/publications/factbook/geos/ns.html>.

With regards to the number of children with disabilities, a national UNICEF study conducted in Suriname in 2000 found that 1.3 percent of children ages 1 to 8 have disabilities.⁴ This finding concurs with the 1980 Census, which also estimated the rate of disabilities as 1.3% in children younger than 4, 1.4% in children aged 5 to 9, 2.1% in children aged 10 to 14, and 2.5% in young persons aged 15 to 19.⁵ The UNICEF study reported to use internationally accepted sampling and questionnaire designs. However, only two districts in Suriname were included in the sample. In light of the significant differences between the ten districts of Suriname and their populations, the results cannot be extrapolated to the national level.

Legislation & Disability Rights

Legal Protections

Suriname has not signed the Organization of American States Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities. Moreover, the Government of Suriname has not issued a statement in support of the creation of a United Nations Convention on the Rights of Persons with Disabilities.

The Ministry of Social Affairs reports that the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities serve as a guideline for Suriname's disability policy.⁶ In practice, however, Suriname's legislation is not in compliance with the UN Standard Rules.

There is no national law that specifically references and protects the rights of people with disabilities in Suriname. While there are general constitutional guarantees protecting human rights and prohibiting discrimination, these do not specifically mention people with disabilities. Article 8 of the 1987 Constitution was amended in 1992 and states "No one shall be discriminated against on the grounds of birth, sex, race, language, religious origin, education, political beliefs, economic position or any other status."⁷ In addition, Article 10 claims that "Everyone shall have, in case of infringement of one's rights and freedoms, a claim to an honest and public treatment of his complaint within a reasonable time by an independent and impartial judge."⁸

In case of violation of rights, any citizen of Suriname can submit a complaint at the Attorney General's Office. According to the Ministry of Justice, they are not aware of ever having received a complaint related to violation of

⁴ UNICEF, *Situational Analysis of children with disabilities in the Caribbean - Suriname*, (Barbados, 2000), 105.

⁵ "People with disabilities in Suriname."

⁶ Steven Powell (Scientific Research and Planning Division, Ministry of Social Affairs & Public Housing), interviewed by author.

⁷ 1987 Constitution of Suriname with Reforms of 1992, www.oas.org/juridico/MLA/en/sur/en_sur-int-text-const.pdf.

⁸ *Ibid.*

rights of persons with disabilities.

Legal Barriers

Legal guardianship can only be granted by the court, when a person is found unable to adequately represent his or her self due to his or her physical or mental state. The person can contest the guardianship or legal representation through the court system. The Ministry of Justice division that facilitates these issues reported being unaware of ever having received a contest or request to overturn legal representation. In their opinion, the court exercises thorough caution in such cases, and acts mostly on medical grounds.⁹

Civic Participation

In Suriname, people with disabilities have the right to vote. People with disabilities also have the right to be elected or appointed to public office. Article 3 of the Constitution states "All Suriname citizens shall be eligible for appointment to any public office in without discrimination."¹⁰

Leaders of disability organizations estimate that between 60 and 80 percent of all election polling stations are accessible. For recent elections, there has been training for election workers and media information regarding special provisions for senior citizens and persons with disabilities. People with visual disabilities usually bring a trusted family member to assist them or request assistance from the election staff to facilitate their voting.

Inclusion

Communication

The government of Suriname does not provide a Braille version of the constitution, and the government does not typically communicate its activities in alternative formats. The national library does provide some material in alternative formats, however these materials and documents are not updated regularly. Most are gifts and donations. Organizations such as the Kennedy School for children who are hearing impaired and the Institute for the Blind have limited access to books, movies, and other materials for individuals with visual and hearing impairments. The Institute for the Blind also has limited opportunities for adults who lose their sight to receive access to vocational training, books, and computer resources.

⁹. Ministry of Justice.

¹⁰. 1987 Constitution of Suriname with Reforms of 1992.

The national news is not captioned for hearing-impaired viewers, and there are no government initiatives to create accessible communication networks. There is no method or national strategy for people with speech impediments or hearing impairments to communicate with authorities in case of natural disaster, civil emergency or criminal assault.

Education

According to the 2001 Statistical Yearbook, there are 21 schools for basic special education, and 11 schools for secondary special education. For the 2001/2002 school year, 740 children participated in primary special education, and 460 in secondary special education.¹¹ The Ministry of Education's Planning and Research Division estimates that approximately 90 percent of children with disabilities who attend school go to a special school, most of which are located in major cities.¹² Inclusive education, where children with disabilities are included in regular classrooms, is rare and happens sometimes in areas where special schools do not exist. At the time of the UNICEF survey, children with disabilities were integrated in 26 regular schools, of which nine were at the secondary level.¹³ Very few children with disabilities advance to the high school level. Since there are fewer high schools for children with special needs, in order to attend high school, children with disabilities often must attend a regular school.

Training on teaching children with disabilities is included in the national teacher curriculum, but not all teachers receive this training. The Ministry of Education also offers a two-year special education program for those who elect this specialization.

Early detection programs are run by both the Ministry of Education and the Ministry of Health. The Ministry of Education has developed a two-part program to detect disabilities in children. The School Nurse Program provides for regular physical check-ups. Currently, less than 20 percent of students participate in this program.¹⁴ In addition the Ministry has made the Pedagogical Institute available to over 80 percent of the schools in Suriname. The Ministry of Health, through its Under-Five Clinics, detects motor, sensory and developmental disabilities. When a disability is identified through early detection, children are referred to the appropriate agency, and parents receive counseling.¹⁵

No known programs integrate family into the education of children with disabilities. In many cases, children are placed outside of the home if families can find placement.¹⁶

¹¹. General Bureau for Statistics, *2001 Statistical Yearbook*, 2002.

¹². Parya Hirasingh (Ministry of Education), interviewed by author.

¹³. Situational Analysis of children with disabilities in the Caribbean – Suriname.

¹⁴. Ministry of Education.

¹⁵. *Ibid.*

¹⁶. *Ibid.*

Employment

The government, the largest employer in Suriname, does not have a policy stating that people with disabilities cannot be discriminated against on the basis of his or her disability.

A limited number of vocational training programs are offered by the national government or NGOs. Among the various vocational training programs for people with intellectual disabilities are programs teaching agriculture, handicraft, furniture production, and other vocational skills.

Health Services

There are limitations on health insurance coverage that result in discrimination against persons in need of long-term care, however, persons with disabilities are eligible for free medical care through the Ministry of Social Affairs. The Ministry of Health also provides funds for the health care, rehabilitation services, physical therapy, counseling, and auxiliary equipment rental through the Revalidation Center.¹⁷ While the national government has funded limited rehabilitation services in the major city of Suriname, it has not implemented community-based rehabilitation programs.

Training on the provision of care for people with disabilities is not available for physicians, either during or after medical school. There are some specialized programs in physical therapy, prosthetics, and orthotics.¹⁸

Housing

People with disabilities are eligible for public housing that is integrated into the community. In addition, there are centers operated by NGO's that provide peer counseling and referral services to people with disabilities. However, there are no housing subsidies available for persons with disabilities in Suriname.

Institutionalization

There are thirteen institutions in Suriname operating with the specific mission of providing long-term housing and care to people with disabilities. These institutions provide services such as psychological and psychiatric counseling, rehabilitation services, and education and training.

¹⁷ Marian Macnack (Medical Education Bureau, Ministry of Health), interviewed by author.

¹⁸ *Ibid.*

Institutions include:

- Esther Stichting
- Huize Betheljada, which has 18 patrons
- Foundation for the Blind
- Foundation “In de Ruimte”, which has 10 patrons
- Mr. Huber Foundation, which has 26 patrons
- Esther Foundation
- Huize Tyl Tyl
- Kennedy Foundation, which has 33 patrons
- Matoekoe, which has 28 patrons
- Psychiatric Care Institution (PCS)
- Kraberie Foundation, which has 47 patrons
- STIGESU, which has 8 patrons
- Foundation Wi Oso.

In theory, individuals have the right to refuse treatment from institutions. However, people with disabilities are sometimes placed in institutions against their will, mostly in cases of mental disabilities or if parents are unable to care for a child with a disability.

The Disability Care division at the Ministry of Social Affairs is responsible for providing support to persons with disabilities in institutions and for handling any complaints and reports of abuse.¹⁹ In practice, this division is hardly functioning and does not fully serve the needs of people with disabilities in these institutions. There are some private advocacy organizations acting on behalf of persons with disabilities. Over the past year, there have not been any investigations of the incidence of death and abuse at any of these institutions. There is little concomitant evidence of reported abuse or coerced treatment in the aforementioned 13 institutions, with the exception of PCS. PCS is the government institution for the mentally ill, where patients are often violent or non-responsive.

Accessibility

Suriname does not have a national policy or any regulations stating that public buildings and facilities, including schools and government buildings, must be accessible to people with disabilities. An informal survey of buildings conducted by the IDRM, estimates that only 20 to 30 percent of public buildings are accessible. The main post office is accessible.

¹⁹. Wil Bergtop (Coordinator, Disability Care Division, Ministry of Social Affairs & Public Housing), interviewed by author.

Disability Action & Awareness

The Ministry of Social Affairs is considered the focal point for disability policy and planning. This ministry facilitates the National Board on Disability, as well as a disability division. The National Board on Disability is the national advisory organization. It advises the government on policies and programmes regarding persons with disabilities.²⁰ Other ministries have their own offices that deal with disability issues. The Ministry of Education has an office for special education. The Ministry of Health has different departments involved in provision of services for persons with disabilities, such as the Medical Education Bureau (MEB) for children with learning disabilities and behavioral problems. Unfortunately, there is no evidence of integration and coordination across ministries.

There is no national action plan, however, persons with disabilities are specifically referred to in most current policy documents, including the Multi-Annual Development Plan (MOP), the Government Policy Declaration, and policy documents from various ministries. The 2000 – 2005 Government Declaration identifies persons with disabilities as a priority group for poverty eradication efforts.²¹ The 2000-2005 Policy Document from the Ministry of Labour, Technology and Environment identifies persons with disabilities as a priority population for vocational training and small entrepreneurship. The 2001 – 2005 Policy Document from the Ministry of Social Affairs states that the United Nations Standard Rules will be used as a reference and framework for the development of a multi-year policy plan for improvement of the living conditions of people with disabilities.²² Finally, the national policy for 2001 – 2005 recognizes that persons with disabilities and their families suffer from isolation and disadvantage and are not sufficiently protected by legislation and policy in Suriname.

Through Suriname's NGO network, the Federation for Private Social Organizations (VPSI), the country is a member of the Caribbean Association for Mobilizing Resources and Opportunities for people with Developmental Disabilities (CAMRODD). One main goal of CAMRODD is to monitor the situation of persons with disabilities and to support national efforts to improve the development of services for and with persons with disabilities in member countries.²³ CAMRODD is allied with Inclusion International and has recently been added to the Inclusion Inter-American division.

²⁰ Marja Themen and Hugo Soekhlal (National Disability Board), interviewed by author.

²¹ *2000-2005 Government Policy Declaration*, 69.

²² Ministry of Social Affairs and Public Housing, *Policy Document 2001 – 2005*, (Paramaribo, 2001).

²³ CAMRODD, *Blueprint: Guidelines for the 21st century*, second edition, (2000).



United States of America¹

Key Factors: U.S. disability laws have attracted worldwide attention, particularly since passage in 1990 of the Americans with Disabilities Act (ADA), which is America's comprehensive federal statement affecting the lives of persons with disabilities.² In the U.S., disability laws have undergone a shift from a model of medical oversight to civil rights.³ Contemporary U.S. disability policies and laws emphasize social and economic participation of persons with disabilities and reducing their dependence on government entitlement programs. However, despite legal protections for people with disabilities, advances in technology and transportation, integrated education, accessible homes, and advocacy, people with disabilities remain disadvantaged in the United States compared to people without disabilities.⁴

¹. Report by James Schmeling, Helen Schartz, and Peter Blanck. James Schmeling is the Associate Director of the Law, Health Policy and Disability Center (LHPDC) at the University of Iowa; J.D., University of Iowa College of Law. Helen Schartz is the Director of Research at the LHPDC; Ph.D. and J.D., University of Iowa. Peter Blanck is the Charles M. & Marion Kierscht Professor of Law and Director of the LHPDC; Ph.D., Harvard University; J.D., Stanford University. For information on the LHPDC activities see <http://disability.law.uiowa.edu>.

². See Peter Blanck, Eve Hill, Charles Siegal, and Michael Waterstone, *Disability Civil Rights Law and Policy*, 2003, herein referred to as Treatise.

³. Peter Blanck, (Ed.) *Employment, Disability, And The Americans With Disabilities Act: Issues In Law, Public Policy, And Research*, 2000. See also Peter Blanck & Michael Millender. "Before disability civil rights: Civil war pensions and the politics of disability in America". *Alabama Law Review*, 52, 1–50 (2000).

⁴. The disability rights movement in the U.S. has more than 50 years of history from which to draw. This chapter relies on the body of disability research generated in the U.S. to gather and report information as well as research studies of the authors of this chapter where appropriate. We did not conduct interviews with leading figures in the disability field, but drew from survey data and reports from the U.S. Census Bureau and the 2004 National Organization on Disability (NOD)/Harris Poll and from legislation and policy pertaining to disability or impacting people with disabilities.

Definition of Disability⁵

Under the Americans with Disabilities Act of 1990 (ADA), a person is an individual with a disability if he or she falls into one of the following categories: An individual with an actual disability; an individual with a record of a disability; or an individual who is regarded or treated as if he or she has a disability (“regarded as”).⁶ In addition to having a disability, to be protected under Titles I and II of the ADA, an individual must be a qualified individual with a disability. The ADA defines a “qualified individual with a disability” as a person who can perform essential job functions with or without the provision of reasonable accommodation (§ 12111 (8)).

In 1999, the U.S. Supreme Court concluded that mitigating measures, things that may be done to correct or mitigate an individual’s impairment, must be considered when determining whether an individual has a disability under the ADA (*Sutton v. United Air Lines, Inc.*, 1999). The Court held that one may have a disability under § 12102(A) of the ADA if they are substantially limited in a major life activity despite the mitigating measures. For example, in *Bragdon v. Abbott* (1998), the Court decided asymptomatic HIV disease is a disability within the language of the ADA. The Court held that from the moment of infection asymptomatic HIV disease is a physical impairment that substantially limits the major life activity of reproduction, and thereby a covered disability under the ADA. Ultimately, determining whether an individual is disabled under the ADA requires an individualized inquiry in each case.

Subsequently, interpretation of the ADA’s phrase “substantially limited” was the issue in *Toyota Motor Manufacturing v. Williams* (2002). The Supreme Court held that for a plaintiff to be substantially limited in performing manual tasks, the plaintiff must demonstrate an impairment that prevents or severely restricts activities of central importance to people’s everyday lives. Household chores, bathing, and brushing one’s teeth are among the manual tasks of central importance to people’s daily lives (*Toyota Motor Manufacturing v. Williams*, p. 202).

In the U.S., the benefits programs of the Social Security Administration, which administers federal government programs, including disability insurance programs and the supplemental security income program (SSI) for the aged, blind and disabled, use definitions of disability to qualify for benefits that are different than the ADA’s definitions.⁸ SSDI provides monetary benefits to an insured individual who “is under a disability” (Social Security Act, 42 U.S.C. § 423 (a)(1) (2000)). Disability is defined as an “inability to engage in any substantial gainful activity by reason of any . . . physical or mental impairment which can be expected to last for a continuous period of not less than 12 months” (§ 423 (d)(2)(A)).

⁵ This section draws from Part 2, Chapter 3, Section 3.1 of Blanck, et al., *supra* note 2. For full discussion of the intricacies of the definition of disability under the ADA, see Treatise, Chapter 3 in its entirety.

⁶ 42 U.S.C. § 12102(2)(A) (2000); *Id.* § 12102(2)(B); *Id.* § 12102(2)(C).

⁷ *Id.* § 12111(8).

⁸ See generally Social Security Online, <http://www.ssa.gov/org/ssaorg.htm>.

The individual's impairment must be "of such severity that she is not only unable to do her previous job but cannot, considering her age, education, and work experience, engage in substantial gainful work which exists in the national economy" (§ 423 (d)(1)(A)).

Disability Population

Several sources of U.S. disability data are available, each with particular definitions of disability. Surveys of disability include the National Health Interview Survey (NHIS), the Survey of Income and Program Participation (SIPP), and the Current Population Survey (CPS).⁸ The National Health Interview Survey on Disability The National Health Interview Survey on Disability (NHIS-D) was a special survey conducted approximately ten years ago. The National Organization on Disability (NOD) conducts a survey on disability issues for the NOD/Harris Survey of Americans with Disabilities.⁹ The 2000 U.S. Census included disability questions in the long form, administered every ten years. The American Community Survey (ACS) from the Census Bureau includes the same questions as and will replace the long form, and will be administered annually. This chapter relies on data from the 2000 Census because of its broad participation and on the 2004 NOD/Harris Poll because of its timeliness.

The 2000 Census uses two questions with six subparts to identify disability. A person is reported as having a disability if he or she answers affirmatively to any of the questions or subparts [paraphrased]

Question 16. Does this person have any of the following long-lasting conditions:

- a. Blindness, deafness, or a severe vision or hearing impairment?
- b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

Question 17. Because of a physical, mental or emotional condition lasting 6 months or more, does this person have any difficulty doing any of the following activities:

- a. Learning, remembering, or concentrating?
- b. Dressing, bathing, or getting around inside the home?
- c. Going outside the home alone to shop or visit a doctor's office [for individuals 16 years old or over]?
- d. Working at a job or business [for individuals 16 years old or older]?

⁸ National Health Interview Survey, <http://www.cdc.gov/nchs/nhis.htm>; Survey of Income and Program Participation, <http://www.sipp.census.gov/sipp/>; Current Population Survey, <http://www.bls.census.gov/cps/cpsmain.htm>.

¹⁰ National Health Interview Survey on Disability, June 14, 2004, http://www.cdc.gov/nchs/about/major/nhis_dis/nhis_dis.htm; NOD/Harris Survey of Americans with Disabilities 2000, <http://www.nod.org/content.cfm?id=1035>; NOD/Harris Survey of Americans with Disabilities 2004, <http://www.aod.org/content.cfm?id=1527>.

The U.S. Census reports are based on people living in households, excluding those living in nursing homes, institutions, and group homes. One Census publication indicates that approximately 7.8 million people live in group quarters, 4,059,039 institutionalized, and 3,719,594 non-institutionalized settings.¹¹ With the exclusion of this segment of the population, people with disabilities may be underreported by the census.

According to the 2000 Census, the disability status of the civilian non-institutionalized population, broken out by age group, is included in Table One.¹² The total for these age groups, 19.3% of the population, is similar to the percentage cited in the Americans with Disabilities Act of 1990, one in five people.

Table 1: Percent and Frequency of Disability by Age for U.S. Population

Age Group	Percent of Population	Number
5 to 20	8.1	5,214,334
21 to 64	19.2	30,553,796
65 and older	41.9	13,978,118
Total	19.3	49,746,248

Poverty is prevalent among people with disabilities, according to Census figures. Approximately 17.6 percent (8.7 million) people with disabilities (aged 5 and above) live in poverty compared to 10.6 percent of people without disabilities. The distribution of people with disabilities in poverty is greatest for children: five to 15 year olds with disabilities had a poverty rate of 25 percent compared to 15.7 percent rate for their peers without disabilities. Of people 16 to 64 years old, 18.8 percent with disabilities, compared to 9.6 percent without disabilities, live in poverty. People with disabilities 65 years old or older had a 13.2 percent rate of poverty compared to 7.4 percent for their peers without disabilities.¹³

Waldrop and Stern have analyzed the Census 2000 disability data in *Disability Status: 2000, Census 2000 Brief*. They note that disability data are used by federal agencies to develop programs and distribute funds serving the elderly population and people with disabilities. The programs include the Carl D. Perkins Vocational and Applied Technology Training Act, the School Dropout Demonstration Assistance Act, State Literacy Initiatives, the Rehabilitation Act, employment and job training programs for veterans under the Disabled Veterans Outreach Program, the Older Americans Act, Medicare and Medicaid, and federal education programs.¹⁴

¹¹ Total Population in Households and Group Quarters by Sex and Selected Age Groups, for the United States: 2000, <http://www.census.gov/population/cen2000/grpqtr/grpqtr01.pdf>.

¹² U.S. Summary: 2000, Census 2000 Profile. Table DP-2. Profile of Selected Social Characteristics: 2000, <http://www.census.gov/prod/2002pubs/c2kprof00-us.pdf>.

¹³ *Id.*

¹⁴ Judith Waldrop and Sharon M. Stern. *Disability Status: 2000, Census 2000 Brief* (March 2003), <http://www.census.gov/prod/2003pubs/c2kbr-17.pdf>.

The NOD/Harris Survey of Americans with Disabilities used the following questions to identify people with disabilities:

1. Does a health problem, disability, or handicap CURRENTLY keep you or anyone in your household who is 18 years old or over from participating fully in work, school, housework, or other activities?

[If yes to question one:]

2. Is there anyone in your household 18 years old or over, including yourself, who: has a learning disability of any kind; has any emotional or mental disability or condition; has any handicap or disability that limits the ability to speak or communicate with others; has any handicap or disability that limits hearing; has any vision or sight-related handicap or disability, except for ordinary eyeglasses; or has any physical handicap or disability that limits use of the legs, arms, or hands?

[If no to question one:]

3. Is there anyone in your household 18 years old or over, including yourself, who: has any physical handicap or disability other than those we have already mentioned; considers himself or herself a person with a disability; is someone whom most other people would consider a person with a disability?

An affirmative response for any of the three questions is reported as a person with a disability. The survey asks questions about severity of disability and age of disability onset. Severity and onset data are important because disability is a heterogeneous category. Many measures, including income, education, home ownership, health status, and insured status vary by severity, type of disability, and age at onset.

Consistent with Census findings, the 2004 NOD/Harris Poll found that more people with disabilities than without live in lower income households. Almost three times the number of people with disabilities (26 percent), compared to those without disabilities (9 percent), have household incomes \$15,000 or below.¹⁵

¹⁵ See NOD/Harris Survey of Americans with Disabilities, 2004, *supra* note 18.

Legislation & Disability Rights

Legal Protections

With regard to international law, the U.S. has not acceded to the relevant documents. It has not signed the OAS Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, and the government has expressed that it will not become party to the proposed UN convention of disability rights.¹⁶ In response to the Special Rapporteur's request for information, however, the U.S. reported its use of the UN Standard Rules.¹⁷

Nationally, the U.S. has addressed disability law in more than 100 laws since 1956, many in the areas of physical access, employment, transportation, and housing.¹⁸ Perhaps the most important of these is the Americans with Disabilities Act of 1990. The ADA is composed of six sections or titles. The preface, § 12101, identifies people with disabilities as "a discrete and insular minority who have been faced with restriction and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society." (§ 12101(a)(7)). The preface sets out the goals of assuring "equality of opportunity, full participation, independent living, and economic self sufficiency" (§ 12101(a)(8)) for individuals with disabilities. The ADA also protects individuals from retaliation if they assert rights on behalf of individuals with disabilities or encourage or assist people with disabilities to assert their rights.¹⁹ Finally, each title of the ADA protects individuals who associate with individuals with disabilities.²⁰

Among the purposes of the ADA is to "provide a clear and comprehensive national mandate for the elimination of discrimination against people with disabilities," (§ 12101(b)(1)) and to ensure that the federal government plays a central role in enforcing these standards (§ 12101(b)(3)).

ADA Title I sets forth the antidiscrimination provisions for employment. "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment" (§ 12112). Covered entities are defined as employers, employment agencies, labor organizations

¹⁶. OAS, Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities 1999, <http://www.oas.org/juridico/english/ga-res99/eres1608.htm>; "Statement by Ralph F. Boyd, United States Assistant Attorney General for Civil Rights, to the UN General Assembly Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities" (press release from the United States Mission to the United Nations) 18 June 2003.

¹⁷. Dimitris Michailakis, *Government Action on Disability Policy: A Global Survey* (Liber Publishing House: Stockholm) 1997.

¹⁸. This chapter draws extensively from the list of disability-related legislation in Robert Silverstein. "Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy," *85 Iowa Law Review* 1691 (2000), http://disability.law.uiowa.edu/lhpdc/rrtc/documents/silverstein/IA_LAW_OVERVIEW_SEPT_11_00.doc. It reorganizes by topical area and omits many laws with less direct relationship to disability rights or which merely amend existing laws in minor ways, or reauthorize legislation without substantial change.

¹⁹. *Id.* § 12203.

²⁰. *Id.* § 12112(b)(4); 28 C.F.R. §§ 35.130(g), 36.205 (2003).

or joint-labor management committees (§ 12111)e Although a covered entity is forbidden from discriminating, it is not required to make accommodations that create a financial or administrative “undue hardship,” (§ 12111(10)) or create a situation where an employee is a significant risk to the health or safety of others (or to self according to the Supreme Court’s interpretation of the law) in the workplace.

Under the ADA, employers are not required to hire or retain employees who pose a direct threat to the health or safety of others in the workplace. In *Chevron U.S.A., Inc. v. Echazabal* (2002), the Court addressed the ADA direct threat defense. The Chevron Court was asked whether the direct threat defense would apply to an employer who refuses to hire a job applicant with a disability because the job would possibly endanger the applicant’s own health. The Court held that the ADA allows an employer’s refusal to hire a job applicant with a disability where the applicant’s job performance is demonstrated to endanger his own health.

Title II of the ADA prohibits discrimination by state or local governments. Part A defines the antidiscrimination provisions, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity” (ADA, 42 U.S.C. § 12132 (2000)). Part B is devoted to the circumstances and requirements for non-discrimination in public transportation. One central element of Title II involves the Olmstead “integration mandate” discussed below.

Title III of the ADA provides antidiscrimination requirements for accommodations and services operated by private entities. The requirement is that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation” (ADA, 42 U.S.C. § 12182(a) (2000)).

An accommodation must make reasonable modifications in its policies, practices, and procedures, unless it demonstrates that doing so would fundamentally alter the nature of its goods, services, or facilities. Older facilities must remove architectural barriers if it is “readily achievable” to do so (ADA, 42 U.S.C. § 12182(b)(2)(A)(iv) (2000)), while facilities (or alterations) that post-date the ADA must be designed to be accessible to individuals with disabilities to the “maximum extent possible” (§ 12183(a)(2)).

A variety of other national laws deal with the issue of disability. The Social Security Act has, through various laws and amendments, established the Social Security Disability Insurance Program. The Social Security Act Amendments of 1965 (P.L. 89-97) authorized the Medicare and Medicaid programs. The Social Security Amendments of 1972 (P.L. 92-603) authorized Medicare for SSI beneficiaries with disabilities after a waiting period and established the Supplemental Security Income (SSI) program that provides cash benefits for people who are aged, blind, or disabled, including children with disabilities comparable in severity to adult recipients.

The Social Security Act Amendments of 1980 (P.L. 96-265) use work incentives to help benefit recipients work by authorizing continued cash payments (section 1619(a)) and Medicaid eligibility (section 1619(b)) for SSI recipients

who are able to work at substantial gainful activity levels. The Employment Opportunities for Disabled Americans Act (P.L. 99-643) made these work incentives permanent.

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193) further redefined the SSI disability definition for children and required redeterminations of disability to be done prior to age eighteen. The Balanced Budget Act of 1997 (P.L. 105-33) changed the requirements for redeterminations for child SSI eligibility to use adult criteria within one year after the recipient's eighteenth birthday. The Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170) established the ticket-to-work program for people with disabilities to obtain services related to employment.

The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) created rights for people with developmental disabilities and established a system of protection and advocacy organizations in each state to assist with legal enforcement of the rights of people with disabilities. Extending the protection of people with disabilities, Civil Rights Commission Act Amendments of 1978 (P.L. 95-444) expanded jurisdiction to the Civil Rights Commission to protect against disability discrimination. The Civil Rights of Institutionalized Persons Act (P.L. 96-247) expanded legal protection to people who were institutionalized, authorizing the U.S. Department of Justice to enforce the rights of people with disabilities in mental hospitals or other facilities. The Developmental Disabilities Act of 1984 (P.L. 98-527) allowed access to the records of persons with developmental disabilities residing in institutions for protection and advocacy systems, providing opportunities to protect the civil rights for people in institutional settings.

There also are state laws protecting disability rights. For example, California exemplifies a state with a history, even pre-ADA, of legal protections for people with disabilities. The California disability antidiscrimination statute, the Fair Employment and Housing Act ("FEHA"), prohibits discrimination in public and private employment, and contains a reasonable accommodation requirement.²¹ Another California statute, the Unruh Civil Rights Act, guarantees people with disabilities accommodations in business establishments.²²

After the U.S. Supreme Court's case law narrowed interpretation of the ADA's definition of disability, California responded by distinguishing its state law protections from the federal limits. The 2000 FEHA amendments provide greater protection than the ADA in several ways.²³ FEHA's definition of physical and mitigating measures." FEHA's definition of physical and mental disability requires

²¹. See generally Cal. Gov't Code §§ 12900-12996 (2003).

²². See Cal. Civ. Code § 51 (2003) ("business establishment" has been interpreted very broadly to include even government bodies) see *Gibson v. County of Riverside*, 181 F.Supp.2d 1057 (C.D. Cal. 2002); see also Cal. Civ. Code § 54 ("Equal Rights to Public Facilities") and § 55 ("Right to Full Access to Public Facilities"); see Cal. Gov't Code § 11135 (prohibiting discrimination by state agencies and recipients of state funding).

²³. For an excellent comparison of FEHA, as amended, with the ADA, see Legal Aid Soc'y Emp. L. Ctr., *Disability Discrimination in the Workplace – State Versus Federal Law Protections*, www.employmentlawcenter.org/adafehachart.pdf.

a “limitation” of a major life activity, as opposed to the “substantial limitation” required by the ADA.²⁴ The FEHA amendments reject the mitigating measures analysis, providing that “under the law of this state, whether a condition limits a major life activity shall be determined without respect to any mitigating measures.”²⁵ Further, the FEHA amendments provide that “working” is a major life activity, and that a person who is limited in working need not be limited in a class or broad range of jobs.²⁶

Legal Barriers

The significant legal barrier for obtaining protection under the ADA is the determination of whether an individual has a disability covered by the law, and whether the individual is qualified for the employment, program, or service being offered. As discussed, the major U.S. Supreme Court cases on the ADA concern interpretations of the law’s definition of disability. This requirement of determination of disability status and coverage is different than other civil rights protection regimes wherein status and coverage often is readily apparent.

Civic Participation

Civic participation of people with disabilities includes activities such as voting rights and access to the courts. The Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435) required registration and polling places for federal elections to be accessible to persons with disabilities. The 1993 National Voter Registration Act (P.L. 103-31) expanded voter registration, allowing mail voter registration and registration in offices where people with disabilities might receive services such as public assistance offices and vocational rehabilitation programs. The Help America Vote Act (HAVA) of 2002 is a comprehensive law involving the administration of federal elections, voting machines, polling places, and voter registration.²⁷ Included within HAVA are provisions related to the accessibility of polling places and voting machines to enable persons with disabilities to participate in the electoral process, and to vote independently and privately. HAVA requires states to adopt election procedures, including provisional voting, statewide voter registration databases and voter identification requirements.

²⁴. Compare Cal. Gov’t Code § 12926(c) with 42 U.S.C. § 12102(2)(A) (2000) and 29 C.F.R. Pt. 1630(j) (2003).

²⁵. Cal. Gov’t Code § 12926.1 (2003).

²⁶. Cal. Gov’t Code § 12926.1. This is consistent with a different section of the statute, which provides that “major life activities shall be broadly construed and shall include physical, mental, and social activities and working.” *Id.* §§ 12926(i)(1)(C), (k)(1)(B)(iii).

²⁷. Full text of HAVA is available online from the Federal Election Commission at http://www.fec.gov/hava/law_ext.txt.

As in voting, when courtrooms are not physically and programmatically accessible, people with disabilities are denied meaningful participation in the proceedings. Title II of the ADA ensures that individuals with disabilities actively and meaningfully participate in the state judicial system.²⁸ Title II prohibits discrimination against qualified individuals with disabilities by state and local governmental entities, including the state courts, and requires facilities and programs to be accessible.²⁹ Title II and implementing regulations from the U.S. Department of Justice (DOJ) mandate that inaccessible witness stands, jury boxes, jury deliberation rooms, restrooms, and parking spaces be eliminated.³⁰ State courts must modify policies, practices or procedures to allow participation by a person with a disability when barriers may not be otherwise eliminated; for instance, the state court may move the case to an accessible courtroom.³¹

Because not all accessibility issues are architectural, Title II of the ADA requires effective communication with people with disabilities.³² For this reason the DOJ requires public entities to provide auxiliary aids, preferably of the individual's choice, to meet the communication needs of persons with disabilities.³³

²⁸. Title II compliance requires courts provide accessible parking and public entrance to areas where court services are conducted; “[R]estrooms, drinking fountains, and telephones also must be accessible to people with disabilities if they are provided for the general public . . . [also, a] alarm systems must be usable” Jeanne A. Dooley & Erica F. Wood, “Program Accessibility”: How Courts Can Accommodate People with Disabilities,” 76 *Judicature*, (1993)250e

²⁹. Keri K. Gould, “And Equal Participation for All . . . The Americans with Disabilities Act in the Courtroom,” 8 *J.L. & Health* 123, 132–33 (1993–1994) (“Congress, by enacting the ADA, sought to . . . includ[e] state and local courthouses within the statute’s definition of public services.”) In contrast, Title II of the ADA does not cover federal court programs and services. *Id.* at 133 n.79. But see *Id.* (noting that the reason for this is that programs and services must comply with the Rehabilitation Act of 1973). The Judicial Conference of the United States has a policy of providing accommodations for people with hearing and communication disabilities. See generally Press Release, U.S. Bankruptcy Ct., W.D.N.Y. 1 (Dec. 1, 2000), <http://www.nywb.uscourts.gov/notices/nta0005.pdf> (citing “Guidelines for Providing Services to the Hearing-Impaired and Other Persons with Communications Disabilities,” in *A Guide To Judicial Policies And Procedures* ch. III, pt. H, at 37). In addition, federal buildings must be accessible under the Architectural Barriers Act, 42 U.S.C. §§ 4151–4156 (2000), which has as standards the Uniform Federal Accessibility Standards, and the Americans with Disabilities Act Accessibility Guidelines (ADAAG). U.S. *Gen. Servs. Admin., Design And Construction: Accessibility For The Disabled*, http://www.gsa.gov/Portal/gsa/ep/contentView.do?contentId=8152&contentType=GSA_OVERVIEW.

³⁰. See Gould, *supra* note 42, at 152. Title II requires a public entity to make its programs accessible, except where it would result in a “fundamental alteration in the nature of [the] . . . program . . . or in undue financial and administrative burdens.” 28 C.F.R. § 35.150(a)(3) (2003).

³¹. See Gould, *supra* note 42, at 147–49. See also Peter Blanck, Ann Wilichowski, and James Schmeling, *Disability Civil Rights Law and Policy: Accessible Courtroom Technology*, 3 William & Marybill of Rights J., 825-42 (2004).

³². See 28 C.F.R. § 35.160(a).

³³. The choice is to be given “primary consideration” by the public entity. *Id.* § 35.160(b)(2). “[U]nless it can demonstrate that another effective means of communication exists or that use of the means chosen would not be required under § 35.164.” *Id.* pt. 35, app. A, § 35.160. *Id.* pt. 35, app. A, § 35.102 (“For instance, public school systems must provide . . . appropriate auxiliary aids and services whenever necessary to ensure effective communication”).

DOJ regulations identify auxiliary aids and services for persons with hearing impairments to include qualified interpreters, note takers, written materials, amplifiers, captioning, and teletypewriters (TTYs).³⁴ For persons with vision impairments, aids and services include qualified readers, taped text, and Braille formats, and for persons with speech disabilities they include “TDDs, TTYs, computer terminals, speech synthesizers, and communication boards.”³⁵

Inclusion

Communication

Communication may include in-person communication and electronic communication. Communication in employment, in access to programs and services of government, and in access to accommodations may be covered by the ADA. Interpreters are often a reasonable accommodation, as are communications in alternative formats, such as Braille, large print, and others. The Telecommunications for the Disabled Act of 1982 (P.L. 97-410) required workplace telephones used by persons with hearing aids and emergency phones to be hearing-aid-compatible. The Hearing Aid Compatibility Act of 1988 (P.L. 100-394) required most telephones manufactured or imported into the United States to be compatible for use with telecoil-equipped hearing aids. The Telecommunications Accessibility Enhancement Act (P.L. 100-542) required the federal telecommunications system to be accessible to individuals with hearing and speech impairments.

The 1988 Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407, Tech. Act), recognizing the expense, complexity and difficulty for individuals to obtain the technology, provided grants to states for assistive technology programs. In 1994, the Technology-Related Assistance for Individuals with Disabilities Act Amendments (P.L. 103-218) reauthorized the 1988 Tech Act. This reauthorization focused on systems change and advocacy, including consumer involvement to increase assistive technology access. The Assistive Technology Act of 1998 (P.L. 105-394) reauthorized programs from the Technology-Related Assistance for Individuals with Disabilities Act and limited state's eligibility for systems change grants to 13 years. Reauthorization of the Tech Act is pending before Congress. The 2004 reauthorization debate is focused on educators and students with disabilities, adult service providers and their clients, and employment providers and employees. The proposed changes would align the Tech Act with other disability-related legislation, including the Individuals with Disabilities Act and the Workforce Investment Act.

³⁴ For example, the regulations mention “computer-assisted transcripts,” which almost simultaneously display transcript proceedings for individuals who may be deaf or hard of hearing. The regulations state, however, that in certain situations an interpreter may be warranted. *Id.* pt. 35, app. A, § 35.160.*Id.* § 35.104(1).

³⁵ *Id.* § 35.104(2). U.S. *Dep't Of Just., Americans With Disabilities Act: Title II Technical Assistance Manual*, at II-7.1000 (1993), <http://www.usdoj.gov/crt/ada/taman2.html>.

According to the 2004 NOD/Harris Poll, more than eight out of ten people with (83 percent) and without (87 percent) disabilities report using cordless telephones or speakerphones. Other accessible technology (AT) used by people with disabilities and found to be at comparable rates to people without disabilities include closed captioning (15 percent), automatic door openers or remotely controlled lights (26 percent), large text on computer monitors (16 percent), automatic check deposit (62 percent), and online banking (34 percent). Yet, one out of every 6 (17 percent) 2004 NOD/Harris Poll respondents with disabilities reported there was AT that they needed but did not have. Among the needed communications AT were computer software (5 percent) and hearing aids (15 percent).

The Television Decoder Circuitry Act (P.L. 101-431) requires closed caption circuitry to be included in televisions, which have been adopted widely by people with and without disabilities and are changing the way television news provides information to people, with written text crawls on the screen. Part of the Telecommunications Act of 1996 (P.L. 104-104) ensures that manufacturers of telecommunication equipment and providers of telecommunications services make their products and services accessible to people with disabilities when readily achievable.

Enacted as part of the Workforce Investment Act of 1998 (WIA), Section 508 of the Rehabilitation Act requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, be usable by persons with disabilities.³⁶ The implementation of Section 508 was designed to spur innovation throughout the e-commerce industry. Federal agencies may not purchase, maintain, or use EIT that is not accessible to persons with disabilities, unless accessibility poses an undue burden. The EIT Accessibility Standards detail the requirements for federal entities.³⁷ Section 508 does not require private companies that market technologies to the federal government to modify the EIT products used by company employees, or to make their Internet sites accessible to people with disabilities.³⁸

³⁶ Workforce Investment Act of 1998, Pub. L. 105-220, 112 Stat. 936 (1998); see Blanck, et al., *supra* note 2 at Part 9, Chapter 27 for a discussion of WIA.; 29 U.S.C. § 701(b)(1) (2000).

³⁷ Architectural and Transp. Barriers Compliance Bd., Electronic and Information Technology Accessibility Standards, July 23, 2003, <http://www.access-board.gov/sec508/508standards.htm>.

³⁸ Department of Justice, Information Technology and People With Disabilities: The Current State of Federal Accessibility, Executive Summary & Recommendations (Report from Attorney Gen. Janet Reno to President Bill Clinton, Apr. 2000), <http://www.usdoj.gov/crt/508/report/exec.htm>.

Education

Education laws require states and school districts to provide education to children with disabilities, including vocational education. The Education of the Handicapped Act (EHA) of 1970 provided for education of children with disabilities. The Education for All Handicapped Children Act (P.L. 94-142) mandated a free and appropriate public education for children with disabilities, regardless of the child's disability. The Higher Education Act Amendments of 1986 (P.L. 99-498) provides construction/renovation grants and loans to higher education institutions for compliance with the Architectural Barriers Act of 1968 and section 504 of the Rehabilitation Act of 1973.

In 1990, the Carl D. Perkins Vocational Educational Applied Technology Amendments (P.L. 101-392) provided students with disabilities access to vocational programs and services. The Education of the Handicapped Act Amendments of 1990 (P.L. 101-476) provided education for vocational and life skills to students with disabilities. The Individuals with Disabilities Education Act Amendments (IDEA) (within the Education of the Handicapped Act Amendments of 1990, P.L. 101-476) renamed EHA to accord with new terminology (disabled rather than handicapped) and provided for improved transition services and access to assistive technology. The School-to-Work Opportunities Act of 1994 (P.L. 103-239) focused on transition from school to work, and included youth with disabilities in these activities.

Education is the foundation for transition to higher education and employment. SSA initiatives, such as the Youth Transition Process Demonstration, assist youth with disabilities to maximize their economic self-sufficiency as they transition from school to work. Focused on people with disabilities from ages 14 to 25 who either receive SSI, SSDI, or Childhood Disability Benefits (CDB) or youth who could receive these benefits, the Youth Demonstration promotes collaboration among state, local, and federal agencies for transition services and supports. The U.S. Department of Labor funds a national center on youth with disabilities to provide technical assistance in this area (National Collaborative on Workforce and Disability / Youth, 2004).

Tied closely to education and to employment are state vocational rehabilitation (VR) programs. The Rehabilitation Act of 1973 (P.L. 93-112) revised funding for VR programs. Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112) prohibited discrimination against qualified persons with disabilities in a program or activity receiving federal funds, including employers and educational institutions. The Rehabilitation Act Amendments of 1986 (P.L. 99-506) allow supported employment as an outcome of VR. It required states to plan for individuals making the transition from school to work. The Civil Rights Restoration Act (P.L. 100-259) amended the act's definition of an individual with a disability and applied section 504 broadly to universities and not the department within the university which received the federal funds. The Rehabilitation Act Amendments of 1992 (P.L. 102-569) increased access for people with the significant disabilities to state VR systems, and gave individuals increased control of their rehabilitation, as well as opportunities for career advancement.

Employment

According to the 2000 Census, 56.6 percent of adults with disabilities aged 21 to 64 were employed, compared to 77.2 percent of those without a disability. Among men, 79.9 percent of those without a disability work compared to 60.1 of those with disabilities.³⁸ Among women, 67.3% of those without a disability work compared to 51.4% of those with disabilities. The Census found 10.4 million men with disabilities work and 8.2 million women with disabilities work.³⁹

In 2004, the NOD/Harris Poll reports that 35 percent of people with disabilities aged 18 to 64 worked full or part-time, an increase of 3 percent from the 2000 poll.⁴⁰ Of those not working according to the 2004 poll, almost two-thirds (63 percent) of people with disabilities would prefer to work.⁴¹ Of those who are disabled and not working, two-thirds (67 percent) report they are unable to work due to a health problem or disability. A smaller proportion (8 percent) report they are not working because they cannot find a job that accommodates their disability.

In addition to the antidiscrimination provisions of the ADA, employment is addressed in several U.S. laws. The Small Business Act Amendments of 1972 (P.L. 92-595) provided for loans for sheltered workshops and for people with disabilities to start their own microenterprises. In 1977, the Tax Reduction and Simplification Act (P.L. 95-30) allowed the use of tax credits to promote employment of people with disabilities, encouraging businesses to hire individuals with disabilities, disadvantaged youth, welfare recipients, and persons who are chronically unemployed. The Federal Advisory Committee Act (P.L. 96-523) permits personal assistant services (PAS) for federal employees with disabilities. The Job Training Partnership Act (P.L. 97-300, JTPA) replaced the Comprehensive Employment and Training Act (CETA) and emphasized training for private sector jobs. The Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508) continued the use of tax provisions, founding the Disabled Access Credit for small businesses to comply with the ADA. The Civil Rights Act of 1991 (P.L. 102-166) was passed to authorize jury trials, and compensatory and punitive damages, in employment discrimination lawsuits overturning restrictions imposed by the U.S. Supreme Court.

The Workforce Investment Act of 1998 (P.L. 105-220) consolidated several job training programs and provided that people with disabilities be served without discrimination in the workforce investment system. The law reauthorized the Rehabilitation Act of 1973 and linked it to the workforce system. It added outcome measures for accountability of the system to taxpayers.

³⁸ U.S. Summary: 2000, Census 2000 Profile. Table DP-2. Profile of Selected Social Characteristics: 2000, <http://www.census.gov/prod/2002pubs/c2kprof00-us.pdf>.

³⁹ See Waldrop and Stern, *supra* note 21.

⁴⁰ As compared to 78 percent of people without disabilities working, as found in the 2004 poll. The definition of disability used by the NOD/Harris Survey varies from that used by the U.S. Census, so findings are not directly comparable.

⁴¹ As compared to 42 percent of people without disabilities who would prefer to work, as found in the 2004 poll.

WIA established state and local Workforce Investment Boards responsible for developing a “one-stop” delivery system of accessible, innovative, and comprehensive employment services. The WIA boards partner with local VR agencies, businesses, and job training and education programs to assist local communities in increasing employment.⁴² Among the services provided by one-stop systems are assistance in job search activities, career planning, job skill assessments and training, and childcare resources. One-stops provide resources for job and entrepreneurial training, transportation and housing assistance, and access to affordable health coverage.⁴³ WIA implements youth services in the One-Stop intended to improve employment and education for youth with disabilities.

WIA is to help individuals with disabilities achieve employment, economic independence, and inclusion into society (29 U.S.C. § 701(b)(1) (2000)). It is the federal funding vehicle for states to provide rehabilitation services and employment opportunities to people with disabilities.⁴⁴ A qualified person with a disability is entitled to benefits and services provided under WIA. One-stops and service providers must administer their programs in the most integrated setting possible (Implementation of the Nondiscrimination and Equal Opportunity Provisions of the Workforce Investment Act of 1998, 29 C.F.R. § 37.7(d) (2003)), and not impose criteria that screen out individuals with disabilities (§ 37.7(i)). They must provide accommodations to qualified applicants, participants, and employees with disabilities, unless doing so causes undue hardship. They also must make reasonable modifications to policies and practices to avoid discrimination (§ 37.8(a)–(b)).

The Employment and Training Administration (ETA) of the U.S. DOL oversees the comprehensive workforce system. ETA's mission is “to contribute to the more efficient functioning of the U.S. labor market by providing high quality job training, employment, labor market information, and income maintenance services primarily through state and local workforce development systems.”⁴⁵ The primary vehicle for providing services to consumer in the workforce system is the One-stop center. Expanding the workforce system to serve people with disabilities will improve employment opportunities for the large group of qualified people with disabilities who want to work. Almost half (42 percent) of people with disabilities polled by the NOD/Harris poll reported being aware of the workforce system's One-stop centers.⁴⁶ Not only were people with disabilities aware of the centers, but also people with and without disabilities report using their services at similar rates.⁴⁷

⁴². See Blanck, et al., *supra* note 2.

⁴³. Michael Morris & Laura Farah, “Building relationships at a community level: Lessons learned from work incentive grantees (WIGs) (Rep. No. 1),” (working paper, Law, Health Policy & Disability Center, University of Iowa College of Law, Iowa City, IA, 2002), http://disability.law.uiowa.edu/lhpd/projects/dol_techdocs/PolicyBrief_Lessons_Learned.doc.

⁴⁴. Lex Frieden, Letter to the Honorable John A. Boehner, Chair, Education and the Workforce Committee (March 18, 2003), http://www.ncd.gov/newsroom/correspondence/boehner_03-18-03.html.

⁴⁵. <http://www.doleta.gov/etainfo/mission.cfm>.

⁴⁶. As compared to 41 percent of people without disabilities.

⁴⁷. I.e., 26 percent of people with disabilities versus 22 percent of people without disabilities.

Another means for enhancing employment opportunities relates to use of federal and state tax incentives available to employers and individuals with disabilities. In 2002, the GAO reported that the business tax incentives (e.g., the Work Opportunity Credit, Disabled Access Credit, and the Barrier Removal Deduction) were not used widely.⁴⁸ One factor cited is lack of familiarity with the incentives. Strategies to increase awareness and usage cited by the GAO include improving outreach through coordination and clarification of incentive requirements. In accord with GAO's findings, the 2004 NOD/Harris Poll finds that 12 percent of people with disabilities claim available credits or deductions, such as federal and state tax deductions and credits designed to assist people with disabilities in employment.⁴⁹ Tax deductions and credits may be used to pay for workplace accommodations or PAS.

One component of economic self-sufficiency related to work is the ability to accumulate assets by saving earnings. The 2004 NOD/Harris Poll reveals that the majority of people with disabilities are "asset poor" (e.g., 58% responding compared to 36% of people without disabilities). Asset poor individuals and their families have insufficient financial resources to support themselves at the poverty level for three months without other means of support.⁵⁰ The mechanisms for enhancing asset accumulation for low-income Americans have focused on the development of financial education and savings strategies, such as the development of IDAs, which are matched savings accounts for the poor. Yet, only 6% of people with disabilities responding report having an IDA, compared with twice as many (13%) people without disabilities. One goal of the Assets for Independence Act of 1998 (AFIA) is education in IDA programs for people in poverty with disabilities.

Health Services

Access to health care for Americans with disabilities generally is through private insurance from employment or a family member's employment, Medicaid, Medicare, or private health insurance. Many do not have any access to insurance. In addition to Medicaid and Medicare under the Social Security Act, the Family and Medical Leave Act (P.L. 103-3) allows employees up to twelve weeks of leave (unpaid, or using paid sick leave where available) for their own recovery from serious health conditions, to care for family members with serious health conditions or for new-born and adopted children.

⁴⁸ GAO Report GAO-03-39 Business Tax Incentives: Incentives to Employ Workers with Disabilities Receive Limited Use and Have an Uncertain Impact (2002). (1 out of 790 corporations and 1 out of 3,450 individuals with a business affiliation used the Work Opportunity Credit in 1999. Only 1 out of 680 corporations and 1 out of 1,570 individuals with a business affiliation reported using the Disabled Access Credit).

⁴⁹ Of those 12 percent, 55 percent claimed both federal and state and 25 percent claimed only federal.

⁵⁰ See Assets for Independence, a program of the Office of Community Services in the Administration for Children and Families within HHS, <http://www.acf.hhs.gov/assetbuilding/assets.html>.

The Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) allows for private health insurance to be available and renewable, and limits exclusions of pre-existing conditions. The Mental Health Parity Act of 1996 (P.L. 104-204) (provisions implementing Act added in P.L. 105-34) prohibits insurance companies from capping mental illness lifetime benefits at lower levels than for other medical conditions.

The Balanced Budget Act of 1997 (P.L. 105-33) expanded insurance coverage to low-income children not already covered by Medicaid with the establishment of the State Children's Health Insurance Program (SCHIP). It required states to continue Medicaid coverage for children with disabilities who were receiving SSI benefits as of August 22, 1996 and who would have been eligible except their eligibility terminated because they did not meet the new SSI childhood disability criteria mentioned above. It established the first Medicaid Buy-In programs, which authorizes states to allow people with disabilities who were employed and whose family income was less than 250 percent of the poverty level to buy Medicaid insurance coverage. Premiums are based on income. The law continued eligibility for SSI "qualified alien" non-citizens lawfully residing in the United States who received SSI as of August 22, 1996. It provided "qualified aliens" access to SSI if they were lawfully residing in the United States on August 22, 1996 and met the SSI definition of disability or blindness. It permitted states to require participation by adults in Medicaid managed care, with some exemptions.

Together, these national policy initiatives have been aimed at diminishing the health care barriers to work for disabled persons who want and are capable of working (Jensen & Silverstein, 2000; Silverstein, 2000). The Ticket to Work and Work Incentives Improvement Act (P.L. 106-170) (TWWIIA), for instance, expands the availability of health care coverage for individuals with disabilities in several ways. States may allow disabled people with incomes over 250% of poverty level to "buy into" Medicaid health insurance programs if they are otherwise eligible for SSI. Individuals whose medical conditions have improved, making them ineligible for SSI or SSDI, may buy into Medicaid if they continue to have a severe determinable impairment. Under TWWIIA, Medicaid premiums and other cost shares are determined on a sliding scale. For those persons with incomes between 250% and 450% of poverty level, premiums may not exceed 7.5% of their income. As of February 2004, twenty-eight states have implemented and five more have authorized Medicaid Buy-In programs.⁵¹

TWWIIA extends Medicare coverage for people returning to work from SSDI to 8.5 years without payment of a Medicare Part A premium. After 8.5 years, four and one half years longer than previous eligibility, the individual may continue to receive Medicare by paying the premiums for both Part A and Part B.

The changes in health insurance options are meant to stimulate SSDI beneficiaries to return to work (e.g., after being injured on the job) without risking the loss of health insurance coverage by retaining Medicare coverage.⁵² TWWIIA allows for an expedited reinstatement of benefits for SSDI recipients whose benefits were terminated because of increased earnings from work and who are unable to work because of a disability. The beneficiary may receive

⁵² See Blanck, et al., *supra* note 2.

⁵¹ Allen Jensen, State Medicaid Buy-In Programs Summary Table: Implementation, Authorization, Studies and Enrollments – February 23, 2004 update, http://www.uiowa.edu/~lhpd/work/summary_tables/StateMedBuyIn_summarytable.doc.

SSDI for up to six months during the period that the Social Security Administration is considering the reapplication.

Healthcare also plays a role in the acquisition of assistive technology (AT). The NOD/Harris Poll indicates a high percentage of people learned about AT that they use from doctors (49%) or other healthcare professionals (22%), which include physical therapists and rehabilitation specialists. Current efforts at informing people with disabilities about AT have focused on government programs (4%), community centers and disability organizations (4%), the media (13%), and the Internet (5%) as sources. While these appear to be important sources of information about AT, along with family and friends (14%) and other people with disabilities (6%), healthcare professionals appear to be at least a major source of information for people with disabilities. However, as with communication, many people with disabilities lack the necessary AT, ranging from devices such as walkers or canes (8 percent) and non-mechanized assists such as railings and bars (9 percent) to complex devices such as motorized wheelchairs (19 percent) and mechanized assists such as lifts and chairs (7 percent).

Only about half (57 percent) of those who needed additional assistive devices had attempted to acquire them. For the 43 percent who did not attempt to acquire these devices, 61 percent did not attempt to do so because the devices were too expensive. Of those who did attempt to obtain the devices, more than half (54 percent) reported they could not afford them. AT enables people with disabilities to improve their participation in society. Of the respondents who needed AT that they did not have, 37 percent reported that the device would help them live independently, 25 percent to leave their homes, and 18 percent to socialize with family and friends.

Housing

As mentioned, Title II of the ADA prohibits discrimination by state or local governments. Part A defines the antidiscrimination provisions, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity” (ADA, 42 U.S.C. § 12132 (2000)). Part B is devoted to the special circumstances and requirements for non-discrimination in public transportation. A core element of Title II involves the “integration mandate.”

Perhaps the most significant Title II case is *Olmstead v. L.C. ex rel. Zimring* (1999). In *Olmstead*, the Court held that Title II requires a state to place persons with mental disabilities in community settings rather than in institutions when the state’s treatment professionals determined that community placement is appropriate, the transfer is not opposed by the affected individual, and the placement may be accommodated, taking into account the resources of the state and the needs of others with mental disabilities. In response to the *Olmstead* decision, President George W. Bush issued Executive Order 13217 (Community-Based Alternatives for Individuals with Disabilities).⁵³

⁵³. <http://www.whitehouse.gov/news/releases/2001/06/20010619.html>.

The order provides guidance to federal agencies requiring the Attorney General, the Secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the Commissioner of the Social Security Administration to work cooperatively to implement *Olmstead*. It also requires the federal government to work with state governments and to provide technical assistance to the states to effectively implement *Olmstead* at the state level. The Department of Health and Human Services published the federal agency's final reports of action to eliminate barriers and promote community integration, including Justice, Labor, Health and Human Services, Housing and Urban Development, Transportation, Education, Veteran's Affairs, the Social Security Administration and the Office of Personnel Management.⁵⁴ Many focus on housing and community integration.

States have reacted differently to the *Olmstead* decision. The National Conference of State Legislatures published the report "The States' Response to the Olmstead Decision: How are States Complying?"⁵⁵ The report finds progress, including new state legislation for compliance. The report also finds challenges due to state fiscal environments in response to the economic challenges nationwide. The report found that states were focusing on areas such as helping people make the transition from institutions to the community; promoting affordable and accessible housing; improving the recruitment and retention of direct care workers; allowing funding to follow the individual rather than the providers; and improving transportation that complies with the ADA requirements.

One encouraging finding from the 2004 NOD/Harris Survey is that more than half (58 percent) of people with disabilities (and 61 percent without disabilities) report owning their homes. Housing for people with disabilities is covered by a variety of systems and laws, including housing laws, and Medicaid waiver law. The Housing and Community Development Amendments of 1974 (P.L. 93-383) includes people with disabilities in the Section 8 rent subsidy program. It also extended Section 202 direct loans to nonprofit agency projects for persons with mental as well as physical disabilities.

Another effort towards integrated housing in the community is found in the Omnibus Budget Reconciliation Act (P.L. 97-35), which authorized home and community-based waivers in place of institutional care where the costs of doing so were equivalent or less than providing institutional care that would otherwise be required. The Consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272) expanded the Home and Community-Based Waiver to pre-vocational services and supported employment for previously institutionalized individuals and authorized waiver services for children dependent on ventilators who would otherwise continue to be institutionalized. The Balanced Budget Act of 1997 (P.L. 105-33) expanded the availability of Home and Community-Based Waiver habilitation services to those who had not been institutionalized previously, making such services available to people who already were integrated into community housing and preventing unnecessary institutionalization.

⁵⁴. <http://www.hhs.gov/newfreedom/final/>.

⁵⁵. <http://www.ncsl.org/programs/health/forum/olmsreport.htm>.

The Housing and Community Development Act of 1987 (P.L. 100-242) required HUD to allocate fifteen percent of section 202 funds for non-elderly persons with disabilities. The 1988 Fair Housing Act Amendments (P.L. 100-430) extended protection from discrimination in housing to people with disabilities and required that people with disabilities be allowed to modify their homes to meet their needs for accessibility and safety. In 1990, the National Affordable Housing Act (P.L. 101-625) established funding authority for supportive housing for people with disabilities.

Accessibility

Accessibility of buildings is addressed by The Architectural Barriers Act of 1968 (P.L. 90-480), which requires federal buildings to be accessible to people with disabilities. Section 502 of The Rehabilitation Act of 1973 (P.L. 93-112) established the Architectural and Transportation Barriers Compliance Board to enforce the Architectural Barriers Act of 1968. The ADA also addresses physical access to buildings.

Transportation for people with disabilities has been addressed in regard to mass transit (Urban Mass Transportation Act Amendments of 1970 (P.L. 91-453)). The Federal-Aid Highway Act of 1973 (P.L. 93-87) allowed the Highway Program to provide curb cuts and other features for the safety of people with physical disabilities and to provide accessible rest stops. The Amtrak Improvement Act of 1973 (P.L. 93-146) ensures elderly and disabled people are not denied intercity transportation on Amtrak. The Air Carriers Access Act (P.L. 99-435) prohibits discrimination by air carriers and gives enforcement authority to the U.S. Department of Transportation. The Intermodal Surface Transportation Efficiency Act of 1991 (P.L. 102-240) increased funds for facilities to meet transportation accessibility needs of people who are disabled.

The Architectural and Transportation Barriers Compliance Board (Access Board) develops guidelines for accessibility under the ADA. The U.S. Department of Justice issues final regulations for most of ADA Title II and III, while the Department of Transportation issues final regulations for the transportation provisions of Titles II and III. In 1991, the Access Board published the Americans with Disabilities Act Accessibility Guidelines (ADAAG) for new construction and alterations in places of public accommodation and commercial facilities.⁵⁶ The ADAAG contains requirements applicable to most buildings and facilities (sections 1 through 4) and to certain types of buildings and facilities covered by title III of the ADA: restaurants and cafeterias (section 5) medical care facilities (section 6); mercantile and business facilities (section 7); libraries (section 8); transient lodging (section 9) and to transportation facilities (section 10). In 1998, two additional sections were added to the ADAAG for Title II covered State and local government buildings and facilities, which addresses judicial, legislative, and regulatory facilities (section 11) and detention and correctional facilities (section 12).⁵⁷

⁵⁶. 36 CFR part 1191.

⁵⁷. 63 FR 2000.

In addition to the ADAAG, the Architectural Barriers Act of 1968 (42 U.S.C. 4151 et seq.) requires federal facilities (i.e. facilities designed, built, altered or leased with federal funds) to be accessible to persons with disabilities. The Access Board's guidelines are used as a basis for enforceable standards issued by the Department of Defense, the General Services Administration, the Department of Housing and Urban Development, and the U.S. Postal Service. The Uniform Federal Accessibility Standards (UFAS) were developed by these agencies to implement the Architectural Barriers Act. Other federal agencies use UFAS as accessibility standards for purposes of compliance with section 504 of the Rehabilitation Act of 1973.

Another development in accessibility of the built environment is the enactment of accessibility and visitability requirements for homes by cities and states. Typically, these are part of the local building code or state laws. Such visitability codes require compliance with accessibility elements, including home entries without steps, interior doorways and hallways wide enough for wheelchairs, light switches location and function, electrical outlet location, and particular features in bathrooms. Some codes require mandatory compliance, while others are voluntary, though some voluntary programs include incentives. Additionally, codes vary by whether the housing is built with subsidized funding or private funding alone.

Disability Action & Awareness

As discussed, the Social Security Disability Insurance (SSDI) program defines disability as an inability to engage in "substantial gainful activity" and requires a medical assessment of the disabling condition. The Rehabilitation Act of 1973 initially was grounded in a medical approach to disability, promoting the conception of individuals with disabilities as impaired and needing to be cured through rehabilitation. By contrast, the rights model focuses on the environment that subordinates persons with disabilities and provides that government secure full involvement in society for persons with disabilities.⁵⁸

Beginning in the 1970s, concepts from the independent living philosophy were integrated into the national disability policy. Title VII of the Rehabilitation Act initiated funding for independent living services or Centers for Independent Living (CILs). Not only did the CILs provide services for individuals with disabilities, but also they were to be operated by individuals with disabilities.⁵⁹ The evolving policy of inclusion fostered federal and state laws from accessibility in voting and air travel,

⁵⁸. Existing state laws and programs, compiled by the RERC on Universal Design at Buffalo, <http://www.ap.buffalo.edu/idea/visitability/existing%20state%20laws.htm>, and existing city laws and programs, <http://www.ap.buffalo.edu/idea/visitability/existing%20city%20laws.htm>. For guidelines and discussion of visitability, see <http://www.ap.buffalo.edu/idea/visitability/> and their publication at <http://www.ap.buffalo.edu/rercud/Visitability/VisBk%20Ver3-7-03.pdf>.

⁵⁹. See Blanck and Millender, *supra* note 3. See also Kate D. Seelman, "Employment of individuals with disabilities—opportunities and challenges—The best of times/the worst of times," (paper presented at the Employment and Disability Policy Summer Institute, Cornell University, Ithaca, NY July 17, 2000); See also Richard K. Scotch and K. Schriener, "Disability as human variation: Implications for policy," *Annals of the American Academy of Political and Social Science*, 549, 148–159 (1997).

to independence in education and housing culminating with passage of the ADA, and supplemented by Federal and state disability-related legislation and generic legislation.⁶¹

In support of national disability policy, the National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting Americans with disabilities. In its 1986 report *Toward Independence*, NCD proposed that Congress enact a civil rights law for people with disabilities. By 1990, when the ADA was signed into law, NCD's purpose became to promote policies, programs, and procedures that guarantee equal opportunity for individuals with disabilities; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration.

Other disability advocacy groups in the United States include the National Organization on Disability (NOD), the Disability Rights Education and Defense Fund. (DREDF), Disability Rights Advocates (DRA), the National Council on Independent Living (NCIL), and the Bazelon Center for Mental Health Law. DREDF is a law and policy center dedicated to advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education of attorneys, advocates, persons with disabilities, and parents of children with disabilities. DRA is dedicated to advancing the civil rights of people with disabilities. Operated by and established for people with disabilities, DRA pursues its mission through research, education, and legal advocacy. DRA's mission is to ensure dignity, equality, and opportunity for people with disabilities throughout the United States and worldwide. The National Council on Independent Living (NCIL) is the oldest cross disability and grassroots organization run by and for people with disabilities. NCIL represents over 700 organizations and individuals including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.



Corpuscle Danse performing at the John F. Kennedy Center for the Performing Arts during Opening Ceremonies of the 2004 International VSA Arts Festival.

⁶⁰. ILRU Directory of Independent Living Centers & SILCs, Vol. 26 (2004).

⁶¹. National Council on Disability. *Achieving Independence: The Challenge For The 21st Century: A Decade Of Progress In Disability Policy: Setting An Agenda For The Future* (1996).

Uruguay

Key Factors: Uruguay is facing an economic and social crisis driven by a series of domestic and international factors. Since 2000, the poverty rate has risen 45%, and Uruguay's Peso was depreciated in June 2002. That year the average actual salary fell an average of 10.7% compared to 2001. Over 70,000 Uruguayans have migrated to foreign countries seeking employment opportunities. At the same time, efforts have been made by the government to control public spending, resulting in a continued lack of inclusion and social integration for people with disabilities.¹



Terminology

The terminology used to refer to people with disabilities varies within Uruguay's legislative framework. Although recent disability legislation uses the phrase "personas con discapacidad", translated as "people with disabilities," other terms remain in use. For example, Law 16095 uses both "personas con discapacidad" as well as "discapacitada," translated as "disabled people."² Law 13102 uses the word "lisiado," translated here as "crippled."³ Law 644 uses the word "lisiado," translated as "handicapped." Likewise the Civil Code 1279 uses the term "sordomudos" translated as "deaf-mute." When directly quoting from legal documents, the original terminology has been utilized.

Definition of Disability

One of the main legal definitions of disability in Uruguay can be found in Law 16095, also known as the Equalization of Opportunities Act. The law provides the following definition: "a person with disabilities is any individual having a permanent or long-term functional impairment, either physical or mental, which according to his or her age and social environment implies considerable disadvantages for his or her familial, social, educational or labor integration."⁴ This definition is regularly used by a variety of organizations within the country including the Pan American Health Organization (PAHO), the Ministry of Sports and Youth, the Ministry of

Research assistance was provided by Alfredo Martinote.

¹ Daniel Olesker, *Informe sobre Evolucion de la Pobreza en el Uruguay: 1998-2000* [Report on the Evolution of Poverty in Uruguay: 1998-2000], www.fing.edu.uy/adfi/mail/adur/doc00044.doc.

² Law 16095, *Equalization of Opportunities Act*, art. 2, 26 October 1989.

³ Law 13102, *Automobiles for the Crippled*, 18 October 1962; Felipe Martín (Director, Municipality Of Montevideo, Division Of Traffic And Transportation), interviewed by author, 20 October 2003.

⁴ Law 16095.

Transportation and Public Works, the Ministry of Education and Culture, the National Library, and the Catholic University. The National Civil Service Office, which is in charge of monitoring the enforcement of part of Law 16095, also uses this disability definition.

Although the definition is widely used, not all organizations have adopted it. According to the Ministry of Public Health, for example, no classification of disability is officially used. The School of Medicine of the Republic's University (UDELAR) uses the definitions of the World Health Organization's (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the International Classification of Functioning, Disability and Health (ICF).⁵ The definition of disability used by the Division of Traffic and Transportation of the Municipal Government of Montevideo, Uruguay's capital city, is taken from Law 13102 and Order 22515.⁶ They state that "a crippled person is any individual having some major permanent or temporary impairment, which may extend for a period of about 5 years, affecting limb functionality."⁷

Disability Population

The last national census of Uruguay, completed in 1996, recorded a population of 3,163,763 with more than half the country's population concentrated in Montevideo, the capital city.⁸ The National Institute of Statistics (INE) does not yet possess official statistics on people with disabilities although a survey intended to identify the number of persons with disabilities was recently conducted. In conjunction with the National Honorary Disability Committee (CNHD), the INE designed the 2003-2004 National Disability Survey. The survey is still in progress and will be completed in September 2004. The data is collected through a module added to the Continuous Household Survey.⁹

Although there are no official numbers, different organizations possess their own estimates of the number of people with disabilities. The CNHD estimates that 10% of the total population is comprised of people with some kind of disability.¹⁰ The Inter-American Research and Documentation Center on Vocational Training of the International Labor Organization (CINTERFOR/ILO-Uruguay), on the other hand, reports that the rate of people with disabilities aged 16 to 40 is 15.5% of the total population.¹¹ The PAHO office in Uruguay states that the actual rate of people with disabilities might amount to 25%.¹²

⁵ World Health Organization (WHO), ICF, 22 May 2001, www.who.int/classification/icf/whares/wha-en.pdf; <http://cm.coe.int/ta/rec/1992/92r6.htm>.

⁶ Felipe Martin.

⁷ Law 13102.

⁸ National Institute of Statistics and Census, *Census of 1996*, <http://www.ine.gub.uy/>.

⁹ Orual Andina (Managing Director, INE), interviewer, Montevideo, Uruguay, 14 August 2003.

¹⁰ Professor Ana Stasiuc (President of the National Honorary Disability Committee), interviewed 14 Oct 2003.

¹¹ Project "RLA/94 /MO5/SPA/," "Apoyo a la integración normalizada de las personas con discapacidad en las instituciones de formación profesional en Latinoamérica" [Support for the Normalized Integration of People with Disabilities at Vocational Training Institutes in Latin America], information provided by Pedro Weinberg (Director, CINTERFOR) and Fernando Vargas (Conslutan, CINTERFOR), Montevideo, Uruguay 12 September 2003.

¹² Pan American Health Organization (PAHO), Uruguay.

Without baseline information on the number of people with disabilities, it is impossible to accurately know whether there has been a change in the size of the disability population. However, some evidence suggests that the number has increased in recent years. The Banco de Seguros del Estado (Government Insurance Bank) reports more accidents, and the Social Security Bank reports that the number of applications for pensions due to accidents or illnesses has increased.¹³ Additionally, the National Institute For Minors (INAME) has experienced an increase in the number of children with disabilities they are assisting.¹⁴

Legislation & Disability Rights

Legal Protections

People with disabilities in Uruguay are protected by a variety of general and specific legal documents. Internationally, Uruguay has signed and ratified a variety of instruments approved by the United Nations General Assembly and other organizations under the UN system. Unlike treaties, some instruments like the UN Standard Rules have no binding effect.¹⁵ Nevertheless, Uruguay has voted in favor of and co-sponsored several resolutions protecting the rights of people with disabilities, indicating a strong commitment to the issue.¹⁶ Uruguay signed the American Convention on Human Rights on 22 November 1969 and ratified it through Law 15737 on 19 April 1985. The country also signed the International Agreement on Civil & Political Rights and the International Agreement on Economic, Social, & Cultural Rights.¹⁷ Among the ILO instruments followed by Uruguay are Convention 159, which was ratified on 13 January 1988, and Convention 128, which was ratified on 28 June 1973.

The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities was approved by the Senate and the House of Representatives on 24 May 2001 through Law 17330.¹⁸ The ratification instrument was deposited on 20 July 2001. Regarding compliance

¹³. Daniel Delgado Sicco (Director, Government Social Security Bank), interviewed August 2003.

¹⁴. Dr. Stella Lopez (Director, National Institute For Minors), Comprehensive Community-Based Support And Promotion (Siapsi) Project. The institute acknowledged that in addition to an increase in the disability population, the increased need for their services may also be linked to worsening poverty or inadequate response by other agencies.

¹⁵. Silvia Izquierdo (General Bureau of Political Affairs, Director Ministry of Foreign Affairs, Multilateral Affairs Bureau), interviewed 1 August 2003.

¹⁶. Ministry of Foreign Affairs.

¹⁷. Law 15737, *American Convention on Human Rights*, <http://www.parlamento.gub.uy/Leyes/Ley17330.htm>; Law 123571, 10 July 1969.

¹⁸. Law 17330, *Approval of the Inter American Convention on the Elimination of all Forms of Discrimination against Persons with Disability*, art. 1, 9 May 2001, <http://www.parlamento.gub.uy/Leyes/Ley17330.htm>; <http://www.sordos.com.uy/legislacion/l17330.htm>;

with the convention, the Ministry of Foreign Affairs reported that a Delegate Committee will be charge of monitoring compliance although the committee has not yet been created. Additionally, when Uruguay requires reports on the domestic implementation of other treaties not specifically focused on disability issues, reports typically include specific information on disabilities.¹⁹

The National Constitution can be interpreted as guaranteeing protection for some people with disabilities.²⁰ Section 46 states that “the Government shall protect extremely poor and low-income people, who, given their chronic physical or mental inferiority, are unable to work. The State will fight against social vices by enforcing the Law and International Conventions.”²¹

With regard to laws solely concerned with people with disabilities, Law 16095, which was enacted in October 1989, was based on the World Program of Action Concerning Disabled Persons. It provides comprehensive protection for people with disabilities, and created the National Honorary Disability Committee as a coordinating body for disability policy. Order 431/999 provides enforcement mechanisms for some sections of the original law, specifically those sections ensuring access to employment within the public administration.²² Other sections have not yet been regulated, and some existing regulations are already outdated. However, lack of regulations should not influence compliance. Sections 7, 72, and 332 of the Constitution mandate that laws be complied with even if they have not yet been regulated.

Law 16095 also explicitly refers to the human rights of people with disabilities. Among the rights of people with disabilities that enumerated are:

the right to respect for their human dignity, the right to live a dignified life, the right to measures that allow them to attain higher independence, the right to receive medical, psychological and functional assistance, including prosthesis and orthopedic devices, medical rehabilitation and social reinsertion, education, training and occupational rehabilitation, and to job placement; the right to economic and social stability and the right to dignified living standards, to live within his or her family or in a foster home, to be protected against any exploitation, discriminatory, abusive or degrading treatment; to be advised by competent attorneys, when such assistance is deemed essential to safeguard the person and estate. If a lawsuit is brought against a person with disabilities, the proceedings shall be consistent with his or her physical and mental conditions.²³

¹⁹. Ministry of Foreign Affairs.

²⁰. Constitution of the Oriental Republic of Uruguay, www.parlamento.gub.uy/constituciones/const997.htm; www.georgetown.edu/pdba/Constitutions/Uruguay/uruguay96.html.

²¹. <http://www.factum.com.uy/document/constit/sec02.html>.

²². Decree 431/999, *Resolving effective compliance of the integral protection system of persons with disability*, D.O., 10 January 2000, <http://www.sordos.com.uy/legislacion/d431.htm>.

²³. Law 16095, *Equalization of Opportunities Act*, 26 October 1989, www.parlamento.gub.uy/leyes/ley16095.htm.

In keeping with these rights, the law lays out specific provisions in a broad range of topics including all the service areas listed above, as well as transportation, accessibility, service provider training, social security, disability prevention and awareness raising programs.

With regard to social security legislation, Law 16713 allows for the retirement of a person who acquires a disability, as well as establishes non-contributory retirement assistance for both the elderly and people with disabilities.²⁴ Law 16074 created occupational accident and occupational disease insurance.²⁵ Law 17266 provides that a person with disabilities may continue to receive a disability pension while being gainfully employed.²⁶

According to Law 17497 all buildings constructed under government contracts must be accessible to people with disabilities.²⁷ Resolution 878/98, Record 1748 of the National Telecommunications Administration (ANTEL) offers a certain amount of free telephone service to those people with disabilities who possess a phone line.²⁸ Law 17378 provides for the protection of people who are deaf and officially recognizes the Uruguayan sign language.²⁹ In addition, a municipal resolution in Montevideo prevents discrimination in the issuance of drivers licenses to persons who are deaf.³⁰

The National Institute for Minors receives and records all the reports of abuse or ill-treatment of children with disabilities. Once a case is verified, it is separately documented if it is a disability case. No similar records are maintained regarding adults with disabilities.

Legal Barriers

The Civil Code was amended in June of 2001, however it still contains provisions concerning certain types of disabilities.³¹ Section 1279 declares that “minors, the insane and deaf-mute persons who cannot make themselves understood in writing or by means of the sign language, pursuant to Law 17378 of 25 July 2001, are considered totally incapacitated. In the latter case,

²⁴ Law 16713, *Creation of a Provisional System*, art. 14, 3 September 1995, www.bcu.gub.uy/autoriza/afesen/ley16713.htm.

²⁵ Law 16074, *Occupational accident and disease insurance*, art. 1, 10 October 1989, www.parlamento.gub.uy/leyes/ley16074.htm.

²⁶ Law 17266, 22 September 2000, www.parlamento.gub.uy/leyes/ley17266.htm.

²⁷ Law 17497, *Establishment of Accessible Facilities for Persons with Disabilities in State Contracted Projects*, art. 1, 28 May 2002, www.presidencia.gub.uy/ley/2002052802.htm.

²⁸ Resolution 878/98, *Resolution of the Director of ANTE*, Record 1748, 15 April 1998, Act no. 1748, www.sordos.com.uy/legislacion/res_ANTEL.htm.

²⁹ Law 17378, *Recognition of Sign Language as the natural language of persons who are deaf and their communities*, art. 1, 25 July 2001, www.parlamento.gub.uy/leyes/ley17378.htm.

³⁰ http://www.sordos.com.uy/legislacion/resol_imm_libreta_conducir.htm.

³¹ Law 16603, *Civil Code*, 19 October 1994.

the intervention of a sign language interpreter is mandatory in order to make a decision on an individual's incapacity." Section 432 on guardianship uses similar language, stating "legally incapacitated persons over the statutory age shall be subject to general guardianship. These comprise insane individuals, despite their lucid intervals, and deaf-mute individuals who cannot make themselves understood in writing or through the sign language, pursuant to Law 17378 of 25 June 2001. In this latter case, the intervention of a sign language interpreter shall be mandatory in order to make a decision on guardianship."³²

Additionally, in Article 80, Section 1 of the National Constitution of 1996, citizenship is "suspended for persons with physical or mental disabilities that prevent them from acting freely and reflexively."³³

In some cases, outdated laws remain in force. Two examples are the 1936 Law 9581 on Assistance for the Mentally Ill and the 1948 Law 11139 establishing the Institute for Psychopaths.³⁴ Both were enacted to solve housing problems faced by people with psychiatric disabilities at the time, but neither has been amended or updated to reflect more contemporary ideas about psychiatric disabilities.

Civic Participation

Article 173 of the 1999 Electoral Law protects the right of all citizens of Uruguay to vote and provides that no one can prevent any citizen from exercising that right. Article 95 of the law specifies that persons who are blind or who cannot walk by their own means may be accompanied to the voting booth by a person they trust.³⁵ The only restrictions are for those mentioned above who have been stripped of their legal rights.

Voting is mandatory for all citizens in Uruguay, including people with disabilities. Yet there is often a series of accessibility challenges entailed in reaching a polling station. Moreover, information about campaigns is not available for some people with disabilities to make fully informed political choices. For example, no Braille, sign language, or captioned information related to the elections is broadcast on television. When a person cannot vote, he or she is required to appear in person and justify their reason for not voting. Architectural barriers and inaccessible transportation and communication often make both voting and attendance at such proceedings difficult for people with disabilities. As stated by Court officials, stairs are one of the major barriers to accessing voting places.³⁶

³² "Approval of Disputed Modifications of Civil Code text," 1996, http://www.parlamento.gub.uy/Codigos/CodigoCivil/1996/Cod_Civil.

³³ Constitution of the Oriental Republic of Uruguay, sec. 3, ch. IV, art. 80, www.parlamento.gub.uy/constituciones/const997.htm; www.factum.com.uy/document/constit/sec03. Citizenship is suspended "due to physical or mental disabilities which prevent an individual from acting freely and making informed decisions."

³⁴ Law 9581, *Assistance for the Mentally Ill*, 8 August 1936, www.parlamento.gub.uy/leyes/ley09581.htm; Law 11139, *Institute for Psychopaths*, 16 November 1948, www.parlamento.gub.uy/leyes/ley11139.htm.

³⁵ <http://www.electionaccess.org/LR/Countries%20M-Z/Uruguay.htm>.

³⁶ Dr. Carlos Alberto Urruty (President of the Electoral Court), interviewed 8 October 2003.

Inclusion

Communication

The National Library has Braille information about the 1996 Constitution that includes a comparison with the 1967 version.³⁷ This document is available in the public services area for reference only. Some additional materials are available in alternative formats, such as Braille, large print, scanned or microfilm copies, or photocopies designed to enhance readability. These materials are updated as items are brought into compliance with the Legal Deposit Law. The last update was made in 2003. Individuals who need materials in alternative formats must submit a request to the Bibliography and Reference Office of the Public Services Department. Alternative communication resources available for people with multiple disabilities and their caregivers are listed in catalogs.

The library does not, however, communicate its activities in alternative formats. Library facilities, including filing cabinets, reading rooms, information search facilities, and bathrooms are not adapted for people with disabilities. Although it is possible to enter the building through a side door, the main library entrance consists of a number of large steps. Library patrons with disabilities are assisted when they need to move around the institution. The library acknowledges the existence of these barriers.³⁸

The national television news is not captioned for viewers who are hearing-impaired. Evidence on attempts to provide accessible information is contradictory. The CNHD reports that there are some government initiatives underway, but all of them are encountering financial barriers.³⁹ The Ministry of Education and Culture, on the other hand, reported no such initiatives to create accessible communication networks.⁴⁰

The National Telecommunications Administration (ANTEL) reported that a fully staffed emergency system is in place to communicate with persons with speech or hearing impairments.⁴¹ However, the National Emergency System has not provided specific instructions on assisting people with disabilities in emergency evacuations. The emergency committee noted that each organization involved in the Emergency System, including government ministries, municipalities, and non-governmental organizations, is independently responsible for developing plans to assist people with disabilities according to its role in the overall system.⁴²

³⁷ US Department of State Bureau of Western Hemisphere Affairs, Background Note: Uruguay, May 2003, <http://www.factum.com.uy/document/constit/cons1997.html>.

³⁸ Raúl Ballarino (Director of the National Library), interviewed 25 September 2003.

³⁹ Professor Ana Stasiuc.

⁴⁰ Leonardo Guzman (Minister Of Education And Culture), interviewed September 2003; Estela Costabile (Director, Department of Education) interviewed September 2003.

⁴¹ Oscar Gonzalez Alvarez, (ANTEL's Director).

⁴² Retired General José Maria Rivero (Director, National Emergency System, Permanent Technical And Operating Management, interviewed October 2003.

Education

No reliable information is available on the number of children with disabilities. The Central Executive Board (CODICEN) estimates that 2.76 % of students aged 6 to 16 attending public schools have a disability.⁴³ Compared to the estimates of the total disability population, this figure is low, suggesting that a large number of children with disabilities may not be attending school. On the other hand, INAME reports that slightly more than half of those aged 6-16 that the organization assists have a disability.⁴⁴ With no consistent information on the number of school-aged children with disabilities, the recently completed National Disability Survey should provide some useful data when its results are released.

The general objective of the National Educational Policy is increased inclusion of children with disabilities in the education system through teacher training, improved accessibility, and the provision of alternative format teaching materials. However, there are no official records on the number of students with disabilities who receive inclusive education. Broadly speaking, children with disabilities are educated at special schools, located in major cities and department capitals. The number of students attending special schools is 8809 countrywide. There are no residential schools.⁴⁵

Special education training is not currently included as a regular subject in the national teacher curriculum. Prior to 1996, teachers could attend a two year post-graduate program at the Superior Teaching Institute which would allow them to specialize in teaching children with disabilities. However, in 1996, the institute closed. Although a private three-month training course has since been offered, it has not fully replaced the training that had been available from the teaching institute. As a result, there is a lack of specialized human resources in the special education field.⁴⁶

The CODICEN offers some training to teachers providing special education. In 2003, four courses were developed. They focused on people with intellectual disabilities, learning disabilities, multiple disabilities, and sensory disabilities. In 2002, teachers were offered training courses in assisting students with mobility disabilities and students who are hearing-impaired.⁴⁷ Uruguay's Labor University (UTU) has permanent staff to provide counseling to students with disabilities. Multidisciplinary teams that cover the whole country are composed of psychologists, social workers, and specialized teachers. For the most part,

⁴³. Sirio Nadruz (Counselor Central Executive Board), interviewed 13 August 2003.

⁴⁴. INAME serves youth up to 21 years of age. Most of the beneficiaries are school-aged with only 5% of the children served by the agency under 5 years of age.

⁴⁵. Central Executive Board (CODICEN).

⁴⁶. *Ibid.*

⁴⁷. *Ibid.*

the programs' services are centered in the capital city of Montevideo, however there are also some privately operated teams that work in the interior of the country. They primarily work with children at the elementary level. The Catholic University also provides its teachers and staff with training on methodologies for teaching people with disabilities.

Architectural barriers continue to exist in many older educational buildings, despite the inclusion of accessibility among the goals of the education policy. All new buildings must be accessible to people with mobility disabilities, thus schools that were built after 2001 are accessible.⁴⁸ However, CODICEN reported that schools built before the new standards took effect are often still inaccessible. There are no accurate data about the number of inaccessible schools. Most government agencies concerned with education are also not accessible. Although a source at the Ministry of Education and Culture reported that its facilities are accessible, upon visiting the ministry's offices, IDRM learned that they are not fully accessible. The CODICEN headquarters is also inaccessible.⁴⁹ In contrast, the Primary Education Council has some adapted facilities for wheelchair users.

Universities typically lack fully accessible buildings as well. Only a small percentage of the Labor University's (UTU) facilities are accessible. Representatives from the Catholic University, on the other hand, reported that their university facilities are accessible. The education department of the University of the Republic Teaching Hospital is not accessible to wheelchair users, although the emergency doors of the hospital are accessible.⁵⁰ The National Nursing School of the university is inaccessible.⁵¹ There are no University-level courses on disability policy, disability rights, or other disability-related issues.

A variety of disability detection programs operate in Uruguay. These services are available through CODICEN, INAME, ANEP, and the Social Security Bank. The CODICEN diagnosis service covers both pre-school and elementary school children. Once a pre-school child with a disability has been identified, the child's teacher is then provided with counseling. Children aged 3 to 5 receive assistance at special schools. For elementary school children, even though the diagnosis program is open to all students, not all students are assisted by special education centers once the diagnosis has been completed due to inadequate resources.⁵²

The INAME program also covers all ages and all types of disabilities.⁵²

⁴⁸. Resolution 2504 /02, file 5788/02, *Draft Standards On Accessibility And Usability Of Buildings And Spaces*.

⁴⁹. CODICEN.

⁵⁰. Professor Sara Mascheroni (Director, Universidad Del Trabajo Del Uruguay, School Management Department), interviewed 5 September 2003; Gelli Campo (Secretary General of Communications, Universidad Catolica Del Uruguay), interviewed 3 September 2003.

⁵¹. Ayde Ballestrino (Director, National Nursing School of the University of the Republic), interviewed 30 September 2003.

⁵². CODICEN.

The program is comprised of multidisciplinary teams that diagnose disabilities, and it is implemented by Attention Centers for Infants and their Families (CAIF) day care centers for young children under five, and Shelter and Communal Centers.⁵³ No data are kept regarding the number of children assisted under this program. The National Public Education Administration (ANEP) conducts an early detection program implemented through an Early Stimulation Center operating at Special Education School 206.⁵⁴ The Social Security Bank program focuses on children aged 0 to 14.

Family participation in the rehabilitation and education of young people with disabilities is encouraged in a number of ways. Special schools often offer family counseling.⁵⁵ The CODICEN integrates the family into the rehabilitation process through its Course for People with Multiple Disabilities.⁵⁶ Within its scope of action, the Social Security Bank, Social Benefits Office, promotes family participation to NGOs that it advises. Education of students with disabilities who do not attend school must be carried out by a member of their family.⁵⁷



Front entrance to the Ministry of Education building.

⁵³. Dr. Stella López.

⁵⁴. National Public Education Administration, http://www.anep.edu.uy/ANEP/anep_sobre_anep.htm; Ministerio De Educación Y Cultura.

⁵⁵. CODICEN.

⁵⁶. *Ibid.*

⁵⁷. *Ibid.*

Employment

Although no official estimates exist of the unemployment rate among people with disabilities, a Peace and Justice Service (SERPAJ) report entitled "Situation of People with Disabilities 1997" puts the unemployment rate at an estimated 90%. The estimated rate for non-disabled workers at the same time was 13%.⁵⁸

Law 16095 established general guidelines for national policies that are supplemented by various other laws including Law 17216 and Law 16736 which created a registry for persons with disabilities intended for labor insertion purposes. Section 42 of Law 16095 mandates that 4% of the budget allocated for vacant government positions be reserved for people with disabilities who meet employment qualifications. The law goes on to say that "such disabled people shall enjoy the same rights and shall be subject to the same duties as established by the labor law applicable to all public officials, notwithstanding the implementation of differential rules when strictly necessary."⁵⁹ Laws 16127 and 17226 both reconfirm the need for complying with this component of Law 16095, however, officials from PROCLADIS report that it is still not enforced, and the public sector is not meeting its required quota.⁶⁰ When the central administration has available positions, applicants are selected by a pre-qualification test or by drawing lots.⁶¹ Leaders of disability organizations report that the number of people with disabilities who have obtained employment through this process is low.⁶²

Section 43 also requires that qualified persons with disabilities be hired "whenever a permission to use property of public or private domain owned by the national or departmental governments is granted for the purpose of running small business establishments." The National Civil Service Office centralizes information about the recruitment of people with disabilities by governmental organizations. In 2000, only three people with disabilities were employed by the Central Administration. In many cases, those hired have only minor disabilities such as missing the tip of their ear or finger. In other cases, there are age restrictions on those allowed to apply for the job.⁶³

There is no specific law or regulation requiring the employment of persons with disabilities by private sector companies. Moreover, there is no specific prohibition of discrimination against persons with disabilities on the basis of disability, when applying for a job in the private sector.⁶⁴

⁵⁸ Peace and Justice Service, <http://www.serpaj.org.uy/inf97/disca1.htm>.

⁵⁹ Final interpolation of Article 42 of Law 16095, Law 17216, www.parlamento.gub.uy/leyes/ley17216.htm; National Budget Law, Law 16736, 2 January 1996, www.todoelderecho.com/Uruguay/penal.htm.

⁶⁰ Law 16127, 7 August 1990, www.parlamento.gub.uy/leyes/ley16127.htm#art32; Law 17226, 29 October 1991, www.parlamento.gub.uy/leyes/ley17226.htm.

⁶¹ National Honorary Disability Committee. For the pre-qualification test, organizations of the National Administration periodically call up persons who fulfill the requirements needed for specific jobs. Then those people must take a test and the person to score highest gets the job.

⁶² Panel discussion.

⁶³ Santos Marichal (Director, National Civil Service Office), interviewed by author, 18 September 2003.

⁶⁴ Sergio Echeverría (Director of the Domestic Coordinating Unit, Ministry Of Labor And Social Security), interviewed by author, 15 September 2003.

The Ministry of Labor and Social Security has no specific department responsible for implementing disability-related policy. The two offices that address disability-related issues are the National Employment Bureau and the National Coordination Bureau.⁶⁵

The National Employment Board is in charge of financing the Occupational Training Program For People With Disabilities (PROCLADIS), implemented by the Christian Youth Association (ACJ). Under this program, occupational training and labor insertion courses are offered to people with any kind of disability. Since the program was launched, a total of 40 courses have been delivered to some 600 participants. Among the topics covered in these courses have been specific training in the following types of jobs: telemarketer, administrative assistant, harvest worker, packaging worker, supermarket cashier, gas station assistant, dairy farm worker, and electric assembler. An average of 200 people take advantage of this program each year. The formal labor insertion rate for program participants has reached over 40%, surpassing the initial target goal of 30%. In the three years the program has been operating, training activities have been suspended twice, once during the first months of 2000 and again during the first part of 2002.⁶⁶

Another important job training program is the Integra Regional Training Program for Blind and Visually-Impaired People. The program is financed by the Inter-American Development Bank and the ONCE Foundation for Latin America (FOAL), and is being implemented in Chile, Argentina, and Uruguay. As of June 2002, training courses had included occupational counseling workshops as well as courses on information technology, data entry, and telemarketing and sales. Seventy-seven (77) people attended the pre-occupational workshop. The data entry courses included 19 people, and 44 completed information technology courses. The sales course attracted 9 participants. Fifteen (15) people who are visually-impaired have been or are under traineeship arrangements at different companies and governmental agencies. These traineeship programs were implemented as a result of meetings with businessmen and high government officials during which the advantages that could be derived from hiring a trainee were explained.⁶⁷

The Social Security Bank has a program designed to promote improved quality of life for people with disabilities by supporting their social and labor integration. The program works to foster participation in education, promote more effective equalization of opportunities, and eliminate architectural barriers. The scope of the program is defined by Law 15800, which re-institutionalized and regulates the Social Security Bank.⁶⁸

⁶⁵. Ministry of Labor and Social Security.

⁶⁶. Dr. Gabriela Zubeldía (Psychologist and Coordinator General, PROCLADIS), interviewed by author, 8 September 2003.

⁶⁷. Integra, <http://fbraile.com.uy/integra/>.

⁶⁸. Law 15800, specifically under sec. 4 subsec. 9, 10, 11 and 13.

According to officials from the PROCLADIS program, the most common barriers currently faced by people with disabilities who are unemployed are related to the deep crisis affecting many companies in the country. Despite an increasing awareness on the part of employers and a perceived interest in hiring people with disabilities who have received job training, the deficit situation and general uncertainty complicate the search for employment.⁶⁹ The private company TATA SA, which is the largest private employer of people with disabilities, asserted that one of the most common barriers to employment is the lack of training programs.⁷⁰ Other barriers included lack of support staff and financial constraints.

Health Services

Health care services in Uruguay are available through both public and private providers. The Ministry of Public Health provides both direct services through a series of hospitals and care centers as well as funding to other agencies. Access to private providers is typically limited to those who can afford health insurance through one of the Collective Medical Care Institutions (IAMCs) or other private insurance. Slightly less than half of Uruguayans have health insurance through an IAMC. The Integrated Committee of the Uruguayan Medical Union reports getting complaints from people with disabilities that are rejected by other IAMCs.⁷¹ Although the cost for IAMCs is typically high, the quality of care that patients receive is often much better than that received at the public hospitals. Thus, only about 40% of the population receives health coverage through a public agency, while around 11% has no formal coverage through any source.⁷²

Although there are no specific figures on the number of people with disabilities without health coverage, leaders of the disability community report that few people with disabilities can afford health insurance. Given the high cost of medical care for people with disabilities, many choose public health care or go without any coverage at all.

Much of the public funding for health services for people with disabilities comes from the Ministry of Public Health. All hospitals in the public health service allocate part of their budget to the care of the people with disabilities. For example, the Teaching Hospital features a rehabilitation area for patients with neurological and other injuries. The Ministry of Public Health also provides financial support to the CNHD for both health-related personnel and activities.⁷³

⁶⁹ Dr. Gabriela Zubeldía.

⁷⁰ Fernanda Brignone (Director of Disability of the Human Resources Department, TATA SA), interviewed 1 October 2003.

⁷¹ National Honorary Commission On Disability.

⁷² PAHO, "General Health Situation and Trends for Uruguay," *Health in the Americas*, 2002.

⁷³ National Honorary Commission On Disability.

The Social Security Bank allocates funds for health care of persons with disabilities through the Social Services and Economic Services departments. The Social Services department offers financial support for both basic institutional needs and special projects at institutions with rehabilitation workshops. The Economic Services department awards special grants to centers dedicated to the assisting people with disabilities.⁷⁴ In 2002, the amount awarded totaled 145,757,980 Uruguayan pesos. The Social Security Bank also finances some rehabilitation services nationwide.

Other publicly funded rehabilitation services are available through the Ministry of Sports and Youth Gardel's House facility and through the Teaching Hospital.⁷⁵ The INAME allocates part of its resources to health care and rehabilitation for children with disabilities assisted by the Institute.⁷⁶ Rehabilitation services are also available to people with disabilities at private institutions and NGOs, however there are not enough services available to meet the current need and more facilities are required. A recent fund-raising drive solicited contributions to create a Rehabilitation Center for children with mobility disabilities. There is no official information regarding community-based-rehabilitation strategies.

With regard to technical assistance, the CNHD implemented a program in November 2003 that was not yet operating at the time of this writing. The program has requested wheelchairs, 12 hearing aids for a school that integrates children who are deaf, and the purchase of 2 computers to support the development of youth with intellectual disabilities. Some non-governmental organizations provide mobility aids to people with disabilities using private funds. These include the Lions Club, the Rotary Club and the Church of Jesus Christ of Latter-day Saints.⁷⁷

Despite the variety of public services available, disability advocates report that some segments of the population are excluded from receiving essential services. The availability of some services is confined to the area around the capital city, while other services are unavailable to those without health insurance.⁷⁸

In Uruguay, training programs on the provision of care to people with disabilities are available in physical therapy, occupational therapy, physiatry, prosthesis and orthotics, and speech therapy. Each year, out of approximately 300 medical students, only 20 go on to receive post-graduate training on the provision of care to people with disabilities.⁷⁹

⁷⁴. Daniel Delgado Sicco.

⁷⁵. Professor Ana Stasiuc (Director, Ministry Of Sports And Youth, Department of Special Services), interviewed 22 September 2003; Dr. Graciela Ubach (Director, Teaching Hospital), interviewed 17 October 2003.

⁷⁶. Dr. Stella López.

⁷⁷. CNHD; Mobility aids provided include wheelchairs, canes, and walkers.

⁷⁸. Panel discussion.

⁷⁹. Graciela Ubach.

Housing

Although it coordinates disability-related programs with other organizations, the Social Bureau of the Ministry of Housing, Land Planning, and Environment has no specific department in charge of disability issues. Among these programs is the Integrated System for Housing Access (SIAV) Program, which was created in 1993. Through the program, people with disabilities are given special consideration and priority in subsidized housing. Households headed by women and that include minors and/or people with disabilities are considered part of a vulnerable population and also accorded social consideration. In order to verify the applicant as a person with disabilities, certification issued by any of the following public organizations is required: the Social Security Bank, the "Banco De Seguros Del Estado," a Green Card issued by the municipality of Montevideo, or a Disability Identification Card.⁸⁰

The Social Services Program of the Social Security Bank has a housing program for retirees and pensioners who are not self-sufficient. Lack of self-sufficiency is determined by a technical team of Social Services.⁸¹ The Social Security Bank does not grant any subsidies for accommodation or housing for people with disabilities from regions of Uruguay other than the capital city.

Leaders of the disability community report that, despite the existence of these programs, most people with disabilities live with their families. Few live in houses acquired through government plans. They also report that a significant number of people with disabilities live in institutions.⁸² There are no independent living centers that provide peer counseling or referral services.

Institutionalization

The Social Security Bank reported that it keeps a national record of institutions, but there are no specific mechanisms for reporting incidents of abuse and/or death in these institutions. Occasionally, cases are prosecuted under criminal law. The number of people assisted by the various institutions is estimated to range from 10 to 150. The leading institutions include the Don Orione Home for men and the Don Orione Home for women. Overall the institutions were reported to offer services such as psychological counseling, psychiatric counseling, rehabilitation services, and education and training. The CNHD found, however, that very few institutions offer these services to their institutionalized patients. People with disabilities have the right to refuse treatment. If an individual has been legally incapacitated, the right to refuse treatment can be exercised by his or her guardian.⁸³

⁸⁰ Ministry of Housing, Land Planning and Environment, Social Division.

⁸¹ Daniel Delgado Sicco.

⁸² Panel discussion.

⁸³ Social Security Bank; CNHD.

The National Institute for Minors (INAME) keeps records of private institutions that have entered into an agreement with the Institute to work with children and adolescents with disabilities. This includes both institutions offering part-time and full-time comprehensive care. The rules and regulations of these agreements govern the care of the children and do not allow forced treatments. Institutions must immediately report any serious situation, hospitalization or death of any patient covered by the agreement to the regional INAME office. Relevant documentation must be provided. The INAME monitors and controls all institutions through the Agreement Division. The INAME keeps its own records of cases of abuse or violence against children with disabilities. Once a case is verified, it is separately documented if it is a disability case.⁸⁴

The institutional approach to people with disabilities has been changing, but an asylum model still prevails. A recent article on the institutionalization of people with psychiatric disabilities acknowledges that “the Psychiatric Hospital, in Montevideo, and Santa Lucia’s Colony for Insane People, located 70 km away from Montevideo, represented a major mental health problem in Uruguay for over a century.” The general conditions were reported to be very poor. Among the changes in recent years have been a reduction in the institutionalized population, community-based assistance, and a “clear distinction between hospitalization needs and housing or shelter needs.”⁸⁵

Accessibility

In addition to Law 16095, which includes provisions on accessibility, there are other national and departmental regulations in force. The Uruguayan Institute of Technical Standards (UNIT) has developed a series of accessibility standards that serve as the basic guidelines in Uruguay.⁸⁶ Law 17497 requires that all construction of public facilities by social, cultural, and sports institutions comply with accessibility standards. The Ministry of Transportation and Public Works has an internal ordinance requiring the application of UNIT accessibility standards to all ministry projects.⁸⁷ CODICEN and ANEP have developed draft accessibility standards for all educational buildings and public spaces.⁸⁸

The municipality of Montevideo issued Order 22463 regarding “special provisions for projects and urban accommodation for people with disabilities” in 1989. The ordinance fully applies to new buildings. Existing buildings must be altered whenever possible. Regulations only became enforceable in March 2002, when the new system for obtaining construction permits became effective.

⁸⁴. INAME.

⁸⁵. Angel M. Gines, “Desarrollo y Estado Actual de la Psiquiatría en el Uruguay” [Development and Present State of Psychiatry in Uruguay], 12 June 2000, <http://www.sitiomedico.com.uy/artnac/2000/09/04.htm>.

⁸⁶. Uruguayan Institute of Technical Standards, www.unit.org.uy.

⁸⁷. Perla Coppola (Directing Committee President, Society of Architects of Uruguay), interviewed 9 September 2003.

⁸⁸. Resolution No. 2504/02, file 5788/02, ANEP, CODICEN.

However, many aspects of the law remain unregulated, making enforcement more difficult. There are no specific penalties for non-compliance, but building permits are not approved until full compliance with all regulations has been demonstrated.⁸⁹ The local government is beginning to monitor enforcement more closely through a new system to obtain construction permits on-site. Other municipalities such as Canelones, Maldonado, Salto, and San Jose, also have regulations currently in force.

The Building Division of the Municipality of Montevideo did not respond to IDRМ requests for information on the number of public buildings accessible to people with mobility disabilities. The Association of Architects reported that a study on access to public buildings in Montevideo was conducted by the National Architecture Bureau of the Ministry of Transportation and Public Works. The study found that only about 5% of the buildings were accessible to people with disabilities.⁹⁰ IDRМ was unable to obtain a copy of the study results. At a recent seminar, the Accessibility Committee of the Association of Architects presented information on the accessibility of a sample of health centers in the city of Montevideo. None of the six centers surveyed could be classified as accessible. While the newer buildings had taken accessibility into account, they still do not fully comply with accessibility requirements.⁹¹



Inaccessible Post Office entrance in Uruguay

⁸⁹. *Ibid.*

⁹⁰. *Ibid.*

⁹¹. Accessibility Committee of the Association of Architects, "Jornada Sobre Accesibilidad A Los Centros De Salud" [Day on Health Center Accessibility] (seminar held at the Sindicato Medico del Uruguay, 29 June 2002.)

Accessibility is not included as a separate subject in the curricula of the School of Architecture (UDELAR), but it is included as a concept in general courses at the school. The Accessibility Committee of the Association of Architects, whose slogan is "Design For All", also works to integrate the concept of universal design in courses.

Sections 56 and 57 of Law 16095 contain specific provisions on accessibility of public transportation at the national level. The law also provides some assistance to private companies adapting vehicles. As of September 2003, no private transportation companies had submitted any adaptation proposal.⁹² There is no mechanism in place to ensure the necessary adaptation of vehicles.

As of October 2003, the bus system in Montevideo had no vehicles that were adapted or designed for the transportation of wheelchair users. Montevideo replaced the bulk of its public buses ten years ago. At that time, the municipality had been unable to gradually replace its aging bus fleet. In early 1993, there was a pressing need for acquiring used buses in working conditions, because the current fleet was obsolete. The mass replacement of buses did not include vehicles meeting accessibility criteria. There are no automotive assembly plants in Uruguay, so adaptation costs would be extremely high.⁹³

Montevideo's Division of Traffic and Transportation reported that some disability organizations offer transportation services for their members, but the scope of these services is limited. Private vans offer adapted transportation for people with disabilities that can afford to purchase such services.⁹⁴

All forms of public transportation are required to reserve a seat marked for use by people with disabilities.⁹⁵ Some additional transportation benefits granted to people with disabilities in Uruguay include: exemptions from automobile taxes, registration benefits, parking benefits, free movement cards, and reduced ticket fares for urban public transportation.⁹⁶

Culture, Sports, and Recreation

Since 1986, recreational activities have been available through NGOs and sports parks that integrate youth with disabilities. "Friendship Day" activities have involved hundreds of athletes over the age of 9 in sports such as swimming, football, handball and athletics. People with intellectual disabilities over the age of 18 have access to the Paralympic Games. The Ministry of Sports and Youth has a Special Services Department that supports 82% of special schools in the capital city and 55% of special schools in the interior of the country. The department manages recreational, pre-sport, and sport activities.⁹⁷

⁹² Contador Jorge Chapital, interviewed by author, Montevideo, 26 August 2003.

⁹³ Felipe Martín.

⁹⁴ *Ibid.*

⁹⁵ Felipe Martín; Resolution 8679/85; Order 24582; Order 365/91-16 July 1991 section 1; Order 95/87- 14 February 1987- section 1; Order 99/86 -13 February 1986-section 45; Order 24022.- 1 August 1988- section 1; Order 25787-30 September 1992- section 32 -volume V. Municipal Digest.

⁹⁶ *Ibid.*

⁹⁷ Ministry of Sports and Youth.

Disability Action & Awareness

The National Honorary Disability Committee (CNHD) is the agency in charge of planning and coordinating disability policy at the national level, providing recommendations to various governmental entities, coordinating activities of non-profit institutions, and promoting awareness. Law 16095 created the CNHD and established its duties and the composition of the committee. The committee brings together delegates from various national government ministries, the Congress of Mayors of the school of medicine and dentistry, CODICEN, INAME, and “each of the most representative disability organizations.”⁹⁸ Members serve for five years. Twenty-five percent of the members of the current committee are persons with disabilities. Despite the existence of the CNHD, however, coordination is generally lacking both within government itself, and between government and the private sector.

There are specific disability offices within only a few government agencies such as the ANEP and the INAME in the Municipality of Montevideo. The minimal number of governmental organizations with specific disability-related offices suggests that the disability issue is not a priority in Uruguay. Additionally, there is no national disability action plan in place.⁹⁹

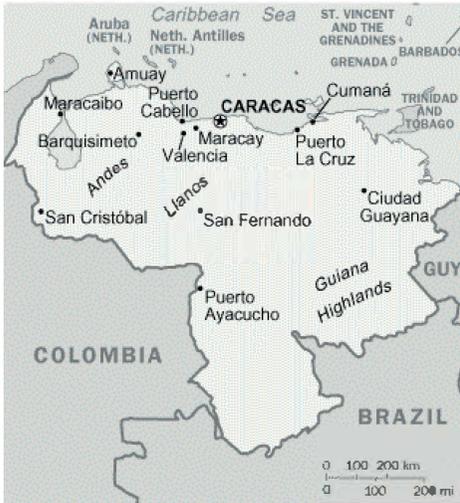
At the national level, there are several NGOs for people with different types of disabilities. These include: the National Plenary of the Disabled (PLENADI); the Uruguayan Chapter, a member of the international network Latin American Group for the Participation, Integration and Inclusion of Persons with Disabilities (GLARP-IIPD); the Association of Parents And Friends of People with Disabilities of Tacuarembó [Amigos y Padres del Discapacitado de Tacuarembó] (APADISTA); and Gardel’s House Center, among others. More general human rights organizations occasionally engage issues of specific importance to people with disabilities, but such action is intermittent.

Disability organizations are usually financed by a combination of governmental contributions for rehabilitation and social services, and by funding from foundations both foreign and national. Collaboration among disability organizations is generally positive in some areas, such as recreational activities. However, there is no coordination, and action is frequently overlapped, making the disability movement less efficient.¹⁰⁰

⁹⁸ Law 16095, sec. 10.

⁹⁹ National Honorary Disability Committee.

¹⁰⁰ Panel discussion.



Venezuela

Key Factors: The legal framework protecting disability rights in the Bolivarian Republic of Venezuela is fairly broad, and the current government appears willing to commit itself to meeting the needs of this sector of the population. However, entrenched barriers such as architectural and communication inaccessibility make elimination of inequalities in daily life more remote.

Terminology

In general, most legal documents in Venezuela refer to people with disabilities as “personas incapacitadas.” There are still some discrepancies, however. One example is that the Labor Act, Chapter II, Section 26, uses the term “minusválidos,” translated as “handicapped.” In this report the original terminology of legal documents has been utilized.

Definition of Disability

There is no single definition of disability in Venezuela. Different agencies and laws each use their own definition. However, the definitions generally focus primarily on individual impairments.

The most prominent legal definition can be found in the Integration of People with Disabilities Act. This act defines people with disabilities as “all those people whose social integration possibilities are reduced due to physical, intellectual or sensory impairment, in its various levels and degrees, that limit their ability to perform any activity.”¹

The draft bill on Comprehensive Care for People with Disabilities uses a somewhat similar definition that identifies persons with disabilities as people who “due to various reasons, whether genetic, congenital or acquired as a result of parnatal, occupational, traffic, home-related or other type of accidents or due to medication intake, exposure to environmental polluting substances, show a reduction - with various statistical values- or prolonged or permanent lack of

¹ Integration of People with Disabilities Act, *Republic of Venezuela Official Gazette 4623 Special Edition*, Year CXX Month XII, sec. 2, 3, September 1993.

any of their sensory, mobility or intellectual abilities.”²

State agencies have developed their own definitions. The National Institute of Statistics (INE) definition maintains that “disability refers to any loss or deficiency of one or more organs or limbs or functions thereof which results in one or several disabilities, or limitations produced by diseases that affect a person’s activity in a permanent way.”³

The definition used in the Ombudsman’s Office identifies disability as “a sensory, mobility or cognitive limitation which somewhat restricts the ability to access the social world.”⁴

Disability Population

The total population of Venezuela was 24.2 million according to the most recent census, conducted in 2001.⁵ The 2001 census contained two questions measuring the size of the disability population in Venezuela. For each person in the household, the primary question used to detect disability asked whether he or she had “total blindness,” “total deafness,” “mental retardation,” “loss or disability of upper extremities,” “loss or disability of lower extremities,” “other,” or “none.” The second question asked whether the person “requires the use of a wheelchair?” The number of people with disabilities according to the census was 927,392, or 4.4 percent of the population.⁶ This figure is the subject of some dispute. The questions used to identify people with disabilities were also criticized during the 1991 census, the first to include such questions.

A different disability population figure is available from the National Council for the Integration of Disabled People. They estimate that there are 1,600,000 people with disabilities, accounting for 6 percent of the total population.⁷ The Pan American Health Organization’s Special Program on Health Analysis suggests an even higher rate, estimating people with disabilities as between 12% and 14% of the population in developing countries.

Important causes of newly acquired disabilities include injuries from firearms and traffic accidents. In addition, the Coordinator of the Social Integration of People with Disabilities Program of Chacao City Hall noted that the environmental disaster at La Guaira in 1999 resulted in people with mobility and psychological disabilities.⁸

² Comprehensive Care for People with Disabilities.

³ Alcira Carnero (Legal Counsel for the INE), interviewed by author, Caracas, 18 July 2003.

⁴ Herbert Corona (attorney-at-law, Ombudsman’s Office), interviewed by author, Caracas, 4 August 2003.

⁵ INE, *Censo: Poblacion y Vivienda 2001*, 2001e

⁶ Alcira Carnero.

⁷ Professor Lenin Molina (Chairman of the National Council for the Integration of Disabled People), interviewed by author, October 2003.

⁸ Juan José Seitz (Coordinator of the Social Integration of People with Disabilities Program of Chacao City Hall), interviewed by author, October 2003. Heavy rainfall brought about the overflow of various affluents and 200 people in the region suffered damages in December 1999.

Legislation & Disability Rights

Legal Protections

Venezuela has signed the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities on 8 June 1999. However, it has not yet deposited the ratification document with the Organization of American States General Secretariat.⁹ Additionally, delegates from Venezuela have participated in meetings of the Iberoamerican Intergovernmental Technical Cooperation Network (RIICOTEC).⁸

There is a broad national legal framework that recognizes the rights of all citizens in Venezuela. People with disabilities are protected by sections 81 and 101 of the National Constitution.¹¹ The Integration of People with Disabilities Act, the Child and Adolescent Protection Act, the Social Security Act, the Social Insurance Act, and the Labor Act provide other legal protections for people with disabilities.¹² The Venezuelan Commission on Industrial Standards issued a set of guidelines, known as the Covenin Standards, for accessibility to the built environment for people with disabilities.¹³ In addition, because Venezuela is a republic, each state has the authority to issue its own regulations, and to conduct plans and programs to guarantee equality of opportunities in its region. State legislation and some municipal ordinances deal with construction and adaptation standards and accessibility of public and private facilities.

These legal protections are not well publicized, so many people with disabilities are unaware of their rights and any recourse that might be available when those rights are violated. This lack of awareness and information limits the effectiveness of these protections.⁸

There are government entities that protect human rights of the population in general, as well as some offices that are exclusively committed to disability rights. These include the National Council for the Integration of Disabled People (CONAPI), and the Ombudsman's Office. Violations of the rights of persons with disabilities must first be reported to CONAPI, whose lawyers should then attend to and register the complaint. Only when CONAPI does not handle the cases do lawyers at the Ombudsman's Office become involved. Although it is the responsibility of both organizations to report violations, in practice few reports have been made, and the offices do not describe the enforcement of disability rights as their main mission.

⁹ OAS, *Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities*, <http://www.oas.org/main/main.asp?sLang=E&sLink=http://www.oas.org/OASpage/humanrights.htm>.

¹⁰ "Celebra RIICOTEC en Mexico su VII conferencia" *Disability World* 20, (Sept-Oct. 2003), http://www.disabilityworld.org/09-10_03/spanish/noticias/riicotec.shtml.

¹¹ Constitution of the Bolivariana Republic of Venezuela, <http://www.parlamento.gub.uy/Leyes/Ley16095.htm>.

¹² Child and Adolescent Protection Act, *Official Gazette* 5266, 2 October 1998.

¹³ Regulation 2733, Normas COVENIN, *Construcción y Adaptación de edificaciones de uso público accesibles a personas con impedimentos físicos* [Construction and Adaptation of Facilities for Public Use by People with Disabilities], 1990.

¹⁴ Panel discussion held with leaders of disability organizations, discussion facilitated by author.

Civic Participation

People with disabilities have the same rights as the rest of the population, including the right to vote and the right of assembly. However, limited accessibility of the built environment and limited communication accessibility are barriers to the exercise of these rights. In the case of voting, election ballots in Braille are available to guarantee secrecy in voting for people who are blind, though there are no interpreting services available for people who are deaf, and stairways, narrow entrances, and other architectural barriers make reaching the polling station difficult for many people with disabilities.

Inclusion

Communication

The Ministry of Education has a Braille publishing house. It also maintains a “Spoken Book” room at the Yaracuy Central Library where the current National Constitution among other documents of interest can be heard. In total, there are 21 public libraries equipped with some auxiliary materials for people who are blind.¹⁵ The National Library and the Simón Rodríguez Public Library in Caracas contain Braille versions of an earlier Constitution. They do not have a Braille version of the current Constitution. In the National Library there are only 71 books available in Braille. Most of the books are short stories, no copies of any other law are available. Organizations such as the Venezuela Federation of Institutions for the Blind (FEVIC) also help provide ancillary material, Braille material and other spoken books.

Spoken books as well as computer programs for people who are visually impaired are increasingly being used in the country. At Venezuela’s Central University (UCV), the Commission for the Integration of UCV Students with Disabilities, is considering the implementation of such programs on their Central Library computers.¹⁶

No television news programs are available in alternative formats such as sign language or closed-captioning. In addition, the National Assembly is discussing a draft of a bill whereby television stations would have to incorporate closed captions or interpreters in the Venezuela Sign Language (LSV) for viewers who are hearing impaired. The Venezuelan Federation of the Deaf is also working on addressing this issue.¹⁷

¹⁵. Special Education Office, [What is the Braille Publishing House and the Spoken Book], Ministry of Education, Culture and Sports, 1-2.

¹⁶. Professor Nancy González (Department for Students with Disabilities at the University of Central Venezuela), interviewed by author, 11 December 2003.

¹⁷. Dr. Linda Gotilla (2nd Defender for the Department of the General Office of Judicial Services, Caracas Ombudsmas’s Office), interviewed by author, Caracas, 16 October 2003; Pedro Poleo (President of the Venezuelan Federation for the Deaf), interviewed by author, Caracas, 11 September 2003.

There is no system in place, such as TTY, for people who are deaf to communicate with the authorities in case of natural disasters or emergencies. Caracas firefighters are reportedly studying how to aid people who are hearing-impaired during disaster and emergency situations. Additionally, in some towns and states, Venezuela Sign Language instruction courses are reportedly being delivered for police officers, firefighters and traffic officers. IDRM was unable to confirm these reports with relevant authorities.

The Telegraphic Postal Institute offers no Braille material and no communication access to people with hearing impairments.¹⁸ The Special Ombudsman's Office for People with Disabilities reported that recommendations for accessible communication are being added to the Postal Service Act under consideration by the National Assembly.

Most other government services are similarly inaccessible. The Caracas Metro transportation system has no announcement signage for riders who are hearing-impaired. There are no interpretation services at courts and notaries' offices. Only when a person who is deaf specially requests an interpreter and is able to provide someone to supply the service will interpretation be available. At the national level there are scarce human resources devoted to this task.

There are various nascent initiatives at the municipal level. The Los Guayos City Hall in Valencia plans to implement a project for the inclusion of LSV interpreters, which the city hall will likely fund. The City Hall also promotes the learning of Sign Language to its employees and appears to be interested in the teaching of this language at the community level.¹⁹

In another regional initiative, Yaracuy State passed a law promoting LSV workshops, aimed at "non-hearing disabled people as a means of establishing a communication system to enable the integration of the disabled people sector into the society."²⁰

Education

Venezuela recognizes the right of all citizens to education. People with disabilities are entitled to receive education, although the majority of students attend special educational centers rather than integrated, regular classrooms. The Ministry of Education does not possess accurate information on the percentage of children and youth in the school system who are attending the special education programs. Schools maintain enrollment numbers, but no cumulative statistics are calculated.²¹

¹⁸ Magali Silva (Social Welfare Management Assistant, Telegraphic Postal Institute Main Office), interviewed by author, Caracas, 23 January 2004.

¹⁹ Mayor Olivo Pinto (Guayos Municipality), interviewed by author, Municipality of los Guayos, State of Carabobo, 25 November 2003.

²⁰ *Equality and Protection for People with Disabilities Act*, ch. II, sec. 17, *Yaracuy State*. FEVENSOR is developing plans for teaching the LSV courses, but IDRM was unable to ascertain whether any courses have already been held.

²¹ Teresa Fajardo (social worker, National Coordinator of the Learning Difficulties Program, Special Education Office of the Ministry of Education), interviewed by author, Caracas, 8 July 2003.

Education for people with disabilities in Venezuela includes early childhood care. Comprehensive care and early stimulation programs are available from the Child Development Center for children through the age of 6. For elementary school children, both special schools and integrated schools make some adaptations for students with disabilities. Children may also receive guidance from an educational unit that is suitable for their individual type of disability. Special education is not yet available in all cities throughout the country. In some states, centers are located only in the state's capital or another major city. Children who live far from the center have difficulty accessing educational services.²²

Children may receive secondary schooling at either special schools or regular schools, however, it is often difficult for students with disabilities to continue into secondary school. Secondary special education is rare, and adaptations and assistance in regular schools are unusual. In general, the integration process typically includes students with no intellectual disabilities. Additionally, CONAPI has demanded a national policy establishing absolute accessibility to all educational facilities, suggesting that current accessibility conditions are not yet sufficient.²³

Disability organizations do not consider the special education system effective. For this reason, some institutions for people with disabilities do not cooperate or coordinate with the Ministry of Education, although the Ministry has expressed a willingness to further adapt its curriculum.²⁴ NGOs also advocate for increased family participation in the education of children with disabilities. The Director of the Association for Supplemental Special Education Development (ASODECO) noted that "we have excellent youth coming from families who are uncooperative, and work becomes harder with these young people."²⁵

The Liberator Pedagogical Experimental University (UPEL) is the main source of special education training for teachers. Teacher training is also available through extension courses. In some states, such as Cojedes, there is an agreement for regular teachers to receive training in special education.²⁶

There are some occupational workshops for youth that are offered as part of the educational system, which offer manual training where students are taught a trade. A cooperation agreement between the Ministries of Education and Labor recognizes the important link between education and employment.²⁷

²² *National Special Education Services and Institutions Directory, Special Education*, (Library of the Ministry of Education, Culture and Sports, September 2002), <http://www.defensoria.gov.ve/lista.asp?sec=190502educacionarchivos-especial.xls>.

²³ Lenin Molina.

²⁴ Educational Planning and Program Office of the General Office of Education Levels and Modes, Ministry of Education, (meeting held at the Ombudsman's Office headquarters, 17 December 2003).

²⁵ Nelly Goncalves (Director and Teacher of ASODECO), interviewed by author, Caracas, 16 January 2004.

²⁶ Teresa Fajardo; Edith Rojas and Sandra Julio Flores (Social Welfare Coordinators), interviewed by author, October and November 2003.

²⁷ Cooperation agreement on schooling and social and occupational integration of people with special educational needs, signed on 2 February 1999 by the INCE, the MECD, and the Foundation for Special Education Development.

Other opportunities for older students include university studies, private boarding schools, private institutes, and courses at the National Training and Education Institute (INCE).²⁸

The Venezuela Central University and the Libertador Pedagogical Experimental University have agreed to accept some students with disabilities. There is a small group of young people with disabilities who are taking courses at each institution. However, students report that the majority of university centers are not well prepared to assist people with disabilities. Universities do not offer courses on disability-related subjects. At Venezuela's Central University, no courses on disability are offered, but some seminars and workshops are available for interested professors or students.²⁹ In addition, this University has an interdisciplinary disability studies program where information is provided and awareness is raised among students and people interested in the disability issue.³⁰ The program is coordinated by Professor Manuel Aramayo, and it is housed in the UCV School of Humanities and Education with the support of the School of Medicine.³¹

Employment

Lack of employment is a serious problem for many people with disabilities. Although none of the institutions consulted by IDRM were able to provide accurate unemployment figures for people with disabilities, the director of CERPIC estimated "that 90% are unemployed in the formal sector and 80% in terms of informal employment."³² In this case, formal employment includes work in private or governmental agencies or businesses that have social benefits. Informal businesses, on the other hand, include peddlers, vendors, and any form of self-employment.

National regulations and policies regarding the employment of people with disabilities primarily derive from the Integration of People with Disabilities Act. Section 18 provides a general statement of rights, which reads "People with disabilities shall enjoy full exercise of their rights. People with physical, sensory or intellectual disabilities shall not be restricted, by reason of level or degree of disability, from fully exercising their rights." Section 23 of the same act specifically addresses the issue of employment, stating that "people with disabilities have the right to work without any further constraints than those resulting from their skill and work training."

The Labor Act also provides a legal framework for employment rights. Chapter II, Section 26 provides a general anti-discrimination statement, although it does not specifically identify people with disabilities among the protected groups.³³ The act also establishes the legality of initiatives aimed at promoting the

²⁸. Teresa Fajardo.

²⁹. Nancy González.

³⁰. Interdisciplinary Disability Studies, <http://www.ucv.ve/discapacidad/>.

³¹. Mevorah Florentin Foundation, "Directory of main organizations of and working for the blind," (newsletter, VI, no. 3, June 2003 17.

³². Salomé Barreto (Director of CERPIC), interviewed by author, October 2003.

³³. *Labor Act, Official Gazette* 36538, 14 September 1998 and *Special Official Gazette* 5152, 19 June 1997.

employment of people with disabilities, stating that “special provisions enacted to protect maternity and the family, and those geared towards the protection of children, the elderly and handicapped people shall not be considered discrimination.”

The Labor Act establishes that employers must hire one person with a disability for every 50 employees. Few employers comply with this provision because neither companies nor people with disabilities are familiar with the details of the law.³⁴ There are no specific policies requiring the government to employ people with disabilities, however, some offices do so.³⁵

Some municipalities are taking concrete actions to address the lack of employment opportunities for many people with disabilities. New ordinances establish tax exemptions for companies that hire people with disabilities. Some city halls offer training courses for people with disabilities in areas such as computers. Several offices of the Baruta City Hall employ people with mobility disabilities or Down syndrome. At the Chacao City Hall, efforts are underway to encourage companies within the municipality to hire staff with disabilities.³⁶

With regard to training, the Social Security Act provides for the creation of a National Employment Institute, which would have as one of its core functions to “train and facilitate reemployment of disabled workers who have suffered occupational accidents or diseases or diseases of any other origin.”³⁷

Other government funded training programs are held jointly by the Ministry of Education, Ministry of Labor, the Rehabilitation of People with Disabilities Center (CERPIC), and INCE. Better results have been reported in the inland region than in the capital city. To date, CERPIC has placed only four people as a result of these programs.³⁸

The Association for Supplemental Special Education, ASODECO, trains people with mild to moderate disabilities. It has a program, “Supported Employment to Create Independence,” that involves an awareness raising campaign. The program has generated agreements with approximately 17 companies for the inclusion of personnel with disabilities, including Ferre Total, McDonalds, Arturo's Chickens, Burger King, Las Lomitas Preschool, the Children's Museum and the movie theater Cinex. ASODECO verified that McDonalds has approximately six employees working under this agreement. ARTURO'S has four employees with disabilities, and the Children's Museum has one who acts as a museum guide.³⁹

³⁴. Herbert Corona.

³⁵. Offices that employ some people with disabilities include: the Ministry of Education, the Rehabilitation of People with Disabilities Center (CERPIC), the National Council for the Integration of Disabled People, and some city halls and governmental institutions.

³⁶. Herbert Corona.

³⁷. *Social Security System Act*, sec. 90, para. 8, *Official Gazette* 37600, 30 December 2002.

³⁸. Salomé Barreto.

³⁹. Nelly Gonçalves (Teaching Director of Association for the Development of Complementary Special Education), interviewed by author, 16 January 2004.

In addition to ASODECO, companies such as Buena Voluntad [Good Will] conduct similar activities with companies such as Wendy's, Panamco, and Praxair. These companies do not have specific policies that state a person with disabilities should not be discriminated against at the time of applying for a job, but have voluntarily decided to employ people with disabilities.⁴⁰

Lastly, there are some private initiatives such as the "Integration Car Wash", where both young people with disabilities, such as people with mental disabilities, Down Syndrome, and hearing impairments, as well as young people without disabilities, work under equal conditions. The project was established by the family of a girl who is deaf, as a result of their own experiences in the disability field. Work accommodations and all devices used at the car wash are specifically designed for people with disabilities. "As far as labor conditions, they are exactly the same as those for normal youth, they earn a basic salary and if they work well during the week, they get a bonus, and tips...are equally distributed among all employees....Attempts are being made so that [all employees] work the same hours....Depending on the youngster's case and disability he or she may work more or less hours."⁴¹

Health Services

Venezuela recognizes a legal responsibility to provide health care to people with disabilities. One government lawyer explained the rationale in this way "Our Constitution is the foundation of the pyramid, there are also international agreements and bilateral treaties which are recognized where health is guaranteed as a part of the right to life. Given that people with disabilities are legal persons, the Government must guarantee their health, understanding that health means quality of life, and therefore we must provide health care to people with disabilities."⁴²

Rehabilitation services for people with disabilities are designed to be available at 42 rehabilitation centers. Services at these centers are provided by a variety of government organizations including the Ministry of Health and Social Development, the Venezuelan Social Insurance Institute (IVSS), the Ministry of Defense, and the Social Welfare and Assistance Institute of the Ministry of Education. Budgets should cover the costs of personnel and service equipment and the center's operation and maintenance.⁴³ Reports from the National Rehabilitation Institute, however, suggest that funding for rehabilitation is insufficient. A newspaper article about the situation maintained that "only thanks to Civil Association 'Help to the Handicapped' (Ayuda al Minusválido) the Institute has not collapsed. For a year now, they have only had enough money to settle salaries,

⁴⁰ *Ibid.*

⁴¹ Seilín Marin (Owner of Integration Car Wash), interviewed by author, 20 January 2004.

⁴² Katy Chesneau D'Amato (Legal Counsel, Ministry of Health and Social Development), interviewed by author, September 2003.

⁴³ Rafael Rojas (Director of the National Rehabilitation Center), interviewed by author, Caracas, 22 October 2003; Lenin Molina.

but there is no budget to cover other costs ...for many years now patients contribute with a minimum payment, currently three thousand Bolivares per consultation fee... if it weren't for patient contribution, we would be forced to close the Institute."⁴⁴

Rehabilitation in Venezuela is marked by inconsistent and ineffective services.⁴⁵ Moreover, people with disabilities are sometimes unaware of where rehabilitation centers are located, and technical aids offered by government and private entities are often insufficient. In November of 2003, people with disabilities protested the irregularity in IVSS services and the distribution of medication for some people with chronic disabilities.

The draft bill on Comprehensive Care for People with Disabilities envisions community-based rehabilitation (CBR) as a core component of care for people with disabilities in Venezuela. Currently only three states have implemented CBR programs — Lara, Zulia, and the Capital District — and even these programs lack adequate supervision.⁴⁶

Among the state-funded organizations providing assistive devices to people with disabilities, CONAPI provides free hearing prostheses, wheelchairs, and canes for people who are blind. Assistance is also available from some city halls, state government entities, the Pueblo Soberano Foundation, the Ministry of Education Foundation for Special Education Development, Fondo Único Social Foundation, and the Ministry of Health. Private organizations that provide assistance include the Polar Foundation, Telcel Foundation, INAGER, Wheelchair Bank (BANDESIR), Palsy Cure Foundation, *Regálame una Sonrisa* (Extend a Smile), Héctor Briceño International Foundation, Mevorah Florentin Foundation, the Children's Orthopedic Hospital Foundation, and the Society of Deaf Friends. All of these private organizations provide assistive devices, rehabilitation services, psychological counseling to people with disabilities and their families, or training workshops in skills such as sewing or computer use. *Regálame una Sonrisa* Foundation offers assistance dogs.⁴⁷

No data is available on the percentage of healthcare professionals who have received training on the provision of care for people with disabilities. It is estimated that primary care physicians rather than specialists have benefited the most from such training. The National Rehabilitation Center offers graduate training in physiatry to twelve physicians each year.⁴⁸

44. Aliana González, "El milagro de Bernardette: El Instituto Nacional de Rehabilitación funciona, una mezcla de autogestión y mística lo hace posible" [Bernadette's Miracle: The National Rehabilitation Center works, a mix of self-management and mystical help makes it possible], *Tal Cual Newspaper*, July 2003, La Nación Section, 416.

45. Maribela Núñez, "Pacientes crónicos protestaron a las puertas de la OPS" [Chronic patients protest at the doors of PAHO], *Periódico El Nacional*, 27 November 2003, sec. B.

46. Carlos Alvarado (National Rehabilitation Director and Labor Medicine Director), response to CIR questionnaire, 18 November 2003. The Comprehensive Care for People with Disabilities Bill was proposed by Lenin Molina Penaloza.

47. Carlos Alvarado.

48. Dr. Rafael Rojas.

The following training programs are available in Venezuela: physical therapy, occupational therapy, speech therapy, and physiatry for nurses and other health professionals in prosthetics and orthotics (P&O). The least developed of these is the prosthetics and orthotics program, which produces technicians trained only to an intermediate level. There are proposals to upgrade the P & O training to produce advanced technicians.⁴⁹

The Children's Orthopedic Hospital offers a residency program where health professionals can become familiar with disabilities. The non-profit, privately funded hospital serves low-income families. It has one of only two Gait Analysis Laboratories in Latin America.⁵⁰

Housing

Venezuela has no national program to provide housing for people with disabilities. There are no national subsidy or assistance programs for people with disabilities who wish to purchase homes.

Each state is developing its own housing laws for people with disabilities, under the supervision of the Special Ombudsman's Office for People with Disabilities, which reviews and makes observations or recommendations before the laws are approved and enacted. The state law of Mérida, for example, reads "Organizations responsible for implementing housing programs in Mérida State are obligated to set aside a quota for people with disabilities. These shall be granted prior to review of socioeconomic conditions of the beneficiary."⁵¹

Similar provisions on housing were adopted by other state legislatures, including those of Yaracuy, Vargas, and Zulia. In almost all laws, the state government, municipalities, or city halls are defined as the entities responsible for promoting or fostering access to housing. They are also in charge of facilitating access to subsidies, credit grants, or any other systems for housing acquisition or improvement.

Some of these local and regional laws have only been enacted very recently and, as a result, have not yet been implemented. Enforcement and monitoring agencies are working to bring recent statutes, regulations and ordinances into force soon.

No independent living centers exist, although some states have considered them in their legislation. For example in Merida, the ordinance on rights of people with disabilities states, "the City Hall shall promote the creation of Residential Centers for people with disabilities who wish to live an independent life, separate from their family, or for those that so require due to abandonment."⁵²

⁴⁹ Carlos Alvarado.

⁵⁰ A lab is also located in Brazil.

⁵¹ *Assistance and Integration of People with Disabilities Act of Mérida State, Official Gazette 659, sec. 21, 3.*

⁵² *Ordinance on rules, rights and protection to people with disabilities, Mérida Municipal Gazette, (11 August 2003), Legal deposit No.79-0151, Special Issue 98, Year IV, sec. 88, para. 3, 22.*

Institutionalization

There are a variety of long-term housing and care institutions for people with disabilities in Venezuela, including hospitals, as well as residential educational facilities and institutions that provide on-going care for those no longer in residence.

The National Rehabilitation Center provides accommodation and care for four months to one year for people with disabilities. Although this is not the Institution's specific mission, they typically lodge an average of 70 patients per month. The institution offers psychological counseling services, psychiatry, rehabilitation, education/training, orthotics and prosthetics. It is the only hospital providing long-term services.⁵³

The Francis of Assisi Blind Girls' Home in Junquito is a private Catholic residential education center. The home is funded through private donations and a small government grant through the Venezuelan Association of Catholic Education (AVEC). As a comprehensive education center, it assists boys and girls who are blind through the twelfth grade. It also admits students without visual impairments, thus encouraging an exchange between both groups. The institution operates as a home for girls, accommodating a fairly large number of girls whose parents live in other remote cities and girls who have been abandoned.⁵⁴

There are 28 National Institutes of Geriatrics and Gerontology (INAGER) that report to the Ministry of Health and Social Development, 15 of which are located in the capital city. These privately funded centers house senior citizens, many of whom have no family.⁵⁵ Those with family may return to their homes in the evenings. Senior citizens receive comprehensive care at these institutes including food, medication, and rehabilitation.

Psychiatric centers, such as the Center for the Care of the Schizophrenic Patient and Family Members in Maracaibo, serve people with chronic mental disabilities, and act as both residential and out-patient facilities. People who have left centers are encouraged to seek employment. They meet at the centers to share concerns and strategies for reintegration into society. The Center in Mava has a radio program that hosts physicians and former patients who inform and educate the community. Although the model has been internationally recognized, this center receives no government support.⁵⁶

⁵³. Rafael Rojas.

⁵⁴. Visit to this institution on 9 December 2003.

⁵⁵. José Miguel Marin, "Gracias a INAGER de Caricuao, 400 ancianos viven felices" [Thanks to INAGER from Caricuao, 400 elderly people live happily], *ASI ES* newspaper, (22 March 2002).

⁵⁶. Marlene Rizk, "Esquizofrenia Controlada" [Controlled Schizophrenia], *El Nacional* newspaper, (6 February 2002), Health section, 1.

A Special Ombudsman on Health and Social Security supervises the aforementioned centers. Representatives document existing conditions during visits to the centers.⁵⁷ That documentation becomes part of the control record through which the Ombudsman's Office makes recommendations and/or observations regarding conditions in those centers. There are no records of institutionalization of people against their will or of cases of abuse, and there have there been no ad hoc investigations.⁵⁸

Accessibility

Section 32 of the Integration of People with Disabilities Act sets forth that "construction, extension and alteration of state or privately-owned property intended for public use, as well as planning and urbanization of public roads, parks and gardens with similar features, shall be performed in such manner so as to ensure they are accessible to and usable by people with disabilities." Regulations establishing building accessibility requirements also include ordinances of the Caracas Metropolitan City Council and other municipalities. These ordinances regulate all forms of architectural barriers including both structural features of the built environment, as well as behavioral uses of public space. For example, peddlers' (*buhoneros*) bundles may prevent the free movement of wheelchair users and people who are blind. In the Municipality of Sucre, Miranda State, the removal of sidewalk newsstands is currently underway.⁵⁹

All accessibility-related statues and regulations and general information on accessibility are available from the NORMA FUND, a non-profit organization that compiles information on technical standards. Also available from NORMA are accessibility standards for people who are deaf or blind, including rules on signage in elevators and hallways.⁶⁰

The research team concluded that compliance with accessibility regulations is low, and the majority of public offices are inaccessible to people with disabilities. For example, none of the Telegraphic Postal Institute's offices are accessible.⁶¹

Noncompliance is largely the result of the lack of awareness about accessibility requirements of both officials and much of the disability community. Venezuela currently lacks the supervising body needed to oversee the enforcement and implementation of existing rules.⁶²

⁵⁷. Asia Villegas (Special Ombudsman on Health and Social Security), interviewed by author, Caracas, 19 January 2004.

⁵⁸. Hebert Corona.

⁵⁹. Working Plan of FONTUR, as cited by Jose Rafael Velásquez (Engineer, Local Investments Management of FONTUR), interviewed by author, Caracas, 2 September 2003; Herbert Corona, (presentation, UCV, 3 December 2003).

⁶⁰. Standards and Quality Certification Fund, <http://www.fondonorma.org.ve/index2.htm>.

⁶¹. Magali Silva.

⁶². Standards and Quality Certification Fund.

The Zulia University School of Engineering offers workshops on accessibility that have been drawing increased interest. There are no exact numbers, but the course initially enrolled five students. Currently, the school offers two sections and employs three professors of the subject. They also offer a universal design course for architects called "Barrier-Free Architecture."⁶³ Universities in Caracas have no required workshops or courses on accessibility within architecture and engineering programs, but an optional course in universal design is available.⁶⁴

In addition to architectural inaccessibility, leaders of disability organizations also report that public transportation is not accessible, and even the system in Caracas is only partially accessible. Trains at the Caracas Metro station can be easily accessed from the platform by people with disabilities, but there are no elevators to carry people from the street level to the subway platform in any station. Only escalators are available, making the stations inaccessible to people who use wheelchairs.⁶⁵

Caracas Metro provides a staff training course on assisting people with disabilities⁶⁶ and is reportedly working on new measures to include people with disabilities. New stations will include accessibility measures, and additions within the Metro system will include outer ramps and special elevators. Braille buttons will be added to some of the newer lines. In addition, there is a project underway to incorporate stair-lifts in some older line stations. Caracas Metro is considering the acquisition of 50 buses equipped to serve people with disabilities.⁶⁷

Other mass transportation companies such as the Valencia Metro, Maracaibo Metro, Merida Trolleybus, Los Teques Metro, Anzoategui Metro, and the National Railroad Institute, are considering the need to allow for the accessibility of transportation systems to people with disabilities. Los Guayos City Hall in Valencia will provide transportation for people with disabilities to service providers such as rehabilitation centers, doctor's offices, or educational facilities. The service has experienced an increase in demand, so the purchase of a larger vehicle is under consideration.⁶⁸

The Urban Transportation Fund, FONTUR, has initiated a pilot program in 22 cities aimed at mass public transportation accessibility for people with disabilities. However, an urban planner with the fund noted the overall transportation problems for people with disabilities, saying "people with disabilities are not treated in a particularly special way. There may be rules which require, for example, a seat be given to a pregnant woman or a crutch user, a mother with a child or an elderly person, but it is not a system that specifically considers people with disabilities."⁶⁹

⁶³. Miguel Yaber (Vice Chairman of the Regional Council for the Integration of People with Disabilities of Zulia State) email response, 25 January 2004.

⁶⁴. Eduardo Luque (Caracas Metro Architecture Division), interviewed by author, Caracas, 9 September 2003.

⁶⁵. José Rafael Velásquez (engineer, Local Investments Management, FONTUR), interviewed by author, September 2003.

⁶⁶. Pablo Mota (Caracas Metro Public Relations), interviewed by author, September 2003.

⁶⁷. Emilio González (Architecture Division), interviewed by author, 18 September 2003.

⁶⁸. Mayor Olivo Pinto.

⁶⁹. Mercedes Clemente (Urban Planner, Urban Transportation Fund), interviewed by author,

An inspection conducted by the Special Ombudsman's Office for People with Disabilities found that although Maiquetia International Airport provides various facilities for use by people with disabilities, some of them are inappropriate or deteriorating. This situation holds for both domestic and international flight terminals, where ramps are in poor condition, and signage at parking lots is poor. In addition, pay phones and support bars in rest rooms are too high, and broadcast information is not sufficiently audible. Positive aspects, such as appropriate elevators for wheelchair access, and elevator panels in Braille at the right height, should be mentioned, however.⁷⁰

Disability Action & Awareness

In Venezuela, the National Council for the Integration of Disabled People (CONAPI) is the national coordinating body for disability policy. In addition to developing national disability policies, CONAPI drafts bills and regulations. The CONAPI is currently working on the reform of the existing Integration for People with Disabilities Act, and is responsible for planning and implementing the 2004 Care Plan. The Council is responsible for advising both public authorities and the private sector on training, accessibility, and all other issues of comprehensive care for people with disabilities. CONAPI is also responsible for maintaining records on the condition and situation of people with disabilities in Venezuela.⁷¹

In addition to its advisory capacity, CONAPI runs a program for the provision of technical aids. It also sponsors social and sports events, disability prevention campaigns, and disability-related research. Programs include all disabilities and also cover those individuals with a disabling disease or disorder. The Council also hears cases on discrimination and should take the steps necessary to ensure appropriate penalties are imposed.

Despite the mandate of CONAPI, there is a lack of coordination and cooperation between government agencies and disability organizations. Cooperation among disability organizations is also sometimes difficult. There are no systematic inter-institutional activities in place to promote awareness raising and disability rights advocacy. This overall lack of coordination ultimately results in diminished programs and services for people with disabilities.

Some awareness raising campaigns have been implemented at the local and regional levels. For example, the Chacao City Hall has conducted awareness-raising campaigns, specifically regarding accessibility, such as the program in which "a wheelchair was placed at the entrance of the city hall and the community was invited to take on the challenge to 'perform your daily activities in a wheelchair.'"⁷²

⁷⁰ Additional information regarding airport services for people with disabilities is available at the airport's web site: http://www.maiquetia.com.ve/guias/frame_6.html.

⁷¹ Integration of People with Disabilities Act.

⁷² Luis Cabezas (Head of Social Project Programs Division), interviewed by author, Chacao City Hall, October 2003.

The Regional Council for the Integration of People with Disabilities in Zulia (CORIPDIS-Zulia) conducts awareness-raising workshops including "Stand in my Shoes," which contend that integration of people with disabilities is essentially a rights issue. Zulia University also conducts workshops on inclusive education and the responsibility of the education system to make inclusion a reality.

Appendices



Jose Isola of CONFIEP (National Confederation of Private Enterprises) visits the tribe Yagua branch of the Amazonas within the framework of a program of accessible tourism in Peru

Appendix A: UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

A/RES/48/96
85th plenary meeting
20 December 1993

48/96. Standard Rules on the Equalization of Opportunities for Persons with Disabilities

The General Assembly,

Recalling Economic and Social Council resolution 1990/26 of 24 May 1990, in which the Council authorized the Commission for Social Development to consider, at its thirty-second session, the establishment of an ad hoc open-ended working group of government experts, funded by voluntary contributions, to elaborate standard rules on the equalization of opportunities for disabled children, youth and adults, in close collaboration with the specialized agencies, other intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons, and requested the Commission, should it establish such a working group, to finalize the text of those rules for consideration by the Council in 1993 and for submission to the General Assembly at its forty-eighth session,

Also recalling that in its resolution 32/2 of 20 February 1991 the Commission for Social Development decided to establish an ad hoc open-ended working group of government experts in accordance with Economic and Social Council resolution 1990/26,

Noting with appreciation the participation of many States, specialized agencies, intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons, in the deliberations of the working group,

Also noting with appreciation the generous financial contributions of Member States to the working group,

Welcoming the fact that the working group was able to fulfil its mandate within three sessions of five working days each,

Acknowledging with appreciation the report of the ad hoc open-ended working group to elaborate standard rules on the equalization of opportunities for persons with disabilities,

Taking note of the discussion in the Commission for Social Development at its thirty-third session on the draft standard rules contained in the report of the working group,

1. Adopts the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, set forth in the annex to the present resolution;
2. Requests Member States to apply the Rules in developing national disability programmes;
3. Urges Member States to meet the requests of the Special Rapporteur for information on the implementation of the Rules;
4. Requests the Secretary-General to promote the implementation of the Rules and to report thereon to the General Assembly at its fiftieth session;
5. Urges Member States to support, financially and otherwise, the implementation of the Rules.

ANNEX

Standard Rules on the Equalization of Opportunities for Persons with Disabilities

INTRODUCTION

Background and current needs

Previous international action

Towards standard rules

Purpose and content of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Fundamental concepts in disability policy

PREAMBLE

I. PRECONDITIONS FOR EQUAL PARTICIPATION

Rule 1. Awareness-raising

Rule 2. Medical care

Rule 3. Rehabilitation

Rule 4. Support services

II. TARGET AREAS FOR EQUAL PARTICIPATION

- Rule 5. Accessibility
- Rule 6. Education
- Rule 7. Employment
- Rule 8. Income maintenance and social security
- Rule 9. Family life and personal integrity
- Rule 10. Culture
- Rule 11. Recreation and sports
- Rule 12. Religion

III. IMPLEMENTATION MEASURES

- Rule 13. Information and research
- Rule 14. Policy-making and planning
- Rule 15. Legislation
- Rule 16. Economic policies
- Rule 17. Coordination of work
- Rule 18. Organizations of persons with disabilities
- Rule 19. Personnel training
- Rule 20. National monitoring and evaluation of disability programmes
in the implementation of the Rules
- Rule 21. Technical and economic cooperation
- Rule 22. International cooperation

IV. MONITORING MECHANISM

INTRODUCTION

Background and current needs

1. There are persons with disabilities in all parts of the world and at all levels in every society. The number of persons with disabilities in the world is large and is growing.
2. Both the causes and the consequences of disability vary throughout the world. Those variations are the result of different socio-economic circumstances and of the different provisions that States make for the well-being of their citizens.
3. Present disability policy is the result of developments over the past 200 years. In many ways it reflects the general living conditions and social and economic policies of different times. In the disability field, however, there are also many specific circumstances that have influenced the living conditions of persons with disabilities. Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development.

4. Over the years disability policy developed from elementary care at institutions to education for children with disabilities and rehabilitation for persons who became disabled during adult life. Through education and rehabilitation, persons with disabilities became more active and a driving force in the further development of disability policy. Organizations of persons with disabilities, their families and advocates were formed, which advocated better conditions for persons with disabilities. After the Second World War the concepts of integration and normalization were introduced, which reflected a growing awareness of the capabilities of persons with disabilities.

5. Towards the end of the 1960s organizations of persons with disabilities in some countries started to formulate a new concept of disability. That new concept indicated the close connection between the limitation experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. At the same time the problems of disability in developing countries were more and more highlighted. In some of those countries the percentage of the population with disabilities was estimated to be very high and, for the most part, persons with disabilities were extremely poor.

Previous international action

6. The rights of persons with disabilities have been the subject of much attention in the United Nations and other international organizations over a long period of time. The most important outcome of the International Year of Disabled Persons, 1981, was the World Programme of Action concerning Disabled Persons, adopted by the General Assembly by its resolution 37/52 of 3 December 1982. The Year and the World Programme of Action provided a strong impetus for progress in the field. They both emphasized the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. There also, for the first time, handicap was defined as a function of the relationship between persons with disabilities and their environment.

7. The Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-Point of the United Nations Decade of Disabled Persons was held at Stockholm in 1987. It was suggested at the Meeting that a guiding philosophy should be developed to indicate the priorities for action in the years ahead. The basis of that philosophy should be the recognition of the rights of persons with disabilities.

8. Consequently, the Meeting recommended that the General Assembly convene a special conference to draft an international convention on the elimination of all forms of discrimination against persons with disabilities, to be ratified by States by the end of the Decade.

9. A draft outline of the convention was prepared by Italy and presented to the General Assembly at its forty-second session. Further presentations concerning a draft convention were made by Sweden at the forty-fourth session of the Assembly. However, on both occasions, no consensus could be reached on the suitability of such a convention. In the opinion of many representatives, existing human rights documents seemed to guarantee persons with disabilities the same rights as other persons.

Towards standard rules

10. Guided by the deliberations in the General Assembly, the Economic and Social Council, at its first regular session of 1990, finally agreed to concentrate on the elaboration of an international instrument of a different kind. By its resolution 1990/26 of 24 May 1990, the Council authorized the Commission for Social Development to consider, at its thirty-second session, the establishment of an ad hoc open-ended working group of government experts, funded by voluntary contributions, to elaborate standard rules on the equalization of opportunities for disabled children, youth and adults, in close collaboration with the specialized agencies, other intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons. The Council also requested the Commission to finalize the text of those rules for consideration in 1993 and for submission to the General Assembly at its forty-eighth session.

11. The subsequent discussions in the Third Committee of the General Assembly at the forty-fifth session showed that there was wide support for the new initiative to elaborate standard rules on the equalization of opportunities for persons with disabilities.

12. At the thirty-second session of the Commission for Social Development, the initiative for standard rules received the support of a large number of representatives and discussions led to the adoption of resolution 32/2 of 20 February 1991, in which the Commission decided to establish an ad hoc open-ended working group in accordance with Economic and Social Council resolution 1990/26.

Purpose and content of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

13. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities have been developed on the basis of the experience gained during the United Nations Decade of Disabled Persons (1983-1992). The International Bill of Human Rights, comprising the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights, the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women, as well as the World Programme of Action concerning Disabled Persons, constitute the political and moral foundation for the Rules.

14. Although the Rules are not compulsory, they can become international customary rules when they are applied by a great number of States with the intention of respecting a rule in international law. They imply a strong moral and political commitment on behalf of States to take action for the equalization of opportunities for persons with disabilities. Important principles for responsibility, action and cooperation are indicated. Areas of decisive importance for the quality of life and for the achievement of full participation and equality are pointed out. The Rules offer an instrument for policy-making and action to persons with disabilities and their organizations. They provide a basis for technical and economic cooperation among States, the United Nations and other international organizations.

15. The purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others. In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles. Persons with disabilities and their organizations should play an active role as partners in this process. The equalization of opportunities for persons with disabilities is an essential contribution in the general and worldwide effort to mobilize human resources. Special attention may need to be directed towards groups such as women, children, the elderly, the poor, migrant workers, persons with dual or multiple disabilities, indigenous people and ethnic minorities. In addition, there are a large number of refugees with disabilities who have special needs requiring attention.

Fundamental concepts in disability policy

16. The concepts set out below appear throughout the Rules. They are essentially built on the concepts in the World Programme of Action concerning Disabled Persons. In some cases they reflect the development that has taken place during the United Nations Decade of Disabled Persons.

Disability and handicap

17. The term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

18. The term "handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms.

19. The use of the two terms “disability” and “handicap”, as defined in paragraphs 17 and 18 above, should be seen in the light of modern disability history. During the 1970s there was a strong reaction among representatives of organizations of persons with disabilities and professionals in the field of disability against the terminology of the time. The terms “disability” and “handicap” were often used in an unclear and confusing way, which gave poor guidance for policy-making and for political action. The terminology reflected a medical and diagnostic approach, which ignored the imperfections and deficiencies of the surrounding society.

20. In 1980, the World Health Organization adopted an international classification of impairments, disabilities and handicaps, which suggested a more precise and at the same time relativistic approach. The International Classification of Impairments, Disabilities, and Handicaps makes a clear distinction between “impairment”, “disability” and “handicap”. It has been extensively used in areas such as rehabilitation, education, statistics, policy, legislation, demography, sociology, economics and anthropology. Some users have expressed concern that the Classification, in its definition of the term “handicap”, may still be considered too medical and too centred on the individual, and may not adequately clarify the interaction between societal conditions or expectations and the abilities of the individual. Those concerns, and others expressed by users during the 12 years since its publication, will be addressed in forthcoming revisions of the Classification.

21. As a result of experience gained in the implementation of the World Programme of Action and of the general discussion that took place during the United Nations Decade of Disabled Persons, there was a deepening of knowledge and extension of understanding concerning disability issues and the terminology used. Current terminology recognizes the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation)

Prevention

22. The term “prevention” means action aimed at preventing the occurrence of physical, intellectual, psychiatric or sensory impairments (primary prevention) or at preventing impairments from causing a permanent functional limitation or disability (secondary prevention). Prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunization campaigns against communicable diseases, measures to control endemic diseases, safety regulations, programmes for the prevention of accidents in different environments, including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Rehabilitation

23. The term “rehabilitation” refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.

Equalization of opportunities

24. The term “equalization of opportunities” means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities.

25. The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.

26. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.

27. As persons with disabilities achieve equal rights, they should also have equal obligations. As those rights are being achieved, societies should raise their expectations of persons with disabilities. As part of the process of equal opportunities, provision should be made to assist persons with disabilities to assume their full responsibility as members of society.

PREAMBLE

States,

Mindful of the pledge made, under the Charter of the United Nations, to take joint and separate action in cooperation with the Organization to promote higher standards of living, full employment, and conditions of economic and social progress and development,

Reaffirming the commitment to human rights and fundamental freedoms, social justice and the dignity and worth of the human person proclaimed in the Charter,

Recalling in particular the international standards on human rights, which have been laid down in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights,

Underlining that those instruments proclaim that the rights recognized therein should be ensured equally to all individuals without discrimination,

Recalling the Convention on the Rights of the Child, which prohibits discrimination on the basis of disability and requires special measures to ensure the rights of children with disabilities, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, which provides for some protective measures against disability,

Recalling also the provisions in the Convention on the Elimination of All Forms of Discrimination against Women to ensure the rights of girls and women with disabilities,

Having regard to the Declaration on the Rights of Disabled Persons, the Declaration on the Rights of Mentally Retarded Persons, the Declaration on Social Progress and Development, the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care and other relevant instruments adopted by the General Assembly,

Also having regard to the relevant conventions and recommendations adopted by the International Labour Organisation, with particular reference to participation in employment without discrimination for persons with disabilities,

Mindful of the relevant recommendations and work of the United Nations Educational, Scientific and Cultural Organization, in particular the World Declaration on Education for All, the World Health Organization, the United Nations Children's Fund and other concerned organizations,

Having regard to the commitment made by States concerning the protection of the environment,

Mindful of the devastation caused by armed conflict and deploring the use of scarce resources in the production of weapons,

Recognizing that the World Programme of Action concerning Disabled Persons and the definition therein of equalization of opportunities represent earnest ambitions on the part of the international community to render those various international instruments and recommendations of practical and concrete significance,

Acknowledging that the objective of the United Nations Decade of Disabled Persons (1983-1992) to implement the World Programme of Action is still valid and requires urgent and continued action,

Recalling that the World Programme of Action is based on concepts that are equally valid in developing and industrialized countries,

Convinced that intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons with disabilities,

Re-emphasizing that persons with disabilities, and their parents, guardians, advocates and organizations, must be active partners with States in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights,

In pursuance of Economic and Social Council resolution 1990/26, and basing themselves on the specific measures required for the attainment by persons with disabilities of equality with others, enumerated in detail in the World Programme of Action,

Have adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities outlined below, in order:

(a) To stress that all action in the field of disability presupposes adequate knowledge and experience of the conditions and special needs of persons with disabilities;

(b) To emphasize that the process through which every aspect of societal organization is made accessible to all is a basic objective of socio-economic development;

(c) To outline crucial aspects of social policies in the field of disability, including, as appropriate, the active encouragement of technical and economic cooperation;

(d) To provide models for the political decision-making process required for the attainment of equal opportunities, bearing in mind the widely differing technical and economic levels, the fact that the process must reflect keen understanding of the cultural context within which it takes place and the crucial role of persons with disabilities in it;

(e) To propose national mechanisms for close collaboration among States, the organs of the United Nations system, other intergovernmental bodies and organizations of persons with disabilities;

(f) To propose an effective machinery for monitoring the process by which States seek to attain the equalization of opportunities for persons with disabilities.

I. PRECONDITIONS FOR EQUAL PARTICIPATION

Rule 1. Awareness-raising

States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

1. States should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.

2. States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.

3. States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.

4. States should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.

5. States should invite persons with disabilities and their families and organizations to participate in public education programmes concerning disability matters.

6. States should encourage enterprises in the private sector to include disability issues in all aspects of their activity.

7. States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them.

8. Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities of their own organizations.

9. Awareness-raising should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.

Rule 2. Medical care

States should ensure the provision of effective medical care to persons with disabilities.

1. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.

2. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.

3. States should ensure that persons with disabilities, particularly infants ~~and children, are provided with the same~~ level of medical care within the same system as other members of society.

4. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.

5. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.

6. States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

Rule 3. Rehabilitation*

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

1. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.

2. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.

3. All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.

4. Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.

5. All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.

6. Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.

7. States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.

Rule 4. Support services

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

1. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.

2. States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.

3. To achieve this, generally available technical know-how should be utilized. In States where high-technology industry is available, it should be fully utilized to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible. Persons with disabilities themselves could be involved in the production of those devices.

4. States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.

5. In rehabilitation programmes for the provision of assistive devices and equipment, States should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness of assistive devices and equipment.

6. States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.

7. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

II. TARGET AREAS FOR EQUAL PARTICIPATION

Rule 5. Accessibility

States should recognize the overall importance of accessibility in the ~~process of the equalization of opportunities~~ in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication.

(a) Access to the physical environment

1. States should initiate measures to remove the obstacles to participation in the physical environment. Such measures should be to develop standards and guidelines and to consider enacting legislation to ensure accessibility to various areas in society, such as housing, buildings, public transport services and other means of transportation, streets and other outdoor environments.

2. States should ensure that architects, construction engineers and others who are professionally involved in the design and construction of the physical environment have access to adequate information on disability policy and measures to achieve accessibility.

3. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process.

4. Organizations of persons with disabilities should be consulted when standards and norms for accessibility are being developed. They should also be involved locally from the initial planning stage when public construction projects are being designed, thus ensuring maximum accessibility.

(b) Access to information and communication

5. Persons with disabilities and, where appropriate, their families and advocates should have access to full information on diagnosis, rights and available services and programmes, at all stages. Such information should be presented in forms accessible to persons with disabilities.

6. States should develop strategies to make information services and documentation accessible for different groups of persons with disabilities. Braille, tape services, large print and other appropriate technologies should be used to provide access to written information and documentation for persons with visual impairments. Similarly, appropriate technologies should be used to provide access to spoken information for persons with auditory impairments or comprehension difficulties.

7. Consideration should be given to the use of sign language in the education of deaf children, in their families and communities. Sign language interpretation services should also be provided to facilitate the communication between deaf persons and others.

8. Consideration should also be given to the needs of people with other communication disabilities.

9. States should encourage the media, especially television, radio and newspapers, to make their services accessible.

10. States should ensure that new computerized information and service systems offered to the general public are either made initially accessible or are adapted to be made accessible to persons with disabilities.

11. Organizations of persons with disabilities should be consulted when measures to make information services accessible are being developed.

Rule 6. Education

States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system.

1. General educational authorities are responsible for the education of persons with disabilities in integrated settings. Education for persons with disabilities should form an integral part of national educational planning, curriculum development and school organization.

2. Education in mainstream schools presupposes the provision of interpreter and other appropriate support services. Adequate accessibility and support services, designed to meet the needs of persons with different disabilities, should be provided.

3. Parent groups and organizations of persons with disabilities should be involved in the education process at all levels.

4. In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.

5. Special attention should be given in the following areas:

(a) Very young children with disabilities;

(b) Pre-school children with disabilities;

(c) Adults with disabilities, particularly women.

6. To accommodate educational provisions for persons with disabilities in the mainstream, States should:

(a) Have a clearly stated policy, understood and accepted at the school level and by the wider community

(b) Allow for curriculum flexibility, addition and adaptation;

(c) Provide for quality materials, ongoing teacher training and support teachers.

7. Integrated education and community-based programmes should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities. National community-based programmes should encourage communities to use and develop their resources to provide local education to persons with disabilities.

8. In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered. It should be aimed at preparing students for education in the general school system. The quality of such education should reflect the same standards and ambitions as general education and should be closely linked to it. At a minimum, students with disabilities should be afforded the same portion of educational resources as students without disabilities. States should aim for the gradual integration of special education services into mainstream education. It is acknowledged that in some instances special education may currently be considered to be the most appropriate form of education for some students with disabilities.

9. Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in schools for such persons or special classes and units in mainstream schools. At the initial stage, in particular, special attention needs to be focused on culturally sensitive instruction that will result in effective communication skills and maximum independence for people who are deaf or deaf/blind.

Rule 7. Employment

States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.

1. Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment.

2. States should actively support the integration of persons with disabilities into open employment. This active support could occur through a variety of measures, such as vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities.

3. States' action programmes should include:

(a) Measures to design and adapt workplaces and work premises in such a way that they become accessible to persons with different disabilities;

(b) Support for the use of new technologies and the development and production of assistive devices, tools and equipment and measures to facilitate access to such devices and equipment for persons with disabilities to enable them to gain and maintain employment;

(c) Provision of appropriate training and placement and ongoing support such as personal assistance and interpreter services.

4. States should initiate and support public awareness-raising campaigns designed to overcome negative attitudes and prejudices concerning workers with disabilities.

5. In their capacity as employers, States should create favourable conditions for the employment of persons with disabilities in the public sector.

6. States, workers' organizations and employers should cooperate to ensure equitable recruitment and promotion policies, employment conditions, rates of pay, measures to improve the work environment in order to prevent injuries and impairments and measures for the rehabilitation of employees who have sustained employment-related injuries.

7. aim should always be for persons with disabilities to obtain employment in the open labour market. For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative. It is important that the quality of such programmes be assessed in terms of their relevance and sufficiency in providing opportunities for persons with disabilities to gain employment in the labour market.

8. Measures should be taken to include persons with disabilities in training and employment programmes in the private and informal sectors.

9. States, workers' organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create ~~training and employment opportunities,~~ including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities.

Rule 8. Income maintenance and social security

States are responsible for the provision of social security and income maintenance for persons with disabilities.

1. States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities. States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.

2. In countries where social security, social insurance or other social welfare schemes exist or are being developed for the general population, States should ensure that such systems do not exclude or discriminate against persons with disabilities.

3. States should also ensure the provision of income support and social security protection to individuals who undertake the care of a person with a disability.

4. Social security systems should include incentives to restore the income-earning capacity of persons with disabilities. Such systems should provide or contribute to the organization, development and financing of vocational training. They should also assist with placement services.

5. Social security programmes should also provide incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity.

6. Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve adequate and secure income.

7. States, in countries where social security is to a large extent provided by the private sector, should encourage local communities, welfare organizations and families to develop self-help measures and incentives for employment or employment-related activities for persons with disabilities.

Rule 9. Family life and personal integrity

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

1. Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counselling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.

2. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.

3. States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society. The media should be encouraged to play an important role in removing such negative attitudes.

4. Persons with disabilities and their families need to be fully informed about taking precautions against sexual and other forms of abuse. Persons with disabilities are particularly vulnerable to abuse in the family, community or institutions and need to be educated on how to avoid the occurrence of abuse, recognize when abuse has occurred and report on such acts.

Rule 10. Culture

States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis.

1. States should ensure that persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community, be they in urban or rural areas. Examples of such activities are dance, music, literature, theatre, plastic arts, painting and sculpture. Particularly in developing countries, emphasis should be placed on traditional and contemporary art forms, such as puppetry, recitation and story-telling.

2. States should promote the accessibility to and availability of places for cultural performances and services, such as theatres, museums, cinemas and libraries, to persons with disabilities.

3. States should initiate the development and use of special technical arrangements to make literature, films and theatre accessible to persons with disabilities.

Rule 11. Recreation and sports

States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports.

1. States should initiate measures to make places for recreation and sports, hotels, beaches, sports arenas, gym halls, etc., accessible to persons with disabilities. Such measures should encompass support for staff in recreation and sports programmes, including projects to develop methods of accessibility, and participation, information and training programmes.

2. Tourist authorities, travel agencies, hotels, voluntary organizations and others involved in organizing recreational activities or travel opportunities should offer their services to all, taking into account the special needs of persons with disabilities. Suitable training should be provided to assist that process.

3. Sports organizations should be encouraged to develop opportunities for participation by persons with disabilities in sports activities. In some cases, accessibility measures could be enough to open up opportunities for participation. In other cases, special arrangements or special games would be needed. States should support the participation of persons with disabilities in national and international events.

4. Persons with disabilities participating in sports activities should have access to instruction and training of the same quality as other participants.

5. Organizers of sports and recreation should consult with organizations of persons with disabilities when developing their services for persons with disabilities.

Rule 12. Religion

States will encourage measures for equal participation by persons with disabilities in the religious life of their communities.

1. States should encourage, in consultation with religious authorities, measures to eliminate discrimination and make religious activities accessible to persons with disabilities.

2. States should encourage the distribution of information on disability matters to religious institutions and organizations. States should also encourage religious authorities to include information on disability policies in the training for religious professions, as well as in religious education programmes.

3. They should also encourage the accessibility of religious literature to persons with sensory impairments.

4. States and/or religious organizations should consult with organizations of persons with disabilities when developing measures for equal participation in religious activities.

III. IMPLEMENTATION MEASURES

Rule 13. Information and research

States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

1. States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.

2. States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities. They should bear in mind the need to protect individual privacy and personal integrity.

3. States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.

4. States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.

5. States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.

6. States should support the exchange of research findings and experiences.

7. States should take measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

Rule 14. Policy-making and planning

States will ensure that disability aspects are included in all relevant policy-making and national planning.

1. States should initiate and plan adequate policies for persons with disabilities at the national level, and stimulate and support action at regional and local levels.

2. States should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status.

3. The needs and concerns of persons with disabilities should be incorporated into general development plans and not be treated separately.

4. The ultimate responsibility of States for the situation of persons with disabilities does not relieve others of their responsibility. Anyone in charge of services, activities or the provision of information in society should be encouraged to accept responsibility for making such programmes available to persons with disabilities.

5. States should facilitate the development by local communities of programmes and measures for persons with disabilities. One way of doing this could be to develop manuals or check-lists and provide training programmes for local staff.

Rule 15. Legislation

States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities.

1. National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation.

2. Legislative action may be needed to remove conditions that may adversely affect the lives of persons with disabilities, including harassment and victimization. Any discriminatory provisions against persons with disabilities must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principles of non-discrimination.

3. National legislation concerning persons with disabilities may appear in two different forms. The rights and obligations may be incorporated in general legislation or contained in special legislation. Special legislation for persons with disabilities may be established in several ways:

- (a) By enacting separate legislation, dealing exclusively with disability matters;
- (b) By including disability matters within legislation on particular topics;
- (c) By mentioning persons with disabilities specifically in the texts that serve to interpret existing legislation.

A combination of those different approaches might be desirable. Affirmative action provisions may also be considered.

4. States may consider establishing formal statutory complaints mechanisms in order to protect the interests of persons with disabilities.

Rule 16. Economic policies

States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities.

1. States should include disability matters in the regular budgets of all national, regional and local government bodies.
2. States, non-governmental organizations and other interested bodies should interact to determine the most effective ways of supporting projects and measures relevant to persons with disabilities.
3. States should consider the use of economic measures (loans, tax exemptions, earmarked grants, special funds, and so on) to stimulate and support equal participation by persons with disabilities in society.

4. In many States it may be advisable to establish a disability development fund, which could support various pilot projects and self-help programmes at the grass-roots level.

Rule 17. Coordination of work

States are responsible for the establishment and strengthening of national coordinating committees, or similar bodies, to serve as a national focal point on disability matters.

1. The national coordinating committee or similar bodies should be permanent and based on legal as well as appropriate administrative regulation.

2. A combination of representatives of private and public organizations is most likely to achieve an intersectoral and multidisciplinary composition. Representatives could be drawn from concerned government ministries, organizations of persons with disabilities and non-governmental organizations.

3. Organizations of persons with disabilities should have considerable influence in the national coordinating committee in order to ensure proper feedback of their concerns.

4. The national coordinating committee should be provided with sufficient autonomy and resources to fulfil its responsibilities in relation to its decision-making capacities. It should report to the highest governmental level.

Rule 18. Organizations of persons with disabilities

States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.

1. States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.

2. States should establish ongoing communication with organizations of persons with disabilities and ensure their participation in the development of government policies.

3. The role of organizations of persons with disabilities could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, and to contribute to public awareness and to advocate change.

4. As instruments of self-help, organizations of persons with disabilities provide and promote opportunities for the development of skills in various fields, mutual support among members and information sharing.

5. Organizations of persons with disabilities could perform their advisory role in many different ways such as having permanent representation on boards of government-funded agencies, serving on public commissions and providing expert knowledge on different projects.

6. The advisory role of organizations of persons with disabilities should be ongoing in order to develop and deepen the exchange of views and information between the State and the organizations.

7. Organizations should be permanently represented on the national coordinating committee or similar bodies.

8. The role of local organizations of persons with disabilities should be developed and strengthened to ensure that they influence matters at the community level.

Rule 19. Personnel training

States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities.

1. States should ensure that all authorities providing services in the disability field give adequate training to their personnel.
2. In the training of professionals in the disability field, as well as in the provision of information on disability in general training programmes, the principle of full participation and equality should be appropriately reflected.
3. States should develop training programmes in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programmes.
4. The training of community workers is of great strategic importance, particularly in developing countries. It should involve persons with disabilities and include the development of appropriate values, competence and technologies as well as skills which can be practised by persons with disabilities, their parents, families and members of the community.

Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Rules

States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalization of opportunities for persons with disabilities.

1. States should periodically and systematically evaluate national disability programmes and disseminate both the bases and the results of the evaluations.
2. States should develop and adopt terminology and criteria for the evaluation of disability-related programmes and services.
3. Such criteria and terminology should be developed in close cooperation with organizations of persons with disabilities from the earliest conceptual and planning stages.

Rule 21. Technical and economic cooperation

States, both industrialized and developing, have the responsibility to cooperate in and take measures for the improvement of the living conditions of persons with disabilities in developing countries.

1. Measures to achieve the equalization of opportunities of persons with disabilities, including refugees with disabilities, should be integrated into general development programmes.

2. Such measures must be integrated into all forms of technical and economic cooperation, bilateral and multilateral, governmental and non-governmental. States should bring up disability issues in discussions on such cooperation with their counterparts.

3. When planning and reviewing programmes of technical and economic cooperation, special attention should be given to the effects of such programmes on the situation of persons with disabilities. It is of the utmost importance that persons with disabilities and their organizations are consulted on any development projects designed for persons with disabilities. They should be directly involved in the development, implementation and evaluation of such projects.

4. Priority areas for technical and economic cooperation should include:

(a) The development of human resources through the development of skills, abilities and potentials of persons with disabilities and the initiation of employment-generating activities for and of persons with disabilities;

(b) The development and dissemination of appropriate disability-related technologies and know-how.

5. States are also encouraged to support the formation and strengthening of organizations of persons with disabilities.

6. States should take measures to improve the knowledge of disability issues among staff involved at all levels in the administration of technical and economic cooperation programmes.

Rule 22. International cooperation

States will participate actively in international cooperation concerning policies for the equalization of opportunities for persons with disabilities.

1. Within the United Nations, the specialized agencies and other concerned intergovernmental organizations, States should participate in the development of disability policy.

2. Whenever appropriate, States should introduce disability aspects in general negotiations concerning standards, information exchange, development programmes, etc.

3. States should encourage and support the exchange of knowledge and experience among:

(a) Non-governmental organizations concerned with disability issues;

(b) Research institutions and individual researchers involved in disability issues;

(c) Representatives of field programmes and of professional groups in the disability field;

(d) Organizations of persons with disabilities;

(e) National coordinating committees.

4. States should ensure that the United Nations and the specialized agencies, as well as all intergovernmental and interparliamentary bodies, at global and regional levels, include in their work the global and regional organizations of persons with disabilities.

IV. MONITORING MECHANISM

1. The purpose of a monitoring mechanism is to further the effective implementation of the Rules. It will assist each State in assessing its level of implementation of the Rules and in measuring its progress. The monitoring should identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules. The monitoring mechanism will recognize the economic, social and cultural features existing in individual States. An important element should also be the provision of advisory services and the exchange of experience and information between States.

2. The Rules shall be monitored within the framework of the sessions of the Commission for Social Development. A Special Rapporteur with relevant and extensive experience in disability issues and international organizations shall be appointed, if necessary, funded by extrabudgetary resources, for three years to monitor the implementation of the Rules.

3. International organizations of persons with disabilities having consultative status with the Economic and Social Council and organizations representing persons with disabilities who have not yet formed their own organizations should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority, taking into account the different kinds of disabilities and necessary equitable geographical distribution, to be consulted by the Special Rapporteur and, when appropriate, by the Secretariat.

4. The panel of experts will be encouraged by the Special Rapporteur to review, advise and provide feedback and suggestions on the promotion, implementation and monitoring of the Rules.

5. The Special Rapporteur shall send a set of questions to States, entities within the United Nations system, and intergovernmental and non-governmental organizations, including organizations of persons with disabilities. The set of questions should address implementation plans for the Rules in States. The questions should be selective in nature and cover a number of specific rules for in-depth evaluation. In preparing the questions the Special Rapporteur should consult with the panel of experts and the Secretariat.

6. The Special Rapporteur shall seek to establish a direct dialogue not only with States but also with local non-governmental organizations, seeking their views and comments on any information intended to be included in the reports. The Special Rapporteur shall provide advisory services on the implementation and monitoring of the Rules and assistance in the preparation of replies to the sets of questions.

7. The Department for Policy Coordination and Sustainable Development of the Secretariat, as the United Nations focal point on disability issues, the United Nations Development Programme and other entities and mechanisms within the United Nations system, such as the regional commissions and specialized agencies and inter-agency meetings, shall cooperate with the Special Rapporteur in the implementation and monitoring of the Rules at the national level.

8. The Special Rapporteur, assisted by the Secretariat, shall prepare reports for submission to the Commission for Social Development at its thirty-fourth and thirty-fifth sessions. In preparing such reports, the Rapporteur should consult with the panel of experts.

9. States should encourage national coordinating committees or similar bodies to participate in implementation and monitoring. As the focal points on disability matters at the national level, they should be encouraged to establish procedures to coordinate the monitoring of the Rules. Organizations of persons with disabilities should be encouraged to be actively involved in the monitoring of the process at all levels.

10. Should extrabudgetary resources be identified, one or more positions of interregional adviser on the Rules should be created to provide direct services to States, including:

(a) The organization of national and regional training seminars on the content of the Rules;

(b) The development of guidelines to assist in strategies for implementation of the Rules;

(c) Dissemination of information about best practices concerning implementation of the Rules.

11. At its thirty-fourth session, the Commission for Social Development should establish an open-ended working group to examine the Special Rapporteur's report and make recommendations on how to improve the application of the Rules. In examining the Special Rapporteur's report, the Commission, through its open-ended working group, shall consult international organizations of persons with disabilities and specialized agencies, in accordance with rules 71 and 76 of the rules of procedure of the functional commissions of the Economic and Social Council.

12. At its session following the end of the Special Rapporteur's mandate, the Commission should examine the possibility of either renewing that mandate, appointing a new Special Rapporteur or considering another monitoring mechanism, and should make appropriate recommendations to the Economic and Social Council.

13. States should be encouraged to contribute to the United Nations Voluntary Fund on Disability in order to further the implementation of the Rules.

Appendix B: OAS- Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With Disabilities

AG/RES. 1608 (XXIX-O/99)

INTER-AMERICAN CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST PERSONS WITH DISABILITIES

(Resolution adopted at the first plenary session, held on June 7, 1999)

THE GENERAL ASSEMBLY,

HAVING SEEN the report of the Permanent Council on the draft Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (CP/CAJP-1532/99)e

CONSIDERING that, during its twenty-sixth regular session, the General Assembly, in resolution AG/RES. 1369 (XXVI-O/96), "Panama Commitment to Persons with Disabilities in the American Hemisphere," instructed the Permanent Council to prepare, through the appropriate working group, a "draft Inter-American Convention on the Elimination of All Forms of Discrimination by Reason of Disability";

BEARING IN MIND that disability can lead to situations of discrimination, and that it is necessary therefore to encourage actions and measures to bring about a substantial improvement in the situation of persons with disabilities in the Hemisphere;

RECALLING that the American Declaration of the Rights and Duties of Man proclaims that all human beings are born free and equal, in dignity and in rights, and that the rights and freedoms of every person must be respected without distinction of any kind;

TAKING INTO CONSIDERATION that the Additional Protocol to the American Convention on Human Rights in the area of Economic, Social, and Cultural Rights, or "Protocol of San Salvador," recognizes that "everyone affected by a diminution of his physical or mental capacities is entitled to receive special attention designed to help him achieve the greatest possible development of his personality"; and

NOTING that resolution AG/RES. 1564 (XXVIII-O/98) reiterates "the importance of adopting an Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities" and, in addition, requests that every necessary effort be made to ensure that this legal instrument is adopted and signed at the twenty-ninth regular session of the General Assembly,

RESOLVES:

To adopt the following Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities:

INTER-AMERICAN CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST PERSONS WITH DISABILITIES**THE STATES PARTIES TO THIS CONVENTION,**

REAFFIRMING that persons with disabilities have the same human rights and fundamental freedoms as other persons; and that these rights, which include freedom from discrimination based on disability, flow from the inherent dignity and equality of each person;

CONSIDERING that the Charter of the Organization of American States, in Article 3.j, establishes the principle that “social justice and social security are bases of lasting peace”^e

CONCERNED by the discrimination to which people are subject based on their disability;

BEARING IN MIND the agreement of the International Labour Organisation on the vocational rehabilitation and employment of disabled persons (Convention 159); the Declaration of the Rights of Mentally Retarded Persons (UN General Assembly resolution 2856 (XXVI) of December 20, 1971); the Declaration on the Rights of Disabled Persons (UN General Assembly resolution 3447 (XXX) of December 9, 1975); the World Programme of Action concerning Disabled Persons (UN General Assembly resolution 37/52 of December 3, 1982); the Additional Protocol to the American Convention on Human Rights in the area of Economic, Social, and Cultural Rights, “Protocol of San Salvador” (1988); the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (UN General Assembly resolution 46/119 of December 17, 1991); the Declaration of Caracas of the Pan American Health Organization; resolution AG/RES. 1249 (XXIII-O/93), “Situation of Persons with Disabilities in the American Hemisphere”; the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN General Assembly resolution 48/96 of December 20, 1993); the Declaration of Managua (December 1993); the Vienna Declaration and Programme of Action, adopted by the UN World Conference on Human Rights (157/93); resolution AG/RES. 1356 (XXV-O/95), “Situation of Persons with Disabilities in the American Hemisphere”^e and AG/RES. 1369 (XXVI-O/96), “Panama Commitment to Persons with Disabilities in the American Hemisphere”; and

COMMITTED to eliminating discrimination, in all its forms and manifestations, against persons with disabilities,

ARTICLE I

For the purposes of this Convention, the following terms are defined:

1. Disability

The term “disability” means a physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment.

2. Discrimination against persons with disabilities

a. The term “discrimination against persons with disabilities” means any distinction, exclusion, or restriction based on a disability, record of disability, condition resulting from a previous disability, or perception of disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a disability of his or her human rights and fundamental freedoms.

b. A distinction or preference adopted by a state party to promote the social integration or personal development of persons with disabilities does not constitute discrimination provided that the distinction or preference does not in itself limit the right of persons with disabilities to equality and that individuals with disabilities are not forced to accept such distinction or preference. If, under a state's internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well-being, such declaration does not constitute discrimination.

ARTICLE II

The objectives of this Convention are to prevent and eliminate all forms of discrimination against persons with disabilities and to promote their full integration into society.

ARTICLE III

To achieve the objectives of this Convention, the states parties undertake:

1. To adopt the legislative, social, educational, labor-related, or any other measures needed to eliminate discrimination against persons with disabilities and to promote their full integration into society, including, but not limited to:

a. Measures to eliminate discrimination gradually and to promote integration by government authorities and/or private entities in providing or making available goods, services, facilities, programs, and activities such as employment, transportation, communications, housing, recreation, education, sports, law enforcement and administration of justice, and political and administrative activities;

b. Measures to ensure that new buildings, vehicles, and facilities constructed or manufactured within their respective territories facilitate transportation, communications, and access by persons with disabilities;

c. Measures to eliminate, to the extent possible, architectural, transportation, and communication obstacles to facilitate access and use by persons with disabilities; and

d. Measures to ensure that persons responsible for applying this Convention and domestic law in this area are trained to do so.

2. To work on a priority basis in the following areas:

a. Prevention of all forms of preventable disabilities;

b. Early detection and intervention, treatment, rehabilitation, education, job training, and the provision of comprehensive services to ensure the optimal level of independence and quality of life for persons with disabilities; and

c. Increasing of public awareness through educational campaigns aimed at eliminating prejudices, stereotypes, and other attitudes that jeopardize the right of persons to live as equals, thus promoting respect for and coexistence with persons with disabilities;

ARTICLE IV

To achieve the objectives of this Convention, the states parties undertake to:

1. Cooperate with one another in helping to prevent and eliminate discrimination against persons with disabilities;

2. Collaborate effectively in:

a. Scientific and technological research related to the prevention of disabilities and to the treatment, rehabilitation, and integration into society of persons with disabilities; and

b. The development of means and resources designed to facilitate or promote the independence, self-sufficiency, and total integration into society of persons with disabilities, under conditions of equality.

ARTICLE V

1. To the extent that it is consistent with their respective internal laws, the states parties shall promote participation by representatives of organizations of persons with disabilities, nongovernmental organizations working in this area, or, if such organizations do not exist, persons with disabilities, in the development, execution, and evaluation of measures and policies to implement this Convention.

2. The states parties shall create effective communication channels to disseminate among the public and private organizations working with persons with disabilities the normative and juridical advances that may be achieved in order to eliminate discrimination against persons with disabilities.

ARTICLE VI

1. To follow up on the commitments undertaken in this Convention, a Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities, composed of one representative appointed by each state party, shall be established.

2. The committee shall hold its first meeting within the 90 days following the deposit of the 11th instrument of ratification. Said meeting shall be convened by the General Secretariat of the Organization of American States and shall be held at the Organization's headquarters, unless a state party offers to host it.

3. At the first meeting, the states parties undertake to submit a report to the Secretary General of the Organization for transmission to the Committee so that it may be examined and reviewed. Thereafter, reports shall be submitted every four years.

4. The reports prepared under the previous paragraph shall include information on measures adopted by the member states pursuant to this Convention and on any progress made by the states parties in eliminating all forms of discrimination against persons with disabilities. The reports shall indicate any circumstances or difficulties affecting the degree of fulfillment of the obligations arising from this Convention.

5. The Committee shall be the forum for assessment of progress made in the application of the Convention and for the exchange of experience among the states parties. The reports prepared by the committee shall reflect the deliberations; shall include information on any measures adopted by the states parties pursuant to this Convention, on any progress they have made in eliminating all forms of discrimination against persons with disabilities, and on any circumstances or difficulties they have encountered in the implementation of the Convention; and shall include the committee's conclusions, its observations, and its general suggestions for the gradual fulfillment of the Convention.

6. The committee shall draft its rules of procedure and adopt them by a simple majority.

7. The Secretary General shall provide the Committee with the support it requires in order to perform its functions.

ARTICLE VII

No provision of this Convention shall be interpreted as restricting, or permitting the restriction by states parties of the enjoyment of the rights of persons with disabilities recognized by customary international law or the international instruments by which a particular state party is bound.

ARTICLE VIII

1. This Convention shall be open for signature by all member states in Guatemala City, Guatemala, on June 8, 1999, and, thereafter, shall remain open for signature by all states at the headquarters of the Organization of American States, until its entry into force.

2. This Convention is subject to ratification.

3. This Convention shall enter into force for the ratifying states on the 30th day following the date of deposit of the sixth instrument of ratification by a member state of the Organization of American States.

ARTICLE IX

After its entry into force, this Convention shall be open for accession by all states that have not signed it.

ARTICLE X

1. The instruments of ratification and accession shall be deposited with the General Secretariat of the Organization of American States.

2. For each state that ratifies or accedes to the Convention after the sixth instrument of ratification has been deposited, the Convention shall enter into force on the 30th day following deposit by that state of its instrument of ratification or accession.

ARTICLE XI

1. Any state party may make proposals for amendment of this Convention. Said proposals shall be submitted to the General Secretariat of the OAS for dissemination to the states parties.

2. Amendments shall enter into force for the states ratifying them on the date of deposit of the respective instruments of ratification by two thirds of the member states. For the remaining states parties, they shall enter into force on the date of deposit of their respective instruments of ratification.

ARTICLE XII

The states may enter reservations to this Convention when ratifying or acceding to it, provided that such reservations are not incompatible with the aim and purpose of the Convention and relate to one or more specific provisions thereof.

ARTICLE XIII

This Convention shall remain in force indefinitely, but any state party may denounce it. The instrument of denunciation shall be deposited with the General Secretariat of the Organization of American States. The Convention shall cease to have force and effect for the denouncing state one year after the date of deposit of the instrument of denunciation, and shall remain in force for the other states parties. Such denunciation shall not exempt the state party from the obligations imposed upon it under this Convention in respect of any action or omission prior to the date on which the denunciation takes effect.

ARTICLE XIV

1. The original instrument of this Convention, the English, French, Portuguese, and Spanish texts of which are equally authentic, shall be deposited with the General Secretariat of the Organization of American States, which shall send a certified copy thereof to the United Nations Secretariat for registration and publication pursuant to Article 102 of the United Nations Charter.

2. The General Secretariat of the Organization of American States shall notify the member states of that Organization and the states that have acceded to the Convention of the signatures, deposits of instruments of ratification, accession, and denunciation, and any reservations entered.

Appendix C: IDRM Regional Report of the Americas 2004 Report Card Questions

Convention Support

Has your government issued a statement in support of the creation of a United Nations Convention on the Rights of Persons with Disabilities?

Legal Protections

Is there a national law that specifically references and protects of the rights of people with disabilities?

Is there a national coordinating organization that develops disability policy?

Education & Employment

Is training on teaching children with disabilities included in the national teacher curriculum?

Does the largest employer of the private sector have a policy that states people with disabilities cannot be discriminated against in employment on the basis of his or her disability?

Accessibility

Is the bus system in the capital city wheelchair accessible?

Is the main post office in the capital city wheelchair accessible?

Health Services & Housing

Is training on provision of care to people with disabilities available for physicians, both before and after they acquire a medical degree?

Is there a center that provides peer counseling and referral services (Independent Living Center) to people with disability in your country?

Communication

Does the government provide a Braille version of the Constitution?

Is the national news captioned for hearing-impaired viewers?



The International Disability Rights Monitor (IDRM) Project is an ongoing collaboration between the International Disability Network (IDN), Disabled Peoples' International (DPI), and many other international and national disability groups. The goals of the IDRM project are to promote the full inclusion and participation of persons with disabilities in society and to advance the use of international law to ensure that the rights of persons with disabilities are respected and enforced. The IDRM research seeks to define and quantify issues of importance to people with disabilities internationally, while strengthening a grassroots network to advance the rights and agenda of people with disabilities in the communities where they live.



Center for International Rehabilitation
211 East Ontario St » Suite 300 » Chicago » IL 60611