ARTICLES

FIRST THORNBURGH FAMILY LECTURE ON DISABILITY LAW AND POLICY

AMERICANS WITH DISABILITIES AND THEIR CIVIL RIGHTS: PAST, PRESENT, AND FUTURE

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I. INTRODUCTION

A. Opening

It is a special honor for me to address distinguished faculty, colleagues and friends of the University of Pittsburgh. I thank particularly Chancellor Mark Nordenberg, and Deans Brubaker, Herring, and Seelman. These individuals and others, in partnership with the Thornburgh Family, have

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shown tremendous generosity and vision to create this marvelous lecture on disability law and policy.

Dick, Ginny, and the Thornburgh family represent the best of the American spirit. They embrace principles of equal rights, inclusion, empowerment and economic independence—all aspirations that underlie the goals of disability law and policy. Dick and Ginny speak of the inspiration for their efforts in disability law and policy coming from their son, Peter.[1] Young Peter suffered severe brain injuries from an accident that left him with mental retardation. Dick and Ginny supported and watched what they call the "small miracles" of Peter's life, with Peter living and working semi-independently today. But, as "miracle makers" themselves, Dick and Ginny fought for Peter's right to a free and appropriate public education, to live and work independently, and to become an equal member of society.

Ginny, along with the late Chris Reeves, is my fellow board member at the National Organization on Disability (N.O.D.). Ginny is the founding director of N.O.D.'s Religion and Disability Program, working countless hours, in communities across the world, to ensure that congregations of all faiths are welcoming to people with disabilities.[2] It is a fitting tribute to the Thornburghs at this inaugural lecture that we take stock of disability law and policy, past, present and future. I am grateful to continue this dialogue, which many before me have begun, and many of our children will continue.

Being in Pennsylvania, I am reminded of when, in November of 1863, 180 miles to the east, Lincoln spoke at Gettysburg about a nation "conceived in Liberty and dedicated to the proposition that all men are created equal."[3] Lincoln was binding the wounds this country endured in the fight for racial equality, recognizing those who died in the cause for liberty. Yet, Lincoln could not know that, among its most profound effects, the Civil War changed conceptions of Americans with disabilities for decades to come. Attitudes toward subsequent generations of persons with disabilities were shaped by political and economic forces coinciding with the growth of the Civil War pension system, our country's first major social insurance scheme.

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1. Though personally familiar with the Thornburgh story, this description is derived from Dick Thornburgh, *Health Care and the Americans with Disabilities Act: Address—Reflections on the Americans with Disabilities Act*, 37 HOUS. L. REV. 987, 997-98 (2000).

2. *See* Nat'l Org. on Disability, *Community Involvement: Religious Participation* (2002), *at* http://www.nod.org (last visited Mar. 3, 2005).

3. Abraham Lincoln, *Gettysburg Address* (Nov. 19, 1863), *at* http://www.loc.gov/exhibits/gadd/gatr2.html (last visited Mar. 1, 2005).

Today, as I begin the First Thornburgh Family Lecture in Disability Law and Policy, we celebrate our friends here at Pittsburgh, we remember the lessons of Gettysburg, and we are thankful for the "miracle" known as the Thornburghs.

B. Background

I have been blessed in many ways. One way has been the privilege to know people in the disability rights movement. During the years I have worked in the area as a teacher, researcher, lawyer, court-appointed expert, and advocate, I have witnessed a sea of change in disability policy, anchored by the passage of the Americans with Disabilities Act (ADA) in 1990.[4] Yet, anniversary celebrations of the ADA's passage have been bittersweet for those of us who take stock of the law's impact on the lives of Americans with disabilities.[5] In August of 2004, columnist Al Hunt wrote in the *Wall Street Journal* that "today, for 53 million disabled Americans the glass of life is both half-full and half-empty."[6]

We celebrate the ADA's transformation of our nation's physical environment, and its prompting to provide accommodations that enable people to join the workforce. But we also observe judicial interpretations of the ADA, anchored by U.S. Supreme Court decisions, that narrow the law's breadth.[7] We could not have predicted the resistance with which many courts have approached the rights and antidiscrimination principles at the core of the ADA.[8]

In this inaugural Thornburgh Family Lecture, I examine forces influencing Americans with disabilities and their quest for civil rights—in the past, present, and what may lie ahead. My goal is to illuminate social, political and economic forces, that we may continue to lay the groundwork for public policies that foster the rights of persons with disabilities.

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4. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-213 (2000).

5. I draw this section from Peter Blanck & Michael Millender, *Before Disability Civil Rights: Civil War Pensions and the Politics of Disability in America*, 52 ALA. L. REV. 1, 1-50 (2000).

6. Albert R. Hunt, *Politics & People: Halting Progress for the Disabled*, WALL ST. J., Aug. 19, 2004, at A13.

7. *See generally* PETER BLANCK ET AL., DISABILITY CIVIL RIGHTS LAW AND POLICY (2003) (discussing cases narrowing the ADA's definition of persons with disabilities).

8. *See, e.g.*, Larry M. Logue & Peter Blanck, *"There Is Nothing That Promotes Longevity Like a Pension": Disability Policy and Mortality of Civil War Union Army Veterans*, 39 WAKE FOREST L. REV. 49, 49-67 (2004) (discussing implications of governmental policy on the lives of persons with disabilities).

II. THE PAST

My colleagues and I use the history of American politics to investigate the evolution of disability rights and the present ambivalence toward disability law and policy. We note that since the 1970s, national policies directed at the rights of people with disabilities replaced a medical conception of disability, which had structured policy for most of the twentieth century.

The medical model had its roots in the Civil War Pension laws, under which disabled Union Army veterans were awarded pensions based on their "incapacity to perform manual labor."[9] The model cast disability as an infirmity that precluded equal participation in society. Yet, after the War, many disabled veterans seeking protection under the law were portrayed as shirkers and free-loaders.

Historian Michael Millender and I find support for this reading of disabled Americans' experiences under governmental policies, such as the pension scheme, which put the medical model into widespread practice. Still, we contend that by focusing on the stigmatization embedded in the medical model, scholars ignore the ways in which Americans with disabilities coped with and contested those limiting attitudes during most of the twentieth century. Little attention focuses on how, through advocacy, persons with disabilities transformed conceptions of disability in the period well before the notion of disability rights was conceivable.

We illustrate this point through examination of the Civil War pension system, a crucial, yet neglected chapter in the history of disability policy in America. We use historical and empirical analysis to examine disabled individuals' encounters with the state in the century before the rise of the disability rights movement. I return to this point later, when describing stories of contemporary Americans with disabilities and their struggle for civil rights.

After the Civil War, the federal government created a pension program for Union Army veterans with disabilities that became, to that time, the world's largest and most generously funded social insurance scheme. In an era when the national government played a minimal role in the affairs of most Americans, Civil War pensions at times consumed almost half of the federal

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9. *What Are "Disabilities"?*, N.Y. TIMES, Mar. 31, 1894, at 4 (on file with author); *see generally* Peter Blanck & Chen Song, *Civil War Pension Attorneys and Disability Politics*, 35 U. MICH. J.L. REFORM 137 (2002) (reviewing pension scheme); Peter Blanck & Chen Song, *"I Don't Believe Any Colored Ex-Soldier Can Get Justice": Disability, Race and Pensions for Union Army Veterans* (LHPDC Working Paper 2004) (documenting discrimination in the operation of the pension system).

budget.[10] Harvard political scientist Theda Skocpol and others acknowledge the significance of the pension scheme in the evolution of the American state.[11] But, only recently have scholars examined the experiences of, and public attitudes toward, disabled veterans as they advocated for their claims.

I have been privileged to work on the largest study of its kind, in collaboration with University of Chicago economist, and Nobel laureate, Robert Fogel. The Chicago research team is examining a massive amount of data in the investigation of some 40,000 white and African-American Union Army veterans.[12] Birth, health, military, pension, and census information is available for analysis, with data on this representative sample available "from cradle to death."

Our studies show that, although most Union Army veterans submitted their pension applications to a sympathetic bureaucracy in Washington, advantages did not accrue to disabled veterans seen as "unworthy," particularly those with stigmatized disabilities, mental disorders, or infectious diseases. The advantages also did not accrue to African-American and foreign-born, particularly the Irish, Union Army veterans, who were significantly less-likely to have access to pensions. When black and foreign-born veterans received pensions, they were substantially lower than those whites received with comparable disabilities.[13]

Our exploration has proven as relevant one hundred years ago as it is to disability rights today. Consider conceptions in the press that persons with disabilities who seek protection under the law are aiming for a special advantage over the nondisabled. An editorial in the *New York Times*, from 1894, reads:

> What are disabilities? . . . The door of fraud was thrown wide open to let in those who were not incapacitated for self-support, and to . . . all who would testify that they had some kind of a disease in their system. It is safe to say that only a fraction of these "disabilities" were . . . intended by the law, loose and liberal as it was.[14]

Forward 100 years to 1998, to an editorial in the *Chicago Sun Times*:

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10. *See* THEDA SKOCPOL, PROTECTING SOLDIERS AND MOTHERS: THE POLITICAL ORIGINS OF SOCIAL POLICY IN THE UNITED STATES 114 (1992) (discussing pensions' share of federal revenues).

11. *Id.*; *see, e.g.*, Blanck & Millender, *supra* note 5, at 1.

12. *See* CTR. FOR POPULATION ECON., UNIV. OF CHI., THE DATA SOURCES INVOLVED IN THE UNION ARMY STUDY (2002), *at* http://www.cpe.uchicago.edu/unionarmy/datasource.html (last visited Mar. 3, 2005).

13. *See supra* notes 8-9 (presenting empirical findings).

14. *What Are "Disabilities"?*, N.Y. TIMES, Mar. 31, 1894, at 4 (on file with author).

> I fear . . . that many able-bodied Americans are latching onto the Americans with Disabilities Act. If these parasites keep filing lawsuits claiming eligibility under a law designed to remedy discrimination against people with genuine shortcomings—and winning—how soon before there's a national backlash that unfairly encompasses the blind, the lame, and others with serious handicaps?[15]

Yesterday and today, these pronouncements profoundly influence attitudes about disability rights. Skepticism toward persons with disabilities is part of a long-held ideology that perpetuates barriers and prejudice toward disabled Americans in employment, education, housing, and daily life activities. Economist Chen Song and I have found these attitudes cut both ways. Union Army veterans who fought at Gettysburg received a "premium" in pensions, not just because of their disability, but because of their involvement with the epic Pennsylvania battle and for what it came to represent in America at the turn of the twentieth century.[16] All else equal, Gettysburg veterans, relative to other non-Gettysburg veterans with similar impairments and backgrounds, were almost three times as likely to have access to pensions and fared better once in the system.[17]

Lest one thinks these attitudes do not have real-life consequences, pension discrimination on the basis of disability, national origin, and race affected long-term mortality rates. Historian Larry Logue and I have found that even accounting for personal wealth, medical history, and rural or urban dwelling, lack of access to pensions meant substantially lower chances of survival.[18]

The lessons learned from the past help us challenge today's misconceptions of disability and disability policy. They remind us of the profound life and death effects our laws and policies have for persons with disabilities. Yet, our studies also show that as veterans were emboldened to seek pensions, those with stigmatized disabilities, blacks and foreign-born Americans with disabilities, and others seized on opportunities to shape conceptions of disability and disability rights which affected their relationship with the state for generations to come.

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15. Michelle Stevens, Editorial, *Disability Law Falls Down*, CHI. SUN TIMES, Sept. 20, 1998, at 37.

16. Peter Blanck & Chen Song, *"Never Forget What They Did Here": Civil War Pensions for Gettysburg Union Army Veterans and Disability in Late Nineteenth Century America*, 44 WM. & MARY L. REV. 1109, 1164 (2003) (describing findings).

17. *Id.*

18. *See* Logue & Blanck, *supra* note 8 (discussing these findings); *see also* Ryan K. Sewell et al., *Union Army Veterans with Hearing Loss and the Evolution of Disability in America During 1862-1920*, 114 LARYNGOSCOPE: J. TRIOLOGICAL SOC'Y 2147, 2147-53 (2004) (describing findings related to aging).

III. THE PRESENT

Despite resistance, the medical model evolved into the 1960s, with the growth of Social Security entitlement programs for the poor and disabled. These programs continued to place people with disabilities in subordinate roles to those who sought to help the disabled adjust to a society structured around the convenience and interests of the nondisabled. Because the medical model did not consider the physical and social environment as disabling, it countenanced segregation and economic marginalization. Because it focused on the needs of the disabled, it did not recognize their rights. This legacy contributed to policies that structured assistance for the disabled as welfare and charity, with public attitudes in accord.

The rights model that began to influence policy in the 1970s viewed people with disabilities as a minority group, entitled to protections that emerged from the struggles for equality of women and African-Americans.[19] During this time, people with disabilities asserted their rights to challenge stereotypes about dependency in education, housing, health care, transportation and employment.[20] In addition, in the 1970s, national disability policy began to integrate concepts of the independent living philosophy. The Rehabilitation Act of 1973[21] initiated funding for Centers for Independent Living. Not only did the CILs provide services *for* individuals with disabilities, but they were also to be operated *by* individuals with disabilities.[22]

The new "disability policy framework,"[23] grounded in equal rights, inclusion, empowerment, and economic independence, fostered passage of laws from accessibility in voting and air travel, to independence in education and housing, and culminated in the ADA. Proposing disability as a social construct, as articulated by a new generation of thinkers such as Justin Dart, Evan Kemp, Judy Heumann, Kate Seelman, I. King Jordon, and, of course, Dick and Ginny Thornburgh, the ADA rights model focuses on laws and practices that isolate disabled persons.[24] Government is to secure equality by

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19. BLANCK ET AL., *supra* note 7, § 1.2.

20. *See* JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993) (reviewing the history of modern disability rights movement).

21. 29 U.S.C. §§ 796-96(f) (2000).

22. *See* Heather Ritchie & Peter Blanck, *The Promise of the Internet for Disability: A Study of On-line Services and Web Site Accessibility at Centers for Independent Living*, 21 BEHAV. SCI. & L. 5 (2003).

23. *See generally* Robert Silverstein, *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy*, 85 IOWA L. REV. 1691 (2000) (describing the new disability policy framework).

24. *See, e.g.*, Harlan Hahn, *The Potential Impact of Disability Studies on Political Science (as Well*

eliminating the physical, economic, and social barriers that preclude equal involvement in society.

In the ADA, Congress recognized the long-standing bias facing persons with disabilities,[25] which resulted in policies that relegated individuals with disabilities to inferior opportunities.[26] Harlan Hahn's seminal articulation of the minority group model is instructive. He writes, "[t]he covert hostility and paternalism that permeates public and judicial perspectives has . . . perpetuate[d] the unequal status of disabled persons."[27]

I have been fortunate to advocate with individuals at the forefront of the disability rights movement, those confronting long-held attitudinal biases. I, and many others, take to heart Dick Thornburgh's view that "Democracy is not a spectator sport."[28] The stories I share next are about individuals who refused to be relegated to sheltered workshops; they wanted real jobs. They did not want to live on welfare checks; they wanted paychecks. They fought to be participants in society and not view the world as outsiders from a nursing home bed.

IV. DISABILITY RIGHTS STORIES[29]

In their book, *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*, Professors David Engel and Frank Munger comment that disability rights laws such as the ADA "presented an extraordinary opportunity to explore from the . . . outset what rights actually did and how they mattered . . . ."[30]

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as Vice-Versa), 21 POL'Y STUD. J. 740, 741 (1993).

25. 42 U.S.C. § 12101(a) (2000).

26. *Id.* § 12101(a)(5).

27. Harlan Hahn, *Accommodations and the ADA: Unreasonable Bias or Biased Reasoning*, 21 BERKELEY J. EMP. & LAB. L. 166, 167 (2000).

28. DICK THORNBURGH, WHERE THE EVIDENCE LEADS 361 (2003) [hereinafter THORNBURGH, WHERE THE EVIDENCE LEADS]; *see also* Dick Thornburgh, Five Themes for Public Administration in the New Millennium: Doing the 'Right Thing' and Doing the 'Thing Right' (Nov. 20, 1998), transcript *available at* http://www.napawash.org/resources/lectures/lecture_transcripts_web_1998.html (last visited Mar. 3, 2005).

29. THORNBURGH, WHERE THE EVIDENCE LEADS, *supra* note 28; *see also* Peter Blanck, *Justice for All? Stories About Americans with Disabilities and Their Civil Rights*, 8 J. GENDER, RACE & JUSTICE 1, 1-32 (2004) (including the stories presented in this paper along with other stories).

30. DAVID M. ENGEL & FRANK W. MUNGER, RIGHTS OF INCLUSION: LAW AND IDENTITY IN THE LIFE STORIES OF AMERICANS WITH DISABILITIES (2003).

A. Don Perkl: Disability Stigma

I met Don Perkl and his family in 1999 at the Madison Packaging & Assembly facility, a sheltered workshop, in Madison, Wisconsin. Don is a person in his early fifties with mental retardation. He does not speak. He and I talked using pictures and a communication board, a device that translates ideas into spoken words. We discussed his employment, job training, and the things he enjoyed.

The Equal Employment Opportunity Commission (EEOC) retained me to testify as an expert witness in a lawsuit that the government, Don, and local disability advocates brought against Chuck E. Cheese for employment discrimination under the ADA.[31] Don had worked at Chuck E. Cheese as a janitor. His job performance was excellent and his co-workers enjoyed working with him.[32] For those without young children or grandchildren, who have not had the occasion to visit Chuck E. Cheese, it is a pizza restaurant with Chuck E. as the theme mouse and star of the automated stage show.

One day, a regional manager visited the Madison restaurant. On seeing Don working at the restaurant, he took the local store supervisor aside and criticized her for hiring one of "those people."[33] After returning to the restaurant on another visit, the regional manager fired Don when the local supervisor refused to do so.

The supervisor testified during the trial that she sought guidance from the company's corporate human resources department, asking, "Can someone please help me with this situation, so we can . . . give this guy a chance? We are an equal opportunity employer, are we not?"[34] The request for guidance was unsuccessful. The supervisor and restaurant staff quit in protest and eventually testified for Don.

At trial, the defense argued that Don was not qualified for the job and the company did not discriminate against him. They defended their actions by claiming there was something threatening about Don, possibly to the children

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31. EEOC v. CEC Entm't, Inc., No. 98-C-698-X, 2000 WL 1339288 (W.D. Wis. Mar. 14, 2000).

32. *Cf.* Press Release, EEOC, Chuck E. Cheese's Must Pay Maximum Damages Under the ADA to Mentally Retarded Employee Following Multi-Million Dollar Jury Award (Mar. 15, 2000), *at* http://www.eeoc.gov/press/3-15-00.html (last visited Mar. 3, 2005) (indicating that Mr. Perkl was fired "despite the vigorous protests of the restaurant's manager").

33. *Id.* (quoting trial testimony).

34. *Id.* (quoting trial testimony).

and patrons at the restaurant. The company retained a local psychiatrist to support these claims. Of course, this was nonsense and misguided prejudice.

As an expert qualified by the court,[35] I testified about the myths and stigma facing persons like Don in employment and other daily life activities. While there was nothing deficient about Don's work performance, there was something very wrong about management's culture and attitudes, at least in this case.

The trial lasted a few days and the case went to the jury. The jury either was in a hurry, or likely knew something all the lawyers and experts did not know or acknowledge. After a four-hour deliberation, the jury found Chuck E. Cheese had unfairly discriminated against Don in violation of the ADA. The jury awarded Don some $70,000 in back pay and compensatory damages, as well as his legal fees.[36] To make its point, the jury sent a message that discrimination against qualified employees based on their disability would not be tolerated. It awarded Don $13 million dollars in punitive damages,[37] to that time the largest monetary award from a jury in an ADA employment case brought by the EEOC.

The award was made despite Chuck E. Cheese's position that Don's mental retardation made it "highly unlikely" he would experience emotional distress because of his termination.[38] Chuck E. Cheese appealed the award, but the court imposed the maximum amount of damages allowed under the ADA,[39] stating "the breathtaking magnitude of an eight-figure punitive damages award demonstrates that the jury wanted to send a loud, clear message."[40]

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35. Defendant filed a motion with the court to disqualify me as an expert witness; the trial judge denied aspects of the motion and allowed me to testify about my research and writings.

36. *See* EEOC, *supra* note 32.

37. *Id.*

38. *See* Leye Jeannette Chrzanowski, *Jury Finds Hiring and Firing Based on Ability Not Myths, Fears and Stereotypes*, GREAT LAKES ADA NEWS SERV., Jan. 31, 2000, *at* http://www.uic.edu/orgs/ada-greatlakes/adanews/001juryfinds.htm (last visited Mar. 3, 2005) (quoting Chuck E. Cheese attorneys).

39. The Civil Rights Act of 1991 provides that for employers with more than 500 employees, compensatory and punitive damages in ADA employment discrimination cases are capped at $300,000, exclusive of attorneys fees and costs. 42 U.S.C. § 1981a(a)(1), (b)(3)(D) (2000); *see* BLANCK ET AL., *supra* note 7, §§ 15.3, 16.3, 17.3 (discussing ADA remedies).

40. *See* EEOC, *supra* note 32.

B. Daniel Schwartz: Defining Disability

After Chuck E. Cheese, I thought Daniel Schwartz's case would be easy. In early 2000, Daniel, his lawyer, Claudia Center, a leading disability public interest advocate, and I met in Los Angeles to review his claims of disability discrimination and failure to accommodate under California's Fair Employment and Housing Act.[41] California's law offers many of the same anti-discrimination protections as, and in some ways exceeds, the ADA.

Daniel has developmental disabilities that limit his life activities such as learning and performing manual tasks.[42] He is married to a woman with serious health conditions. They live independently in their own apartment on modest incomes.[43] Daniel had worked for more than twenty years as a mailroom clerk with a large bank in Los Angeles. Periodically, Daniel requested additional supervision, instructions, and training as accommodations for his developmental disabilities.[44] Daniel received positive performance evaluations and pay increases each year.

In the late 1990s, the bank outsourced its mailroom functions and transferred Daniel, along with those functions, to an offsite location. Daniel's goal was to succeed and maintain his job. On one occasion, when Daniel tried to take written notes about how to run a mail-sorting machine in the new location, his supervisor asked him to stop because Daniel could not write quickly enough. He then wrote the notes for Daniel "as a favor."[45] Daniel's team leader subsequently confiscated the notes, believing this was somehow an "unfair advantage" to Daniel.[46] As an aside, consider the similarity of these negative attitudes to the earlier views I have described of disabled Union Army veterans as shirkers. Daniel's attorney commented that the company

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41. Fair Employment and Housing Act, CAL. GOV'T CODE §§ 12900-12996 (1991 & Supp. 2003). *See generally* Brief for Appellant, Schwartz v. Elec. Data Sys., Inc. (9th Cir. 2003) (on file with author).

42. *See* Appellant's Brief at 10, *Schwartz* (citing Record at EOR 301-08, 658, 866-71, 1658). Schwartz presented evidence of his disability, including medical records and test results, and expert testimony on his substantial limitations. *Id.* at 20-25 (citations omitted).

43. After Schwartz was fired, he was devastated. Having worked his entire adult life, he spent more than one year without employment and was forced to rely on his 87-year-old mother for financial assistance. *Id.* at 16.

44. Developmental disabilities are impairments in childhood development. Mental retardation may be considered a developmental disability. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC & STATISTICAL MANUAL OF MENTAL DISORDERS (4th ed. 1994).

45. Appellant's Brief at 13, *Schwartz* (citing Record at EOR 462, 1634).

46. *Id.* (citing Record at EOR 655, 671-72, 1634).

"never explained how an employee with a developmental disability could have an 'unfair advantage' [from] written notes that described his job tasks."[47]

During this time, staff did not ask Daniel how he might improve his performance,[48] or how to accommodate him.[49] And so, after twenty years of working for the bank, and less than three months with his new firm, Daniel was fired. The reasons given are: mailroom clerk Daniel Schwartz had low performance ratings in interpersonal ability, communication, leadership, and job skills,[50] as well as in his ability to be a "visionary" and "motivate and inspire others."[51] Although the ADA allows employers to determine essential job qualifications,[52] it was not apparent how being a visionary or having a global mind-set was relevant to Daniel's mailroom duties.[53] Shortly after he was fired, while job hunting, Daniel read an advertisement announcing vacancies for the jobs he had done.[54]

After our initial meeting, I traveled to north Los Angeles to interview Daniel at his new job, as a clerk in a small office, sorting mail and performing other tasks. His employer thought Daniel was doing a good job. Daniel was working part-time, and he had no health insurance benefits. He was hoping to find full-time employment to help pay his high health-care costs.

As in Don Perkl's case, I testified as an expert on the discrimination Daniel faced. I discussed Daniel's job skills and work history, and described a man who had worked his whole adult life and who was proud to be a taxpayer. With the close of discovery and summary judgment motions filed, the case came before a Los Angeles federal district court judge. Surprisingly, the judge rendered his opinion from the bench, without reaching the merits of the case.

The judge ruled that because Daniel had worked successfully for years, he could not be "disabled" for purposes of the law, and, therefore, he did not need accommodation.[55] Yes, Daniel worked for twenty years.[56] The

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47. *Id.*

48. *Id.* at 12 (citing Record at EOR 234-36, 251, 732-34, 1665).

49. *Id.* at 12-13, (citing Record at EOR 251, 252, 953-54, 976, 1667).

50. *Id.* at 14 (citing Record at EOR 1262, 1642-44).

51. *Id.* at 14 (citing Record at EOR 981-983, 1281-98, 1300-06, 1321-88, 1642-44, 1646-51).

52. 42 U.S.C. § 12111(8) (2000).

53. Appellant's Brief at 15, *Schwartz* (citing Record at EOR 444, 984, 994-1002, 1642-45, 1688).

54. *Id.* at 14-15 (citing Record at EOR 750-51, 1268, 1652-53).

55. The trial judge dismissed Daniel's claims and adopted verbatim defendant's eleven page "[Proposed] Statement of Uncontroverted Facts and Conclusions of Law." *See id.* at 7 (citing Record at EOR 1777-89).

56. *Id.* at 1.

December 2000 hearing lasted less than two minutes, and the case was dismissed.[57]

Daniel appealed his case to the U.S. Court of Appeals for the Ninth Circuit. Before a decision, Daniel accepted a settlement of more than $100,000, along with his legal fees. Justice for Daniel? Perhaps. Yet, like Chuck E. Cheese, these costs could have been avoided if the employer had taken a modest amount of time to understand the perspective of a qualified employee with a disability.

C. Mario Echazabal: Paternalism, "Direct Threat"

I met Mario Echazabal in the halls of the U.S. Supreme Court during its 2002 term, waiting for oral argument in his case. I was counsel for the National Council on Disability in Mario's case. Along with my colleague Len Sandler and attorneys at a local law firm, Shuttleworth & Ingersoll, I had prepared and filed an amicus brief in the case *Chevron v. Echazabal*.[58] The case involved Chevron's decision not to hire Mario, a job applicant, because he had asymptomatic Hepatitis C.[59] Chevron refused to hire Mario not because he was unqualified for the position he sought in their refinery, but rather because they believed the workplace might worsen his condition, an opinion disputed by Mario's doctors.[60]

Working for an independent contractor, Mario successfully performed the job functions in Chevron's refinery for twenty years without accident or injury to himself or anyone else. He was competent to make decisions about his employment and medical treatment. Chevron was aware of his health status during the years through medical evaluations.[61]

Mario personified the situation the ADA was intended to prevent: paternalism that results in exclusion and isolation. Mario believed he was entitled to decide for himself where he worked. Indeed, assessing and accepting risks, of course within reason, are elements of personal independence and the exercise of adult responsibility. Congress understood

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57. *Id.* at 7 (citing Record at EOR 1860-1865).

58. For a review of our brief and the case from which the discussion here is drawn, see NAT'L COUNCIL ON DISABILITY, POLICY BRIEF SERIES: RIGHTING THE ADA, NO. 9 *CHEVRON V. ECHAZABAL*: THE ADA'S "DIRECT THREAT" DEFENSE 1-7 (2003), *at* http://www.ncd.gov/newsroom/publications/pdf/directthreat.pdf (last visited Mar. 3, 2005).

59. Chevron U.S.A., Inc. v. Echazabal, 536 U.S. 73, 76 (2002).

60. *Id.* at 77.

61. *Id.* at 76.

this, and acknowledged in the ADA that discrimination takes many forms, including paternalism.[62]

The text of the ADA includes a defense defined by Congress that an individual "not pose a direct threat to the health or safety of *other* individuals in the workplace."[63] There is no mention in the statute of threat-to-self as a defense to a charge of employment discrimination.

One of the insidious aspects of paternalistic discrimination is the assumption that people with disabilities are not competent to make informed or safe life choices.[64] Mario's case stemmed from regulations issued by the EEOC after the ADA's passage that permitted employers to refuse to hire a person with a disability if the employer believed that individual posed a direct threat to his *own* health or safety.[65]

The Supreme Court unanimously found in favor of Chevron, and endorsed the EEOC's interpretation of the defense to include a threat to one's own health.[66] The Court reached this conclusion even though the language of the ADA did not contain such a defense and the Act's legislative history cautioned against such an interpretation.[67] I knew we were facing an uphill battle at oral argument when one Justice queried whether our position requires "an employer to take a position that could be completely barbarous,"[68] and commented that a ruling in our favor would force employers to hire "suicidal workers."[69]

The ramifications of Mario's case spread quickly. Employers are barring from jobs qualified workers with disabilities who do not pose risk, but who have asymptomatic conditions like Mario's—perhaps a history of mental

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62. *See* 42 U.S.C. § 12113(b) (2000).

63. *Id.* (emphasis added).

64. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 58, at 9.

65. *Chevron*, 536 U.S. at 78-79 ("The term 'qualification standard' may include a requirement that an individual shall not pose a direct threat to the health or safety of the individual or others in the workplace.") (citing 29 C.F.R. § 1630.15(b)(2) (2001)).

66. *Id.* at 87.

67. *See* NAT'L COUNCIL ON DISABILITY, *supra* note 58, at 19 n.17 (citing H.R. REP. NO. 101-485, pt. 2, at 72 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 354).

68. Transcript of Oral Argument, Chevron U.S.A., Inc. v. Echazabal (No. 00-1406), *at* 2002 WL 371944, at *37 (Feb. 27, 2002).

69. Justice Scalia queried the concept of paternalism facing persons with disabilities:

> [W]hy is Congress only worried about paternalism for the handicapped? Once you eliminate the stereotyping, you have [an] individual determination that this person is . . . going to be harmed. Why does Congress say, if it's a disabled person, he can kill himself, but if it's not a disabled person, oh, no, you can let him kill yourself?

Id. at *39.

illness or a genetic predisposition for certain impairments. The result is to endorse the paternalism that Congress sought to eliminate through the ADA.[70]

After losing his job at Chevron, Mario earned little steady income. A school district hired him as a part-time bus driver with no health benefits. Mario was denied his trade, which he had performed successfully for more than twenty years, because of unfounded fears about his health, and, of course, only perceived liability. In early 2004, Mario passed away. In September 2004, Mario's widow settled his case with Chevron in a confidential agreement.

D. Sara K.: Community Inclusion

ADA Title II requires that the services of state and local governments be available to people with disabilities.[71] Courts have grappled with the scope of Title II and the steps covered entities must take to prevent discrimination. However, one central element of Title II is the requirement that public entities administer their programs in the most *integrated* and appropriate setting.[72]

In *Olmstead v. Zimring*, the Supreme Court considered the reach of this integration mandate.[73] Two women with mental retardation and mental health conditions sued under Title II, claiming the State of Georgia discriminated against them by serving them in institutionalized rather than community settings.[74] The state's professionals determined community placement was appropriate, but none was available.[75] The Supreme Court held this to be unjustified institutional placement and discrimination under the ADA.[76]

Dick Thornburgh was at the forefront of the *Olmstead* decision when he filed an amicus curiae brief on behalf of the National Organization on Disability. Dick asserted the validity of the integration regulations he had issued as Attorney General. Dick later would author another important amicus

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70. A trial court may reach such a decision without considering whether a plaintiff may perform essential job functions with reasonable accommodation; thus, post-*Chevron*, employers may bar qualified workers who do not pose a risk to others, but perhaps only to themselves. The result is to endorse the unjustified paternalism that Congress expressly sought to eliminate.

71. 42 U.S.C. § 12132 (2000).

72. 28 C.F.R. § 35.130(d).

73. Olmstead v. L.C. *ex rel*. Zimring, 527 U.S. 581 (1999); *see also* Helen L. v. DiDario, 46 F.3d 325 (3d Cir. 1995) (holding a state program requiring that a disabled individual receive required care services in a segregated setting, instead of in nursing home, violates ADA).

74. *Olmstead*, 527 U.S. at 602-03.

75. *Id.* at 593-94.

76. *Id*. at 600-04.

brief in the 2004 Supreme Court case, *Tennessee v. Lane*, in which he successfully argued that it was critically important that the *Olmstead* decision, and its integration mandate, not be "undermined by a holding that Congress lacked Constitutional authority to enact ADA Title II."[77]

In the early 1990s, before the *Olmstead* integration mandate, I had been involved in litigation to improve conditions in large state facilities for persons with disabilities, and, where appropriate, to provide residents the opportunity to live in the community. I met Sara in 1991 when she was a resident of the health care unit of the Wyoming State Training School, in Lander, Wyoming. I had been appointed a court overseer in a class action lawsuit against Wyoming brought by those living at the training school.

Beginning with cases in the 1970s, the closure and phasing-down of large public residential facilities for persons with disabilities had been the national trend. Wyoming, like a majority of states, had begun integrated programs for persons with mental retardation. In 1990, a group of plaintiffs residing at the Wyoming Training School initiated the lawsuit against the state.[78] At the time, three hundred adults and children with disabilities resided at the facility.

Sara had spent most of her young life in the hospital unit at the training school. She was a smart and bright-eyed ten-year-old who had spina bifida and other serious health conditions. The *Weston* settlement mandated that children residing at the training school would be the first to move to appropriate community settings.[79]

Understandably, Sara's parents were concerned about her health needs, but they agreed she could leave the hospital facility to live at a smaller health care facility in north central Wyoming, nearer her home. Sara was not expected to live long as a result of her multiple medical conditions. Still, she wanted to live near her family, have time outdoors, and attend the community school.

After residing in the smaller facility, state professionals suggested Sara live at home with her parents with support from the state. With subsequent

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77. Brief for Respondent at *1a, Tennessee v. Lane, 124 S. Ct. 1978 (2003) (No. 02-1667) (Hon. Dick Thornburgh, Nat'l Org. on Disability, Am. Ass'n of People with Disabilities, and ADA Watch as Amici Curiae), *available at* 2003 WL 22733908.

78. For a review of the litigation and settlement in *Weston v. Wyoming State Training School*, No. C90-0004 (D. Wyo. Mar. 13, 1991), see Peter Blanck, *On Integrating Persons with Mental Retardation: The ADA and ADR*, 22 N.M. L. REV. 259, 261 (1992).

79. The Agreement established a Compliance Advisory Board, with one member selected by the state (me) and the other by the Wyoming Protection and Advocacy System. The advisory board had responsibility for assisting the federal court and the parties in the implementation of the Settlement Agreement. Blanck, *supra* note 78, at 267.

discussion and planning, Sara returned to live at home. The rest was an amazing story. Sara quickly adapted to her home life and flourished in mainstreamed classrooms. We saw this now-young teenager flower before our eyes. Not many years before, Sara would have spent her life at the training school in a hospital bed in a remote part of Wyoming.

We also saw parents of *Weston* class members and state officials appreciate the potential for children, like Sara, who wanted to live in their communities with families and friends. Only years later would the Supreme Court endorse this integration mandate in *Olmstead*.[80] As for Sara, the *Olmstead* Court recognized unnecessary institutional placement perpetuates attitudes that many persons are "incapable or unworthy of participating in community life."[81]

In January of 2004, Sara passed away. She was 15 years old. The director of Wyoming's community programs, Bob Clabby, wrote to me: "I have a solid belief that the amount of time we spend on this earth is less important than what we do with the time we have, and Sara inspired many people; not least, I think, you and me."[82]

E. Demetrius: Juvenile Justice

About the time I was working in Wyoming, I also found myself in Columbia, South Carolina, touring the state's Juvenile Justice facility. I was reviewing South Carolina's policy for children with disabilities in its juvenile justice system. The case, *Alexander S. v. Boyd*, was the first ADA Tile II class action against a state's juvenile justice facility.[83]

In South Carolina, I observed the complex needs of children with disabilities in the state juvenile justice system. Disciplinary practices, for instance, had a discriminatory effect on the many children with mental and learning disabilities. I met a young teenager, Demetrius, who was supposed to be in a special education program. But, the state had placed Demetrius in the general education program, where the support he needed did not exist. As a result of his frustration, Demetrius became depressed and slit his wrists. He

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80. *Olmstead*, 527 U.S. at 581.

81. *Id.* at 600-01.

82. E-mail from Robert Clabby, Administrator, Wy. Developmental Disabilities Servs. Div., to Peter Blanck, Director, LHPDC (Sept. 30, 2003, 20:31:35 MT) (on file with author).

83. Alexander S. v. Boyd, 113 F.3d 1373 (4th Cir. 1997). The state conceded that its DJJ facilities were subject to the ADA and its regulations. Alexander S. *ex rel.* Bowers v. Boyd, 876 F. Supp. 773, 803 (D.S.C. 1995) (concluding DJJ subject to Title II's physical and programmatic accessibility requirements).

was prescribed antidepressants with sedative effects and with the side effect of dry mouth, which led Demetrius to drink large amounts of water. The punishment, thereafter, for Demetrius when he acted out was to deny him permission to use the restroom, and he was regularly forced to urinate in his pants.

After a three-month trial, the court ruled the state failed to serve the needs of the children with disabilities in violation of the ADA.[84] A special master was appointed to oversee remediation.[85] The State did not appeal the decision.

V. THE FUTURE

The ideas and stories I have discussed, from the past and present, do not convey the deeply personal aspects of Americans pursuing their disability rights.[86] Yes, Don Perkl prevailed, was back in a sheltered workshop setting for a time, and then secured two part-time janitorial positions. Mario Echazabal chased his "American Dream," only to be thwarted by the paternalistic views of others. If Chevron could deny employment to Mario, *for his own good*, when he had worked in Chevron's refineries for twenty years with no health problems, what is the outlook for millions of like others?

In Daniel Schwartz's case, the court did not address whether Daniel could perform his job with accommodation, which he had done successfully for twenty years. Sara K. wanted to live at home with family and friends, and not visit with them from her hospital bed. Many like Demetrius never will break out of a cycle of poverty, mental illness, and educational deficiencies, despite *Olmstead's* integration mandate.[87]

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84. *Boyd*, 876 F. Supp. at 785-88.

85. *Id.* at 803-05.

86. For the complexity of like stories, see Steve Thunder-McGuire, *Completing Stories*, *in* EMPLOYMENT, DISABILITY AND THE AMERICANS WITH DISABILITIES ACT 447-62 (Peter Blanck ed., 2000).

87. *See* Martin Gould, Presentation Before OSEP Annual Leadership Forum, Panel Presentation, Juvenile Justice (July 16, 2004) (noting that "up to 20 percent of the estimated 100,000 youth in incarceration have serious mental disorders: 20 to 50 percent have attention deficit hyperactivity disorder; 12 percent have intellectual disabilities; and 30 percent or more have specific learning disabilities"), transcript *available at* http://www.ncd.gov/newsroom/testimony/2004/gould_07-16-04.htm (last visited Mar. 3, 2005).

There are many stories like these, good and not good.[88] Too often, courts and lawyers forget that these stories define the disability rights movement. In his 2002 book, *Narrowing the Nation's Power*,[89] John Noonan, a Senior Judge of the Court of Appeals for the Ninth Circuit, said of the plight faced by those pursuing their rights under laws like the ADA: "[T]he courts proceed with an agenda . . . the facts are of minor importance, the persons affected are worthy of almost no attention. The people and their problems . . . [become] . . . grist for the constitutional mill, [and] are incidental."[90]

Our society has not yet come to grips with the fact that millions of persons with disabilities—those living in poverty, in nursing homes and institutions, women, and persons from minority groups—continue to face segregation and isolation, stigma and discrimination.[91] We are learning why organizational cultures promote inclusiveness and diversity, while others choke it off. Although this is a new area of inquiry, large and small private and public organizations have been shown to benefit from including people with disabilities. In a recent series of studies, my colleagues and I study ways organizations further this goal,[92] through a commitment to diversity and inclusiveness,[93] and to combat stigma about disability.

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88. Karen Hirsch, *From Colonization to Civil Rights*, *in* EMPLOYMENT, DISABILITY, AND THE AMERICANS WITH DISABILITIES ACT, *supra* note 86, at 412, 428. *See generally* VOICES FROM THE EDGE: NARRATIVES ABOUT THE AMERICANS WITH DISABILITIES ACT 10, 24 (Ruth O'Brien ed., 2004). Karen Hirsch contends we learn about our culture and its perspectives on disability through the oral histories and narratives of Americans with disabilities.

89. JOHN T. NOONAN, JR., NARROWING THE NATION'S POWER: THE SUPREME COURT SIDES WITH THE STATES (2002).

90. *Id.* at 145.

91. *See* Johnette Hartnett et al., *Asset Accumulation and Tax Policy for People with Disabilities*, DISABILITY STUD. Q. 3-20 (2005).

92. Lisa Schur et al., *Corporate Culture and the Employment of Persons with Disabilities*, 23 BEHAV. SCI. & L. (forthcoming 2005). In June of 2003, my colleagues and I convened a symposium at the Merrill Lynch New York headquarters to enhance dialogue among corporations, persons with disabilities, and researchers on corporate culture and the employment of persons with disabilities. Participants included experts on corporate culture and disability studies, corporate leaders, and government representatives. The proceedings are available at LAW, HEALTH POL'Y, & DISABILITY CTR., CORPORATE CULTURE AND DISABILITY SYMPOSIUM (June 9, 2003), *at* http://disability.law.uiowa.edu/lhpdc/events/merrill_lynch_symp.html (last visited Mar. 3, 2005). *See also* David Klein et al., *Accessible Technology and Corporate Culture at Microsoft: A Methodological Note*, 23 BEHAV. SCI. & L. 65-96 (2005); Leonard A. Sandler & Peter Blanck, *Accessibility as a Corporate Article of Faith at Microsoft: Case Study of Corporate Culture and Human Resource Dimensions*, 23 BEHAV. SCI. & L. 39-64 (2005).

93. For a review of employer diversity and disability policies, see Phoebe Ball et al., *Disability As Diversity in Fortune 100 Companies*, 23 BEHAV. SCI. & L. 97-121 (2005).

A. Is the ADA's Rights Model a Failure?

Today, this perhaps is the major question in disability law and policy. Critics say the law is a failure. In 1994, a writer in the *Washington Times* wrote the ADA "symbolizes the irresponsibility and arrogance of Congress and the federal bureaucracy and is a disservice to many of America's handicapped."[94] In 1999, Chicago economist and Nobel Laureate Gary Becker commented:

> The Americans with Disabilities Act is a misguided attempt to help the disabled, and the problems it created are getting worse as lawyers find new issues to litigate. Clearly, the scope of the act should be radically narrowed. But that may not be enough. Truly disabled workers might be better off were the ADA scrapped altogether.[95]

I reject these criticisms. I believe the ADA disability rights model is succeeding. Indeed, the rights model has become a model for the world. Its fundamental themes are uniting countries in the pursuit of policies to improve the lives of persons with disabilities.

1. Employment

The unemployment rate of persons with disabilities, broadly defined, is unacceptably high, and it increased in the 1990s. However, existing research does not allow for the conclusion that the ADA has caused declines in employment levels. Indeed, to the contrary. Economist Susan Schwochau and I conclude that, since the ADA's passage, studies of employment rates of persons with disabilities vary, depending upon how disability is defined and measured.[96] Thus, by most accounts, employment rates of those who report a work-limiting impairment have declined in the 1990s. Yet, Rutgers economist Doug Kruse found during this same period that employment had

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94. James Bovard, Editorial, *Very Bad Craziness and the Disabilities Act*, WASH. TIMES, July 26, 1994, at A19.

95. Gary S. Becker, *Are We Hurting or Helping the Disabled?*, BUS. WK., Aug. 2, 1999, *available at* http://www.hooverdigest.org/00[illegible]/becker2.html (last visited Mar. 3, 2005), *reprinted in* HOOVER DIG. (2000).

96. For a related discussion, see Susan Schwochau & Peter Blanck, *Does the ADA Disable the Disabled?—More Comments*, 42 INDUS. REL. 67, 67-77 (2003). *See also* Michael A. Stein, *The Law and Economics of Disability Accommodations*, 53 DUKE L.J. 79 (2003) (illustrating the positive economic effects of the ADA and refuting the neoclassical economic critique of the ADA).

risen substantially among those with work limitations or severe functional limitations who report the ability and desire to work.[97]

The benefits to companies of employing qualified workers is well-documented, showing that many large and small businesses look beyond minimal compliance with the ADA. In a study of hundreds of workplace accommodations at Sears Roebuck over the period 1978 to 1996, my colleagues and I found that low cost accommodations for employees with disabilities produced substantial economic benefits, in terms of increased work productivity, injury prevention, reduced workers' compensation costs, and workplace effectiveness and efficiency.[98]

In a developing and large study, in collaboration with the Job Accommodation Network (JAN) and funded by the U.S. Department of Labor, Office of Disability Employment Policy, my colleagues and I have found that many employers report the actual net benefits of providing workplace accommodations to employees with disabilities outweigh the costs.[99] Also, encouragingly, the 2004 N.O.D./Harris Survey of Americans with Disabilities shows that the percentage of people with disabilities who report encountering discrimination in the workplace has declined significantly in the past four years.[100] The proportion of persons with disabilities reporting they were not offered a job for which they were qualified also dropped, from 51% in 2000

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97. Douglas Kruse & Lisa Schur, *Employment of People with Disabilities Following the ADA*, 42 INDUS. REL. 31, 54-56 (2003). For a review essay on this debate, see Samuel R. Bagenstos, *Has the Americans with Disabilities Act Reduced Employment for People with Disabilities?*, 25 BERKELEY J. EMP. & LAB. L. 527, 540-42 (2004) (critiquing Blanck, Kruse, Schur conclusions). *See generally* Peter Blanck et al., *Calibrating the Impact of the ADA's Employment Provisions*, 14 STAN. L. & POL'Y REV. 267 (2003).

98. In studies conducted at Sears, Roebuck and Co. from 1978 to 1996, a period before and after Title I's July 26, 1992, effective date, nearly all of the 500 accommodations sampled required little or no cost. During the years between 1993 and 1996, the average direct cost for accommodations was $45, and, from 1978 to 1992, the average direct cost was $121. The Sears studies show the direct costs of accommodating employees with hidden disabilities (*e.g.*, emotional and neurological impairments comprising roughly 15% of the cases studied) is lower than the overall average of $45. PETER BLANCK, COMMUNICATING THE AMERICANS WITH DISABILITIES ACT—TRANSCENDING COMPLIANCE: 1996 FOLLOW-UP REPORT ON SEARS, ROEBUCK AND CO. 18, 20 (1996), *at* http://disability.law.uiowa.edu/lhpdc/publications/documents/blanckdocs/annen_follow_up_96_sears.pdf (last visited Mar. 3, 2005).

99. Peter Blanck, Preliminary Findings from the JAN Evaluation Study, Keynote Address at the JAN Annual Conference in Orlando (Sept. 2005) (on file with author).

100. *See* NAT'L ORG. ON DISABILITY, LANDMARK DISABILITY SURVEY FINDS PERVASIVE DISADVANTAGES, *at* http://www.nod.org (last visited Mar. 3, 2005) (describing findings).

to 31%, in 2004.[101] The proportion reporting being denied a workplace accommodation dropped by half, from 40% in 2000, to 21% in 2004.[102]

Of course, challenges in the employment arena exist. So much so that disability advocates are proposing a bill that would restore the reach of the ADA that has been narrowed by U.S. Supreme Court cases. High on the list of topics included in an "ADA Restoration Act" is clarification of the definition of disability.[103] The proposed law would reverse the Supreme Court's interpretation in cases like *Toyota v. Williams*, holding that the ADA's definition of disability requires individuals to be substantially limited in a broad range of daily life activities.[104] Under *Toyota*, Daniel Schwartz, whose disability never prevented him from working, and Mario Echazabal, whose disability imposed perhaps some, but not a "substantial," work limitation, could not expect ADA coverage.

In addition, contrary to prior interpretations of the ADA, in the well-known *Sutton Trilogy* cases, the Supreme Court decided that factors that mitigate an individual's impairment—such as prosthetic devices or medication—are to be considered in defining whether that person's impairment is substantially limiting for purposes of the ADA.[105] The ADA Restoration Act would reverse that decision. Some states, like California, have rejected the Supreme Court's approach by amending their state disability antidiscrimination laws.[106]

2. Integration and Public Access

ADA Title II's integration mandate has reached thousands of individuals like Sara in Wyoming.[107] Researchers Sara Rosenbaum and Joel Teitelbaum

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101. *See* HARRIS INTERACTIVE, 2000 N.O.D./HARRIS SURVEY OF AMERICANS WITH DISABILITIES 37 tbl.5 (2000) [hereinafter NOD 2000 POLL]; NAT'L ORG. ON DISABILITY, DETAILED RESULTS FROM THE 2004 N.O.D./HARRIS SURVEY OF AMERICANS WITH DISABILITIES 7 [hereinafter NOD 2004 POLL], *at* http://www.nod.org (last visited Mar. 3, 2005).

102. *See* NOD 2000 POLL, *supra* note 101, at 37 tbl. 5; NOD 2004 POLL, *supra* note 101, at 7.

103. For the text of the ADA Restoration Act of 2004 and extensive commentary, see NAT'L COUNCIL ON DISABILITY, RIGHTING THE ADA (2004), *at* http://www.ncd.gov/newsroom/publications/2004/righting_ada.htm (last visited Mar. 29, 2005).

104. Toyota Motor Mfg., Ky., Inc. v. Williams, 534 U.S. 184 (2002).

105. Sutton v. United Airlines, Inc., 527 U.S. 471 (1999).

106. BLANCK ET AL., *supra* note 7, §§ 21.6-10.

107. *See*, *e.g.*, Rodde v. Bonta, 357 F.3d 988, 995-98 (9th Cir. 2004) (holding that ADA Title II prohibits discrimination in state programs that result from closure of a large public health rehabilitation facility that provides medical services for persons with disabilities).

write in "Olmstead at Five"[108] that the *Olmstead* decision established two fundamental integration principles. First, the unjustified institutionalization of persons with disabilities who desire to, and who can, live in the community, violates Title II. Secondly, and broadly, Title II requires states to affirmatively remedy discriminatory practices in public programs and services.[109]

Despite progress, we see a wave of challenges to Title II, with roots at the intersection of disability policy and constitutional law. The challenge is based in the "new federalism" jurisprudence endorsed by the Rehnquist Supreme Court. Under this approach, the Court has narrowed the ADA's reach, as it has done to age and religion antidiscrimination laws, with gender-based antidiscrimination laws affected to a lesser extent.[110]

Generally speaking, the Court has concluded Congress has narrow constitutional authority to limit states' Eleventh Amendment sovereign immunity from civil rights suits under laws like the ADA. In a 2001 case involving the ADA's coverage of state employees, the Supreme Court held in *Board of Trustees v. Garrett* that Congress exceeded its powers and inappropriately allowed states to be subjected to ADA actions against them for monetary damages in employment discrimination cases.[111] Some legal commentators contend *Garrett* restored balance between federal civil rights legislation and state sovereignty.[112] Others argue the approach is an unfounded product of an activist Court that exceeds its role in limiting Congressional efforts to legislate pursuant to the Fourteenth Amendment civil rights guarantees.[113]

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108. SARA ROSENBAUM & JOEL TEITELBAUM, KAISER FAMILY FOUND., OLMSTEAD AT FIVE: ASSESSING THE IMPACT (2004), *at* http://www.kff.org/medicaid/upload/38426_1.pdf (last visited Mar. 3, 2005).

109. *Id.*

110. For a review of the Court's general antipathy toward federal antidiscrimination law, see NAT'L COUNCIL ON DISABILITY, POLICY BRIEF SERIES: RIGHTING THE ADA, NO. 8 THE AMERICANS WITH DISABILITIES ACT: THE IMPLICATIONS OF THE SUPREME COURT'S DECISION IN *BOARD OF TRUSTEES OF THE UNIVERSITY OF ALABAMA V. GARRETT* (2003), *at* http://www.ncd.gov/newsroom/publications/pdf/alvgarrett.pdf (last visited Mar. 3, 2005).

111. Bd. of Trs. v. Garrett, 531 U.S. 356, 374 (2001); *see also* BLANCK ET AL., *supra* note 7, §§ 16-6 to 16-8 (discussing that the Eleventh Amendment to the U.S. Constitution provides that states generally are immune from suits by citizens for monetary damages, and, in limited circumstances, Congress may abrogate states' sovereign immunity). In 2005, on remand to the federal district court, Ms. Garrett, in *Garrett v. Board of Trustees*, 354 F. Supp. 2d 1244 (N.D. Ala. 2005), was held not to be a qualified person with a disability and her case was dismissed.

112. For a review, see BLANCK ET AL., *supra* note 7, § 10.2.

113. *See, e.g.*, BLANCK ET AL., *supra* note 7, § 10.2; Jed Rubenfeld, *The Anti-Discrimination Agenda*, 111 YALE L.J. 1141, 1154-56 (2002).

In *Tennessee v. Lane*,[114] another Eleventh Amendment case decided by the U.S. Supreme Court in 2004, the Court's new federalism momentum paused, at least for a defined set of circumstances.[115] In *Lane*, two persons with disabilities, a defendant in a traffic case and a court reporter, sued under Title II to vindicate their right of access to the courts.[116] The plaintiffs were excluded from courthouses and proceedings through an inability to access the physical facilities.

Their stories are compelling. George Lane crawled up two flights of steps to attend his court hearing in a building that lacked an elevator. He decided not to make the same attempt when called for a second hearing, and notified the judge he was downstairs. The judge had him arrested for failure to appear.[117] Beverly Jones works as a court reporter in Tennessee. Her work opportunities were limited because courthouses in Tennessee are physically inaccessible.[118]

In *Lane*, the Court decided Congress crafted Title II within its constitutional bounds in preventing states from discriminating against people with disabilities in their fundamental right of access to the courts.[119] The *Lane* plaintiffs were entitled to sue Tennessee for monetary damages under Title II.

As expected, Dick Thornburgh was in the fray in *Lane*.[120] Dick and other leaders from the disability community filed an amicus brief in support of Lane. They wrote:

> The hard-fought gains . . . achieved by the . . . ADA, and the promise of greater equality and opportunity in the years to come, are threatened by the states' . . . challenges to the constitutional validity of the Act. . . . If the Court does not . . . uphold Title II of the ADA . . . , federal disability laws that are . . . beginning to enable disabled persons to participate in critical facets of American life will be undermined before the goal of full integration has been achieved.[121]

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114. Tennessee v. Lane, 124 S. Ct. 1978 (2004).

115. Brief for Petitioner at *15, Tennessee v. Lane, 71 U.S.L.W. 3789 (2003) (No. 02-1667), *available at* 2003 WL 22137324.

116. *Lane*, 124 S. Ct. at 1982-83.

117. *Id.* at 1983.

118. Her requests for accommodations were not successful. *Id.*

119. In this scenario, Title II would be limited to prospective injunctive relief against states (or state officials) and to suits for damages against local governments brought by the United States. *See* BLANCK ET AL., *supra* note 7, § 10.2.

120. Attorney General Thornburgh co-authored an amicus curiae brief on behalf of Mr. Lane. Brief for Respondent, Tennessee v. Lane, 124 S. Ct. 1978 (2003) (No. 02-1667) (Hon. Dick Thornburgh, Nat'l Org. on Disability, Am. Ass'n of People with Disabilities, and ADA Watch as Amici Curiae), *available at* 2003 WL 22733908.

121. *Id.* at 4.

The Court endorsed this view as applied to the fundamental right of access to the courts. Yet, the challenge to the ADA is far from over. On remand, the trial judge denied class action status for other Tennesseans with disabilities on the grounds that courthouses across the state "'have unique designs and . . . features.'"[122] In March 2005, the parties entered into a settlement agreement that requires local courthouses to comply with the ADA or provide alternate court sites and appropriate accommodations that are accessible.[123]

But, at least in the court of public opinion, people overwhelmingly favor states making their courthouses accessible. A February 2004 Harris Poll found that more than 90% of those surveyed believe unacceptable a system that forces someone to leave a wheelchair and crawl up stairs to a courthouse.[124] It is an open question whether future challenges will limit Title II's integration mandate in areas such as transportation, voting, and education, should the Court view these areas as not implicating a fundamental constitutional right.

3. Accommodations by Private Entities

What of ADA Title III? The premise is straightforward: malls, professional offices, hotels, and so on may not discriminate against people with disabilities. Increasingly, places of public accommodation are accessible to people with disabilities.[125] The Supreme Court has ruled in accord. In *PGA v. Martin*,[126] the Court found Casey Martin, a professional golfer with a circulatory disorder,[127] was entitled to the accommodation of riding a golf cart

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122. *TN Courthouse Suit Won't Be a Class Action*, RAGGED EDGE ONLINE, Aug. 18, 2004, *at* http://www.raggededgemagazine.com/dm/08_04.html#759 (last visited Mar. 3, 2005); *see* Rob Johnson, *Disability Case Won't Be Class Action*, ADA WATCH, Aug. 18, 2004, http://www.adawatch.org/LaneClassAction.htm (last visited Mar. 3, 2005).

123. Bill Harless, *Courthouses Get ADA Rules*, NASHVILLE CITY PAPER, Mar. 23, 2005.

124. Press Release, Humphrey Taylor, The Harris Poll, Overwhelming Majorities of Public Find It Unacceptable for States to Claim They Are Exempt from Provisions of Americans with Disabilities Act (Feb. 18, 2004), *at* http://www.harrisinteractive.com/harris_poll/index.asp?PID=440 (last visited Mar. 3, 2005) (discussing findings).

125. *Cf.* JAMES E. PRIEGER, THE IMPACT OF THE AMERICANS WITH DISABILITIES ACT ON THE ENTRY AND EXIT OF RETAIL FIRMS (AEI-Brookings Joint Ctr. for Regulatory Stud., Working Paper 04-23, Nov. 2004) (finding the ADA associated with decreased number of food store retail firms), *at* http://www.aei-brookings.org/publications/abstract.php?pid=877 (last visited Mar. 3, 2005).

126. PGA Tour, Inc. v. Martin, 532 U.S. 661 (2001).

127. *Id.* at 668. This degenerative circulatory disorder obstructs the flow of blood from Martin's right

to allow him to play in tournaments.[128] The Court said accommodations must "give individualized attention" to accessibility requests, and "carefully weigh the purpose . . . of . . . [any exclusionary] rule before determining that no accommodation [is] tolerable."[129]

In 2004, the U.S. Supreme Court agreed to decide another ADA Title III accommodation case with broad implications.[130] The case concerns whether foreign flagged cruise ships that dock at U.S. ports or in U.S. waters must be accessible to persons with disabilities, and whether they may have surcharges for accessible rooms and services. The Courts of Appeal have been split on this issue.

Another question with far-reaching implications is whether Title III requires the Internet to be technologically accessible to prevent a "Digital Divide"; for instance, whether web sites should be designed to work with screen reader software used by blind persons, and other accessible technologies for persons with hearing impairments, dexterity, developmental or learning disabilities.[131] Along with others, I testified before Congress that the activities of private entities on the Internet—travel agents, insurance companies, and online catalogues—are subject to Title III as places, albeit "cyber places," of public accommodation affecting commerce.[132] On this question, the courts are split.[133] In an encouraging development, in 2004, New York Attorney General Eliot Spitzer announced settlements with major travel web sites to make their sites accessible to blind and visually impaired users, commenting that "[a]ccessible web sites are the wave of the future."[134]

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leg to his heart. The disease causes severe pain when Martin walks, and walking creates a significant risk of hemorrhaging, blood clots, and bone fractures.

128. *Martin*, 532 U.S. at 661.

129. *Id.* at 691.

130. Rafe Bartholomew, *On the Docket:* Spector, Douglas et al. v. Norwegian Cruise Line Ltd., MEDILL NEWS SERV., Sept. 28, 2004, *at* http://www.medill.northwestern.edu/~secure/docket/mt/archives/001813.php (last visited Mar. 3, 2005).

131. *See* Peter Blanck & Leonard A. Sandler, *ADA Title III and the Internet: Technology and Civil Rights*, 24 MENTAL & PHYSICAL DISABILITY L. REP. 855-59 (2000) (discussing these issues).

132. *Applying the ADA to the Internet, Hearing Before the House Judiciary Subcomm. on the Constitution*, 106th Cong. (Feb. 9, 2000) (statement of Peter Blanck), transcript *available at* 2000 WL 149460 and 2000 WL 11067880. This would be true to the extent that equivalent services offered on-line or in other accessible formats (*e.g.*, Braille) were not available to people with disabilities.

133. *See*, *e.g.*, Access Now, Inc. v. Southwest Airlines Co., 385 F.3d 1324 (11th Cir. 2004); Hartzell v. Arkansas, No. IJ-2001-3700 (Cir. Ct. Pulaski County, June 2, 2004, *discussed in* INFO. TECH. TECHNICAL ASSISTANCE & TRAINING CTR., COURT ORDERS ARKANSAS ADMINISTRATIVE STATEWIDE INFORMATION SYSTEM TO COMPLY WITH STATE IT ACCESSIBILITY LAW (July 1, 2004), *at* http://www.ittatc.org/news/july_04.cfm#fyal (last visited Mar. 3, 2005).

134. *See* Press Release, Office of New York State Attorney General, Spitzer Agreement to Make Web

Dialogue is needed on the fair and reasonable application of the ADA to private and public Internet services and sites, not only for people with disabilities, but for all underrepresented individuals in society—the poor and isolated, and the vulnerable. A profound question underlies these precepts: Will the Internet help people with disabilities and underrepresented people to participate equally in our society? Or will it further isolate them from the mainstream?[135]

VI. CLOSING

I have highlighted Americans with disabilities and their quest for civil rights. Past, present, and future, some attitudes die hard. After passage of the ADA, in 1991, Attorney General Thornburgh anticipated the challenges ahead when he said:

> [O]ur concern for those with disabilities is . . . about widening the doors . . . of opportunity . . . the doors of perception must be widened among the broader public community, so that we all recognize the right of people with disabilities to come into mainstream society . . . . Above all, to give individuals with disabilities the opportunity of long-term prospects for a future life of hope and achievement.[136]

Years after Dick's insightful comments, individuals continue to battle stigma about disability.

A. Heath v. Heath*: King Solomon and Disability*

In 2004, I was co-counsel with Carolyn Young and others of the Western Law Center for Disability Rights and Proskauer Rose, a large private law firm (acting pro bono), in a California state court custody proceeding between the parents of two young boys, Mike and Sam.[137] At the time of their parents' separation, Mike, three years old, and Sam, then one year of age, remained

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Sites Accessible to the Blind and Visually Impaired (Aug. 19, 2004), *at* http://www.oag.state.ny.us/press/2004/aug/aug19a_04.html (last visited Mar. 3, 2005).

135. PETER BLANCK, COMMUNICATIONS TECHNOLOGY FOR EVERYONE: IMPLICATIONS FOR THE CLASSROOM AND BEYOND (Annenberg Wash. Program Papers, 1994), *at* http://www.annenberg.nwu.edu/pubs/comtech/ (last visited Mar. 3, 2005).

136. Dick Thornburgh, *The Americans with Disabilities Act: What It Means to All Americans*, 64 TEMP. L. REV. 375, 376 (1991).

137. For a description of facts, see Brief for Appellant, *In re* Marriage of Heath, 18 Cal. Rptr. 3d 760 (Cal. Dist. Ct. App. 2004) (No. B171500), *available at* 2004 WL 1513973.

with their mother. Subsequently, Mike was diagnosed with autism and was placed in classes to address his educational and social needs.

Around this time, the trial judge introduced the idea of splitting the children, with one child living with each parent. The parents rejected the idea, and, in 2003, the court awarded the mother primary custody of both children. After the initial custody ruling, the judge allowed the boys' father to have an extended visit with Sam, the younger sibling. At a court hearing after this visit, the father told the court he believed Mike's autism had been holding back Sam's development. The father requested custody of Sam, which the judge granted.

Shortly thereafter, the parents' marriage was dissolved and the children separated, with Mike living with his mother and Sam with his father. The court's decision to separate the children was based only on assumptions about autism—not on expert evidence—and a "hunch" of the negative impact of having a child with autism in the family. The court did not find fault with the mother's parenting. As such, the judge discounted the importance of the brothers' right to live together and the adverse effects of their separation.

We appealed the judge's ruling, arguing that divorcing the brothers only teaches them, and others, that people who are "different" must be segregated from the "normal"; and, in this case, that disability is a detriment to a family relationship. In support of our position, the Alliance for Children's Rights and the Organization for Autism Research wrote: "Autism is not the plague, and an autistic child is no more deserving of quarantine from his siblings than any other child."[138]

In September 2004, the California Court of Appeals agreed with our position and reversed the trial judge's decision.[139] The Appeals Court wrote:

> In the biblical story of King Solomon, two women, each claiming to be the mother of a baby, asked for a decision. King Solomon threatened to split the child in half, ending its life but allowing each woman to have a piece of the child. The true parent revealed herself by saying no, placing the best interests of her child ahead of her own desire to raise the child. Although the children's lawyer described the situation in this case as Solomonic, the court did what King Solomon never intended to do: he split the family and ended the life together of two young brothers.[140]

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138. Brief of Alliance for Children's Rights, Ctr. on Disability & Cmty. Inclusion, & Org. for Autism Research as Amici Curiae in Support of Appellant at 15-16, *In re* Marriage of Heath, 18 Cal. Rptr. 3d 760 (Cal. Dist. Ct. App. 2004) (on file with author).

139. *In re* Marriage of Heath, 18 Cal. Rptr. 3d 760 (Cal. Dist. Ct. App. 2004).

140. *Id.* at 761.

The Appeals Court upheld two principles in California law: "first that the sibling bond should be preserved whenever possible; and, second, that disability, mental or physical, is never to be presumed as a barrier to individual rights."[141] With regard to the later principle, the court stated:

> [I]t is the policy of this state that the existence of a disability does not permit a court to presume detriment. Rather than relying on stereotypes, assumptions, and "hunches" to make a determination concerning the best interests of a child, the court must make an appraisal of the actual circumstances . . . .[142]

The uniting of brothers Mike and Sam reminds us again that the goals of disability rights continue to have as much to do with battling attitudinal barriers and prejudice faced by persons living with disabilities as they have to do with overcoming physical barriers in the world.[143] In 2004, Ginny Thornburgh spoke with passion about these themes on Pittsburgh's radio show, "Disability Matters with Joyce Bender":

> [M]any of [our son] Peter's colleagues are men and women whom . . . [are] underemployed and under utilized. . . . [T]he key . . . is attitude. . . . [I]f we assume that [a] person isn't going to be a . . . solid, creative, hard working person, then they won't be. But if we assume when we meet a man or woman with a cognitive disability that we can restructure the job, that we can tap into the talents and . . . positive attitudes of that person, we're going to have an amazingly loyal and hard working person.[144]

Americans like Ginny and Dick, and Peter Thornburgh challenge and help eliminate outdated attitudes about disability. The Thornburgh dialogue is our dialogue; it is Don Perkyl's, Dan Schwartz's, Mario Echazabal's, Sara K's, Demitrius', and young Mike and Sam's reality. It is George Lane's and Casey Martin's aspiration for inclusion and not segregation, for economic independence and not dependency, for equality and not second-class citizenship, for self-determination and not paternalism, and for respect and not stigma.

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141. *Id.* at 763.

142. *Id.* at 764.

143. *See* e-mail from Carolyn Young to Peter Blanck (Sept. 30, 2004, 10:51:53MT) (describing case status as of Sept. 30, 2004; LAFLA replaced WLCDR as counsel for Monica Heath for proceedings on remand; appeared before the new judge assigned to the case; each brother appointed separate counsel; LAFLA will seek to reinstate the pre-judgment custody order of the brothers living with Ms. Heath) (on file with author).

144. *Disability Matters* (Voice of America radio broadcast, Mar. 16, 2004), *at* http://www.benderconsult.com/radiocaption/031604VA.html (last visited Mar. 3, 2005). Ms. Bender served as a panel discussant on my remarks.

I am optimistic we will achieve these aspirations. But, much work remains in disability law and policy. According to the General Accounting Office, over 40% of those in the Temporary Assistance for Needy Families (TANF) program, those living in poverty, have a disability or a child with a disability.[145] As Congress and the President consider the reauthorization of the TANF, they must recognize the economic plight of persons with disabilities and their family members. They must be particularly mindful of this condition in the important discussion about social security reform and privatization, so as not to dramatically cut future benefits for people with disabilities.[146]

My colleague, Michael Morris, comments: "True freedom and full community participation for Americans with disabilities will not be achieved until we understand the power of assets and wealth creation."[147] The Law, Health Policy & Disability Center is engaged in a large-scale project, funded by the National Institute on Disability and Rehabilitation Research (NIDRR), to unite organizations serving persons with disabilities with financial institutions and the Internal Revenue Service (IRS) in order to identify barriers

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145. *See* LEX FRIEDEN, NAT'L COUNCIL ON DISABILITY TEMPORARY ASSISTANCE FOR NEEDY FAMILIES AND PEOPLE WITH DISABILITIES (Mar. 11, 2004), *at* http://www.ncd.gov/newsroom/news/2004/op-ed04-453.htm (last visited Mar. 3, 2005).

146. *See*, *e.g.*, *Hearing on the Final Report of the President's Commission to Strengthen Social Security Before Senate Finance Comm.*, 107th Cong. (Oct. 3, 2002) (statement of Marty Ford, Co-Chair Social Security Task Force Consortium for Citizens with Disabilities); CONSORTIUM FOR CITIZENS WITH DISABILITIES, CCD SOCIAL SECURITY TASK FORCE REPORT (Dec. 2004), *at* http://www.c-c-d.org/arsocialsecurity.htm (last visited Mar. 3, 2005); *see also* PETER A. DIAMOND & PETER R. ORSZAG, REDUCING BENEFITS AND SUBSIDIZING INDIVIDUAL ACCOUNTS: AN ANALYSIS OF THE PLANS PROPOSED BY THE PRESIDENT'S COMMISSION TO STRENGTHEN SOCIAL SECURITY 1-10 (2002) (noting the President's Commission proposed benefit reductions would apply to all beneficiaries, including people with disabilities and those not choosing individual accounts), *at* http://www.tcf.org/Publications/RetirementSecurity/Diamond_Orszag.pdf (last visited Mar. 3, 2005). An individual opting for individual accounts would need to accept additional benefit reductions to divert part of their payroll taxes to their individual accounts. DIAMOND & ORSZAG, *supra*, at 29. Diamond and Orszag contend it is unlikely persons with disabilities would be able to compensate for benefit reductions from income from individual accounts because of the small size of their individual accounts, interruption to career and income from a disability, and lack of access to individual accounts until retirement age. *Id.* at 19. In accord, Opcin and Stapleton find that the reform proposals could result in greater declines in benefits for persons with disabilities relative to retired beneficiaries, low-wage relative to higher-wage workers, and beneficiaries with early relative to later disability onset. SELIN OPCIN & DAVID STAPLETON, THE EFFECT OF SOCIAL SECURITY REFORM PROPOSALS ON SOCIAL SECURITY DISABILITY INSURANCE, SUPPLEMENTAL SECURITY INCOME, AND PRIVATE DISABILITY INSURANCE vi-viii (2001), *at* http://research.aarp.org/econ/2001_13_ssreform.pdf (last visited Mar. 3, 2005).

147. *See* Michael Morris, Asset Accumulation and Tax Policy 1 (unpublished manuscript), *at* http://disability.law.uiowa.edu/lhpdc/projects/asset_docs/Asset_Accumulation_and_Tax.doc. (last visited Mar. 3, 2005).

and opportunities of public policies. The goal is to improve economic independence, social empowerment, and community integration of persons with disabilities.[148]

In the same spirit, funding is needed for Personal Assistance Services (PAS) through the Medicaid program to ensure that *Olmstead's* integration mandate reaches people with disabilities forced to live in nursing homes and institutional settings.[149] Iowa Senator Tom Harkin champions passage of the MiCASSA (the Medicaid Home and Community-based Attendant Services and Supports Act),"[150] and the "Money Follows the Person" bills. Senator Harkin is working with Senator Arlen Specter of Pennsylvania and others on legislation that allows people with disabilities in nursing homes to live in their homes and communities, by enabling Medicaid funding to be used for personal assistance services, such as for help with dressing and meal preparation.[151] During 2004, the House of Representatives amended the bipartisan Family Opportunity Act to include the Money Follows the Person bill. The Family Opportunity Act would allow families with children who have severe disabilities to "buy into" the Medicaid program to receive health care services and supports they could not otherwise afford through private insurance plans.[152]

In the area of education, the reauthorization of the Individuals with Disabilities Education Act (IDEA)"[153] was signed into law by President Bush in December 2004.[154] The National Council on Disability (NCD) calls for

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148. Mr. Kelvin Ross, from the IRS, spoke on related issues as a discussant on my remarks.

149. Other countries, such as France, are expanding our concept of accommodation and personal assistance to cover, for instance, flexible time arrangements as a form of accommodation for family assistants and those close to the person with a disability. GERARD QUINN, EU NETWORK OF INDEPENDENT EXPERTS ON DISABILITY DISCRIMINATION, BASELINE STUDY ON DISABILITY DISCRIMINATION LAW IN THE EU MEMBER STATES SYNTHESIS REPORT (Draft No. 5, Mar. 2003) (on file with author). *See generally* DISABILITY RIGHTS, IN THE SERIES: THE INTERNATIONAL LIBRARY OF ESSAYS ON RIGHTS (Peter Blanck ed., forthcoming 2005 Ashgate Pub.) (discussing disability laws around the world).

150. OHIO STATEWIDE INDEP. LIVING COUNCIL, MEDICAID COMMUNITY-ATTENDANT SERVICES AND SUPPORTS ACT (MICASSA), *at* http://www.ohiosilc.org/il/micassa.php (last visited Mar. 3, 2005) (citing 147 CONG. REC. S8594-S8596 (daily ed. Aug. 1, 2001)).

151. *See* CTR. FOR AN ACCESSIBLE SOC'Y, THE 'MONEY FOLLOWS THE PERSON' ACT (Aug. 12, 2003), *at* http://www.accessiblesociety.org/topics/persasst/moneyfollowpersonbill.html (last visited Mar. 3, 2005); SENATOR TOM HARKIN, AMERICANS WITH DISABILITIES, *at* http://harkin.senate.gov/disabilities/index.cfm (last visited Mar. 3, 2005).

152. *See* NAT'L COUNCIL ON INDEP. LIVING, ACTION (2004), *at* http://www.ncil.org/Action/index.html (last visited Mar. 3, 2005).

153. Individuals with Disabilities Education Improvement Act of 2004, Pub. L. No. 108-446, 118 Stat. 2647 (codified as amended at 20 U.S.C.A §§ 1400-1412 (2004)).

154. *IDEA Works To Align with NCLB Rule; Paraprofessionals Must Follow Suit*, SPECIAL EDUCATOR (Dec. 10, 2004), *available at* Lexis> Educ. L. > Legal News> Sch. L. Newsletters. For

continued accountability by states in implementing the IDEA.[155] Although President Bush's "No Child Left Behind" initiative includes children with disabilities, in 2004, a *New York Times* article contended that school achievement reports often exclude the successes, failures and needs of students with disabilities.[156]

And so, despite progress and bipartisan leadership, we strive to eliminate the gulf that separates those living in poverty, sequestered in nursing homes, laboring below minimum wage in sheltered workshops, facing a digital divide, lacking adequate health insurance and accessible transportation, and segregated in "special" classes. In a 2000 address, Dick Thornburgh commented: "[T]he fulfillment of the dream of acceptance, understanding, and inclusion of people with disabilities may rest less in passing civil rights legislation and regulations than in winning the hearts and minds of the general public that to include people with disabilities is the right and proper thing to do."[157]

Past, present, and future, how we embrace these issues will profoundly shape the lives of the next generation of children with disabilities. Unlike any generation before them, our children will not know a world without the ADA or the Individuals with Disabilities Education Act, with their vision for equality, economic independence, and self-determination. Our children will expect no less.[158] Dick, Ginny, and Peter Thornburgh will tolerate no less.

From Lincoln's immortal address, spoken in a Pennsylvania town not far from here, we know the task ahead:

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discussion of the changes to the IDEA, see PETE WRIGHT, INDIVIDUALS WITH DISABILITIES EDUCATION ACT OF 2004: CHANGES IN KEY STATUTES, *at* http://www.wrightslaw.com/law/idea/index.htm (last visited Mar. 3, 2005). *See generally* PETER BLANCK ET AL., CASEBOOK ON DISABILITY CIVIL RIGHTS LAW AND POLICY (forthcoming 2005) (discussing IDEA and related caselaw).

155. Press Release, National Council on Disability, National Council on Disability Calls for Accountability, Achievement, and Fidelity for Students with Disabilities as IDEA Reauthorization Looms (NCD #02-351) (Feb. 27, 2002), *at* http://www.ncd.gov/newsroom/news/2002/r02-351.htm (last visited Mar. 3, 2005).

156. Diana Jean Schemo, *School Achievement Reports Often Exclude the Disabled*, N.Y. TIMES, Aug. 30, 2004, at A10.

157. Thornburgh, *supra* note 1, at 988.

158. Similarly, Albert R. Hunt comments:

> Social Security or tax reform and health care are more salient domestic issues for George W. Bush. But if he really means what he says about opportunity and ownership giving everyone 'a bigger stake in the future of the country' there is no better place to start than those millions of Americans who are intellectually and physically disabled.

Albert R. Hunt, *Politics & People: More Attention for Disabilities*, WALL ST. J., Dec. 23, 2004, at A11.

> It is for us the living, . . . , to be dedicated here to the unfinished work . . . to the great task remaining before us . . . that this nation, . . . , shall have a new birth of freedom—and that government of the people, by the people, for the people, shall not perish from the earth.[159]

159. Lincoln, *supra* note 3.