

Technology for Independence: A Community-Based Resource Center

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Despite the prominence of the disability civil rights model—with its values of inclusion and empowerment—the majority of social and policy research conducted to date has not sufficiently included the perspective of persons with disabilities in the research process and as uniquely qualified researchers themselves. This article describes a new project, 'Technology for Independence: A Community-Based Resource Center' (CBRC). Over a five-year period, the CBRC will attempt to enhance community and consumer-directed disability organizations to design, implement, and disseminate research that promotes access to and use of assistive technology (AT). The CBRC will use strategies such as leadership training, participatory action research, technical assistance, web-assisted training, and annual symposia. A primary goal of the CBRC is to increase the capacity of community organizations to conduct research on AT that is scientifically

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rigorous and relevant to disability services, policy, and law. Copyright # 2003 John Wiley & Sons, Ltd.

INTRODUCTION

With the rise of the disability civil rights movement in the last three decades, a wave of research has emerged that focuses on disability as a natural part of life and the necessity for related accommodation in social policies and laws (DeJong, 1979). The new civil rights paradigm has been examined through the lens of a variety of disciplines—disability studies, psychology, sociology, history, economics, computer science, and law—and from interdisciplinary perspectives (Blanck, 2000; Blanck & Schartz, 2001; Hahn, 1985).

The civil rights model replaced a 'medical' conception of disability that had structured research, dissemination of information about disability, and government policy for much of the 20th century (Blanck & Millender, 2000; Hahn, 1985). Focusing on the individual as the locus for intervention, the medical model defined disability as an infirmity that precluded participation in the economy and society. Public policy based on the medical model directed government resources to rehabilitation programs that would enable people with disabilities to 'overcome' their impairments.

The medical model cast 'disabled people' in a subordinate role—in their encounters with doctors, rehabilitation professionals, researchers, and social workers—whose aim was to help them adjust to a society structured around the conveniences of people without disabilities (Blanck & Millender, 2000; DeJong, 1979). Because the medical model never questioned the physical, technological, and social environment in which people with disabilities were to function, it perpetuated their segregation and economic marginalization (Hahn, 1984). The medical model led to governmental policies that viewed support for persons with disabilities as a species of welfare (Blanck & Millender, 2000).

The civil rights model that emerged from the independent living movement views persons with disabilities as a minority group entitled to the same protections instituted through other civil rights movements (Blanck, 1998; Blanck & Millender, 2000; Hahn, 1988). Disability discrimination is a social, and not solely medically justified, concept. This approach was first articulated a generation before the disability rights movement (Fine & Asch, 1988; Meyerson, 1988). However, the emphasis of disability civil rights as a social and cultural construct, and as applied to changing social policy, began with the rise of the independent living movement in the 1970s and prompted the removal of laws and practices that subordinated disabled persons (Abberley, 1987; DeJong, 1979).

In stark contrast to the medical model of disability that stressed welfare and dependency, the civil rights framework proposes that policy foster equality by eliminating the physical, economic, and social barriers that preclude participation of people with disabilities in society (Silverstein, 2000). The framework is reflected in laws such as the Americans with Disabilities Act (ADA), the reauthorization of the Rehabilitation Act, the Individuals with Disabilities Education Act (IDEA), the Technology-Related Assistance for Individuals with Disabilities Act,

and the Ticket to Work and Work Incentives Improvement Act (TWWIIA) (Blanck & Scharzt, 2001). The framework has been applied in research on such areas as labor force participation rates, vocational rehabilitation services, and the provision of health care (Cook & Burke, 2002).

There are strong practical and policy-oriented ties between the disability policy framework, based upon the civil rights model of inclusion and empowerment, and the development and provision of assistive technologies (AT) goods and services. AT is an item, piece of equipment or product, whether acquired commercially off the shelf, modified, or customized, used to improve the functional capabilities of individuals with disabilities (Technology Related Assistance for Individuals with Disabilities Act, P.L. 103 – 218). AT devices include motorized and customized wheelchairs, augmentative communication devices, vehicle modifications, computer equipment, assistive listening devices, home modifications, work-site modifications, and classroom modifications (for a review, see Berven & Blanck, 1999, 2000; Cook & Hussey, 1996; Galvin & Scherer, 1996; Scherer, 1996; Seelman, 1993).

The civil rights model seeks to remove the physical, technological, and attitudinal barriers that hinder the inclusion of persons with disabilities in employment and other social contexts. One goal is to make society accessible to people with disabilities as they affirm their civil rights and pursue educational and employment goals. For millions of person with disabilities, AT plays a fundamental role in support of this goal (Schartt, Scharzt, & Blanck, 2002).

Despite the growing prominence of the disability rights model, in the area of AT (and related ones) the majority of social and policy research conducted to date has not sufficiently included the perspective of persons with disabilities in the research process and as uniquely qualified researchers themselves. Scotch (2002) believes that most researchers do not have impairments and people with disabilities have found it difficult to join the ranks of researchers. Nor has prior research on AT promoted the civil rights model of disability that incorporated collaboration among disability researchers, AT users, and researchers from disciplines such as medicine or technology (Seelman, 2000). Scientifically rigorous and policy relevant research that includes the meaningful participation of persons with disabilities has been lacking.

The National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, has responded to this gap by encouraging the inclusion of people with disabilities in conduct of NIDRR-funded research. Title II of the Rehabilitation Act of 1973, under which NIDRR is authorized, includes the purpose of increasing opportunity for researchers with disabilities. For instance, NIDRR program reviews for Rehabilitation Research and Training Centers (RRTC's) contain performance indicators on the inclusion of persons with disabilities in research. In terms of funding research and development, however, NIDRR is a relatively small federal agency (Seelman, 2000). There is a vast amount of research conducted affecting persons with disabilities that does not include their knowledge of disability in the development, design, and conduct of the research.

This article describes a new project designed to help bridge the gap in research on AT' s inclusion of persons with disabilities. The project, ' 'Technology for Independence: A Community-Based Resource Center' ' (CBRC), is a partnership between the Law, Health Policy and Disability Center at the University of Iowa and the Independent Living Research Utilization at the Baylor College of Medicine.

The project is funded by NIDRR. Over a 5 year period, the CBRC will assist community and consumer-directed disability organizations to design, implement, and disseminate research that promotes access to and use of AT.

The next part of this article examines the disjuncture between researchers and consumers with disabilities interested in AT. The goals of the CBRC to address this gap are then discussed, along with the use of participatory action research (PAR) to engage the disability community and researchers. Lastly, the research and policy implications of the CBRC project are discussed.

RESEARCH AND THE DISABILITY POLICY FRAMEWORK

The lack of significant involvement of people with disabilities in research has created a disjuncture between research and consumers with disabilities interested in AT. Areas of disagreement include the design of AT, environmental access, job training, health care programs, and so on. The disjuncture is lessened for researchers who themselves use AT and live with a disability. Disability scholars have been at the forefront of calling for research that incorporates participation from the disability community (Barnes, 1992; Gill, 2001; Linton, 1998; Oliver, 1992, 1996; Seelman, 1993, 2000; Stone & Priestley, 1996; Zarb, 1992).

The purpose of the CBRC is to expand research on AT for independence and environmental access by enhancing the capacity of community organizations to conduct and evaluate research on AT and related areas. To fulfill this purpose, the CBRC will be providing research method training to individuals with disabilities who work in consumer-directed organizations. This approach is consistent with efforts to facilitate research that is more inclusive of community members (Pfeiffer, 2002; Zarb, 1992). The CBRC's goal is to engage participants with disabilities from community organizations not as 'subjects' of investigation, but instead as participants in the research process. Rather than experiencing research as something that is conducted on the disability community, the CBRC promotes research that is conducted in collaboration with community members.

Part of the CBRC model is to change the relationship of research production by bridging university researchers and disability community-based organizations. The project supports means by which participants may adopt collaborative and participatory techniques, drawing on knowledge from multiple perspectives. These collaborations support a new generation of research and researchers who will formulate questions relevant to individuals with disabilities across a range of environments, including homes, schools, workplaces, and community settings (Blanck, 1998).

The cornerstone of the CBRC model is participatory action research (PAR) (Whyte, 1991). Although there are various conceptualizations of PAR, in general, PAR promotes the collaboration of researcher and community members in the creation of knowledge that advances community action and change. PAR research is frequently conducted at the local level, drawing upon the local knowledge and expertise of community members (Eriksson, 1999). The PAR team research process often is described as similar to Lewin's (1999) 'spiral' of action research represented as interconnected cyclical steps of planning, action, observation,

and reflecting, with each cycle influencing the next one (McTaggart, 1997; Stringer, 1996). In contrast to traditional methods where the researcher acts as expert, in PAR the researcher is a group facilitator and co-investigator with the community (Stringer, 1996).

Participants in the CBRC trainings will be able to more meaningfully participate in the research process through an understanding of research design, assumptions underlying research methods (Schwochau & Blanck, 2000), and the strengths and limitations of approaches such as case studies, sample surveys, archival data set reviews, focus groups, interviewing, and participant observation. Likewise, community members need to evaluate research findings that involve analysis of the assumptions underlying research techniques, not only to put findings in their appropriate context, but also to assess whether the research models themselves are appropriate bases for public policy regarding individuals with disabilities (Blanck & Schartz, 2001).

The NIDRR Long Range Plan on Capacity Building for Rehabilitation Research (Section 3, Chapter 9; 2000) and criticism of the academic 'isolated researcher' by scholars in disability studies in the U.S. and abroad (Abberley, 1992; Drake, 1996; Linton, 1998; Oliver, 1990, 1992, 1996; Parker and Baldwin, 1992; Stone and Priestley, 1996; Zarb, 1992) contributed to the CBRC's emphasis on PAR. In contrast to the PAR model, research that examines disability from an isolated medical model views the experience of disability as located in the individual, with little focus on the interaction between the individual and the environment in which the individual experiences disability. As Seelman (1993) explains, traditional research focuses on individuals, and not on 'populations and environmental accessibility. The implication is that the problem is located with the individual not with the society,' (p. 120).

PAR therefore views research as embedded in a social context (Oliver, 1992). Too often in the past, research has created and perpetuated an unequal relationship in which 'the interviewer presents as expert and the disabled person as an isolated individual inexperienced in research' (Oliver, 1990, p. 8). Often in the past, national surveys have examined disability as functional limitations, not as a relationship determined by the individual *and* environmental supports or barriers (Oliver, 1992; Schwochau & Blanck, 2000).

In research on AT, the medical model which views the individual as the locus of impairment largely ignores the relation among environmental factors, such as the importance of accessible transportation, housing, and differing AT (Berven & Blanck, 1998, 1999, 2000). As discussed by stakeholders of AT and other researchers (Seelman, 1993, 1998), policy analysis must include as an essential element the person-in-environment perspective. Government policy and classification of "disability" within social programs affect consumer access to and training in AT (Seelman, 1998).

Whyte (1995) understood that PAR engages community members in all stages of the research process—including formulating the questions, designing the research, participating in data collection, interpreting the results, and use of the product. By emphasizing active participation, PAR promotes collaborative inquiry, empowerment of community partners through mutual decision-making, and ownership of ideas (Stone & Priestley, 1996; Chataway, 1997). PAR views people as responsible 'agents who participate actively in making their own histories and conditions of life' (McTaggart, 1997, p. 39). In research on disability, the values of inclusion and

empowerment advanced by PAR align with the self-determination principles of the independent living movement.

As discussed in The Loka Institute report entitled *Community-based research in the United States* (Sclove, Scammell, & Holland, 1998) as well as the NIDRR conference report on PAR (Tewey, 1997), researchers have partial knowledge of community-based research and lack methods for documenting and evaluating its impact. PAR provides a forum for dialogue between community members and researchers.

Other communities have used PAR to address their experiences of inequity and exploitative relationships in society. PAR has been advanced in feminist research methodology to address women's oppression (Cancian, 1992; Gorelick, 1991; Maguire, 1987, 1993; Mahlstedt, 1999; Reinhartz, 1992), in work environments to gain knowledge regarding organizational behavior (Blanck & Turner, 1987; Lewin, 1999; Whyte, 1991), in North American community development (Puckett & Harkavy, 1999; Horton, 1993; Jackson, 1993), and in international social development (Anyawu, 1988; McTaggart, 1997; Greenwood, 1999; for a review of the historical use of PAR in North America, see Puckett & Harkavy, 1999).

Bruyère's (1993) Delphi survey of NIDRR Research and Rehabilitation Training Centers found that few researchers employed PAR. Seven years later, the analysis of the NIDRR sponsored research publications by Campbell and Seekins (2000) found over 500 articles and reports that used one dimension of PAR. Our informal review of disability research incorporating PAR indicates its usage in research involving individuals living with mental disability (Morrell-Bellai & Boydell, 1994; Mason & Boutilier, 1996; Rapp, Shera, & Kisthardt, 1993), with chronic illness (Low, Shelley, & O'Connor, 2000), members of the deaf and hard of hearing community (Taylor, 1999), individuals with learning difficulties (Rodgers, 1999), and physical accessibility issues (Brydon-Miller, 1993).

Many of the studies in the PAR research literature examine the power dynamics between community members and researchers (Mason & Boutilier, 1996; Gaventa, 1993; Stone & Priestley, 1996; Zarb, 1992), training persons with disabilities to collect the research data (Morrell-Bellai & Boydell, 1994), methodological concerns (Chataway, 1997; Kondrat & Julia, 1997; McTaggart, 1997), and conflict resolution during the research process (Simonson & Bushaw, 1993).

In the absence of meaningful contributions by individuals with disabilities to the research process, findings have little relevance to daily life. When relevant, research may be directed toward the development of ideas that may be used by advocates to improve the lives of individuals with disabilities.

CBRC DESIGN AND OUTCOMES

The CBRC will solicit the participation of researchers, many with disabilities, who are interested in extending knowledge of research methods to the disability community. Researchers will team with disability community organizations to create knowledge rooted in scientific methods and relevant to the daily experiences of individuals with disabilities.

One of the project's central goals is to enhance knowledge about AT development, use, and potential. A related goal is to further knowledge for individuals and community members to develop informed action on real-world problems facing the

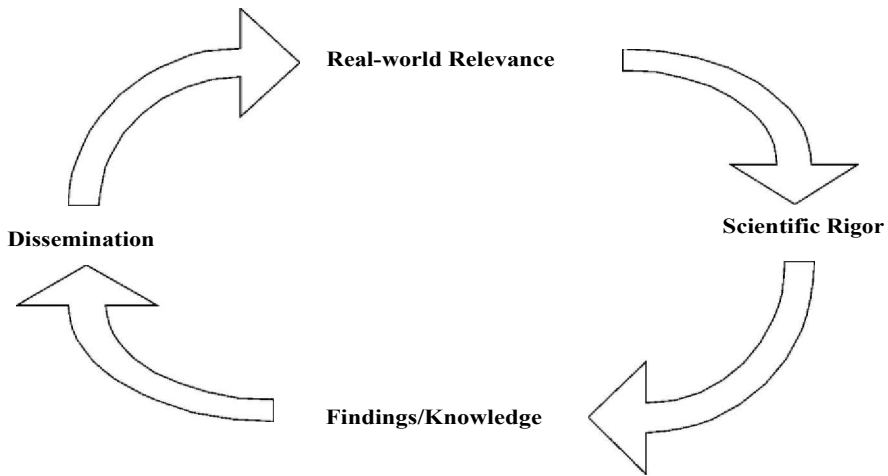


Figure 1. CBRC collaborative research process.

community (Kondrat & Julia, 1997; McTaggart, 1997; Stone & Priestley, 1996). The CBRC will provide technical assistance to these research teams and contribute to the empowerment of the disability community to conduct research as a means to help eliminate environmental and attitudinal barriers to independent living.

CBRC outcomes will be measured, in part, by the ability to enhance the PAR framework for consumer organizations, and by partnerships established between researchers and disability organizations on approaches to AT for independence that incorporate the social model of disability. The collaborative process is summarized in Figure 1.

The collaborative process includes assessment, training and technical assistance to three NIDRR community-based research projects. The NIDRR research projects include (i) 'Community Research for AT' at the California Foundation for Independent Living Centers (CFILC) in partnership with California State University; (ii) 'AT in the Community' at the Washington University School of Medicine Program in Occupational Therapy in collaboration with Paraquad, the St. Louis-based Center for Independent Living; and (iii) 'Information Technology for Independence: Community-Based Research' at the University of Pittsburgh in collaboration with Three Rivers Center for Independent Living, the Community College of Allegheny County Institute of Advanced Technology, the American Foundation for the Blind, and the National Federation of the Blind.

The CBRC collaborative process also pairs disability community members from Centers for Independent Living (CILs) and other consumer-directed disability organizations with university research centers for training and technical assistance. The activities culminate each year in a summer symposium. Over the period of the CBRC grant, new sets of teams will receive training that builds on the previous year's activities. The trainings will be archived on the Web and available to the public.

In addition, the CBRC will maintain a web-based system of information from persons with disabilities on issues related to their use of AT and environmental access. The CBRC will gather and disseminate information on the barriers faced by

under-represented groups with disabilities in society— older adults, minorities, children, and individuals with chronic and episodic conditions (Seelman, 1993). Lack of information about available options, lack of resources for technology and environmental access, and need for devices, equipment, and adaptations which have yet to be developed for use by people with disabilities also will be included. The CBRC will examine the relevancy (and validity) of research questions developed by non-disabled researchers who lack knowledge of the barriers faced by individuals with disabilities, and the inequities in the relationship between the researcher and subject of study (Stone & Priestley, 1996).

Multiple methods will be used to obtain data on AT, including focus groups, surveys—mailed written surveys and Internet-based surveys— and questionnaires. One emphasis will be on developing a database of categories of current or potential technology users who have disabilities. The users will be those with unique technology needs, such as people with sensory impairments, people who are living in rural areas, minorities with disabilities, people who are elderly, those employed in a variety of large and small settings, those with low incomes, people with cognitive impairments, and individuals seeking recreation and leisure-time activities.

The source of respondents for the focus groups, surveys, and questionnaires will be derived from the network of independent living centers and consumer organizations. As a means of assuring that sufficient numbers of respondents in the target disability groups participate in these activities, the CBRC will partner with independent living centers, statewide independent living councils, disability organizations, and vocational rehabilitation programs cf. Ritchie & Blanck, 2003. These organizations will be commissioned to recruit participants and to oversee the administration and collection of information.

The information obtained will be disseminated to CBRC partners for comment, validation, and generation of other research needs and questions. After the review process is complete, the CBRC will establish a resource web site on AT needs and usage. The findings also will spur discussion forums, such as 'technology and people with sensory impairments,' 'technology for leisure pursuits,' 'technology in rural areas,' and 'technology for seniors.' Through these forums, other information on the AT needs of people with disabilities will be gathered.

NEW GENERATION OF CONSUMERS OF RESEARCH

The CBRC's team approach will offer nationwide training to the NIDRR Community-Based Disability and Rehabilitation Research Projects on Technology for Independence and other research teams. The additional teams will be selected on the diversity of the research and the likelihood of collaboration beyond involvement with the CBRC.

The NIDRR-funded community research centers will select one team to participate in the training, in addition to participating themselves. The CBRC will select the remaining teams in collaboration with the community research projects in a competitive process designed to elicit relevant research questions and projects. The teams will receive annual training, beginning with the audio-conferences and distance learning, and culminating in on-site symposia, where they will pursue methods training on their research projects.

The CBRC also will conduct a 'state of the science' conference in collaboration with the NIDRR community research centers on Technology for Independence. Topics and speakers will be chosen in partnership with community organizations that have participated in the CBRC. The goal is to build research capacity among the NIDRR research projects, disability organizations, university researchers, and people with disabilities.

The information derived from the CBRC will be archived for use by successive research teams, community organizations, and the public. The CBRC materials then may be applied to new developments in AT such as the application of AT device warranty laws and telecommunications equipment distribution programs.

Lastly, the CBRC will examine the complex parameters of research ethics in PAR, including the protection of human subjects in nontraditional research. In the CBRC and PAR, for instance, the community-based researchers serve multiple roles— as providers of services and as research partners. Therefore, one ethical issue is defining clearly the roles of the researchers and participants.

CONCLUSION

This article has described a new project, 'Technology for Independence: A Community-Based Resource Center.' Over a 5 year period, the CBRC is to increase the capacity of community and consumer-directed disability organizations to design, implement, and disseminate research that promotes access to and use of AT for independence. The CBRC will use a combination of strategies to enhance the ability of community organizations to conduct research that is scientifically rigorous and relevant to social policy. If successful, the CBRC will help to prepare a next generation of researchers with disabilities, many of whom will work in community settings using PAR to study AT for independence.

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