

Advocacy Issues and Strategies for the 21st Century: Key Disability Rights Informants

Background: Learning from the experiences of other minority groups, disability rights advocates and researchers think the inaccessibility of society stems from prejudice against disability deeply rooted in cultural attitudes and embodied in inaccessible physical environments. People with disabilities can divest themselves of the stigma that has been traditionally associated with their status and redefine themselves as a minority group more in need of civil rights protection, accessible environments, and workplace accommodations than of mere public understanding.



Research questions:

1. What do selected leaders in the disability community think are the top five issues that must be addressed during the next ten years for people with disabilities to participate fully in their communities?
2. What do selected leaders from communities that are traditionally under-represented among disability leadership perceive to be the top five issues? Are there commonalities and differences between their perceptions?
3. What topics for research and advocacy do they perceive are necessary to advance their agenda for the broader disability community and for their specific constituency?

Purpose and anticipated benefits: This project strove to insure that diverse voices were included in the national disability research and advocacy agenda that identified the top five issues that must be addressed during the next 10 years for people with disabilities to participate fully in their communities. With this information, identified research needs can advance this agenda and recommend alliances necessary to help achieve this outcome.

Who: Bonnie O'Day, Ph.D., and Marcie Goldstein, M.A., conducted key informant interviews with 16 disability advocacy and research leaders; half were visible leaders in shaping national disability policy during and after passage of the Americans With Disabilities Act; half were state and local leaders representing constituencies who had not had a visible presence at the national level.

When: 2000-2002

Method: Besides attending the two discovery conferences, researchers conducted a literature review of documents contributing to a disability research and advocacy

agenda: The Long Range Plan for Fiscal Years 1999-2003 (National Institute on Disability and Rehabilitation Research); The New Paradigm on Disability: Research Issues and Approaches (National Institute on Disability and Rehabilitation Research); and Closing the Gap: A Ten Point Strategy for the Next Decade of Disability Civil Rights Enforcement (National Council on Disability). Researchers developed an interview instrument that included six open-ended questions and several probes, including a discussion of their top five research and advocacy priorities for the next ten years and how they thought research could advance the disability advocacy agenda. Before the 30-minute phone interviews, the 16 participants were sent a copy of the interview instrument and summaries of the NIDRR and NCD documents described above. The taped interviews were professionally transcribed. Responses were sorted into six domains: key issues, issues for specific constituencies, research needed to advance these issues, advocacy activities needed to advance these issues, collaboration between researchers and advocates, and other comments. Responses were further sorted into content areas within each domain, such as health care, assistive technology, etc. Then responses were sorted a third time to develop common themes and to identify overarching issues.

Results: Two overarching themes emerged: the impact of poverty among people with disabilities and the connections among various advocacy issues. Participants tended to look at disability issues through the lens of the low-income status of people with disabilities and the advocacy issues as related rather than discrete. For example, they would identify the issue of unemployment as key, and then talk about how important health care, education, housing, and technology are to reaching full employment.

When asked to identify the top five disability issues, interviewees agreed the top five issues were: health care, employment, technology, long-term care, and civil rights enforcement. They thought that research could be a valuable tool in promoting disability rights and that advocates with disabilities should be more involved in establishing research agendas. As 13 of the 16 participants thought they represented a particular constituency, researchers asked these individuals what they perceived as the top five issues for their particular group. Several mentioned the five issues above, citing applications to their particular communities.

Additionally, three additional common themes arose: participation in the broader disability movement, problems with service systems, and cultural issues. When asked what disability research was needed to promote the common disability agenda and the agenda for a particular constituency, three common themes emerged: research on the efficacy of services and legislation, integrating disability issues into the broader research agenda, and quantifying the characteristics of the disability population.

When asked what advocacy strategies should be used to promote their disability agenda, participants said that the current strategies had worked relatively well and should be continued: community organizing, litigation, public education, and public demonstrations. Two additional strategies were recommended: building a stronger, more inclusive disability rights movement and becoming more involved in the political process. All participants said that research could advance the disability advocacy

agenda. They stressed the need for increased communication and information exchange between researchers and advocates.

Project output:

- O'Day, B.L. & Goldstein, M. (2005, Spring). Advocacy issues and strategies for the 21st century: Key informant interviews. *Journal of Disability Policy Studies*, 15(4).
- O'Day, B., & Goldstein, M. (2003). *Advocacy and research for the 21st century: Interviews with key disability rights informants*. Lawrence, KS: Research and Training Center on Independent Living, University of Kansas.