

FOCUS

What Consumers and Researchers Say About Research

The National Center for the Dissemination of Disability Research (NCDDR) and the Research Utilization Support and Help (RUSH) project at the Southwest Educational Development Laboratory conducted two studies in 2005 with different audiences in order to learn more about their perceptions of research and how best to get information to diverse groups of end users.

The first study involved directed interviews with expert researchers. The second study used a modified focus group technique with consumers in three geographic locations. These studies attempted to gather new information about research needs and practices directly from target audiences in order to help guide program activities. This issue of *Focus* shares the findings from the two studies and suggests potential implications.

Directed Interviews

From March to September 2005, the NCDDR conducted directed telephone interviews with four researchers from three projects that focus on issues of diversity and are funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The purpose of the interviews was to ask these experts to identify

- potential barriers to effective outreach to diverse audiences, and
- strategies to overcome barriers and achieve effective outreach.

Potential Barriers to Effective Outreach

The expert researchers identified a number of barriers that may hinder outreach to target audiences from diverse backgrounds, including format, technology, and research issues.

Format barriers. The experts agreed that the manner in which information is packaged and presented may pose a significant barrier. Research results written in a scientific manner often use words that may be difficult for the layperson to understand. Similarly, each of the

experts mentioned that providing information only in English presents another barrier to some consumers.

Technology barriers. The experts identified the Internet as an amazing tool that facilitates reaching a diverse and large group of people; however, they cautioned that it should not be the sole strategy for disseminating a message. While many people have access to a computer, economically disadvantaged individuals and people with disabilities are less likely to have such access.

Research barriers. Each of the experts mentioned the underrepresentation of individuals from minority backgrounds among those who are conducting research. The experts also cautioned against trying to generalize research results to a group or target system that was not part of the study sample. One expert said, "Do you have people [within your study] from the target group to which you are trying to disseminate? If not, then you could be selling something that doesn't fit their needs."

Effective Strategies to Reach Diverse Audiences

The experts identified a number of ways to reach people with disabilities from diverse settings. Suggestions included using the population's language and existing community resources; directly involving community members in research studies; and increasing the visibility of diversity in research.

Get involved in the community. The experts agreed that building trust through community involvement is key. One suggested there is a need for researchers to volunteer in the community. All agreed that hiring a diverse staff to help conduct research is important.

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Staff should include representatives from the community whenever possible. One expert said, "Every time we do surveys in the community, we hire students that are from that background or hire people in the community themselves; that way we lend the agency credibility."

Meet the needs of the target system. Learning about the target population's culture, environment, and needs is critical for conducting effective outreach. One of the experts suggested creating consumer-friendly versions of research results. Such plain-language summaries, in both English and native languages, could enhance understanding.

Use community-based outlets. All the experts interviewed agreed that one can reach a large segment of a target group by utilizing community-based media outlets, including television, radio, and print. In addition, the experts suggested reaching out to the places where people gather within the community, such as houses of worship, schools, and recreation centers.

Build on past research. The experts emphasized that it is important to continue to build on completed successful research, such as previous work that had a positive effect on the target system you wish to reach.

Reach other researchers. One important audience mentioned by the experts was other researchers. One expert said, "The whole notion of getting issues of diversity into the mindset of researchers means we have to do more to publicize the research that is ongoing with respect to diversity. We need to make sure it gets published in many different journals that professionals read." According to the experts, most researchers were not taught to be sensitive to diversity while they were pursuing their degrees. One commented that "diversity has to be integrated throughout the curriculum in the training programs in this country. If they did that, they would have to integrate diversity into research."

Focus Groups

From February to June 2005, the RUSH project conducted a study utilizing a modified focus group design in which a group of individuals representing a variety of perspectives responds to a set of questions on a specific topic. The interaction among the members of the group adds to the information gained from the individual responses (Kreuger & Casey, 2000).¹

Focus groups were conducted with consumers at Centers for Independent Living: two in Washington, DC; two in Austin, Texas; and one in Chicago. In

addition, one focus group with a group of students with disabilities was held on campus at Northwestern University in Chicago. A total of 51 consumers participated, representing diverse age, disability, ethnicity, gender, and educational backgrounds. The objectives of the study were to

- assess how people with disabilities value disability research as something important to their lives;
- assess the extent to which people with disabilities seek out and use outside information to make decisions in their lives;
- establish how people with disabilities access information;
- identify barriers to obtaining information experienced by people with disabilities;
- determine how people with disabilities would improve upon the ways in which disability research is made available/targeted to them;
- assess what new types of disability research information not currently under investigation would be most helpful to people with disabilities; and
- assess how disability research could better meet the needs of people with disabilities.

Value and Use of Research

The majority of the participants across all six focus groups shared a general perception that disability research is certainly necessary and that more should be funded. However, few participants could identify the findings of any recent disability research. The trend among participants' comments was that the most useful information for people with disabilities is practical research that can be applied to their daily lives in terms of gaining employment, accessing public transportation, and dealing with other everyday issues.

Locating research results. The majority of participants said they rely on information "trickling down" to meet their needs. One participant stated that he felt research was a benefit to him indirectly in the form of products such as assistive/adaptive technology devices. He also felt that research findings were not getting to physicians as much as they should. He said, "If the doctors don't know where to find the research . . . how will I be able to find it?"

Reaching specific target systems. The majority of focus group participants said they want more research information about their specific disability but have difficulty finding such information. One participant said there is an abundance of disability

¹ Kreuger, R.A., & Casey, M.A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.

research being pursued but not enough research specific to cognitive disabilities.

Barriers to Accessing Information

Focus group participants identified a number of barriers to their ability to access research information and ultimately benefit from that information.

Internet access. The Internet was a very popular tool among most participants, who indicated that they obtained information from the Internet to find a job, locate public transportation, shop, learn about useful products, and communicate with friends. Fewer than half of the participants actually owned a computer, and even fewer had Internet access at home. Cost was a prohibitive factor for some. Others indicated that there were places where they could get online (at work, independent living centers, public libraries, schools, or friends' and relatives' homes). Internet accessibility issues were also identified as a barrier by participants with a variety of disabilities.

Language and cultural differences. Two participants noted that English was not their first language, and both indicated a very strong preference to receive information in their native language. Participants also voiced a need for more information about various social and cultural aspects of living with a disability. Many described research focused on "curing" them as a barrier and said they would rather see research on improving the quality of life for a person with a disability.

Lack of trust. Several participants discussed feelings of ambivalence or skepticism toward researchers, their motives, and the work produced. The consensus was that people with disabilities need to look out for themselves and question research findings before accepting them as facts to use in their lives. One consumer said, "Everybody has a hidden agenda. Who funded the project? What was the purpose? What are they looking for? What are they getting out of it? You've got to look at all of those things to even decide."

Marketing concerns. Participants indicated that researchers should try to reach consumers with disabilities more deliberately to inform them of advances from which they might benefit. Two students pointed out that researchers should think about why consumers would want this information, not simply why researchers want consumers to have it.

Media concerns. The majority of focus group participants identified the portrayal of and reporting about people with disabilities in the mainstream media as very limiting, thereby complicating access to useful information on disabilities.

Social concerns. A large number of participants identified common social attitudes that view people with disabilities as "whiny," professionally incompetent, or otherwise incapable of leading their own lives as barriers that not only shaped their social interactions but also impeded their access to helpful disability information.

Consumers' Information and Research Needs

Consumer participants indicated that they would like to see more real world research-based information that focused on everyday life needs such as employment, transportation, and housing. Some voiced interest in seeing more research on various social and cultural aspects of living with a disability. One student said she could benefit from research findings related to women's issues and disability, while others spoke in broader terms, such as desiring "research on all of the social and cultural factors that create the exclusion of different people in society."

More useful products. Participants offered ideas on products they would like to see developed or marketed to a greater degree, such as laser canes and hats that could sense upcoming obstacles for people who are blind, new and innovative audio equipment, and different kinds of chairs or scooters for people with mobility impairments.

Make it simple. Participants spoke of the need to simplify the manner in which disability research is presented. One stated that a simpler vocabulary would be easier for non-researchers to understand, and several participants stated that they would prefer to receive research information "in plain English." A frequent comment from many participants was that a clearinghouse is needed through which people with disabilities could access services and other information they might use in their everyday lives.

Varied formats. Participants also noted the need for researchers to produce helpful information in more diverse and user-friendly formats to respond to the needs of individuals with various disabilities.

More researchers with a disability. Students and consumers both suggested that disability research of all kinds could benefit greatly by including more people with disabilities as researchers.

More public education. Many of the participants directly addressed the perception that educating the general public about disabilities could help eliminate social barriers and prejudices that currently constitute significant obstacles to receiving useful research-based information. One consumer stated, "I think disability-related issues are human issues . . . everybody should know this stuff and not just one particular group."

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Implications

The findings from the NCDDR and RUSH studies provide some insight into the perceptions of researchers and consumers on the current state of disability research, its usefulness to consumers with disabilities (including those from diverse backgrounds), and the need for effective strategies to improve the dissemination and utilization of research results. Although the two studies involved different audiences and the focus was not the same, a number of similar issues were raised in the responses obtained.

Research experts and consumers identified similar barriers to access to research-based information by consumers. These include the following:

- Complex, jargon-filled language makes information difficult to understand and apply.
- English-only presentation limits usability for some consumers.
- There is limited access to computers for many consumers.
- A lack of trust exists between researchers and consumers.
- Research and results often are not targeted to meet consumers' needs.
- There is limited understanding of cultural differences and needs.

Other similarities were found when consumers identified research-based information needs and the experts named strategies to improve outreach to diverse audiences.

These strategies include the following:

- Engage consumers in research planning to determine what research is most needed to enhance the quality of their daily lives and to make research more generalizable.
- Use familiar community resources to help build understanding and trust between consumers and researchers.
- Present and package research-based information in a variety of alternate formats to meet the needs of targeted users.
- Develop user-friendly formats that use plain language to describe research-based information.
- Translate plain language research-based information into other languages.
- Ensure that computer-based materials are accessible, culturally sensitive, and available in other formats.
- Recruit and train more researchers with disabilities and from minority backgrounds.
- Raise awareness and understanding of differences based on cultural diversity, including a culture of disability.

The NCDDR and the RUSH project will use the information obtained directly from experts and consumers in planning for future activities and technical assistance. The goal is to help NIDRR-funded researchers respond to the need for research-based information that will enhance the quality of life for diverse consumers with disabilities.

Available online: <http://www.ncddr.org/kt/products/focus/focus12/>



The NCDDR assists, through information and technical assistance, NIDRR grantees with identifying and crafting dissemination strategies. These strategies are designed to meet the needs of a grantee's unique target audience. NCDDR also analyzes and reports on dissemination trends relevant to disability research.



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