Recruiting People With Disabilities as Research Participants: Challenges and Strategies to Address Them

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As service professionals strive to become more focused on the needs and aspirations of people with disabilities, soliciting information directly from individuals about their perceptions of their lives has become increasingly important (Freedman, 2001; Rapley, 2003; Schalock, 1994; Sigelman, Budd, Spanhel, & Schoenrock, 1981; Sigelman et al., 1980). People with disabilities are taking a larger and more primary role in the planning, evaluation, and delivery of services. Consequently, the nature of research efforts has been evolving from one in which investigators treat people with disabilities as subjects to one that includes these “subjects” in the design and implementation of the research. Conducting such studies requires careful planning on the part of researchers. In this paper we reflect on the challenges of surveying people with disabilities and discuss possible strategies to address these challenges.

Our experience is based upon a face-to-face interview study of adults with disabilities conducted over a 2-year period in two cities within a large southwestern state. Project Asking Consumers to Indicate Their Own Needs and Strengths (ACTIONS) was designed to enable researchers to gather information about the perceptions of people with a wide range of disabling conditions about their life. The state’s Council on Developmental Disabilities, which funded the study, planned to use this information in their planning process.

Project ACTIONS’ advisory group decided that those individuals we recruited should have the capacity to consent to participation, operationally defined as individuals who did not have a legal guardian. The recruitment plan included surveying individuals with a range of disabling conditions, including physical/mobility impairments, whether congenital or the result of trauma; developmental disabilities, including cognitive impairments (in the mild to moderate range); and other disabling conditions. Both males and females were recruited into this multi-ethnic sample.

Institutional Review Board Requirements

In 1978, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued The Belmont Report, in which three ethical principles guiding the protection of human subjects in research were delineated (National Commission, 1978). These principles include respect for the individual’s autonomy, beneficence (i.e., a positive balance between risks and benefits of research), and justice (i.e., equitable recruitment techniques and fair treatment of research subjects). The more vulnerable the population, the more rigorous the procedures must be to ensure that participation is informed and truly voluntary. As Freedman (2001) stated, informed consent incorporates three key elements: capacity, information, and voluntariness. Although persons with cognitive limitations should not be presumed to be incompetent to make this decision based solely on their diagnosis, great care must be taken to ensure that potential participants not only understand the facts of the research situation, but also appreciate how the study applies to them in the context of their life.

To protect the privacy of those receiving services, the local Institutional Review Board prohibited the Project ACTIONS researchers from directly contacting individuals with disabilities until they had indicated interest in participating in this research. Instead, the Board approved publicizing the study through flyers or information packets to service providers and disability groups. Providers and other key stakeholders were asked to explain the project to people who had disabilities with whom they had contact and to encourage them to return the flyers if they were interested in participating. Unfortunately, individuals had to read the flyer or have someone available to read the flyer to them. They also had to comprehend and be able to indicate interest by calling the toll-free study num-
Unfamiliarity With and Distrust of the Research Process

People’s motivation to participate in a research project is influenced by their personal beliefs and past experiences (Verheggan, Jonkers, & Kok, 1996). Some, especially those with significant disabilities, may be unfamiliar with the process because they have had limited opportunities in the past to make choices about participating in research. In other cases the research purpose may seem irrelevant to peoples’ needs, or they may have participated in previous studies where they provided information but never saw the information used.

When Project ACTIONS interviewers attempted to schedule appointments with those who had already agreed to be interviewed, they occasionally encountered resistance from family members or staff. We attempted to clarify that the study was being conducted by a center for disabilities studies in conjunction with a nonprofit research organization, both of which were independent of the service delivery system and that all information would be kept confidential. Some individuals and family members, however, may have been concerned that their responses might jeopardize the services they were receiving. In fact, an interviewer reported that when she contacted one individual to set up the interview, the woman wanted to call her physician first because she was afraid she would lose her insurance benefits.

Some staff members also were concerned about this research. The confidentiality of the process was questioned, particularly how individuals with disabilities had been located. Researchers in clinical studies have reported that providers are apprehensive that information uncovered in such studies could be used to judge the quality of their care (Ellis et al., 2001), and some staff members contacted by Project ACTIONS investigators may have had similar concerns. In fact, a number of people preferred to be interviewed at their work site, rather than their home, in some cases to avoid interference from family or residential staff.

We also encountered groups or individuals who did not consider themselves as having disabilities, although they did have a clearly identifiable impairment. Watson (2002) found that many of his informants did not identify themselves as persons with disabilities. He suggested various reasons for this, including the rejection of physicality as a determinant of the self and a desire to avoid the marginalizing that may accompany being labeled “disabled.” Many people with disabilities see their disability as so much a part of their being that they do not consider impairment as an identifier. Researchers need to be sensitive to these issues in the recruitment process and respect individual’s privacy rights concerning their disability status.

People with disabilities from minority com-
Recruiting Through Gatekeepers

In many situations researchers will not be able to reach people with disabilities without working through “gatekeepers” who have access to the target population. Because we could not be given lists of individuals with disabilities to approach directly, we had to publicize the study through programs that provided services to such individuals or groups that advocated for them (although we did also distribute some fliers in housing complexes). Administrators were contacted and asked to assist in reaching individuals with disabilities, and they often indicated that they would be willing to cooperate with the study researchers. Many times, however, they delegated responsibility to already overburdened staff members, who frequently had no time, interest, or incentive to assist with recruitment. In addition, some staff members indicated that such studies were not helpful to their program; consequently, they were reluctant to become involved. If they did assist, they often did so to allow individuals with disabilities the opportunity to tell us their story and to earn the monetary compensation we were providing interviewees.

Implications of Recruitment Strategies

Researchers must recognize the implications of their recruitment strategies for the conclusions that can be drawn from their findings. For example, if we contact only those who are most accessible through the service delivery system, then we are missing many who are outside that system and may have important things to tell us about their service needs. If we recruit only through advocacy groups, we miss the many individuals who are not “plugged in” to those systems. Snowball sampling, which involves asking participants to recruit other individuals they know who might be interested in the study, can reach some individuals. Although this method could identify individuals who might not otherwise be located, it could bias the results because friends and acquaintances may share common experiences and attitudes.

When we survey only those who can communicate verbally, then we are not hearing from those people who use nontraditional methods of communication. Although adaptive devices and human translators can help in this process, it will still be difficult for many, particularly those with severe impairments, to communicate effectively with unfamiliar interviewers. Researchers must think carefully about the trade-offs implied in the choices they make about interviewing people who need others to help them communicate or understand the questions being asked. On the one hand, speaking through others can bias the message the individual with disabilities may want to send, particularly when the “translators” may have their own perspective on the interview topic. On the other hand, not interviewing individuals who use nontraditional communication methods not only biases our findings, because it leaves out an important segment of people with disabilities, but also reinforces their disenfranchised status. Whatever recruitment decisions are made, researchers must clearly identify the implications of these decisions for the generalizability of their findings and, when possible, compare the characteristics of their samples with the characteristics of the populations from which the samples are drawn.

Suggestions for Improving the Recruitment Process

How could the recruitment process be improved? Our experience suggests that there are two key components: building strong collaborative relationships and promoting appreciation (and reinforcements) for research.

Individuals with disabilities are more likely to volunteer if they know and trust explain the study to them and help them “navigate” the enroll-
ment process. Although Project ACTIONS had a project advisory group, which included state-level representatives from agencies that serve people with disabilities as well as self-advocates and researchers, there was limited involvement from local gatekeepers. Unfortunately, parents and individuals with disabilities in the specific study locations may not have known the advisory group members. Building relationships at the local level takes time, but it should be seen as an indispensable part of research. A well-developed recruitment plan, such as the comprehensive process described by Pletsch, et al. (1995), is also essential.

We learned too late that some individuals asked their direct service staff members questions about the study, which the staff member was not able to answer. Therefore, researchers should focus on identifying direct service staff who understand and value the research and can interpret the purpose of the study for people with disabilities, their families, and other staff members. Freedman (2001) proposed that trained neutral educators be used to explain the proposed research to potential participants with cognitive impairments. Such individuals could ensure that the information is presented in clear, concrete, and nonthreatening ways, which may be particularly important when the proposed research methodology could be interpreted as having therapeutic intent.

Interviewers must be well-trained, not only in conducting interviews but also in explaining the overall purpose of the study, so they can answer questions from prospective interviewees as well as their family and even direct service staff members. To that end, it may be helpful to provide a script that interviewers can use to answer questions from interviewees.

The interviewers were responsible for contacting the interviewee and scheduling the interview at a convenient time and location. Although this part of the process generally worked smoothly, interviewers did occasionally show up for interviews and find that the interviewee was not present. Sometimes individuals had unexpected medical appointments, but other times the individuals took advantage of the opportunity to work more hours or occasionally they forgot about the appointment. Interviewers must be compensated at rates that reflect their expertise as well as the time required to make multiple contacts to complete interviews.

Project ACTIONS interviewers felt that the participants enjoyed the interview process because it gave them a chance to tell their story, was a change from their usual routine, but especially because they were paid for the interview. Following guidelines for research with human subjects, the amount of the incentive was not enough to be considered coercive, yet did serve the objective of providing some recognition and compensation for the participant’s time. We learned from the interviewers that this incentive seemed to have great significance; it was unrestricted funds that the individuals could choose to spend as they saw fit.

Beyond adhering to the highest standards of ethical conduct in recruitment, researchers should convey an attitude that shows we see people with disabilities as partners in the research endeavor, not just passive recipients. Part of giving individuals the respect they deserve is offering to pay them for their time. Sharing openly the information we have obtained and inviting their perspectives on the meaning of our findings also demonstrates a spirit of partnership.

Administrators might be more supportive of research if they recognized its potential benefits. For example, a quality of life survey can be an effective training tool that promotes person-centered values to everyone involved in the process, including direct service staff. Most important, such research recognizes people with disabilities for their contribution, provides them an opportunity to express their needs, and gives people who receive services a stronger voice in policy-making decisions.

Researchers must also be willing to listen to administrators and policy makers about the kinds of data that are relevant to their work and then consider incorporating these ideas into their research. Although it may not always be possible to provide direct service staff with monetary incentives for their involvement, researchers, administrators, and policy makers must seek ways to acknowledge and appreciate their efforts to promote research that can benefit the people they serve. For example, researchers may be able to offer best practices training on topics of interest to agency staff in return for their active cooperation in research. In systems with career ladders, staff involvement in research could become a factor in advancement. Researchers must also listen to direct service staff members about the types of incentives that would be meaningful to them because incentives will undoubtedly vary from situation to situation.

All of us in the research community must take responsibility for promoting the value of our research with people who have disabilities and their families. In referring to her research with African American children with speech impairments, Harris...
(1996) pointed out that researchers’ responsibility goes beyond ethical considerations typically covered in institutional review board protocols to social responsibility for eschewing research that perpetuates negative stereotypes of those studied. Researchers need to anticipate potential points of resistance among research participants and deal with them proactively. For example, many individuals from vulnerable groups will be unfamiliar with the informed consent process, so recruitment must be carefully planned to include ample time to explain the project and its procedures. Finally, Harris urged researchers to take as much care in leaving a community when the study is completed as they did when entering it. We should recognize that self-disclosure among those in a vulnerable population enhances what Harris described as the “interpersonal meaningfulness” of the encounter between researchers and those researched. In these situations, researchers should take extra responsibility for debriefing study participants.

References
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