

Conducting Disability Research with People from Diverse Ethnic Groups: Challenges and Opportunities

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This study identified challenges and available supports for conducting research and engaging in outreach and dissemination activities with people with disabilities from diverse ethnic backgrounds. Seventy nine researchers funded by the National Institute of Disability and Rehabilitation Research (NIDRR) participated in the study. The results indicated that most of the respondents (72%) conduct research with people with disabilities from diverse backgrounds and that the most significant challenges for conducting research were finding research protocols, surveys and questionnaires developed or adapted for minorities with disabilities and recruiting research team members who are ethnic minorities or ethnic minorities with disabilities. The findings have implications for practices related to the hiring and training of research team members and for building national networks, where researchers can share their experiences and strategies for outreach and dissemination efforts with populations from diverse ethnic backgrounds.

The most recent U.S. census data show that people from diverse ethnic and racial backgrounds represent about one third of the country's total population (30%). Migration patterns have contributed to increases in the cultural and linguistic diversity of the U.S., including the number of people with disabilities from different ethnic or cultural backgrounds. About 15.3% of all Latinos (who represent 12.55% of the population), 20% of African Americans (representing 12.06% of the population), 9.9% of Asians (representing 3.73% of the population), and 21.9% of Native Americans (representing 0.74% of the population) have disabilities compared to 19.7% for Whites (representing 69.13% of the population) (Fujiura, Yamaki & Czechowicz, 1998; U.S. Bureau of the Census, 2000).

African, Hispanic, Asian and Native American individuals with disabilities have been identified as generally underserved in terms of their overall access to social and public health services (Granados, Puwula, Berman, & Dowling, 2001; Wilson, 2005; Wilson & Senices, 2005). People from these ethnic backgrounds with disabilities typically receive fewer comprehensive services (see Belgrave & Walker, 1991; Zea, Quezada, & Belgrave, 1994) and experience significant obstacles in obtaining the services they need when compared with White consumers. Some of these obstacles include: lack of affordable health services, limited availabili-

ty of bilingual health providers, limited knowledge about resources, and communication and cultural barriers to obtaining meaningful information and support from local agencies (Balcazar, 2001; Balcazar, Keys, & Suárez-Balcazar, 2001; Granados et al., 2001; Lillie-Blanton & Hudman, 2001; National Council on Disability, 1997; Suárez-Balcazar, 1998). As a result of these obstacles, individuals with disabilities from these ethnic groups are less likely to achieve positive independent living and rehabilitation outcomes. For example, research has found that African Americans have lower acceptance rates for vocational rehabilitation services, fewer successful employment closures, and less income than Whites who received similar services (Capella, 2002; Feist-Price, 1995; Herbert & Martinez, 1992; Olney & Kennedy, 2002; Wilson, 2002). The rehabilitation field needs a better understanding of the factors that limit access for people with disabilities from diverse ethnic backgrounds to vocational, health and other social services which in turn may lead to poor independent living and rehabilitation outcomes. The federal government promoted outreach to minorities with disabilities through the Rehabilitation Act of 1973 (P.L. 93-112) and its subsequent amendments; it has also promoted and funded research on issues and strategies that would help people from diverse ethnic groups with disabilities achieve positive outcomes (NIDRR, 2006). Despite these efforts, researchers have difficulty recruiting minorities with disabilities to their studies, but no research in our field has specifically documented why that is the case.

Several scholars in other fields have noted the challenges of conducting research with populations from diverse ethnic backgrounds. For example, Papadopoulus and Lees (2002) pointed out

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the difficulty of responding to the different needs, experiences, values and beliefs of ethnically diverse groups in health research. Porter and Villarruel (1993) argued that a unicultural perspective in research prevails, which assumes that the constructs and explanations of relationships between variables are universally applicable across different cultures. This bias, they propose, curtails researchers' awareness or use of alternative strategies in research, outreach, and dissemination. A similar point was raised by Leininger (1995) who proposed that without cultural awareness, researchers and service providers tend to impose their beliefs, values and patterns of behavior upon cultures other than their own, making it harder to recruit and sustain the participation of people from diverse ethnic groups in research.

Moreover, the rehabilitation field must improve the access and involvement of people from diverse ethnic groups in disability-specific research endeavors. For instance, Balcazar (2001) and Wright and Leung (1993) advocated that outreach, recruitment and dissemination research efforts should be culturally sensitive to the linguistic differences, communication styles, and cultural attributes of various minority groups. Likewise, a 1997 National Council on Disability (NCD) report, and others (e.g., Miyakee, 2002) have discussed the need to develop culturally appropriate information and research about disability issues. According to the NCD report, all individuals, including service providers and researchers who work with people with disabilities need to build their capacity to conduct their work in culturally appropriate ways.

The lack of representation of ethnically diverse people with disabilities in rehabilitation research creates shortcomings in the new knowledge that is produced, our collective understanding of issues that impact minority populations and the programs and policies that might be developed based on research findings (Brach & Fraser, 2000; Goode, Sockalingam, Brown, & Jones, 2000; Vihn-Thomas, Bunch & Card, 2003). Yancey, Ortega and Kumanyika (2006) conducted a review of the participation of minority populations in health-related research. They concluded that although there has been a substantive increase in both quantitative and qualitative scholarly work on the topic of minority recruitment and retention in public health research, there are still few leading investigators from populations with substantive health disparities. Identifying and recruiting minorities with disabilities to participate in research, understanding different cultural belief systems, or communicating with prospective participants to make the research process a comfortable experience can be overwhelming tasks for many researchers. Unfortunately, many investigators may not have bicultural and bilingual staff in their research teams and many may not have access to interpreters. In fact, those few with access to interpreters have often reported challenges related to the quality of interpreter services (Mayeno & Hirota, 1994). Further, many researchers may not have critically examined the ways in which their research practices influence their ability to effectively involve people with disabilities from diverse ethnic backgrounds in their work.

Little information is available about the specific challenges and issues faced by disability researchers working with popula-

tions from diverse ethnic groups. Information of this type could be used to implement strategies that would allow for the increased inclusion of and address the information gap about people with disabilities from different cultural backgrounds. The purpose of this study was to identify the challenges and opportunities experienced by leading NIDRR-funded disability researchers in their efforts to engage ethnic minorities with disabilities in outreach, research, and dissemination activities.

Method

Participants and Procedure

Seventy nine researchers who were identified by NIDRR staff as principal investigators receiving NIDRR grant funding participated in this survey study. We administered the survey to a group of NIDRR researchers (n=23) attending a special conference on minorities with disabilities research. Following the meeting, we sent the survey via the U.S. Postal Service and electronic mail to an additional 115 directors of NIDRR-funded research centers using contact information provided to us by NIDRR. Forty seven researchers responded via the Postal Service and another nine responded via e-mail, for a response rate of 49% for the postal and electronic mail portions of the sample.

Instrument

The authors developed a two-page survey that included a total of 20 Likert-type items, two open-ended questions and two Yes/No questions. We developed the questions based on an extensive literature review about the challenges of conducting research with populations from diverse ethnic backgrounds, as well as our observations and experiences in conducting outreach, research, and dissemination with minority groups. The instrument was not pilot tested. Likert-type items asked respondents to rate the extent of the challenges they experience, and their satisfaction conducting outreach, research, and dissemination activities with minorities with disabilities on a scale from 1 to 5, where 1 was either "not at all" or "very unsatisfied" and 5 was "to a great extent" or "very satisfied". Other questions asked participants to identify their current position and affiliation, the populations with whom they work, whether or not they have researchers from diverse ethnic backgrounds in their teams, whether or not they see a need for cultural competence training of their staff, and the top challenges and support resources they encounter when conducting outreach, research, and dissemination with minorities with disabilities. What follows is a detailed description of the results.

Results

All participants were funded by NIDRR to conduct disability research at the time of data collection. The majority of the survey respondents (66%) directed or coordinated research activities; other respondents identified themselves as professors (14%) and other professionals (5%). Fifteen percent of participants did not respond to this question.

The majority of participants (72%) reported that they conducted research with people from diverse backgrounds with disabilities, including African Americans (54%), Latinos (54%),

Asian Americans (42%), Native Americans (40%) and Pacific Islanders (29%). Moreover, 60% of respondents indicated that they conduct research with more than one ethnic minority group. Almost a fourth of the researchers (22.8%) indicated that they conducted research with all major populations (African Americans, Latinos, Asian Americans, Native Americans, and Pacific Islanders). Other respondents reported conducting research only with African Americans and Latinos (10%), African Americans, Latinos, and Asian Americans (7.6%), or with African Americans, Latinos, Asian Americans, and Pacific Islanders (3.8%). In addition, 54% of respondents had researchers from ethnic minority backgrounds working at their center or program, including African Americans (34%), Latinos (35%), Asian Americans (30%), Native Americans (11%) and Pacific Islanders (4%).

Using cross tabulations, we assessed whether or not there was a match between the ethnic group of at least one staff on the research team and the research participants. Forty one percent of respondents provided ethnic data on both research staff and research participants. At these sites, we found that 80% of research teams had both Latino staff and research participants, 78% had African American staff and participants, 59% had Asian American staff and participants, 20% had Pacific Islander staff and participants, and 17% had Native American staff and participants. Only three respondents reported having a complete match between research staff and participants: African American, Latino, and Asian American staff and participants ($n=2$ research teams) and Latino staff and participants ($n=1$ research team). Of the 18 respondents (22.8%) who indicated working with all five of the ethnic populations mentioned above, seven (38.8%) did not report having any ethnic minority staff. The other teams had incomplete ethnic matches.

The quantitative results related to outreach, research, and dissemination are reported in Table 1. An analysis of the mean responses for each item revealed that all of the responses were between 2.26 and 3.69 ("a little" and "to a considerable extent"). Based on the means, the most significant challenges for researchers (defined herein as a mean of greater than 3.0 "to some extent") in the area of outreach were challenges related to recruiting and motivating people from diverse backgrounds with disabilities to participate in research. In terms of research, the most significant challenges were finding research protocols, surveys and questionnaires developed or adapted for minorities with disabilities and recruiting research team members who are ethnic minorities or ethnic minorities with disabilities. Finally, in terms of dissemination, the most significant challenge was to disseminate findings to ethnically diverse groups with disabilities in a language other than English. We also found that more than 10% of respondents endorsed the highest point on our Likert scale ("very great" challenge) and confirmed that the above-identified challenges were the most significant for these participants, and also revealed an additional challenge in this area of research: finding someone who can translate materials into the preferred language (other than English) of research participants.

Also worthy of note are the areas where NIDRR researchers reported the least significant challenges. Less than three percent of respondents reported challenges related to identifying social and community settings attended by people with disabilities from diverse ethnic groups, including their views when conducting research and outreach, and disseminating materials about their project to the target population.

A within subjects analyses of variance revealed that participants experienced different levels of challenges with outreach, research, and dissemination activities with people from diverse ethnic backgrounds, ($F(2, 98)=4.92, p=.01$). Follow-up paired t-tests showed that participants experienced similar levels of challenge conducting outreach and research activities, $t(51)=-.92, p=.36$. Further, outreach and research activities were both found to be more challenging than conducting dissemination activities, $t(62)=2.24, p=.03$ and $t(52)=3.37, p=.00$, respectively.

Despite the reported challenges of outreach and research, participants reported being between "neutral" and "satisfied" with their outreach to people with disabilities from diverse ethnic backgrounds ($X=3.19, SD=1.09$), with their current efforts to do culturally competent research ($X=3.47, SD=.84$), with their efforts to disseminate information and research findings to diverse populations ($X=3.09, SD=.94$), and with what they could offer to people with disabilities from diverse ethnic groups ($X=3.28, SD=.99$). A within subjects analysis of variance revealed that participants experienced different levels of satisfaction with these aspects of research with minorities with disabilities, $F(2, 142)=5.02, p=.01$. Follow-up paired t-tests showed that participants' satisfaction with their outreach efforts was similar to their satisfaction with their research efforts, $t(73)=-1.94, p=.05$, and their dissemination efforts, $t(73) =.77, p=.44$, and that their satisfaction with their research efforts was higher than their satisfaction with their dissemination efforts, $t(71) =3.56, p=.00$.

In an open-ended question, we asked respondents to report their top three challenges in conducting outreach, research and dissemination with ethnic minorities with disabilities. The most commonly reported challenge was related to accessing research participants, in particular establishing contacts and building trust in ethnically diverse communities. After respondents successfully recruited individuals with disabilities from different ethnic groups to participate in their research, they reported a number of challenges to maintaining their involvement (i.e., motivating them to stay involved and successfully complete follow up contacts), and ensuring that the focus and methods of the research were relevant to them. Respondents also reported challenges related to language barriers, most especially the cost of translating materials into other languages, including Braille; challenges with funding transportation, babysitting, and incentives to participants to facilitate their involvement in research activities; and challenges in identifying and hiring staff who were minorities or minorities with disabilities.

In another open-ended question, we asked respondents to report their top three resources or supports for conducting outreach, research, and dissemination with people with disabilities

from diverse groups. The most commonly mentioned resource was relationships with key community contacts (i.e., leaders within diverse communities including tribal governments and translators) and organizations (i.e., independent living centers, community-based organizations, churches, schools and vocational rehabilitation offices). The second most commonly mentioned resource was research partnerships within and across universities (i.e., students with disabilities from minority backgrounds, ethnic minority center [in-house] staff, their university's office related to minorities, Historically Black Colleges and Universities, local Hispanic colleges and research partners from large urban areas). The third most commonly mentioned resource was Federal government initiatives to increase and improve research with minorities with disabilities, including funding and special meetings and conferences (i.e., NIDRR, the National Institute of Health, the Rehabilitation Services Administration and the National Science Foundation).

Forty percent of NIDRR researchers reported a need for cultural competence training for their staff and themselves. NIDRR researchers explained their responses in these ways: 13% believed that there is always an ongoing need for training related to cultural issues; 10% wanted training to be specifically tailored to their program and address research; and 8% believed that their staff needs training because of a lack of experience with the target community. Only six percent of the respondents reported that they

already provide ongoing cultural competence training to their staff.

Discussion

The results of this study paint a mixed picture of the success of current efforts to involve people with disabilities from diverse cultural backgrounds in outreach, research, and dissemination activities. Our findings suggest that although research is being conducted with minorities with disabilities, a number of challenges hinder their progress. As a result, the desired impact or outcome of the research may not be achieved because of these challenges. The results also indicate that respondents have developed strategies for improving outreach, research, and dissemination activities with people disabilities from diverse ethnic backgrounds. Further, we found that about half of the NIDRR funded programs employed ethnic minority staff, but only a few provided their staff with ongoing training related to cultural competence. However, survey respondents shared that they experienced some challenges, especially related to recruiting and motivating minorities with disabilities to be involved in their research, identifying research protocols and instruments appropriate for use with minorities with disabilities, finding someone to translate materials into languages other than English for research and dissemination purposes, and, most especially, recruiting research team members who are themselves from diverse ethnic backgrounds and have

Table 1

Descriptive Statistics for Survey Items

	N	Frequency*	Mean	SD
Outreach	68	—	2.84	.90
Identify/recruit minorities with disabilities to participate in research	77	10.4%	3.06	1.12
Reach out to community gatekeepers and leaders who might provide entry into minority communities	75	6.7%	2.83	1.14
Identify social and community settings attended by minorities with disabilities	74	2.7%	2.47	1.06
Motivate minorities with disabilities to participate in your research	74	10.8%	3.14	1.04
Research	55	—	3.00	.76
Understand the culture of minorities with disabilities participating in your research	78	2.6%	2.76	.91
Use means and ways of communicating with minorities that are culturally sensitive	75	5.3%	2.69	1.09
Find research protocols, surveys and/or questionnaires developed or adapted for minorities with disabilities	74	25.7%	3.59	1.14
Find someone who can translate materials into the preferred language (other than English) of research participants	73	11.0%	2.73	1.30
Develop culturally appropriate intervention strategies	74	5.4%	2.94	1.07
Use participatory research and intervention strategies to involve minorities in research	73	5.5%	2.68	1.12
Include the views of minorities with disabilities when conducting research and outreach	76	1.3%	2.63	.99
Conduct research that is culturally competent	69	4.3%	2.78	1.08
Recruit research team members who are from minority backgrounds	74	21.6%	3.14	1.34
Recruit research team members who are minorities with disabilities	71	38.0%	3.69	1.33
Dissemination	71	—	2.64	.95
Disseminate materials/information to minorities with disabilities in another language	72	11.1%	3.00	1.21
Disseminate materials about your project	76	2.6%	2.26	1.09

* Frequency of responses of a challenge "to a very great extent."

disabilities. These findings were similar to those reported by Yancey et al. (2006) in their review of 95 health-related research studies published between 1999 and 2005.

Respondents generally indicated that they experienced few challenges identifying social and community settings frequented by minorities with disabilities, and many had developed relationships with people who could facilitate entry into minority communities. According to these data, researchers know where to find minorities with disabilities, but are challenged by convincing and motivating them to participate in research, and maintaining their participation over time. For example, African American participants may challenge researchers due to factors like cultural mistrust (Alston & Bell, 1996) if centers do not have research team members who share or understand aspects of their culture. Researchers often lack resources to accommodate participants' needs for transportation or other costs related to data collection, posing significant challenges to successfully recruiting and retaining minorities with disabilities. Further, across both English and non-English speaking participants, outreach is more successful when researchers can clearly articulate the benefits of participation to minorities with disabilities. These benefits include monetary incentives, access to information about services, resources and disability rights, and could be extended to include opportunities for participants to identify the focus and goals of research projects, such as in participatory action research projects. Such efforts would involve minorities with disabilities in the research process at the very beginning, making their involvement more meaningful (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998).

Many respondents reported that they regularly included the views of minorities with disabilities, understood their culture, communicated with them in culturally sensitive ways and conducted culturally competent research. These findings suggest that although researchers experience challenges with outreach, once they get participants involved in research endeavors, they feel comfortable communicating and working with them in culturally sensitive and appropriate ways. However, these findings are juxtaposed with others (e.g., Gil & Bob, 1999) that show significant research challenges due to language barriers, a lack of appropriate assessment protocols, surveys and questionnaires in languages other than English, a lack of research team members who are bilingual and a lack of knowledgeable translators. Furthermore, these contradictory findings may be due to a difference between researchers' perceptions and participants' views. Future research should examine the views of potential research participants, particularly from culturally diverse backgrounds, with regards to their perceived role in rehabilitation research. The extent to which particular groups of minorities are omitted from research because of their lack of English fluency is not clear. Other studies that document under-representation of various ethnic groups in research (e.g., Hernandez, Horin, Donoso & Saul, 2007; Fenton, Batavia, & Roody, 1993) indicate that it is critical for researchers to develop, translate and empirically validate instruments that are likely to be used with people with disabilities from different ethnic groups in order to meet their needs. In addition, given the dearth of trained researchers from different cultural and linguistic backgrounds, it is also critical that researchers think creatively about

how to identify and employ community members to help in their research activities, including recruitment of paraprofessionals who can be instructed to conduct outreach and training in the target communities (see Balcazar, Meldrum, Murvay, & Garate, 2004).

Our survey assessed the challenges and opportunities NIDRR funded researchers experienced with reaching out to, researching and disseminating findings to minorities with disabilities. This study is a first step in understanding the challenges and opportunities experienced by disability researchers who involve minorities with disabilities in their work. The results are limited due to our data collection method and survey instrument which is vulnerable to selective responses. In particular, two thirds of our sample (the 23 researchers at the special conference on minorities with disabilities) may have higher levels of efficacy related to conducting research with ethnic minority individuals with disabilities because this group included all of the NIDRR projects funded to address the needs of ethnic minority groups. In addition, some of the research participants may have felt compelled to respond in socially desirable ways (Bellini, 2002; Middleton, et al., 2000).

There are several ways future research can build on the findings of the present study. Future research may include in depth interviews to deepen our understanding of researchers' experiences working with people with disabilities from different ethnic groups. Future research should also identify the successes and/or failures of respondents in including people with disabilities from diverse backgrounds in their research, and identify the conditions under which specific strategies work in outreach, research, and dissemination activities. In addition, future research could examine types of initiatives and programs that agencies like NIDRR introduce to increase collaboration, partnerships, and promote successful involvement of people with disabilities from diverse cultural backgrounds in research activities. The degree to which researchers change their research designs and/or target populations because of their inability to recruit sufficient participants from certain minority backgrounds reduces our collective ability to better understand the significant institutional and psycho-social barriers to independent living that many minorities with disabilities face, as well as the specific challenges of involving minorities with disabilities in research.

We now offer several recommendations to address these challenges, based on the data from this study, previous literature reviews (e.g., Balcazar, 2001; the National Council on Disability, 2003), and our experiences working with different communities of minorities with disabilities at the Center for Capacity Building for Minorities with Disabilities Research.

Recommendations for improving outreach, research, and dissemination with people with disabilities from diverse ethnic groups

1. To address a lack of access to diverse researchers and communities, consider building partnerships with universities located in large urban cities or rural areas and/or minority institutions of higher education where

minority researchers and populations are more present. Federal funding agencies encourage researchers to develop proposals that include partnerships among multiple sites. These collaborations should consider the strengths of the various institutions and the resources they contribute to the overall project.

2. Consider forming partnerships and establishing collaborations with organizations serving people with disabilities from diverse ethnic backgrounds. Agencies and their consumers can help identify important issues to be researched and likely have consumers who would be interested in participating in research if they see the project as relevant and beneficial. These include small grassroots organizations in ethnic communities or on Native American reservations. In addition, review existing models of building collaborations (see Suárez-Balcazar, Harper & Lewis, 2005) which provide guidelines on how to establish collaborative partnerships with communities for the purpose of conducting research.
3. Recruit research team members who have disabilities and are from the target community. It may be difficult to identify trained researchers with these characteristics. However, many community members could be trained and effectively participate on research teams. The individuals can help to define community problems worthy of study, recruit participants, collect data, make sense of results and assist in disseminating the research findings in ways that are meaningful to the community. This may also be an effective way to develop bicultural and bilingual research staff.
4. Accommodate potential research participants' needs, including those that are disability-related, as well as those related to language translation, transportation, child care, or unstable living situations. Researchers should maintain personal contact with participants, since this contact is the primary recruitment vehicle for most health-related studies, as well as adapt study methods and procedures to fit the culture of the target population to positively influence participants' retention over time (Yancey et al., 2006).
5. Consider using participatory research methods and sharing power in the researcher-researched relationship by asking participants to define the research focus, goals and methods; to assist with interpreting the findings and to develop actions to address community problems (see Balcazar et al., 1998 and Jason, Keys, Suárez-Balcazar, Taylor, Davis, Durlak & Isenberg, 2004 for models of participatory research).
6. If translation of assessment instruments is necessary, make sure that the translations are checked for equivalence of meaning and measurement, using back-to-back translation methods (Dana, 1996). Also select

tests based on their appropriate cultural orientation and validation for the particular target population of interest (Brislin, 1993).

7. The National Center for Dissemination of Disability Research is working to create a forum where researchers can discuss strategies that work, learn about best practices, and about successful ways to increase the participation of people from diverse cultural backgrounds in researcher efforts. However, researchers' participation has been limited. Researchers should investigate this and other related resources.

Stimulating greater collaboration between multiple research sites (several universities or agencies) has the potential to enhance researchers' capacity to effectively involve minorities with disabilities in research, thus increasing the diversity of our collective research base, the validity and generalizability of our research findings and our understanding of the issues that negatively impact the lives of ethnic minorities with disabilities. If these strategies, including getting help from experts, using best practices, partnering with communities, and increasing consumer involvement, are combined, it is more likely that researchers would experience greater success at involving larger numbers of minorities with disabilities in their work, contributing to the existing knowledge base about people with disabilities from diverse groups.

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