Critical issues in researching domestic violence among people of color with disabilities

NOTICE: This is the authors version of a work that was accepted for publication in *Journal of Aggression, Maltreatment and Trauma*. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms, may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in *Journal of Aggression, Maltreatment and Trauma*.

Citation:

Lightfoot, E. & Williams, O. (2009). Critical issues in researching domestic violence and people with disabilities. *Journal of Aggression, Maltreatment and Trauma*, 17(2), 200-219.

Abstract

While there are a number of programs emerging providing services to people of color with disabilities who experience domestic violence, there is little research on the needs of this population. Using data collected from two national focus groups of nineteen expert informants, this article outlines key areas of research needed for providing better services to people of color who are Deaf or have disabilities, and appropriate research methods for collecting data with this population. Respondents indicated that a research agenda should include investigating the scope of the problem, in-depth needs of domestic violence survivors, cost-effectiveness of culturally and disability specific programs, and development of best practices through in-depth evaluations of existing programs.

Key Words:

Disabilities
People of Color
Deaf or Hard of Hearing
Domestic Violence
Research Methods
Data Collection

Introduction

The purpose of this article is to provide some guidance on conducting future research related to domestic violence involving people of color with disabilities. There is currently almost no research knowledge related to domestic abuse involving people of color who have physical or sensory disabilities, or who identify as being Deaf or HOH. The limited research on the topic of domestic violence involving people with disabilities has found that people with disabilities experience higher rates of domestic abuse (Powers, Curry et al. 2002), experience additional types of domestic abuse such as withholding medications or being moved without permission (Gilson, Cramer et al. 2001), and are likely to be abused by paid caregivers as well as by family and informal caregivers (Nosek, Foley et al. 2001). A recent exploratory study has found that that people with disabilities of different racial and ethnic backgrounds have additional barriers for receiving appropriate services and different

experiences and understandings of domestic abuse (Lightfoot and Williams, 2008). However, there is little information about how to make domestic violence services for people of color with disabilities both accessible and culturally appropriate or on which prevention or treatment techniques are most effective in working with people of color with disabilities.

Future research exploration of this issue will be helpful for developing appropriate services. However, a key ethical and practical principle in conducting research involving people with disabilities is that disability research must be both useful and meaningful for people with disabilities themselves (French and Swain 1997; National Council on Disability 1998; Kitchen 2000; Duckett and Pratt 2001). Many people in the disability community assert that for research to be meaningful and useful to people with disabilities, as well as to ensure that research is accurate and does not harm people with disabilities, and is perhaps even emancipator, people with disabilities must be involved at least as either co-researchers or consultants in the research process (French and Swain 1997; Priestley 1997; Zarb 1997; Kitchen 2000). Thus, in order to develop a research agenda and develop appropriate methodologies for research in the area of domestic violence involving people of disabilities with color, people of color with disabilities must be involved from the initial stages.

To gather input on developing a research agenda and develop appropriate methodologies, expert informants; the majority who were people of color with disabilities fully involved in the area of culturally appropriate, accessible domestic violence services participated in focus groups. Facilitators asked focus group participants to discuss the types of information that agencies needed from research, to provide insight recruiting people of color with disabilities to participate in domestic violence research, to address confidentiality and ethical issues in research, and to discuss data collection issues and other part of the research process they felt was important. The results from this focus group provide a foundation for conducting future research on this topic.

Methods

Nineteen domestic violence service providers and advocates from across the United States participated in two, three-hour focus groups during winter of 2003 on issues related to people of color with disabilities who experience domestic violence. While the first two hours of each focus group focused on services needs and issues which are reported in another article in this volume (Lightfoot & Williams, 2008), in the third hour participants provided input into developing methodology for future research in the area of domestic violence among people of color with disabilities, including recruitment, confidentiality and other ethical issues. The first focus group explored research involving Deaf or Hard of Hearing (HOH) people of color experiencing domestic abuse. This group consisted of nine female service providers or advocates, and included seven people who were Deaf or HOH and seven people of color. The second focus group, which studied research involving people with physical or other sensory disabilities who experienced domestic violence, consisted of one male and nine female service providers or advocates, and included six people with disabilities and seven people of color. All participants were recruited based on their professional experience in the field of domestic violence, not for personal experience with domestic violence.

The data collection method involved the use of laptop computers connected to a local area network and supported by GroupSystems software. This arrangement allows participants to enter data simultaneously, and to read and respond to others input efficiently.

All input is anonymous, and neither the researchers nor the participants know who has entered which comments. The two facilitators of the focus groups both had extensive experience in using GroupSystems software with people with disabilities (Pappas and Davenport 1994), and accommodations were available to ensure participation by all members.

Researchers asked participants to provide input into appropriate research topics, sampling, definition of terms, confidentiality, ethics and other methodological issues. The focus group related to research involving Deaf or HOH people of color resulted in 109 total inputs, approximately 12.1 separate inputs per participant. The focus group related to research involving people of color with physical or other sensory disabilities resulted in 107 total inputs, approximately 10.7 inputs per participant. The focus groups uncovered a number of themes and recommendations for research that are detailed below.

Findings

There were several overarching themes that emerged throughout many parts of the research section of both groups. These overarching themes include the research axiom, nothing about us without us; the admonishment not to revictimize survivors; the necessity of knowledge of Deaf and Disability culture; and a call to avoid racial or ethnic assumptions. These broad themes will be described below, followed by more specific items related to research topics, recruitment, confidentiality and data collection.

Broad Research Themes

Nothing about us without us. The most prominent theme in both focus groups was that researchers should recognize the axiom among disability and Deaf culture: Nothing about us, without us. What this means is that Deaf and HOH People, people with disabilities, and people of color have often been the subjects of research without any input into any aspect of development of research questions, research design, data collection, research analysis or research dissemination. Respondents in both groups were clear that survivors should be involved in the research process and should have a vital role in any studies about intimate partner violence in communities of color with disabilities. As one participant noted, researchers must never assume that they are the only expert in the room. Any research on domestic violence among people of color with disabilities or among Deaf or HOH people of color must include people with disabilities, Deaf people, and people of color as co-researchers or integral consultants to the research team. Researchers were urged to be cautious about assuming the beneficial nature of research, and to ensure that research knowledge was actually disseminated in ways that could help benefit the lives of people of color with disabilities.

Avoid revictimization. Researchers must be careful not to revictimize survivors. Researchers need to be familiar with and knowledgeable about speaking with victims of domestic abuse and intimate partner violence. If conducting interviews, the researchers need to ensure that the interviews will not result in the victim having to re-live the trauma or be too intrusive of recounting the experiences. Some suggested that survivors should be allowed to define their own experiences, rather than having to follow the researchers set terms. For example, one respondent said,

If an African American woman recognizes that she has experienced abuse or violence in her relationship but does not see herself as a victim of domestic violence,

the issue is that she recognizes the reality of her situation regardless of how she defines it herself.

A counselor should be available to provide support during focus groups, and give all research participants information about local service providers that are both accessible and culturally competent that they can contact. Several suggested that it was important to do follow-up calls with research participants, to ensure that they have the support that they need. One respondent suggested that there should be

A realization why victims may want to participate in a study. Many are still searching for talented people and high quality services that will help them deal in a sensitive way with what has happened to them and resolve some feelings of anger and powerlessness.

Finally, researchers should be careful not to take advantage of the fact that many people of color with disabilities rely on the system. Such people may feel compelled to participate in research as they fear it is in some way tied to losing their funding. As one participant noted,

Poor people, who may be poor because of socio-economic history, race or many other challenges have very public lives because they are dependent on public money to survive. It is important not to ever be seen as taking advantage of that fact.

Knowledge of Deaf culture and Disability culture. Researchers must be aware of Deaf culture and Disability culture. As one respondent noted, researchers should consider disability as a cultural and political identity, rather than a disease or diagnosis. While this theme was evident in both focus groups, it was particularly strong in the Deaf and HOH focus group. Participants urged researchers to be aware that many Deaf people regard Deafness as a cultural identity, not a disability. However, despite the participants strong opinions that researchers be aware of the predominant views about disability culture and Deaf culture, respondents warned researchers not to assume that all Deaf people or people with disabilities have been exposed to Deaf culture or Disability culture, particularly among people of different cultural backgrounds. As one respondent noted, be cautious not to become stuck with one standard concept of deafness in interviews and developing questions.

Further, researchers need to know particular aspects of the Deaf or Disability culture that may have direct relevance on how people access services or will participate in research. For example, researchers need to be aware of the enforced secrecy of abuse within the Deaf and HOH community in order to protect Deaf institutions and agencies. People feel that if it the abuse was known, the important services would be cut so they keep quiet. This is an important issue within the Deaf community, and researchers who are not familiar with this will likely not get accurate information about domestic violence among Deaf people of color.

Avoid cultural, racial and/or ethnic assumptions. A number of respondents recommended that researchers should avoid making assumptions based on culture, race or ethnicity, and should gain knowledge about ethnic groups before conducting research. Researchers should be especially careful not to group everyone into one box. For example, if researching within the boundaries of 4 nations, do not assume that the language or disadvantages of one tribe is the same for all. It is important for researchers not to generalize about any ethnic group. Or, as one participant said, Don't generalize or put people in boxes, hell, get rid of the little boxes, people are bigger than that.

Potential Research Topics

Researchers asked participants to discuss the types of information that agencies needed in order to provide better domestic violence services and supports for people of color with disabilities or who are Deaf and HOH, including information that was necessary to advocate for more services. Participants discussed six major areas for future research: the scope of the issue, needs assessments, costs and effectiveness of culturally appropriate services, development of best practices, accessibility of domestic violence programs and the criminal justice program, and broader contextual aspects of the issue. These research topics are discussed below.

The scope of the issue. The most commonly mentioned type of research information needed for providing better services or supports to people of color with disabilities was an accurate assessment of the scope of the issue. In particular, participants said that knowledge regarding the prevalence of people of color with disabilities who experience domestic abuse was of primary importance. This data is needed on both a national and local levels, and should include comparisons between various ethnic groups and types of disabilities.

Participants gave a variety of reasons for the importance of this type of knowledge. First, there is little information about the size of the population who are people with disabilities of color, or who are Deaf or HOH people of color. As one participant noted, I think the perception is that the number is small, when in reality it is much greater. Second, there is also little information about the prevalence of domestic violence among Deaf and HOH people of color or people with disabilities of color. Participants in the Deaf and HOH focus group observed that there is little discussion that domestic violence occurs within their community, and even less discussion about abuse involving Deaf or HOH people of color. One participant remarked that data was necessary to show that domestic violence does exist in the Deaf and HOH community. Participants also noted that an addition to the general incidence of domestic violence involving people with disabilities of color, there also needs to be information on regional variations, types of perpetrators (e.g. partners, family members, and paid caregivers), income levels, and race and ethnic backgrounds of both perpetrators and victims.

Finally, respondents indicated that an important research topic is to compare the types and amount of domestic violence that people of color with disabilities face in comparison to that of white people with disabilities. A number of respondents also noted that it was important to get accurate information on the gender of survivors among people of color with disabilities or Deaf and HOH people of color as well. Men with disabilities may be more likely to experience domestic violence than men without disabilities, and this may have differences among people of different racial and ethnic backgrounds as well.

Needs assessments. A related, prevalent theme was the necessity for in-depth needs assessments regarding appropriate domestic violence services for people of color who have disabilities or who are Deaf or HOH. In both focus groups, participants stressed the necessity of concrete information on the specific needs people of color with disabilities have for both prevention and services after abuse has occurred. Needs assessments should focus on the diversity within the disability community, illustrating that people of color with disabilities and Deaf and HOH people are so diverse that specialized services are indeed necessary.

Costs and effectiveness of culturally appropriate services. There are currently a small number of agencies providing culturally appropriate domestic violence services to people with disabilities, yet little is known of the costs or effectiveness of these services. There is a need for detailed information on how these culturally appropriate services operate, such as: types of services provided, types and amount of outreach, amount of services provided, backgrounds of staff, types and amount of domestic violence and diversity training provided to staff, and hours of in-service training. There is a need for documentation of how effective programs serving these populations may require more in-depth and/or lengthy services. One participant said,

I provide for smaller numbers of victims, but provide ten to twenty times more hours of services to individuals because of the complex barriers in the system and society. So my outcomes usually look small, but I am doing very broad work and very intense work. [It is important to] count hours, not individuals served.

Accurate knowledge of the extent of services which people of color with disabilities need when encountering abuse is necessary for developing future services.

Of particular importance is to ascertain information on the costs of providing services that are both culturally competent and accessible, and on the positive outcomes that culturally competent services have on individuals. As one respondent said, data is needed to show how big of a difference culturally competent services make in reducing victimization and/or minimizing its effects. There is a need for both cost-effectiveness analyses of services and outcomes of analyses of services.

Development of best practices. A related theme was the need for developing best practice guidelines on providing culturally appropriate domestic violence services for people with disabilities. Several respondents noted that there is a limited knowledge on appropriate intervention and advocacy methods that work for Deaf people or people with disabilities, and almost nothing on people of color who have a disabilities or who are Deaf. Participants suggested that developing and evaluating model programs that provide completely accessible and culturally appropriate services would be a useful strategy for creating best practice guidelines.

Accessibility of domestic violence programs and criminal justice system. Participants urged researchers to study the accessibility of domestic violence programs and public agencies involved in domestic violence issues, such as the police and the court system. Participants related that information on the generally agreed upon lack of accessibility and cultural competence of current domestic violence services would be helpful in advocating for more accessible, and culturally appropriate services. For example, information on the extent to which authorities rely on children to relay sensitive information for a Deaf parent in domestic violence situations instead of qualified sign language interpreters could be used to highlight the needs for accessible services. Information on the impact of this inaccessibility on people of color who are Deaf or have a disability would also be useful, such as the avoidance of reporting violence or seeking help due to the lack of accessible services.

Broader context. Finally, several respondents suggested that it was important to get a better picture of the broader political situation of the disability community in the area of domestic violence services. In order to know about domestic violence among people of disabilities of color, it is also important to know the extent of funding for disability services in general, the accessibility of transportation and housing, the homelessness rate, and the income levels of people with disabilities. One respondent noted that research into the

broader context in which domestic violence occurs is helpful for understanding how to provide appropriate services. Specifically, inquiry into communities which are high risk due to external factors, such as gang violence, drugs, depressed areas, and poor living conditions among the Deaf African Americans would be helpful for designing outreach for Deaf African Americans.

Recruiting Research Participants who are Deaf or HOH

Respondents were asked about appropriate sampling procedures for conducting research among survivors of domestic violence in the Deaf and HOH communities of color, and among people of color with disabilities. Specifically, they were asked how researchers would identify and recruit survivors who were people of color with disabilities or who were Deaf or HOH to participate in research studies. While there were some similarities between the focus groups, the general themes differed enough that these themes are organized separately by population.

National, state and local Deaf and HOH organizations. The most commonly reported method suggested by participants for recruiting Deaf and HOH people of color for research projects was through Deaf organizations, which are organizations that are run by Deaf people for Deaf people. The most common response among the Deaf and HOH issues focus group was to look at the large, national Deaf and HOH organizations. The National Association of the Deaf was cited often as being a good starting point for recruitment, as they have links with many other Deaf organizations, including any national organizations focusing on abuse in the Deaf community. In order to reach Deaf and HOH people of color, participants suggested national Deaf organizations focusing on particular ethnicities, such as Black Deaf Advocates, National Hispanic Council of the Deaf and Hard of Hearing, National Asian Deaf Congress, and Deaf Women United.

Participants also pointed to statewide or local Deaf and HOH organizations for recruiting participants. For example, in Minnesota, the Minnesota Association of Deaf Citizens would be a good starting place. In addition, most states have a Commission for the Deaf, which may be able to provide information on local organizations that could be a contact for recruiting potential research participants.

Many respondents suggested recruiting subjects through Deaf Clubs, Deaf social events, Deaf churches or Deaf community service centers. Many suggested that Deaf clubs were the best place to recruit Deaf people, as they usually draw various types of deaf people and they usually have information on other local organizations. To find Deaf people, it is helpful to go to places where Deaf people hang out, such as clubs, coffee shops, bars, or bowling alleys frequented by Deaf people. It is easier to recruit in places where there is a high population of Deaf or HOH residents.

Deaf and HOH service providers. Several respondents also suggested recruiting via Deaf or HOH service providers, though this theme was much less prevalent than that of Deaf run organizations and clubs. Recruiting via service providers would be most useful if a research project was being conducted in a city that had a domestic violence program specifically serving Deaf and HOH people. Other types of agencies that provide services to Deaf people, such as schools, social services or interpreter organizations, may be useful for recruiting Deaf and HOH people of color to participate in research.

Reaching Deaf and HOH people not involved in Deaf community. One caveat of the previous recruitment strategies is that it would be very difficult to recruit Deaf people who do not participate in the Deaf community. As one respondent said,

Deaf victims living with hearing abusers are often isolated away from Deaf groups, so you would only tend to get those who are still involved in the Deaf community. Those who are isolated can only be identified by the police, social workers or others who have seen them for reported abuse issues.

The only suggestion made in the focus groups for recruiting Deaf people of color who do not participate in the Deaf community was through African American churches.

Other recruitment issues in the Deaf and HOH community. Focus group participants had a number of other suggestions for successfully recruiting Deaf and HOH survivors of color. A key point is that it was crucial for Deaf people to actually do the recruiting.

Do not send hearing researchers on their own, they will not be able to obtain any useful information. Hearing researchers need to make friends with key deaf grassroots leaders, and allow these leaders to lead them into locating appropriate interviewees.

While it is possible for hearing people to recruit Deaf professionals, hearing people would probably not be able to recruit Deaf survivors of domestic violence.

In addition, there were several warnings participants made regarding recruiting Deaf or HOH people for research activities. First, some participants recommended that interpreters not be involved in the recruiting process. Some participants considered interpreters a poor source for insight into the Deaf community, and their information on Deaf or HOH people may be inaccurate unless an interpreter comes from a Deaf family and/or participates fully in the Deaf community. Second, several respondents said that it was important to check the legitimacy of comments and the individual being interviewed. As one respondent put it, do not fall for individuals that may claim deafness or minimal hearing loss (yes, there are actually people out there like that). Further, there was a warning not to rely on a single source for getting an appropriate sample. The Deaf and HOH community is very diverse, and thus recruitment needs to come from a variety of sources. Finally, it was recommended that researchers be wary of recruiting too many professionals to provide insight into the Deaf community, as it is actually the grassroots that defines and breathes the actual lives.

Recruiting People of Color with Disabilities

Disability agencies and service providers. Unlike the Deaf and HOH focus group, the people of color with physical and other sensory disabilities focus group suggested primarily disability services providers as a primary location for recruiting research subjects. Many respondents listed a variety of types of disability service providers and general service providers as a good place for recruiting people to participate in research projects. The types of service providers recommended included: disability agencies, senior centers, hospitals, para-transit, schools, vocational rehabilitation, workshops, day programs, and assistive living facilities. Several respondents suggested that when recruiting via service providers, it was important to recruit from a broad array of service providers. Another respondent recommended identifying the individual within the agency that is in charge of record keeping, and enlisting this person to assist in locating the target group. Only one respondent

suggested looking at disability organizations run by people with disabilities, such as Centers for Independent Living.

Community locations and events. A key theme was the researchers need to recruit where people of color with disabilities are. A number of respondents suggested churches as a good place for recruiting people of color with disabilities. One person suggested that a researcher could contact clergy asking them to hold congregational meetings within specific communities of color, and address the issues of domestic violence among people with disabilities both in the congregation and the community. Other locations suggested included grocery stores, libraries and hospitals. Several respondents thought community events, such as community functions, craft fairs or disability fairs, could be a good place to recruit participants for research projects, particularly in rural areas. These would also be appropriate venues for providing more education within all communities about healthy relationships, violence, and abuse, and about people with disabilities.

Community organizing/community education/participatory action research. A theme unique to the people of color with disabilities focus group was that researchers should use community organizing, community education and/or participatory action research as a means of building long-term, ongoing ties with the community. The community itself needs to understand and determine why they need more research, and what they get out of participating in a research project. Community leaders need to be involved in disseminating information to the communities, and research should be tied directly with continuing education about the issues of disability, cultural competency and domestic violence. As one respondent noted it is important to take a long-term approach. The outreach will take much longer compared to mainstream groups and credibility will need to be established. Relationships with trusted leaders will need to be established. Recruitment of subjects through community organizing also means developing contacts and participating in the events of community organizations, such as libraries, community groups, churches, and community centers.

Other recruitment issues among people with disabilities of color. While in the Deaf and HOH group many people said it was important to have a Deaf person doing the recruiting, in this group respondents focused on the importance of having a person of color doing the recruiting. One respondent suggested having people of color recruiting within communities of color with disabilities, and people with disabilities recruiting white people with disabilities. A number of people also suggested that it was important that people of color with disabilities be provided assurances that there would be no repercussions of participating in a research project.

People with disabilities have been poked and prodded and researched almost to death (and I mean that quite literally). People with disabilities are often frightened of the medical industry because its been a source of a lot of control, abuse, and pain.

African Americans in particular tend to be non-trusting of the researcher due to their historical experience, such as the Tuskegee experience. Further, one should be cautious about assuming the beneficial nature of research. In addition, researchers should respect the voluntary nature of research, and that some people may simply get tired of being studied.

A number of people recommended that an honorarium be provided in order to recruit people of color with disabilities, as well as transportation costs and food. If accessible transportation is needed, the researcher should arrange and pay for that as well.

People may also fear participating in research projects for fear of losing their independence, particularly that by participating in research they will be inviting service providers into their home or even be placed in a nursing home.

Confidentiality in Research with Deaf and HOH People of Color

Focus group participants were also asked about general confidentiality issues in research, and in particular how to ensure confidentiality in research regarding intimate partner violence among people of color with disabilities. In both groups, respondents noted the difficulty in ensuring confidentiality, as well as the primary importance of maintaining confidentiality when completing research. However, as there were unique confidentiality concerns for each population, the results are divided according to the two focus groups.

Confidentiality is almost impossible. The most pervasive theme in the Deaf and HOH focus group was that confidentiality would be extraordinarily difficult to maintain for a number of reasons. First, the Deaf and HOH community is very small, and has often been referred to as a fish bowl society. Because it is very small, information can travel rapidly, even across the country. Further, even if you took the names out of a report, many people within the Deaf community would still be able to figure out about whom the researcher was talking. Second, if a hearing person is conducting an interview, then there will necessarily be an interpreter, which will further limit the amount of confidentiality. Many respondents were skeptical of researchers being able to maintain confidentiality, with comments such as ha, you must be joking on this question, as typical responses. However, they did suggest various ways for at least improving the likelihood of confidentiality.

Accurate, trustworthy interpreters. Many respondents stressed that having accurate, trustworthy interpreters was vital for maintaining confidentiality. As one interpreter noted, Some interpreters are known to be gossips, and you wont get anywhere if you use those interpreters. While certified interpreters follow a code of ethics, respondents were still skeptical about confidential information being shared by interpreters. In general, participants greatly preferred Deaf researchers rather than hearing researchers using interpreters for collecting data.

Fully explain confidentiality procedures. A major theme was that confidentiality procedures must be fully explained to the research participants, including how a participant would be identified in a report, which people would have access to the information, the purpose of the research, and what happens when a breach of confidentiality occurs. There should be a signed consent form reassuring participants that information will not be released without their permission. As the Deaf community is such a small world, not even the most remotely identifying characteristics should be released. Researchers must ensure that research is conducted in a way that its legitimacy is not questioned. Thus, it is important for an appropriate university or professional research committee to supervise the research. Further, respondents indicated that anyone in violation of confidentiality procedures must receive appropriate discipline and be banned from future research with this population.

Sensitivity to Deaf culture. Respondents noted that it was very important for researchers to have and demonstrate a high sensitivity to the Deaf culture. In particular, it is important for a researcher to know that a breach of confidentiality would be one of the greatest fears among Deaf people who have experienced domestic violence. One participant

said that this pervasive fear was so great that researchers simply should not ask Deaf survivors any personal information in research, but should only be asked for general input into the broader issue.

Secluded interview location. Finally, several respondents suggested that any interviews or other contacts with Deaf and HOH participants of color be conducted in a secluded location. It is vital that others in the Deaf community not see the Deaf subject participating in a research project on this topic, as this information would rapidly spread throughout the Deaf community.

Confidentiality in Research with People of Color with Physical or Other Sensory Disabilities

As in the Deaf and HOH Issues focus group, in the Disabilities focus group several people also noted the difficulties of ensuring confidentiality in research studies. As one respondent said,

This is so difficult because we know that people with disabilities have little privacy or even the right to privacy and confidentiality. Everything about folks is in a file somewhere. I don't know if you can ever assure someone of confidentiality.

Confidentiality procedures. The most common response by respondents was to explain the confidentiality procedures of the research project in detail, including both the purpose of research, and the mechanisms to ensure confidentiality. Participants should sign a consent form. If researchers say the information will be confidential, then the researchers must not break this confidentiality. It was also suggested, Perhaps you can talk to the respondent about the importance of confidentiality and ask her or him what they would need to feel confident about the confidentiality of the conversation.

Anonymity. The disability issues focus group also recommended that researchers gather information anonymously if possible, and that researchers not ask for real names or use real names in reports. There were several methods suggested as appropriate means to gather anonymous information, including phone banks or web surveys. For research that cannot be anonymous, such as focus groups or in-person interviews, the data should be collected in a secluded location.

Media outreach. A final suggestion was that media outreach could be conducted to explain the type of research that would be done in the community. This would make the research project known as being legitimate in the community, and then confidentiality procedures could be explained at the initial contact with potential participants.

Data Collection Issues

Participants made a variety of suggestions regarding the actual process of data collection. These include making sure research procedures are accessible, using appropriate language, using unstructured data collection techniques when possible, ensuring that research participants are comfortable, using culturally appropriate data collection techniques, being cautious of the presence of caregivers during interviews, and using people of color with disabilities as interviewers.

Accessibility of research procedures. Researchers should ensure that all research is conducted in a manner that is accessible to all participants, including having materials available in alternate formats (e.g. Braille, large print, computer disk, lower reading levels, other languages), and conducting research interviews or focus groups in physically accessible locations and with certified interpreters present. The research questions should be kept simple to be more accessible for all respondents, or modified based on individual comprehension levels. Information on data collection and confidentiality procedures should be provided in the language of the participant.

Use appropriate language. Another predominant theme was that researchers should ensure that they use appropriate language when conducting research. People first language (e.g. person with a disability, rather than disabled person or handicapped) should always be used in all aspects of research. Respondents also indicated that it is important to use the term Deaf and HOH, and never to use the terms Hearing Impaired or Deaf/Mute, which are considered offensive to many Deaf and HOH people. Similarly, one person said that the word Deaf should always be capitalized as it is used by those who identify with the Deaf culture.

Use unstructured data collection techniques. Participants in both focus groups recommended that researchers use unstructured or minimally structured interview methods. Participants advised researchers not to grill victims, but rather to simply allow them to share their own experiences. This not only creates a more comfortable environment for people who have been victims of violence, but also helps keep the researcher from pre-determining the outcomes of the study. One respondent recommended that questions must be broader to not guide the flow of responses the researcher wishes to find, but to find what is really needed for the group.

Make research participants comfortable. Participants suggested that researchers should create an informal, relaxed atmosphere for the research participants. Researchers should ask research participants what they needed to feel safe to participate in the study.

One Deaf participant articulated that being too formal may result in interviewees feeling intimidated or inferior. She advised:

It is best if the interview was conducted in a relaxed, informal situation. This includes the basic appearance of the interviewers. Do not show up in suits. Show up in comfortable clothing. Show the Deaf that you are there to learn more, not to intimidate or oppress.

This may also involve the researcher being creative and flexible in where and how they obtain their information. For example,

If working with the elderly, face-to-face meetings are appreciated. If working with battered women, they may feel more comfortable within the surroundings of the local domestic violence shelter. If working with people of color with disabilities, they feel most comfortable in an environment that is suitable to their needs.

Use culturally appropriate data collection techniques. Researchers were advised to use data collection techniques that are culturally appropriate to people depending on both their disability and their racial or ethnic background. For example, an approach based on an oral tradition would be beneficial for people of color that come from such traditions, particularly older people who may be excellent spokespeople and knowledgeable sources within their particular community. Researchers also need to recognize and understand the degree of illiteracy among Deaf and HOH people. English, Spanish or other written lan-

languages are the second language for most Deaf and HOH people. When doing research it is important not to assume that Deaf and HOH people can read or write in English or Spanish or the native oral language of their ethnic community, and thus should collect data using the appropriate language of the participant, which may be ASL or signed English, or one of the many other world sign languages, such as Mexican Sign Language or Puerto Rican Sign Language.

Caregivers present during interviews. Several respondents pointed out the difficulties of conducting research when people have caregivers present. Researchers must be sure that they are speaking with the survivor, not the caregiver. If a caregiver is around or needed, have general questions that can be asked in front of the caregiver first. Try to ask sensitive questions in privacy, away from any caregiver. This is extremely important, as many people with disabilities experience abuse from their caregivers, whether their caregiver is an intimate partner, other family member, friend, or paid personal assistant. As mentioned above, participants also recommended avoiding having interpreters present during interviews by having Deaf interviewers.

People of color with disabilities as interviewers. Many also said it was important to have Deaf people of color or a people of color with a disability involved in conducting interviews. For example, when interviewing Deaf or HOH people of color, researchers should try to find Deaf or HOH interviewer, and if possible, a Deaf interviewer who is a person of color.

Discussion

The results of the focus group give researchers and those involved in the disability community a sense of the research needed to help agencies address the needs of people of color with disabilities who experience domestic violence. The expert informants, all with experience in this arena, indicated that the most important research need on this topic was information regarding the scope of the issue, including information on general prevalence rates on domestic abuse involving people with disabilities and Deaf people, as well as prevalence rates based on demographics, such as race and ethnicity, type of disability, and gender, as well as prevalence of different types of abuse. Participants also pointed to a need for in-depth needs assessments, cost-effectiveness studies of existing programs, and the development of best practices through evaluation of model, culturally and disability specific programs. Participants indicated that information regarding accessibility or lack of accessibility would be useful, and a further inquiry into the broader context of abuse, including information on the politics of service provision and the external risk factors for abuse, would help provide a more contextual understanding. A general theme from the focus groups was that research was necessary to prove to funding agencies and others that tailored, culturally appropriate domestic violence services for people who were Deaf or had a disability were necessary.

The overarching theme that emerged from this study of ensuring that people with disabilities were integrally involved in disability research, known in the disability community as nothing about us without us was not surprising. This has been a well-known concept among disability activists in the United States and abroad for several decades, and has more recently begun to enter the mainstream of research in the United States. The National Council on Disability (NCD), the independent federal agency providing consultation on disability issues, released a report entitled Reorienting Disability Research (National

Council on Disability 1998), which admonishes United States researchers to include people with disabilities integrally in all aspects of research, from planning and developing research, to collecting and analyzing data. In the area of domestic violence involving people of color with disabilities, this admonition may be even more important in regards to the sensitivity of the topic and the variety sources of discrimination and oppression that people of color with disabilities may have faced in their lives.

Some of the methodological findings from the focus group are appropriate for research involving people with disabilities in general, such as ensuring that research procedures are accessible, using accurate and trustworthy interpreters, using appropriate language and being aware of the Deaf and/or Disability culture. In addition, there were a number of suggestions that were unique to either the subject matter of domestic violence involving people with disabilities, or to the needs and experience of people of color with disabilities, or to the combination. Researchers must be cognizant of the victimization that people with disabilities of color experiencing domestic violence have experienced in their lives, and must be especially intent on making sure that their participation in research does not revictimize people. Many of the methodological suggestions made by participants were made in the context of this theme. For example, the issue of confidentiality, which is very important in all research activities, may be of even greater importance in researching domestic violence in the Deaf community, in which privacy and enforced secrecy are present. Researchers have to keep this in mind when designing research on this topic with this population, as research procedures which might be appropriate in other situations, such as using interpreters or having a caregiver present, might be inappropriate in this instance.

Finally, researchers must ensure that researchers do not make assumptions about entire groups of people based on limited knowledge. There is a great diversity among people within ethnic groups, as well as among Deaf and HOH people or people with physical or other sensory disabilities. Researchers can learn about some general trends among people of color or people of various ethnic backgrounds with disabilities who experience abuse, but must be careful not to draw conclusions that are too broad.

References

- Duckett, P. and R. Pratt (2001). The researched opinions on research: visually impaired people and visual impairment research. Disability & Society **16**(6): 815-835.
- French, S. and J. Swain (1997). Changing disability research: Participatory and emancipatory research with disabled people." Physiotherapy **83**: 23-32.
- Gilson, S., E. P. Cramer, et al. (2001). Redefining abuse of women with disabilities: A paradox of limitation and expansion. Affilia **16**(2): 220-235.
- Kitchen, R. (2000). The researched opinions on research: disabled people and disability research. Disability & Society **15**(1): 25-47.
- Lightfoot, E. & Williams, O. (2008). The intersection of disability, domestic violence and diversity: Results of national focus groups. Journal of Aggression, Maltreatment and Trauma, **xx**, **xx**.
- National Council on Disability (1998). Reorienting disability research. Washington, DC, Author.
- Nosek, M., C. Foley, et al. (2001). Vulnerabilities for abuse among women with disabilities. Sexuality and Disability **19**(3): 177-189.
- Pappas, V. and E. Davenport (1994). Empowering people with disabilities: The role of electronic meetings. Online Information 94, 18th International Online Information Meeting, Oxford, England, Learned Information (Europe) Ltd.
- Powers, L. E., M. A. Curry, et al. (2002). Barriers and strategies in addressing abuse: A survey of disabled women.s experiences. Journal of Rehabilitation **68**(1): 4-14.
- Priestley, M. (1997). Who.s research? A personal audit. Doing disability research. C. Barnes and G. Mercer. Leeds, The Disability Press: 88-107.
- Zarb, G. (1997). Researching disabling barriers. Doing disability research. C. Barnes and G. Mercer. Leeds, The Disability Press: 49-66.