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Helping Women with Disabilities and Domestic Violence: Strategies, Limitations, and Challenges of Domestic Violence Programs and Services

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ABSTRACT

Purpose: **To describe the types of services provided to women with disabilities at community-based domestic violence programs in the state of North Carolina, the challenges faced, and strategies used to provide the services.**

Methods: **We conducted a statewide cross-sectional survey of community domestic violence programs and had a response rate of 85%.**

Results: **Of the participating programs, 99% provided services to at least one woman with a physical or mental disability in the preceding 12 months; 85% offered shelter services to women with physical or mental disabilities. Most respondents (94%–99%) reported that their programs were either somewhat able or very able to provide effective services and care to women with disabilities. The respondents also described challenges to serving women with disabilities, including lack of funding, lack of training, and structural limitations of service facilities. Strategies used by the programs to overcome these challenges were networking and coordinating care with organizations that specifically serve disabled populations.**

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Conclusions: **Domestic violence programs in North Carolina provide services to women with disabilities but are faced with challenges stemming from limited funding, physical space, and training. Collaborations between domestic violence and disability service providers are necessary to improving the services and care delivered to women with disabilities who experience domestic violence.**

INTRODUCTION

Participants in the 1997 International Leadership Forum for Women with Disabilities identified violence as a priority area for research and action.[1] The Americans with Disabilities Act of 1990 defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities."[2] Although little is known about violence experienced by women with disabilities, a few studies have suggested that it is a common problem.[3,4] In many of these studies, the most common perpetrator of the emotional and physical abuse was an intimate partner.[3,4]

Among the general female population in the United States, the prevalence of violence against women and intimate partner violence is high. A recent report describing the findings of the National Violence Against Women Survey estimated that 1.5 million women experience physical or sexual violence from a current or former intimate partner each year in the United States.[5] Between 42% and 52% of female victims sustained an injury,[5,6] and 41% required medical care as a result of a physical assault by their intimate partner.[6] Of women coming for care to emergency departments and community clinics, 15%–30% have a history of intimate partner violence.[7–9]

Research examining the experience of intimate partner violence among women with disabilities suggests that this type of violence may be equally, or perhaps more, prevalent in this population of women. In a qualitative study of 31 women with physical disabilities, Nosek[3] found that 25 women (81%) described some experience of sexual, physical, or emotional abuse in their lifetimes. Among the 55 total abusive incidents described by the participants, 15 were sexual, 17 were physical, and 23 were emotional.[3] Young et al.[4] mailed questionnaires to 439 women with physical disabilities and asked each woman to recruit a nondisabled female friend ($n = 421$) to also complete a questionnaire to serve as the comparison group. The study found no difference in the rates of abuse experiences among women with and without physical disabilities. Both groups reported relatively high rates of abuse; 62% of each group reported experiencing physical, emotional, or sexual abuse at some point in their lifetime. For both groups, intimate partners were the most common perpetrators of either emotional or physical abuse.[4] Using a statewide sample of female noninstitutionalized North Carolina residents, S.L. Martin et al. (unpublished observations, 2002) found that women with disabilities were as likely to experience physical violence as were nondisabled women. Likewise, the most common perpetrator of the physical abuse was an intimate partner.

Although the limited available research on this topic indicates that disabled and nondisabled women appear to be at similar risk for abuse, women with disabilities may be at risk of experiencing longer durations of abuse than women without disabilities.[4] This longer duration may be associated with increased vulnerability because of both societal factors and physical limitations. In their article examining key issues about abuse among women with disabilities, Nosek et al.[10] noted that women with disabilities may encounter perceptions of cultural devaluation and assumptions of powerlessness that contribute to isolation and decreased credibility. Economic dependence on the perpetrator also exacerbates barriers to ending a violent relationship. They also speculated that because women with disabilities may perceive fewer opportunities to explore their sexuality and learn to set boundaries, they may be more vulnerable to tolerating violent or abusive behavior from their sexual partners.[10] In their study examining abuse by personal assistance providers, Saxton et al.[11] suggested that reliance on others for personal care and repeated difficulty locating and retaining personal assistance providers may also contribute to increased tolerance of abuse.[11]

Women with disabilities may also encounter increased durations of abuse as a result of difficulty in actively seeking services because of fac-

tors related to specific disabilities. These may include the inability to physically escape the abuser and dependence on the perpetrator for essential activities of daily living among women with physical disabilities, as well as difficulty obtaining services because facilities are inaccessible or unable to accommodate the needs of clients with physical disabilities.[3,4,12] Women with mental, hearing, or communication disabilities may have difficulty disclosing the abuse and asking for help. Additionally, disabled victims may require special transportation, communication aides, accommodations, and other types of services to address their special needs, many of which may not be available at traditional domestic violence programs.[12–14]

Dependence on others for basic support needs also introduces women with disabilities to the risk of disability-related abuse. Such abuse occurs when the perpetrator prevents or withholds necessary care or assistance to control, humiliate, threaten, or hurt the disabled woman.[15] Examples of this type of abuse include damaging or withholding assisting devices, such as wheelchairs, telephones, or supplemental oxygen; abandoning the victim in uncomfortable, vulnerable, exposed, or embarrassing positions; and refusing to assist in vital needs, such as using the bathroom, eating, or drinking.[15–17]

The issues of violence against women with disabilities and the potential lack of services for such victims are of particular concern when one considers the proportion of women in the United States who have a disability. Although estimates of the prevalence of disability among women differ, it is clear that many women have some type of disability. For example, findings from the National Health Interview Survey estimated that >15% of the noninstitutionalized civilian women in the United States have a disability,[18] and the Centers for Disease Control and Prevention (CDC) reported that 24% of the noninstitutionalized civilian women in the United States have a disability.[19]

To address these concerns, advocates for domestic violence victims in the state of North Carolina expressed a desire to understand the proportion of clients contacting domestic violence programs who are disabled and the types of services that domestic violence programs were currently offering women with disabilities. In addition, the advocates were interested in the limitations and challenges programs faced in trying to serve women with disabilities and the strategies domestic violence service providers were using to overcome those challenges. These advocates included representatives from the North Carolina Coalition Against Domestic Violence, a grass roots advocacy coalition representing most of the domestic violence service organizations in the state, and the North Carolina Domestic Violence Commission, a state organization within the North Carolina Council of Women charged with advising policy to protect victims of intimate partner violence. A collaborative, working group for this project was assembled that included experts from the fields of victims' advocacy, public health research, disability research and advocacy, and women's health. Other contributors to this project represented expertise in substance abuse, legal issues, and cultural competency.

The working group conducted a review of the literature that revealed no studies examining how domestic violence programs address the needs of women with disabilities. Through consensus, we developed the following objectives for this project:

1. To describe the services that domestic violence programs in the state of North Carolina provide to women, including those with disabilities;
2. To document the limitations and challenges faced by domestic violence programs in their attempts to provide services to women with disabilities; and
3. To learn what strategies domestic violence programs have utilized to overcome the challenges they faced in providing services to women with disabilities.

MATERIALS AND METHODS

A multidisciplinary group of researchers and practitioners designed a self-administered written survey that was mailed to all domestic violence programs in North Carolina. The survey sought to assess the services provided, challenges faced, and resource and training needs in serving women's particular concerns related to disabilities, mental illness, language/cultural barriers, and substance abuse. For each of these issues, a representative with particular expertise in that area compiled a list of topics or questions to be

addressed in the survey. For example, the representative from the North Carolina Office on Disability and Health generated a list of questions relating to women with disabilities and intimate partner violence services. The advocates and other members of the group then reviewed this list to select key questions and to refine the wording and format of the questionnaire. Each section of the questionnaire addressed a particular issue and consisted of several closed-ended questions and two or three open-ended questions.

In the section regarding women with disabilities, the group reached consensus to include questions addressing the following topics: (1) the general types of services provided by the domestic violence programs, (2) whether the programs have served women with particular types of disabilities within the past years, (3) whether the general services were available to women with disabilities and strategies for adapting and providing these services, (4) how the programs' judged their abilities to provide services to women with disabilities, (5) challenges faced in serving women with disabilities, and (6) resources needed to better meet the needs of this population of women. We defined disability as "limitations in physical or mental functioning caused by one or more health conditions." A preliminary questionnaire was pilot-tested by staff members of the North Carolina Coalition Against Domestic Violence, and their suggestions were incorporated into the final version. In a meeting of the full working group, all members reviewed and approved the final questionnaire.

We compiled a list of domestic violence service providers in North Carolina from the membership lists of the North Carolina Coalition Against Domestic Violence, the list of programs receiving funding from the North Carolina Council for Women, and additional programs known to other members of the working group. The group identified 85 domestic violence programs. The advocacy representatives in the group confirmed the contact information by calling each of these programs.

We created a cover letter that included logos from the North Carolina Coalition Against Domestic Violence, North Carolina Domestic Violence Commission, and University of North Carolina at Chapel Hill (UNC-CH). Representatives from each of these institutions (P.N.D., L.S., J.C.C.) signed the letter. The cover letter explained the study and reassured participants about the confidentiality of their responses. Each letter was addressed to either the domestic violence program's executive director or the director of client services. Only the researchers in the working group knew which programs responded to the survey, and this information was kept confidential. Advocates in the working group contributed to the interpretation of the results from the pooled data. The UNC-CH School of Medicine's Institutional Review Board for the Committee on the Protection of the Rights of Human Subjects found that our project proposal and questionnaire satisfied exemption criteria.

We conducted the first mailing in December 2000. At the suggestion of the advocacy representatives in our working group, who identified December to be a particularly hectic month for domestic violence programs, we sent a postcard reminder in early January. There was a second mailing to nonrespondents in January 2001. In March 2001, trained interviewers from the UNC's Injury Prevention Research Center contacted the programs that had not yet responded and administered the survey by telephone interview. Of the 85 surveys mailed, 65 were returned by mail, 7 were completed by telephone interview, 12 were never returned, and 1 was returned to sender, resulting in a response rate of 85%. We performed univariate analyses of the closed-ended questions. In calculating frequencies, we eliminated missing variables from the denominators. Answers to the open-ended questions were analyzed for content and thematic trends.

RESULTS

General services

Among the domestic violence programs in North Carolina responding to the survey (n = 72), nearly all (92%) offered 24-hour hotline services for victims of domestic violence, and a majority (65%) offered hotline services for victims of sexual assault. Eleven percent offered 24-hour hotline services for suicide prevention (Table 1). Of the 68 programs that answered questions regarding counseling services, most provided counseling for crisis intervention (99%) and for survivors of domestic violence (99%). A smaller percentage of programs offered counseling for children who have witnessed domestic violence (79%) and for survivors of sexual assault (68%).

Table 1. Percentage of Programs Offering Various Types of Services

Services offered	*% of domestic violence programs* (n)
Domestic violence hotline counseling	92 (66)
Sexual assault hotline counseling	65 (46)
Domestic violence victim counseling	99 (67)
Sexual assault victim counseling	68 (46)
Crisis intervention counseling	99 (67)
Counseling for children witnessing domestic violence	79 (54)
Suicide prevention counseling	11 (7)
Shelter services	86 (62)
Court advocacy	99 (70)
Transportation assistance	80 (56)
Legal services	44 (31)
Other	46 (33)

Many of the domestic violence programs provided shelter (86%, $n = 61$) and transportation (79%, $n = 56$) for their clients, and all but 1 responding organization provided court advocacy services. Slightly less than 50% of the 72 respondents stated they provided other services to their clients that were not mentioned in the questionnaire. Among these other services were support groups; parenting, job, or life skills classes; professional training and education; specific types of legal services; batterer's intervention; case management and referrals; medical care; child care; and emergency financial assistance.

The number of clients served on an annual basis varied greatly among the programs. The estimated number of hotline calls received by the programs ranged from 0 to 6000 per year, with a mean of 792. The estimated number of women counseled each year ranged from 0 to 3000, with a mean of 551. The estimated number of women in shelter each year ranged from 0 to 815, with a mean of 188.

Serving women with disabilities

Of the 67 domestic violence programs in North Carolina that answered questions about services for women with disabilities, 99% reported that they had provided services to at least one woman with a physical or mental disability in the preceding 12 months. When asked to describe the various types of disabilities among their clients with disabilities, 73% of the domestic violence programs reported that they had served women with mental retardation or developmental disabilities, and 69% had served women with physical disabilities or mobility impairment. Thirty-eight percent of the domestic violence programs had served women with hearing impairments, and 25% had served women with a visual impairment. These proportions were not mutually exclusive (Table 2). The majority of respondent programs that offered emergency shelter also offered shelter services to women with physical or mental disabilities (95%), and 77% of these programs stated that their shelter facilities were wheelchair accessible. Sixty-nine percent of domestic violence shelter facilities could accommodate a client's seeing-eye dog, and 58% reported they could accommodate a client's personal care attendant.

Programs' ability to meet the needs of women with disabilities

In response to questions regarding the capability of domestic violence programs to meet the needs of clients with disabilities, between 94% and 99% of the programs reported being either somewhat able or very able to provide effective outreach, anticipate needs, provide basic services, provide access to facilities, and collaborate with community disability-related service providers. Of the 56 programs that offer transportation services to their clients, 33 reported being somewhat able to offer transportation assistance, and 22 reported being very able to do so. Of all respondents, 16% reported having difficulties communicating with women who have hearing, speech, or learning disabilities (Fig. 1).

Challenges to serving women with disabilities

Responding to the question, "What challenges have you encountered in trying to meet the needs

TABLE 2. PERCENTAGE OF DOMESTIC VIOLENCE PROGRAMS SERVING CLIENTS WITH PARTICULAR TYPES OF DISABILITIES

Type of disability	*% of domestic violence programs serving women with particular types of disabilities* (n = 67)
Mental retardation/developmental disabilities	73
Physical disability/mobility impairment	69
Hearing impairment	38
Visual impairment	24
Other	9

of clients with disabilities?" programs described two main challenges: lack of funding and structural limitations in program facilities. The domestic violence service providers explained that lack of funding made it difficult to ensure adequate staffing, provide sufficient training for staff, purchase equipment, and make the structural changes in their shelters necessary to meet the needs of women with disabilities. They often felt forced to choose between other possible services and services specific to women with disabilities. One program director described this problem:

> Money is always the biggest challenge. Having accessible facilities requires awareness and funding. Awareness is happening. Funding is required in so many different areas that choosing priorities is difficult.

Several respondents admitted that they often prioritized basic, more general services because wo-

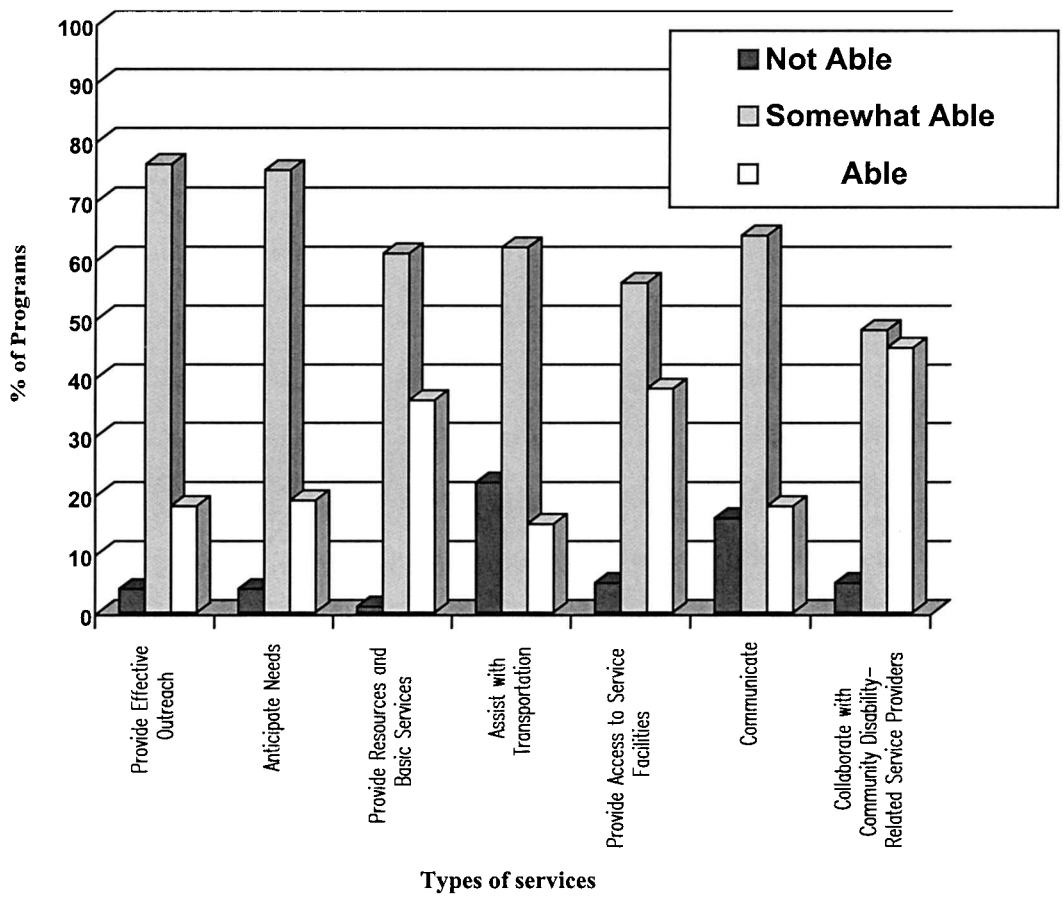

FIG. 1. Programs' self-reported ability to provide specific services to clients with physical or mental disabilities ($n = 71$).

men with disabilities did not constitute a large proportion of their clients.

Structural limitations in shelter and program facilities constituted a challenge to providing services to women with physical disabilities. Many shelters lacked the space to store medical equipment or to house personal care attendants. Several reported an inability to accommodate assistant dogs. They also mentioned that many shelters do not have bedrooms on the ground floor and could not afford to construct entrance ramps or convert bathrooms to make facilities wheelchair accessible. Others described a lack of special equipment for the hearing or visually impaired client.

Strategies for overcoming challenges

When asked to share the types of strategies that worked well to be able to serve women with disabilities, the overwhelming response was to network with other agencies and services that address the needs of disabled individuals. Participants noted that successful networking required an in-depth knowledge of what services are available in the community, how women can access those services regardless of ability to pay, and what application processes are necessary for various types of assistance. Several people commented on the importance of cross-referrals between agencies, as well as the need for domestic violence agency staff to serve on boards of other agencies in the community and to participate in cross-training activities in order to establish good working relationships with these agencies.

Respondents described that having equipment in-house for the hearing impaired, having appropriately trained staff, and providing education about domestic violence and sexual assault to others in the community through outreach services improved their ability to serve women with disabilities. A few programs also described creative strategies, such as recruiting volunteers from other organizations and agencies serving the disabled, paying for rental vans or other accessible transportation, and working with legal advocates to remove perpetrators from the women's homes.

Resource and training needs to improve services for women with disabilities

When asked, "What kinds of technical assistance and resources would be helpful to you in providing greater access to your services for women with disabilities?" most responses revolved around training, support with outreach, and increased resources and staffing. Training issues included information on strategies for improving their ability to offer emergency shelter services to women with disabilities, education on physical and mental disabilities, lessons on sign language, information on alternative funding sources, ways to upgrade or improve shelter accessibility, and guidance from model programs on establishing better community networking. Respondents mentioned wanting outreach support to help reach women with hearing or visual impairments and those with developmental disabilities. More resources, especially funding, was an often-cited need in order to hire more staff and provide appropriate training on disability-related issues; improve and expand shelter accessibility; purchase equipment, such as a teletypewriter (TTY) phone system for the hearing impaired, fax machines, and Internet access; and hire interpreters for sign language and braille.

DISCUSSION

The impetus for this study came from domestic violence advocates in the state of North Carolina expressing a desire to address outreach, shelter, and counseling services offered by domestic violence programs to victims with disabilities. The general objectives of developing the multidisciplinary working group were to expand knowledge, bring various advocates and researchers together, learn about areas that could be targeted for program expansion and further investigation, and provide domestic violence programs with ideas and information concerning how they could better serve women with particular needs. In addition, the domestic violence advocates in the working group described their intention to use the information learned from the survey to develop and target training initiatives and programs for domestic violence victims' advocates as well as for other community groups.

Our study illustrated that the vast majority of North Carolina domestic violence programs have served women with disabilities as clients. Although we did not obtain the exact numbers of women with disabilities served by the programs and, thus, cannot estimate the proportion of clients for which the programs provided services,

the majority of programs indicated that they offered services to women with disabilities and reported that they were at least partially able to provide outreach, counseling, and other general services to women with disabilities despite limitations in space, structural access, communication, trained staff members, and funding. Almost all programs providing shelter services offered these services to women with disabilities, although one third noted that their shelter facilities were not accessible to wheelchairs. Slightly fewer were at least partially able to offer transportation services to women with physical disabilities and to communicate with women with hearing or speech disabilities. These responses suggest that the programs attempted to accommodate clients with disabilities rather than turning them away, reflecting the grass roots, advocacy character of community domestic violence programs that attempt to meet the needs of clients through resourcefulness, creativity, and adaptation.

Despite their general "can do" attitudes, the domestic violence programs did recognize barriers that limit their ability to provide the best care to women with disabilities. The primary challenges reported were lack of funding to purchase additional equipment and make structural changes to facilities and providing specific training on disability issues for staff. Because many community domestic violence programs often rely on private donations and grant funding, dealing with limited resources is likely an ongoing concern. Although all respondents expressed a willingness and desire to provide services to women with disabilities, these programs are likely to struggle with prioritizing their expenditures even with some additional funding, unless it is specifically designated for disability-related services. This becomes a particular concern as programs are required to meet the Americans with Disabilities Act criteria for accessibility.

Although not mentioned by the respondents, another legal consideration regarding women with disabilities that may have implications for domestic violence service providers is the mandatory reporting laws in many states. Similar to laws requiring report of knowledge of abuse of children or the elderly to law enforcement and legal authorities, several state statutes require reporting of abuse perpetrated against any person with a disability. This may also serve as a barrier to providing confidential counseling or services to women with disabilities who are not willing to involve police in their intervention.

Several programs identified increased support funding, help with infrastructure, and training of staff and volunteers as additional elements that would improve their ability to serve women with disabilities. They also mentioned that an effective strategy to overcoming these challenges was networking with other community programs that address the needs of individuals with disabilities. Experts and advocates for people with disabilities have suggested this emphasis on partnering with local disability organizations.[20,21] With the assistance of disability experts, domestic violence service providers could better assess a woman's functional capabilities and then improve the tailoring of any intervention or counseling offered to her.[22] For example, common strategies for safety planning to escape escalating abuse may not be feasible for women who are physically dependent on their perpetrators.[10] Safety planning may then need to involve creative methods of communicating for help and will need to include disability-related strategies, such as packing spare equipment and medical supplies.

Both types of service organizations may benefit from each other's expertise through coordination of services, sharing of materials, expanding outreach, and collaborating on funding applications. For example, cross-training between violence and disability advocates would improve service provision to women with disabilities. Educational programs on domestic violence for disability services would not only increase awareness among providers but also could benefit the women directly through increased opportunities for outreach. Training programs for domestic violence victims' advocates could improve understanding of how to provide personal assistance to women who need help with specific activities and how to incorporate changes to increase accessibility, such as doorways wide enough to allow passage of a wheelchair, common areas and sleeping rooms on the first floor, visual and auditory alarm systems, educational information in braille, and TTYs for telephone communication. Collaboration between the two types of service organizations may also increase awareness of the various types of disability-specific abuse that these women may face.

As an outcome of this project, the working group has compiled the overall results of the sur-

vey into a report distributed to all the state's domestic violence programs. Additionally, North Carolina Coalition Against Domestic Violence in collaboration with the North Carolina Office on Disability and Health has developed, as part of their training institute, workshops for advocates to learn how to address the specific needs of clients with disabilities. These advocacy organizations have committed to foster increased collaboration with other advocacy and community organizations working with women with disabilities. Representatives from the North Carolina Office on Disability and Health have begun working with domestic violence programs to provide information on the American Disabilities Act and universal design, as well as suggestions and advice for the design and structural layout of centers and shelters.

The findings of our study must be viewed in light of its limitations. Although the high response rate of 85% suggests that the study results described almost all the community domestic violence programs in North Carolina, the data may not reflect the experiences and situations faced by hospital-based domestic violence programs or programs in other states. Additionally, the study is cross-sectional in design and relies on self-reporting from representatives of the domestic violence programs. This exposes the data to both recall and response bias. Despite the provision of a definition for disability, we acknowledge that our definition was broad, thus vulnerable to multiple interpretations. We did not distinguish between temporary disabilities and permanent disabilities, nor did we assess severity of disability. These differences could have some influence on our participants' answers as well on service needs and methods of delivery. For example, interpreting a healing physical injury as a temporary disability may present different service implications from those of women with permanent disabilities.

Further research is necessary to address these limitations and expand knowledge and information regarding the experience of violence among women with disabilities and how best to identify and address this problem. Improved understanding not only of the needs of the women but also of the needs, abilities, and limitations of the community service organizations representing them is needed to develop effective methods of coordinating and delivering care and services to this population.

Our study begins an understanding of the situations experienced and the challenges faced by domestic violence programs in their quest to provide services to women with disabilities. As healthcare providers and other professionals expand their screening and interventions to address the issue of domestic violence, specifically abuse of women with disabilities, an improved understanding of the community resources to which these women could be referred is necessary.

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