

Safety First Initiative

Needs Assessment Report

Institute for Human Development, University of Missouri-Kansas City
Metropolitan Organization to Counter Sexual Assault
Rose Brooks Center

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The vision of the Safety First Initiative is: *“to change the mindset in the Kansas City metropolitan area resulting in a sustained, collaborative response that provides culturally competent, respectful, accessible, empowerment based services to women with disabilities who are victims/survivors of violence.”*

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EXECUTIVE SUMMARY

The Executive Summary provides a summary of the full report with an emphasis on the major findings, implications, and recommendations.

In October of 2006, the Safety First Initiative was funded by the Department of Justice, Office on Violence Against Women. This Kansas City Collaborative is a partnership between the Metropolitan Organization to Counter Sexual Assault (MOCSA)-a leader in sexual assault services, the University Center for Excellence in Developmental Disabilities-the Institute for Human Development (IHD), and Rose Brooks Center-a local domestic violence shelter. As a part of this project, a needs assessment was conducted to guide the strategic plan for addressing identified needs of women with disabilities who are victims and survivors of violence.

Through this needs assessment, the collaborative hoped to identify and assess the (a) range of currently available services, (b) the nature and accessibility of available services, (c) the incidence of violence against women with disabilities, (d) the collaborative system of response, and (e) needs for training and capacity building. The results of the needs assessment will inform the development of a strategic plan with the purpose of improving services for victims/survivors of violence. By building upon the needs assessment, the strategic plan will define strategies for addressing barriers, service gaps, and needed improvements in service systems.

Vision

The vision of the project is: *“to change the mindset in the Kansas City metropolitan area resulting in a sustained, collaborative response that provides culturally competent, respectful, accessible, empowerment based services to women with disabilities who are victims/survivors of violence.”*

Key Findings

A number of recurring themes emerged across multiple stakeholders. Women with disabilities and services providers discussed issues regarding believability, and the under-reporting of abuse in Kansas City. Whilst stakeholders in the Kansas City area reported that services for both women with and without disabilities are available, there is the perception that these services are not always comparable for women with disabilities; they don't always get what they need. Along these same lines, the needs assessment also found that the system for linking victim services and disability services together in Kansas City is lacking in many ways. Lastly, training and capacity building regarding needs of and services for women with disabilities who have experienced violence are needed.

Implications

The results of the needs assessment indicate multiple areas of need, service gaps and system issues. The needs assessment revealed an array of existing services in Kansas City for women

with disabilities that have experienced violence. However, the general perception is that there is a need to improve services. Existing and future services should be accessible to women with disabilities who have experienced violence. The services should also be empowerment based resulting in more “comfort, control, and confidence” for women with disabilities.

Apparent throughout the needs assessment was the reluctance among disability service providers to participate in the process. There were two hypothesized reasons for this reluctance. One reason was that some disability service providers perceive that the issue is not applicable to their specific work setting or to the women with disabilities that they serve. Another reason was the perceived stigma and culpability associated with participating in the needs assessment processes. To expand awareness of the issue, collaborative opportunities between victim service providers and disability service providers should be fostered and resources shared. Leadership and administration staff of both victim assistance agencies and disability service providers need information about the issue and shared responsibility in addressing the needs of women with disabilities who have experienced violence. Those in leadership should support frontline providers with needed information about their responsibility to respond to women with disabilities who report abuse.

Findings from the needs assessment highlight the need for service provider training and capacity building in identifying the needs of and service provision for women with disabilities who have experienced violence. Both victim assistance agencies and disability service providers need more information regarding: cross-discipline practices and philosophies, respectful communication with women with disabilities, strategies for addressing the unique needs of women with disabilities, strategies for addressing the needs of women who have experienced trauma, and connecting women with disabilities who have experienced violence to the range of services they require. Service providers shared the perception that they need additional training in order to provide ideal services to women with disabilities who are victims/survivors of violence. Increased opportunities for sharing information across disciplines would facilitate collaboration. Additionally it would stimulate new awareness of issues related to women with disabilities and improve services thus making services more responsive.

Recommendations, Strategies, & Conclusion

The following recommendations and strategies translate the findings and implications into suggestions for implementation. Overall, there are six recommendations. These six recommendations address the integrated nature of the findings and implications by involving the collaborative and community agencies at multiple levels.

1. Always involve women with disabilities at every stage of implementation.
2. Devote time and energy to building partnerships between victim assistance providers and disability service providers. This is in response to the hesitancy of disability service provider participation in the needs assessment.

3. Address system challenges as well as the need for program enhancements. A suggested strategy is to form an advisory group of agency leaders (i.e. executive directors) who have the authority to designate resources to this issue, as well as have community presence and influence, to address gaps in services and training needs. Needs for program enhancements can be discussed and strategies for addressing needs can be problem solved.
4. Build the capacity of collaborative partners to enhance existing programs and address service gaps. One strategy is to provide training to all partner agency staff as well as cross-agency training. Another strategy is to designate and support an agency individual as the “champion” on this issue. This role of champion would be a primary resource to facilitate information sharing across disciplines as well as be a resource for women with disabilities. A third strategy would be for the Collaborative partners to build on existing services in order to better serve women with disabilities who have experienced violence.
5. Address the need for improved services by looking first within the core collaborative partner agencies. Issues of accessibility of facilities, policies, and practices should first be addressed by these agencies and then lessons learned will be valuable to share with the community.
6. The final long-term recommendation is to provide broad-based community awareness with a goal of improving collaboration across disciplines and reducing the perceived stigma associated with the topic of violence and sexual assault. Strategies for the Collaborative include providing leadership to community agencies in the forms of (a) awareness campaigns and training opportunities, (b) becoming a community resource for information, and (c) constructing a system of ongoing information, data, and response.

The overarching finding of the needs assessment is that there is a pervasive need for basic information and general awareness about the needs of women with disabilities who have experienced violence. In general, the reluctance among disability service providers to participate in the needs assessment is telling of the need for relationship building between victim assistance agencies and disability service providers, combined with the need for information on the topic. The comments from domestic violence and sexual assault providers identified a commitment to serving women with disabilities, but unfamiliarity about how to best do so. Women with disabilities are often faced with the additional barriers of not being believed, not being able to get to services, and the assumption that services will not be appropriate for them because of their unique needs. Conducting the needs assessment has begun the community discussion on this issue, but much dialogue and relationship building is still needed to enhance services for women with disabilities who are victims and survivors of violence. In order for women with disabilities who are victims and survivors of violence to have the “comfort, control, and confidence” they need, the Kansas City service system must enhance both the capacity of and coordination of victims’ services and disability services to appropriately meet the needs of women with disabilities.

INTRODUCTION

In October 2006, the Safety First Initiative was funded by the Department of Justice, Office on Violence Against Women. This Kansas City Collaborative is a partnership between a Kansas City leader in sexual assault services (the Metropolitan Organization to Counter Sexual Assault), a leader in domestic violence services (Rose Brooks Center), and a leader in disability services, the University Center for Excellence in Developmental Disabilities (Institute for Human Development). The mission of the project is to enhance the capacity of service providers and improve the coordination of supports and services for women with disabilities who are victims/survivors of violence in the Kansas City Missouri metropolitan area.

The Safety First Initiative is a three-year, grant-funded project with technical assistance provided by the VERA Institute of Justice. With support and assistance from VERA, during the first phase of this project, the collaborative partners spent a significant amount of time solidifying the collaboration by building their working relationships and knowledge of each other's areas of expertise. Preliminary activities included creating a collaboration charter, which outlines the manner in which the partners will work together including such elements as: shared values and assumptions; the project's mission, purpose, and vision; timeline and milestones of the collaboration; members, roles and contributions; the collaborative decision making and conflict resolution processes; and statements on confidentiality and mandated reporting. The vision of the Safety First Initiative is:

“To change the mindset in the Kansas City metropolitan area resulting in a sustained collaborative response that provides culturally competent, respectful, accessible, empowerment based services to women with disabilities who are victims/survivors of violence.”

Other activities during the first phase of the project revolved around building the collaborative partner's knowledge of both the unique needs of women with disabilities and the unique needs of women who are victims/survivors of violence. A community forum was also held in October of 2007 to share information with the Kansas City service provider community and to lay the foundation for future work together. In order to inform and ground the work of the Safety First Initiative in the community that it serves, an advisory group was also established at the onset of the project. The advisory group is comprised of key stakeholders within the Kansas City service provider community and includes representatives from disability service providers, victim assistance agencies, and women with disabilities.

During this first phase of the project, the collaborative also spent a significant amount of time designing and conducting a needs assessment in order to develop a strategic plan for addressing identified needs. Through this needs assessment, the collaborative hoped to identify the (a) range of currently available services, (b) the nature and accessibility of available services, (c) the incidence of violence against women with disabilities, (d) the collaborative system of response, and (e) needs for training and capacity building. The results of the needs

assessment will inform the development of a strategic plan with the purpose of improving services for victims/survivors of violence with disabilities. By building upon the needs assessment, the strategic plan will define strategies for addressing barriers, service gaps, and needed improvements in service models/systems. Implementation of the strategic plan will be the second phase of the project.

Purpose of the Needs Assessment & Research Questions

The overarching purpose of the needs assessment was to examine the collaborative system of response to women with disabilities who have experienced violence. As the rates of violence against women with disabilities are dramatically high nationwide, as well as in Kansas City, and these rates are likely underreported, the needs assessment sought to achieve a basic understanding about the incidence of violence against women with disabilities in Kansas City. Rather, a greater emphasis was placed on understanding the service system supporting women with disabilities who are victims/survivors of violence. Thus, the needs assessment was completed within the following purpose areas and with the following research questions:

- 1.) Range of Currently Available Services:** What is the range of services available for victims/survivors with and without disabilities?
- 2.) The Nature and Accessibility of Available Services:** Are available services empowerment-based, culturally responsive, and respectful?
- 3.) Incidence of Violence Against Women with Disabilities:** What is the incidence of violence against women with disabilities in Kansas City? *(Assumed to be underreported.)*
- 4.) The Collaborative System of Response:** How are domestic violence, sexual assault, and disability services integrated in a response to violence against women with disabilities?
- 5.) Needs for Training and Capacity Building:** What are the areas of needed information and training identified by service providers and women with disabilities?

METHODOLOGY

This needs assessment involved mixed methodology including both qualitative and quantitative data. The research design primarily followed a qualitative model of Participatory Action Research with a Naturalistic Inquiry design, supplemented with quantitative data. Because of a commitment to conducting a client-centered needs assessment, this study employed a Participatory Action Research approach whereby women with disabilities, their families, and other stakeholders are integral parts of the processes. The design of the research processes adhered to the research rigors of Naturalistic Inquiry (credibility, dependability, confirmability, and transferability). Finally, quantitative data, primarily in the form of analyses of existing data sources (i.e. agency databases), were used for the purpose of broadening the scope of the needs assessment beyond that which is feasible with qualitative efforts. All data, in narrative form, was thematically sorted into emerging themes.

By including stakeholders in the needs assessment process of inquiry, stakeholders will learn along the way about the current status of services for victims/survivors with disabilities, be better equipped to influence positive change, and be ready to join forces in implementing a strategic plan for improving services for women with disabilities who are survivors/victims of violence.

Data Sources

Data sources for this needs assessment included both qualitative and quantitative data, as well as relevant documents/materials (i.e. brochures, training manuals, web-based information, and screening tools). Qualitative data included interviews, focus groups, review of documents/materials in current use by relevant agencies and programs, and observational/field journals. Quantitative data included relevant pre-existing data sources.

The participants in this needs assessment included professionals, women with disabilities, families of women with disabilities, advocates, and survivors/victims with experience and knowledge about the service arenas of domestic violence, sexual assault, and disability services. Participation in the needs assessment study included options for being members of the research team, members of the advisory group, expert de-briefer, and key informants through interviews and/or focus groups. With particular regard to women with disabilities, it is important to note that because disability and the limitations experienced is a matter of perception, this target group was comprised of those who identified themselves as having a disability. Focus groups and interviews were conducted. Interviews with women survivors with disabilities occurred face-to-face. Focus groups and interviews were conducted using a semi-structured protocol consisting of guiding questions to facilitate a dialogue. For all focus groups and interviews, participants received information about the purpose of their project, were reassured that all information shared is kept confidential, and asked for their consent to continue. With the utmost regard for the protection of the participants rights, all protocols and processes were approved by a social science institutional review board.

Field notes consisted of case story records describing the services and responses of women reported to have a disability and to be receiving services from MOCSA or Rose Brooks. In total, ten case stories were collected. Other documents included review of (a) current training materials on maltreatment endorsed by the Missouri Department of Mental Health, Division of Developmental Disabilities, (b) definitions of abuse in state law, and (c) state policies in responding to abuse.

Table 1 lists the focus groups scheduled, representative stakeholder group, and number of participants, along with the number of interviews conducted and case stories provided.

Table 1. Needs Assessment Primary Data Sources

| Focus Group Date | Focus Group Participant Type* | # of Participants |
|------------------|---|--------------------------|
| 8/1/07 | Domestic Violence Provider | 10 |
| 8/3/07 | Disability Agency Provider | 3 |
| 8/8/07 | Women with Disabilities | 3 |
| 8/10/07 | Medical Service Provider | 0 |
| 8/13/07 | Direct Care Worker | 0 |
| 8/17/07 | Family Members of Women with Disabilities | 1 |
| 8/20/07 | Women with Disabilities | 2 |
| 8/22/07 | Law Enforcement Representative | 5 |
| 8/23/07 | Disability Agency Provider | 2 |
| 8/27/07 | Sexual Assault Agency Representative | 8 |
| 9/1/07 | Women with Disabilities | 0 |
| 9/25/07 | Family Members of Women with Disabilities | 0 |
| 9/26/07 | Disability Agency Provider | 2 |
| 1/23/08 | Disability Agency Provider | 11 |
| 4/9/08 | Disability Agency Provider | 15 |
| | TOTAL Focus Group Participants | 62 |
| | Interviews | # of Participants |
| | Disability Agency Provider | 8 |
| | Women with Disabilities | 1 |
| | Family Members of Women with Disabilities | 1 |
| | TOTAL Interviews | 10 |
| | Case Stories | # of Case Stories |
| | Rose Brooks Center | 5 |
| | MOCSA | 5 |
| | TOTAL Case Stories | 10 |

**Some service provider focus groups included women with disabilities who are service providers.*

Advisory Group

As a study employing Participatory Action Research, a nine member advisory group was established at the onset. The advisory group is comprised of key stakeholders representing domestic violence services, sexual assault services, disability services, medical services, women with disabilities, and family members of women with disabilities. The task of the advisory group is to offer insight, guidance, and support to the needs assessment process. Table 2 lists advisory group member roles and affiliation.

Table 2. Advisory Group Membership

| Role | Affiliation |
|--|--|
| Program Director | Special Neighbors |
| SANE Nurse | St. Luke's Hospital Emergency |
| Director of Quality Services | Alphapointe Association for the Blind |
| Self-Advocate | People First of Missouri |
| Director Advocacy and Support Services | Mental Health Association of the Heartland |
| Director, Independent Living Program | The Whole Person |
| Community Support Specialist | EITAS |
| Parent of a Survivor & former Board Member | MOCSA |
| SANE Nurse | Truman Medical Center-Hospital Hill |

Strengths, Challenges & Limitations

One of our most significant challenges was the recruitment of disability service providers and women with disabilities to participate in our needs assessment. When service providers were asked about their hesitation to participate, the responses included *“we provide a safe environment for women with disabilities; therefore the topic does not pertain to us.”* Or, from personal care providers we heard, *“I cannot bring my client to an interview or focus group. That would imply that abuse has occurred and it may have been my fault.”* A family member that attended a focus group opened the discussion by stating that, *“We should not be talking about this topic. It is too sensitive.”* These statements seem to suggest that there is a general discomfort with the topic.

Along these same lines, terminology may have also created an unforeseen barrier to needs assessment participation. Advertising for focus groups and interviews included the phrase *“violence against women.”* Upon discussing the reluctance of many disability service providers to participate in the needs assessment, one disability service provider pointed out that she does not use that term when discussing abuse and assault against women with disabilities, nor does she refer to any maltreatment as *“violence.”* A recent research article on the perceptions of people with disabilities regarding abuse used the terminology *“seriously wrong things some people do to people with disabilities (West, Gandhi & Palermo, 2007).”*

The strength of the needs assessment design was the flexibility that Naturalistic Inquiry afforded in order to get a broad based understanding of the perceptions of services for women with disabilities who are survivors of sexual assault and/or domestic violence. Additionally, the involvement of stakeholders in the needs assessment design and process has established some initial relationships for continuing to gather information and initiating a strategic plan. Overall, despite the challenge with focus group and interview attendance, the data reflects recurring themes across stakeholder groups as outlined in the following findings.

KEY FINDINGS

It should be noted that the Safety First Collaboration is statutorily prohibited from providing direct services or working within the criminal justice system in regards to this project. Rather, our focus is on creating sustainable systems change within the victims' services and disability service provider arenas. Thus, some of our needs assessment findings fall out of the scope of the recommendations that we are able to make.

1. Disability Service Provider Participation—

General Discomfort with the Topic

As previously stated, when disability service providers were asked about their hesitation to participate, the responses included *“we provide a safe environment for women with disabilities; therefore the topic does not pertain to us.”* Or, from personal care providers we heard, *“I cannot bring my client to an interview or focus group. That would imply that abuse has occurred and it may have been my fault.”* A family member that attended a focus group opened the discussion by stating that, *“We should not be talking about this topic. It is too sensitive.”* These statements seem to suggest that there is a general discomfort with the topic.

As a result of this hesitancy to participate, the majority of our findings are based upon input from victims' service agencies and women with disabilities. Where possible, we also incorporated information from disability service providers.

2. Range of Currently Available Services—

Services Are Available, Accommodations May or May Not Be

What is the range of services available for survivors with and without disabilities? The purpose of this question was to gain a general understanding of services available for women without disabilities in the Kansas City area as compared to services for women who have a disability. During this discussion in focus groups and interviews a recurring theme emerged. Service providers think services for women with and without disabilities in Kansas City exist. However, serving women with disabilities often requires accommodations, which may or may not be available.

In all focus groups and interviews, the types of programs available for women who are victims of violence were discussed. For example, one victim service provider explained: *“MOCSA has a program, Synergy has a program. Battered women's shelters will get in contact with someone with a program.”* Other focus group participants listed *shelter services, counseling services, or financial assistance* as services that are available to women. However, a disabilities service provider added that services are available for women who have experienced violence who have a disability *“if they can find them, if they are aware of them, and if they are referred directly to them.”*

Education and Awareness of Options

Many women with disabilities need more information so that they can feel safe and be safe. A family member of a survivor with a disability stated, *“I need to know services are available. I need to know who qualifies. I need to know what they qualify for. The basics, who, when, why and knowing that the services fit her needs.”* One domestic violence service provider echoed this comment, *“There are options out there. She just needs to know what those options are. Not everyone realizes that there are shelters out there, there are services out there. It is still amazing that people have no clue there are options.”* In reference to women with disabilities who are victims of violence and awareness of local resources, one local disability service provider stated: *“There is no targeted marketing to this group of people, you know, (saying) this is where you should go.”*

Accommodating Women with Disabilities

Domestic violence service providers felt that services in general were available for women, but may be limited due to space capacity.

“We may be a little bit more limited to how many we can accommodate at one time because of the number of handicapped beds or handicapped bathroom. But the services are available and if the whole facility is full then we can’t accept them. That is the same as if somebody doesn’t have a disability if they’re full they’re full.”

Overall, domestic violence service providers described a commitment to providing accommodations for women with disabilities. The types of accommodations described included providing interpreters, accommodations to the physical environment, and adapting therapy services. However, there are situations in which needed accommodations pose a challenge.

“I do think for most disabilities most shelters are able to provide accommodations, but there are some types that they may not be, for example when I worked at Hope House we had a lady that had a language barrier at the time we did not have an interpreter but we worked to get one, the same as wheelchair, I think when shelters are presented with these things they may not at first be able to accommodate but they will work to provide them accommodations.”

This same thread can be found in a field observation from a MOCSA volunteer about Jane, a woman that was sexually assaulted by her neighbor and was *“not able to access all counseling services due to her disability. In fact, if MOCSA did not have an outreach site within a medical facility, it is possible that she would not have been able to access counseling at all.”*

3. The Nature and Accessibility of Available Services—

Accessibility Goes Beyond Physical Accessibility, Services Should Be Respectful

The needs assessment asked the question, are existing services empowerment-based, culturally responsive, respectful, and accessible? Findings show that women with disabilities experience a wide range of accessibility issues when trying to utilize services. Commonly, these issues are beyond the need for physical accommodations. Rather, accessibility issues pertain to service location, service provider attitudes, and the understanding of the various issues women with disabilities face on a day-to-day basis.

Issues regarding accessibility and what makes a service accessible were brought up in nearly every focus group. While it is important that services and organizations provide physical accommodations, women with disabilities agree that it is often the subtle details that need also to be addressed, such as service provider attitude, service location, or understanding of the needs of women with disabilities that make services accessible. Women with disabilities want to access services with a feeling of empowerment. However, the opportunity to receive respectful, empowerment-based, services is often limited due to:

- challenges of transportation to and location of services;
- the tendency to not believe a woman with a disability when she reports an incidence of abuse;
- victim service providers' limited experience of working with women with disabilities;
- disability service providers' lack of acknowledgement and subsequent lack of knowledge of working with victims of trauma.

Much of the commentary from focus groups and interviews did not center on what service providers need to effectively serve women with disabilities. Rather, much of the discussion became about *what* effective services for women with disabilities look like. Overall, providing accessible services, information and education, safety planning, and most importantly services that are respectful make women *feel safe* to utilize those services and that equates to effective services.

Transportation & Location

Overall, transportation for people with disabilities is challenging. Affordable public transportation in Kansas City is sparse in general, but especially for individuals with disabilities. This lack of transportation tends to result in feeling isolated. *"Transportation is difficult for everybody. Location to me is another difficult thing. We tend to stay at home and stay out of the loop of everything, which makes us more vulnerable,"* commented a woman with a disability. For example, in the case of one survivor, her disability kept her isolated in a number of ways. She was victimized by abusive tactics at the hands of her batterer, one of which was being isolated from her family and friends. Although she is now divorced from her abuser, she still remains extremely isolated. She is a prime candidate for a support group so that she can

connect with other women experiencing similar symptoms of trauma. However, her disability makes it difficult for her to drive at night which in turn keeps her from attending and gaining the benefits of a support group.

Believing Women with Disabilities

While victim assistance agencies believe that their services are accessible and welcoming, women with disabilities are at times hesitant to access services due to the issue of believability. One woman with a disability shared, *“I need people to believe me right off the bat when I tell them something has happened. A lot of people assume that we are either making it up, or it wasn’t that bad.”* This statement was echoed by service providers, according to a disability service provider *“if they’ve got mental problems, it might not be believable.”* This issue is illustrated in one field observation of a woman with severe mental health issues that a MOCSA worker met at a psychiatric hospital because of her claims of sexual assault by her boyfriend. Due to her past history she was deemed not believable. As told by the MOCSA worker:

“She had presented a day or two before to the emergency room claiming she had been raped. The hospital social worker told us that because of her previous admission to the psychiatric ward, a Kansas City policeman refused to take a report and the hospital decided not to do a SANE examination of her.”

Other field observations provide evidence that underreporting occurs because women with disabilities themselves do not feel they will be believed. One example, a woman with a seizure disorder reported being sexually assaulted while in a seizure state. There was abundant physical evidence of the sexual assault. However, the woman refused to report the incident to police. Reporting of the incident was delayed because she thought it a possibility that the incident was a hallucination. She presented to the hospital 48 hours after the assault occurred. Because her memory of the assault was poor, she felt she would be treated with skepticism by the police.

Comments from a local disability service provider staff in regards to the incidence of violence against women with disabilities ranged from skepticism to grappling with the issue of consent.

“It (sexual violence) seems to come up a lot. What I mean by that is usually we have a false accusation and it can’t be substantiated. People do not understand their mandated responsibilities though.”

“We also have people who consent to sex and they get embarrassed about it and say they were forced or it wasn’t their choice.”

Believability was a common theme throughout this needs assessment. Service providers need to listen to and respect a woman with a disability’s input. One woman with a disability stated that *“staff is important. I need staff that understands me and listens to me.”* Women with disabilities require both victim assistance service providers and disability service providers to provide services where they know they will be listened to and believed. This in turn makes them feel that services are accessible and safe to utilize.

Knowledge & Experience

Providing services to women with disabilities requires consideration for the unique needs specific to the complexity of the disability and to the specific needs of victims/survivors of violence. Ideally, service providers understand (a) the need for privacy regarding the disability and associated needs, (b) respectful communication, and (c) the potential need for increased intensity of services due to the disability and the pervasive effects of trauma. In general, the focus group and interview respondents believed that this understanding would increase with experience. As one family member commented:

“People with disabilities need service providers that are aware of medical issues, ability to have more personal privacy, service providers need to be willing to get through the disability to the person. Service providers need to have some experience working with a disability.”

One woman with a disability commented that service providers who do not have experience working with people with disabilities are not always respectful in terms of communication. For example, they do not always listen or value their opinions. *“They (service providers) make assumptions about me, and they tell me that things are consumer run when they are not. I find myself being socially isolated and I have a hard time getting access to things I need.”*

Service providers echoed this statement, *“I think there are issues about people with disabilities- others that work with them are uncomfortable in communicating (trying to communicate) with them. There is a shyness about it and service providers come off as stand-offish.”*

It is also important to note that the limited participation of disability service providers in the needs assessment and their hesitancy in discussing the issue of violence against women with disabilities also points to the need for disability service providers to build their own knowledge and capacity in addressing issues of violence against women with disabilities. For example, on the topic of abuse by personal care attendants, when one local disability service provider staff member was questioned about the subject, they stated: *“I have heard about PCA violence but don’t know anything about it.”*

Lack of Peer Support

Many women with disabilities experience isolation from their peers, and from other forms of support on a daily basis. This can make them feel unsafe, according to one woman with a disability. *“It is important that women with disabilities have access to one another and to the support they need.”* This can include giving women with disabilities the opportunities to interact with others. As stated by a woman with a disability, *“My personal opinion is that we need more interaction among each other so that we know we are not alone. People with disabilities need to know they are not isolated.”*

Providing Safety

Though limited, responses from disability service providers illustrate their need to build their own capacity to effectively respond to women with disabilities who are victims of violence.

Safety planning was specifically identified as a need. According to one local disability service provider:

“We need safety planning pieces. Some of our more independent people can go out in the world without us, you know, they are at the bus stop by themselves and anything can happen.”

The Role of Advocates in Providing Effective Services

One issue surrounding provision of effective services that arose in the journal observations was the role of advocates in helping women not only navigate the system, but also in accessing services. This issue was also addressed in focus group and because of the times it was mentioned it is salient to the topic.

Advocates play many roles. One example of the many roles an advocate serves involves a woman with a sight disability who came to the Kansas City Municipal Court as a victim/witness in a domestic violence case, and who needed help in a number of areas. The advocate on the case coordinated with the case worker and helped the woman through the process of gaining an Order of Protection. The advocate also helped arrange transportation for all related court dates, explained court procedures and kept in contact with the victim for a number of weeks after.

4. Violence Against Women with Disabilities in Kansas City—

Incidence

What does violence against women with disabilities look like in Kansas City? Answering this broad question began with (a) gathering data reporting the incidence of abuse among women with disabilities receiving state provided services, and (b) gathering data indicating the numbers of women receiving services from the area domestic violence shelters and MOCSA who self-report to have a disability. These pre-existing data sources provide background and context for understanding what violence against women with disabilities looks like in Kansas City, although it should be noted that the incidence is likely underreported.

Incidence of Reported Abuse: Jackson County Missouri (2006-2007)

The Missouri Department of Mental Health (MODMH), Division of Mental Retardation and Developmental Disabilities (MRDD) provides support services to eligible persons and their families who have developmental disabilities. The Division provides a wide array of services from residential living facilities to community programs. An internal investigation is required when a consumer, a family member, or a service provider alleges abuse. Table 3 provides a snapshot of the 2006-2007 year as related to women with disabilities receiving MODMH services and the number of abuse investigations occurring that year in Jackson County Missouri. In Table 3 the data is sorted by type of disability, by age, and by the setting in which the alleged incident occurred. In total, there were 55 alleged incidents of abuse investigated in 2006-2007.

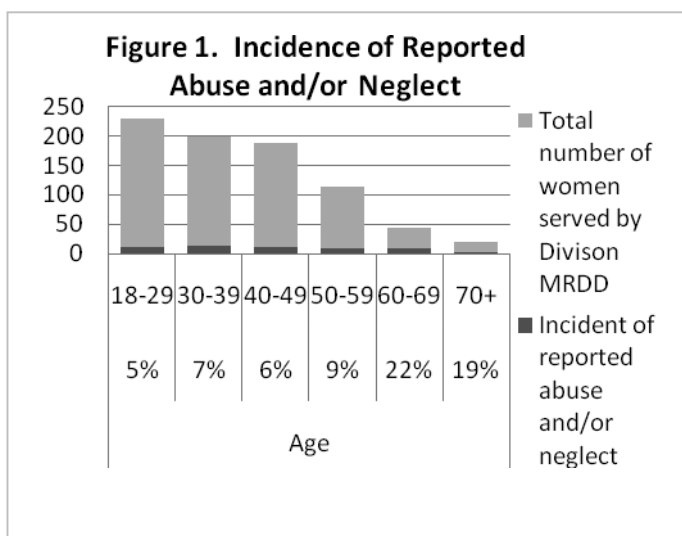
Table 3. Abuse Investigations, Jackson County Missouri, November 2006-November 2007

| | Type of Abuse | | | | Total |
|----------------------------|---------------|----------|--------|---------|-----------|
| | Sexual | Physical | Verbal | Neglect | |
| Disability | | | | | |
| Cognitive Disability Only | - | 6 | 7 | 13 | 26 |
| Physical Disability Only | 1 | - | - | - | 1 |
| Multiple Disabilities | 2 | 9 | 5 | 8 | 24 |
| Other | - | 3 | 1 | - | 4 |
| Age | | | | | |
| 18-29 | - | 5 | 2 | 4 | 11 |
| 30-39 | 2 | 4 | 3 | 4 | 13 |
| 40-49 | 1 | 6 | 3 | 1 | 11 |
| 50-59 | - | 2 | 3 | 4 | 9 |
| 60-69 | - | 1 | 1 | 6 | 8 |
| 70+ | - | - | 1 | 2 | 3 |
| Setting | | | | | |
| ISL | - | 12 | 6 | 16 | 34 |
| Group Home | 3 | 4 | 7 | 4 | 18 |
| Day Habilitation | - | 1 | - | 1 | 2 |
| Other Community Setting | - | 1 | - | - | 1 |
| Total 55 alleged incidents | | | | | |

Approximately 40% of the investigated incidents involved women with multiple disabilities. Multiple disabilities included combined cognitive and physical disability, and in some cases, the addition of a mental illness. At approximately an equal count, twenty-seven women were diagnosed with a cognitive disability ranging from mild to profound. Across the span of age, diagnosis, and setting, a majority of the investigations were of alleged neglect, followed closely by physical abuse. It is interesting to

note that while the number of investigations relating to sexual abuse is low, they all involved women with either physical disabilities as a diagnosis, or women with multiple disabilities. All three alleged incidents occurred in a group home setting.

In comparison with the total numbers of women served by the Division of MRDD, the overall rate of reported abuse and neglect is 7%. As shown in Figure 1, the greatest incidence rate is among women ages 60 and older (19-22%). Among women in the other age brackets, an approximate rate of 7% was consistent.



Incidence of Self-Report Disability: MOCSA

In 2007, 176 out of 993 women (17.8%) utilizing MOCSA services reported having a disability, with the largest percent self-reporting a mental health disability (58%). Over twenty-one percent of women reported having a physical disability. Women self-report at time of intake. Table 4 provides more detail.

| Type of Disability Reported | Number of Self Reports | Percentage |
|----------------------------------|------------------------|-------------|
| Physical disability | 38 | 21.6% |
| Mental Health disability | 102 | 58.0% |
| Developmental disability | 17 | 9.7% |
| Dual disabilities | 14 | 8.0% |
| Other disabilities-not specified | 5 | 2.8% |
| Total reported disability | 176 | 100% |

Incidence of Self-Report Disability: Domestic Violence Shelters

Approximately half of the women served by Rose Brooks Center self-reported a disability in 2007. Women self-report at intake. Intake data elements are tracked in the Alice Database, shared by the Kansas City metropolitan area domestic violence programs. The program allows each agency to generate agency-only reports and aggregate reports for all domestic violence programs and agency clusters. Forty percent of women utilizing all domestic violence shelters (Rose Brooks Center, Kansas City; Newhouse, Kansas City; Hope House, Independence and Lee's Summit) in the Kansas City area reported having a disability. Detailed counts from the Rose Brooks Center as well as all domestic violence shelters in Jackson County may be found in more detail in Table 5 and 6.

| Type of Disability Reported | Number of Self Reports | Percentage |
|--|------------------------|--------------|
| Physical disability | 53 | 20.9% |
| Mental health disability | 57 | 22.4% |
| Developmental disability | 8 | 3.1% |
| Physical disability and mental health disability | 15 | 5.9% |
| Total Reporting Disability | 133 | 52.3% |

| Type of Disability Reported | Number of Self Reports | Percentage |
|--|------------------------|--------------|
| Physical disability | 219 | 17.6% |
| Mental health disability | 247 | 19.8% |
| Developmental disability | 13 | 1.0% |
| Physical disability and mental health disability | 21 | 6.2% |
| Total Reporting Disability | 500 | 40.1% |

5. The Collaborative System of Response—

Gaps in Linkages Between Service Providers

How are community agencies and services integrated in Kansas City? The needs assessment identified the ways that community agencies, programs, and systems are integrated in an approach to providing a collaborative response to violence against women with disabilities. The results indicate gaps in the linkages between services in Kansas City for women with disabilities who are survivors of violence and indicate the critical need to build relationships between service providers, specifically between victim assistance agencies and disability service providers. Beyond the gaps in linkages between service providers, findings also include the need to build the capacity of service providers to meet a variety of disability needs.

Service providers and family members alike agree there are issues not being addressed for women with disabilities who have experienced violence because victim services and disability services are not linked together in a way that can address the specific needs of women with disabilities who have experienced violence. Service providers and women with disabilities emphasized the point that victim services for women with (or without) a disability exist, however, they are in their own isolated pockets and are difficult to access—especially for women with disabilities. One illustrative comment from a woman with a disability was:

“Women’s services, [are needed] period. I mean, there are a lot of little separate kinds of places, but there isn’t one place to go to, like a one stop shop. So I would like something like that.”

Disconnects Between Provider Agencies

One theme that arose from the focus groups is the disconnect between victims’ assistance providers and disability service providers. Many providers said they didn’t know about services for women with disabilities and that services for them are lacking. One service provider expressed frustration with the lack of services available:

“I am noticing that in the forensic program I work with, we are seeing more people with disabilities that are victims of violence. Nurses in the nursing homes are reporting more assault, sexual and physical stuff. They have begun to have the training, so they recognize it better. But even so, there are just no services for them [people with disabilities that are survivors of violence], you know, you are just kind of challenged-I mean, are we sending them back to a safe environment and are there any services available in those environments?”

Service providers may know of one or two organizations that may provide some basic services, but their knowledge of resources for women having disabilities does not go beyond the basic. As a law enforcement officer observed, *“You know, generally we use Rose Brooks as a viable*

resource for a lot of our victims and, I think we just kind of leave it at that and hope that if somebody [with a disability] needs additional resources, that Rose Brooks handles that." Victim assistance agencies conveyed a lack of awareness about the available resources in the disability service provider community. One journal entry provided the example of Aliah, a transitional housing resident, and her ability to manage her income. *"Staff is very concerned the resident's problems with bill paying, spending beyond her means and giving away her money to family and friends will create a huge risk for being abused again."* In a follow-up interview concerning Aliah, the transitional housing coordinator was asked if the team had consulted with a disability provider who helped persons with cognitive developmental or other disabilities. They had not talked to anyone outside of the team and were not aware of any agency providing these services. This demonstrates the lack of knowledge that some service providers have of women with disabilities or available services to help them.

Capacity to Provide for All Disability Needs

Other services providers are in agreement that basic needs can be addressed but their particular organization lacks the capacity to address other more specific needs without help or support from other organizations. As summarized by one sexual assault service provider expressing her frustration:

"I sometimes feel, as a service provider, that the needs of people with disabilities are just way over our heads. We can offer advocacy, and counseling. But sometimes the needs are so astronomical that not even our social workers can deal with them. These people have disabilities, and I just think the services are very, very, lacking."

6. Needs for Training and Capacity Building—

Building Relationships and Knowledge

How do service providers describe their ability to accommodate women with disabilities? Results from the focus groups and interviews indicate that service providers lack training relating to disability, sexual assault and violence. Similarly, the findings also show that women with disabilities lack awareness and training on the same related issues. Service providers indicated the need for more awareness and training on issues related specifically to disabilities. Service providers are concerned that their lack of knowledge about issues regarding disabilities prevents them from providing or finding the proper services. The lack of education and training on related issues also widens the chasm between the services provided (or lack thereof) and the services needed.

Service providers, law enforcement, and the community at-large need information and training, and to build capacity on issues related to violence against women with disabilities. Victims assistance agencies need education on disabilities related issues, how they address women with disabilities, and the terminology used when talking about people with disabilities.

Disability service providers need education on how to address issues of violence and the women they serve. Women with disabilities need awareness and training on how to speak up (such as saying no), where to go, and how to report. In other words, *“Information needs to get out to everybody from providers to people with disabilities.”*

Training Initiative for Disability Service Providers

The full extent of training related to abuse and violence is not known. Every service provider follows their own protocols in terms of educating their employees. Training is available through The Missouri College of Direct Support for disability service providers on maltreatment for vulnerable adults and children. The unit on maltreatment is divided into five learning objectives that discuss abuse, neglect, and exploitation: defining, prevention, reporting, documenting, and follow-up. Disability service providers are provided information on each section related to the learning objective of the course. The goals of the course are to identify, protect, and effectively document incidences of maltreatment on vulnerable adults and children. Kansas City is not currently taking full advantage of this resource. Only four organizations and 22 learners in total are participating in the training program.

Sensitivity Training for All Service Providers

During one focus group a service provider who happened to be a woman with a disability expressed the need for disabilities sensitivity training and/or awareness for service providers:

“Even people in my own field, my peers use words like ‘higher functioning’ or ‘lower functioning’. That implies that somebody’s..... I don’t know, it is that whole terminology for example, implying that someone is lazy when they may actually be on four and five medications that make them tired. I think education and awareness about the fact that we are just people is really a need. I have had psychiatrists tell me I need my medication tweaked, and they use words like, ‘decompensate’. I am not a humidifier, I am a person.”

Illustrating the need for sensitivity training, a Domestic Violence Service Provider observed:

“Just having knowledge of the resources for each kind of disability and perhaps having a good understanding of different cognitive or mental disability-so you get whether or not someone might have an issue with being touched in certain ways, addressed in certain ways.”

Knowledge of every specific disability is not necessary to provide services. Rather this statement illustrates a need for awareness and sensitivity training on the part of service providers.

Need for Education for Women with Disabilities

Service providers stated the need for awareness and education for women with disabilities. Women with disabilities are often reluctant to say, “No” either because they do not understand

“No” to be an option or they may fear the consequence of saying, “No.” Also, women with disabilities may not understand how to keep themselves safe or how report an abusive incident if it happens. In a dialogue among disability service providers the following comments were shared.

“We provide education to women with disabilities. And there again, on the education side there are a lot of women with disabilities that first of all do not know that they can say ‘no’. They don’t know how to go about reporting it [violence or assault], and they do not know how to keep themselves safe once they do [report it]. Education and communication between women with disabilities is crucial.”

In a focus group for law enforcement officers, additional training needs for both women with disabilities and law enforcement officers were identified. *“I think there definitely needs to be some education for us on what resources are available for people with disabilities. But there is also a need for training from us to women with disabilities on what we have to do [to investigate a case].”*

Capacity Building

As our goal is to create sustainable systems change, training in and of itself is not sufficient. The Collaboration believes the need for training also speaks to the need for relationship and collaboration building. Furthermore, training should also be accompanied by necessary and appropriate changes in policies and standards of practice. In essence, the Collaboration believes that training should be part of a larger plan for capacity building: capacity building for victims’ assistance agencies in serving women with disabilities; and capacity building for disability service providers in serving victims/survivors of violence.

With regards to the Collaborations’ support of capacity building, the collaborative partners believe capacity building should begin with building relationships and supporting our own capacity in a specific, focused manner. Meaning, by focusing on changes within our own organizations and with a select few partners, we will be able to serve as the example of change for others to follow.

IMPLICATIONS

The results of the needs assessment indicate multiple areas of need, service gaps, and system issues. As identified in the discussion of the findings, the most prominently reported needs are building community linkages between victim service agencies and disability service providers, improving services for women with disabilities that have experienced violence, and increasing opportunities for training and capacity building. Gaps in services included the need for peer support and safety planning education for women with disabilities. The identified system issues were fundamental in nature with a need to cultivate leadership buy-in and partnerships for building a community-wide response system. The following section discusses the needs, service gaps, and system issues. However, it is important to note that there is much overlap across the three areas. For example, recognition of and response to a need for training and capacity building will have an effect on improving services and likewise, critical to improving services is addressing the need for training and capacity building.

Addressing Needs for Service System Enhancement

The needs assessment revealed an array of services for women with disabilities that have experienced violence exist, and in general, service providers share a commitment to accommodating women with disabilities who are victims/survivors of violence. However, service providers and women with disabilities identified numerous ways in which program enhancements would improve services, thus promoting “comfort, control, and confidence” for women with disabilities.

Building Community Linkages

Domestic violence and sexual assault providers shared that they were unfamiliar with the range and types of services women with disabilities commonly receive that supports their daily life. Similarly, the disability service providers reported being unfamiliar with the range of service options for women with disabilities who have experienced violence. This cross-discipline unfamiliarity is an obstacle to providing effective services for women with disabilities. By creating opportunities for cross-discipline sharing and collaboration, familiarity will increase and linkages between services arenas will facilitate the coordination of services for women with disabilities.

Improved Services for Women with Disabilities

Stakeholders identified a critical need for improved services for women with disabilities; both in existing services and in future services. Services should be accessible and empowerment-based resulting in services that provide comfort, promote confidence, and afford women with disabilities control. Planning for improved services should begin with consideration for how the woman with a disability is going to access the services. Specifically, consideration begins with planning for how the woman will get to services and if the services are tailored such that she is able to experience the full benefits. The needs assessment findings indicated that women with

disabilities are isolated from services and peer support, often due to lack of transportation and tendency to not be believed. Improving service accessibility would increase the likelihood that women with disabilities would utilize services.

It is also important to re-iterate the meaning of accessibility. Accessibility does not relate to mere physical accessibility. Accessibility also encompasses the realms of the communication environment, the information environment, and the social and policy environment. This expanded view of accessibility came through in the needs assessment, although needs assessment feedback may not have necessarily been expressed using these terms, the idea that accessibility is more than just physical was expressed and accessibility was discussed in almost every focus group.

Increased Opportunities for Training & Capacity Building

Findings from the needs assessment highlight the need for more training in identifying the needs for services as well as the provision of services. Service providers need more information regarding cross-discipline practices and philosophies, respectful communication with women with disabilities, strategies for addressing the unique needs of women with disabilities, strategies for addressing the pervasive needs of trauma victims/survivors, and connecting women with disabilities to the range of services they need.

Domestic violence, sexual assault, and disability service providers shared the perception that they need additional training in order to provide ideal services for women with disabilities who have experienced violence. Disability service providers need more information on serving women with disabilities who have experienced violence. The expressed reluctance to participate in the needs assessment process among disability service providers suggests a need to focus attention on building relationships and increasing opportunities for information to be shared across disciplines. This would facilitate collaboration, stimulate new awareness of issues related to women with disabilities, and improve services such to be more responsive.

Gaps in Services for Women with Disabilities

In the needs assessment, women with disabilities as well as service providers identified a need for peer support, education, safety planning, and advocacy. While each of these services may be available at individual agencies, there is no one system addressing these four needs. Women with disabilities, as well as service providers, indicated a need for peer support. In particular, women with disabilities wanted the outlet to talk to other women with disabilities that have experienced violence. Disability service providers shared that women with disabilities need an understanding and strategies about how to keep themselves safe. Lastly, the needs assessment identified that advocates providing guidance to women with disabilities who have experienced violence and are navigating the system of services, would be beneficial. Currently, advocates are available through the domestic violence shelters, MOCSA, and the court system. However, the advocates are not necessarily linked to any disability service providers making it difficult to provide seamless support for victims/survivors with disabilities.

Systems Issues

As referenced in the methodology and apparent in the findings, there was reluctance among disability service providers to participate in the needs assessment process. Much of this reluctance was due to the perception that the issue was not applicable to their service setting or to the women with disabilities they serve. Additionally, direct service providers expressed concern that participation in the needs assessment would imply wrongdoing on their part, or on the part of their organization. To expand awareness of the issue, collaborative opportunities between domestic violence, sexual assault, and disability service providers should be fostered. Leadership/administrative staff (i.e. executive directors and program directors) need information about the issue and shared responsibility in addressing the needs of women with disabilities who have experienced violence. Furthermore, in order to address the perceived stigma and culpability among direct service providers, leadership staff should support frontline service providers with needed information about their responsibility in responding to women who report abuse and strategies and resources for supporting women.

RECOMMENDATIONS, STRATEGIES & CONCLUSION

The following recommendations and strategies translate the findings and implications into suggestions for implementation. Overall, there are six recommendations. These six recommendations address the integrated nature of the findings and implications by involving the collaborative and community agencies at multiple levels.

1. Always involve women with disabilities at every stage of implementation.
2. Devote time and energy to building partnerships between victim assistance providers and disability service providers. This is in response to the hesitancy of disability service provider participation in the needs assessment.
3. Address system challenges as well as the need for program enhancements. A suggested strategy is to form an advisory group of agency leaders (i.e. executive directors) who have the authority to designate resources to this issue, as well as have community presence and influence, to address gaps in services and training needs. Needs for program enhancements can be discussed and strategies for addressing needs can be problem solved.
4. Build the capacity of collaborative partners to enhance existing programs and address service gaps. One strategy is to provide training to all partner agency staff as well as cross-agency training. Another strategy is to designate and support an agency individual as the “champion” on this issue. This role of champion would be a primary resource to facilitate information sharing across disciplines as well as be a resource for women with disabilities. A third strategy would be for the Collaborative partners to build on existing services in order to better serve women with disabilities who have experienced violence.

5. Address the need for improved services by looking first within the core collaborative partner agencies. Issues of accessibility of facilities, policies, and practices should first be addressed by these agencies and then lessons learned will be valuable to share with the community.
6. The final long-term recommendation is to provide broad-based community awareness with a goal of improving collaboration across disciplines and reducing the perceived stigma associated with the topic of violence and sexual assault. Strategies for the Collaborative include providing leadership to community agencies in the forms of (a) awareness campaigns and training opportunities, (b) becoming a community resource for information, and (c) constructing a system of ongoing information, data, and response.

The overarching finding of the needs assessment is that there is a pervasive need for basic information and general awareness about the needs of women with disabilities who have experienced violence. In general, the reluctance among disability service providers to participate in the needs assessment is telling of the need for relationship building between victim assistance agencies and disability service providers, combined with the need for information on the topic. The comments from domestic violence and sexual assault providers identified a commitment to serving women with disabilities, but unfamiliarity about how to best do so. Women with disabilities are often faced with the additional barriers of not being believed, not being able to get to services, and the assumption that services will not be appropriate for them because of their unique needs. Conducting the needs assessment has begun the community discussion on this issue, but much dialogue and relationship building is still needed to enhance services for women with disabilities who are victims and survivors of violence. In order for women with disabilities who are victims and survivors of violence to have the “comfort, control, and confidence” they need, the Kansas City service system must enhance both the capacity of and coordination of victims’ services and disability services to appropriately meet the needs of women with disabilities.

