

“Nothing About Us Without Us”

“ . . . there is a saying in the disability community ‘Nothing about us without us.’ What that means is that people with disabilities are essential in every discussion about meeting our needs. If none of the people doing the planning have disabilities themselves, important perspectives are lost on what will truly be meaningful to people with disabilities.”

-A survey respondent

Acknowledgements

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- Ellery Russian, Communities Against Rape and Abuse, *Project Partner*
- Leigh Nachman Hofheimer, Washington State Coalition Against Domestic Violence, *Project Partner*
- Gretta Fiske Jarolimek, Alternatives to Violence of the Palouse, *Pilot Site Co-Leader of the Co-Advocacy Disability and Domestic Violence Task Force, Pullman, WA*
- Marshall Mitchell, Washington State University, *Pilot Site Co-Leader of the Co-Advocacy Disability and Domestic Violence Task Force, Pullman, WA*
- Nancy Eichenberger, DV Center of Grays Harbor, *Pilot Site Co-Leader of the Co-Advocacy Task Force, Hoquiam, WA*
- Robin Sutherby, Self-advocate, *Pilot Site Co-Leader of the Co-Advocacy Task Force, Hoquiam, WA*

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Title taken from James Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment*, University of California Press, 1998, a leader in the disability rights movement in the United States

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Introduction

What is the Disability Advocacy Project¹ of the Washington State Coalition Against Domestic Violence (WSCADV)?

In 1999, the Washington State Coalition Against Domestic Violence (WSCADV) approached Abused Deaf Women's Advocacy Services (ADWAS) to help initiate a statewide domestic violence and disability advocacy project. WSCADV worked with ADWAS to convene 2 community meetings of 120 representatives from domestic violence and disability service providers, state agencies, and survivors – 60% of attendees were people with disabilities. We observed a wide divide between the two fields about the meaning of survivor self-determination and safety, best practices for advocacy, and even the definition of domestic violence. Battered women's shelters view victims with disabilities as a "hard to serve" population beyond their capacity to help, and disability advocates tend to have limited information about the dynamics of domestic violence. Yet, the stories of survivors at the meetings confirmed high incidence rates of abuse experienced by people with disabilities and an apparent inability to intervene among service providers and institutions, and these insights helped shape our Disability Advocacy Project design.

In 2002, WSCADV obtained funding to expand the work of the Disability Advocacy Project. Communities Against Rape and Abuse (CARA) and Washington Protection and Advocacy System (WPAS) joined our efforts as **Project Partners**. The project partners served on the initial training faculty, helping to develop an educational and resource manual to increase the skills of domestic violence advocates, along with producing training curricula and model protocols, and advising on all phases of the project.

Who Are the Project Partners?

Washington State Coalition Against Domestic Violence (WSCADV) has served as a non-profit network of over 60 community based domestic violence programs in Washington since 1990. **Leigh Nachman Hofheimer**, Program Coordinator, co-leads the *Disability Advocacy Project*, which she initiated. She has 20 years of experience in domestic violence advocacy, training, curriculum development, building collaborations and systems advocacy.

¹ When we use the term "disability," we are including the Deaf community and different parts of the Deaf community. We know that many communities use Deaf and disability as separate terms. We use the term disability inclusively and also believe that people with disabilities who are talking about "disability culture" can learn from the experiences and model of Deaf culture and pride.

Abused Deaf Women's Advocacy Services (ADWAS) was the first organization in the country to provide fully accessible services to Deaf and Deaf-Blind victims of domestic violence and sexual assault. ADWAS is led and staffed by Deaf people. With the support of a U.S. Department of Justice grant, 15 Deaf communities around the country have worked with ADWAS to start their own programs. In addition to victim advocacy, ADWAS trains, publishes educational materials, and staffs the TTY line for the National Domestic Violence Hotline. ADWAS is developing the first transitional housing project for Deaf/Deaf-Blind domestic violence survivors in the nation. **Cathy Hoog**, Social Change Specialist, co-leads the *Disability Advocacy Project*. She is Deaf and grew up in a Deaf family. She has 24 years of experience working with people who are Deaf or Deaf-Blind, including individuals with a wide range of disabilities.

Communities Against Rape and Abuse (CARA) emerged in 2000 out of community organizing to undermine the root causes of sexual violence by a group of activists in Seattle, Washington. CARA promotes a broad agenda for liberation and social justice while prioritizing anti-rape work. CARA operates a Black People's Project, a Young People's Liberation Project, a Safety Project and a Disability Pride Project. **Ellery Russian** staffs the Disability Pride Project, which organizes people with disabilities through healthy sexuality workshops, a sexual assault support group, peer education and building self-advocacy skills, activism against involuntary institutionalization, and an annual community art exhibit.

Washington Protection and Advocacy System (WPAS) is the state-designated, federally mandated protection and advocacy agency for Washington State. WPAS has been a leader in efforts to stop abuse in state institutions and in the community. In recent years, WPAS successfully brought lawsuits that address serious abuses in psychiatric hospitals and in the community. WPAS has become active in organizing, training and policy work to fight the widespread abuse – particularly domestic violence and sexual assault – of people with disabilities. **David Lord**, J.D., MSW, has been a staff attorney for WPAS since 1994. He trains, consults and advances the WPAS public policy agenda. He has over two decades of experience working in the disability community.

Goals of the Disability Advocacy Project for 2004 - 2006

- Improve the safety and autonomy of victims with disabilities in their own communities.
- Encourage partnerships and co-advocacy between domestic violence and disability advocacy groups.
- Support leadership by women with disabilities to identify informal

ways that survivors seek to increase their own independence and safety, especially those who cannot or will not use crisis services.

- Help domestic violence shelter programs increase physical and service delivery accessibility as well as local partnerships with disability groups.
- Increase advocacy skills among advocates.
- Document a wide range of community-based strategies for advocacy and action.

Pilot Site Projects

Funding allowed the *Disability Advocacy Project* to offer an exciting project that would promote community mobilization and co-advocacy between domestic violence and disability advocates at the local level by developing pilot site projects in two communities (one rural and one urban) in Washington State. The two selected pilot sites were: Alternatives to Violence of the Palouse in Pullman, WA (rural area) and DV Center of Grays Harbor in Hoquiam, WA (small urban area). The length of the pilot site project is December 2004 – September 2006.

The main activity of the pilot sites was to organize a local domestic violence and disability task force and support a co-advocacy approach to work with survivors with disabilities. Each pilot site task force was co-led by a local community-based domestic violence victim service agency and a person with a disability who is a self-advocate or works with a disability advocacy organization or group. The task force was required to have a significant number of people with disabilities as members. The Project Partners of the Disability Advocacy Project provided ongoing technical assistance, site visits and support to each pilot site.

Within this report, each pilot site tells their story of recruiting members, building relationships and identifying access issues that changed practices within the domestic violence victim service agency and in their community partnerships. In the future, they will continue to work together to support the autonomy and safety of survivors through domestic violence advocacy.

Goals of the Pilot Sites

- Increase comprehensive access to domestic violence advocacy programs and support for people with disabilities experiencing domestic violence.
- Increase leadership of people with disabilities on the subject of domestic violence.

- Strengthen community partnerships between disability advocates and domestic violence advocates.
- Help WSCADV identify specific barriers to access and possible issues for policy reform.

Each pilot site accomplished the following activities:

- a) Developed a local task force with shared leadership by disability and domestic violence advocates, people with disabilities and survivors.
- b) Recruited local community members, advocates and service providers who could talk about the experience of living with a disability and the impact of domestic violence in the lives of people with disabilities.
- c) Project Partners provided cross-training to the task force on domestic violence and disability.
- d) Completed the WSCADV self-assessment guide on domestic violence and disability to improve the accessibility and community partnerships at the local domestic violence program.
- e) Identified local community resources and barriers for victim access, self-determination and safety.
- f) Prioritized the work of the task force and plans for improving access to domestic violence services.
- g) Developed sustainability plans to continue task force activities.

Women with Disabilities Leadership Initiative

The Disability Advocacy Project partner, Communities Against Rape and Abuse (CARA), initiated a public discussion series in 2005 attended by women survivors with disabilities in Seattle. The title of the series was “What's the Deal?: Sharing our personal experiences of the politics, tricks and skills of ‘dis’ability.” Many participants commented that they had never before been in such a diverse group of people with disabilities.

Out of this discussion series, informal leadership emerged from survivors who were participants. The Project Partners engaged in one-on-one conversations with these survivors to identify strategies these women used to find support from family and friends, navigate institutional barriers to safety and otherwise increase their autonomy despite their abuser’s attempts to undermine their decision-making and safety.

Goals of the Women with Disabilities Leadership Initiative

- a) Identify peer-to-peer education models on informal ways that women find support from family and friends, navigate institutional barriers to safety, and otherwise increase their independence from an abuser and from institutions.
- b) Identify how domestic violence and disability agencies can support the development of these peer-to-peer strategies.
- c) Write a report about the project for community members and service providers, so they can learn about the experiences of violence and abuse among people with disabilities.

In This Report

Chapters One and Two – Pilot Site Projects in Pullman and Hoquiam, Washington: These chapters chronicle the story of two different pilot site projects that have successfully connected disability advocates, and social service providers with their local domestic violence program. In most cases, the domestic violence and disability advocates involved had not previously known each other. Each pilot site project and the task force they set up is a model of building bridges between complex experiences.

Chapter Three – Discussion Series and Women with Disabilities Leadership Initiative: Through a public discussion series and personal conversations, the Disability Advocacy Project learned from women with disabilities who encountered and overcame barriers to self-determination and safety. Survivors shared their experiences of operating outside traditional social service systems and government agencies to find support, protect their autonomy and increase their safety. Their survival and coping strategies can help us think about which barriers to access are the most important to remove, how to develop effective advocacy practices and identify system reform issues.

Chapter Four – Disability Advocacy Project Survey: In November 2005, the Disability Advocacy Project conducted a statewide survey to identify barriers that people with disabilities face and ask how these barriers impact survivors of domestic violence. This chapter provides an analysis of the data that was collected. The survey responses will guide the future activities of the Disability Advocacy Project and its partners.

Chapter 1

Pilot Site Project Alternatives to Violence of the Palouse, Pullman

Charting a New Course for Accessing Domestic Violence Services: No Maps, No Guides, No Problem!

Background On Pilot Sites

The Disability Advocacy Project offered a new pilot project in 2004 to promote community mobilization and co-advocacy between domestic violence and disability advocates at the local level. Two sites would be selected in different communities (e.g., one rural and one urban) in Washington State. The two community-based domestic violence victim service agencies that participated as pilot sites are: Alternatives to Violence of the Palouse in Pullman, WA and the Domestic Violence Center of Grays Harbor in Hoquiam, WA.

In both pilot site communities, the task force members had representation from social service agencies, disability advocacy agencies, domestic violence advocacy agencies and individuals with disabilities (self-advocates). In their communities, social service agencies provide available state or federal medical or economic assistance and help individuals navigate the social service system. Employees are often in the role of case worker/manager or supported employment worker. Disability advocacy agencies are generally private non-profits directed by people with disabilities on behalf of people with disabilities and provide services such as advocacy with systems that people with disabilities use. Additionally, disability advocacy agencies provide individual advocacy to support a person's ability to living independently in their community. Community-based domestic violence agencies are private non-profits which, like disability advocacy organizations, are guided by the experience of survivors and offer services that range from 24-hour crisis lines, emergency shelter, support groups and individual and system advocacy on behalf of survivors of domestic violence.

The main activity of the pilot sites was to organize a local domestic violence and disability task force and support a co-advocacy approach to work with survivors with disabilities. Each pilot site task

Create opportunities for leadership for persons who have not previously come to the table, persons with disabilities.

force was co-led by a local community-based domestic violence victim service agency and a person with a disability who is a self-advocate or works with a disability advocacy organization or group. The task force was required to have a significant number of people with disabilities as members.

In The Beginning

At the outset, it seemed like most projects we have embarked on as a dual domestic violence and sexual assault advocacy agency. Gather up individuals in your community, find folks who are willing and able to be stakeholders and start up a task force to discuss the co-occurring issues of domestic violence and disability. There have been ample studies that prove the relationship between the two, so surely we would be picking up where other groups have left off; surely there would be some sort of a framework that we would be using. In the first conversations Alternatives to Violence of the Palouse (ATVP) had with the Project Partners (WSCADV, ADWAS, WPAS), it became clear that this would be different. Rather than telling us what was required, the Project Partners were fairly cryptic. While we certainly appreciated the concept of going where the community took the idea, the lack of structure initially felt foreign and insecure. The lofty goals were laid out for us by the Project Partners, but it was up to us to apply these goals to our community to enhance access for victims of domestic violence with disabilities.

Partnering

A definite strength of the pilot project design was the use of co-leaders, one representing the domestic violence community and one representing the disability community. One thing that the Project Partners were explicit about was that this would be a co-led venture. Project Partner David Lord of Washington Protection and Advocacy System provided Gretta Fiske Jarolimek, ATVP's Coordinator of Sexual Assault Services, with the initial referral to a disability advocate in our community, Marshall Mitchell. This co-leader referral proved to be a crucial part of the success of this venture. Marshall was serving as Washington State University's ADA Compliance Officer at the time, although true to university culture, he was doing much more, including teaching several courses in the Disability Studies Program. Marshall proved to be the perfect project co-leader for Gretta. He recognized the problem, was advocacy-minded, and had plentiful connections to possible task force members.

Seeking Membership

Typically, when agencies like Alternatives to Violence are tasked with

coalition-building with a specific community, they go straight to other service providers. The “solutions” that professional task forces devise is fairly predictable: when a group of attorneys are gathered together, their solution may be a lawsuit; when a group of medical personnel are gathered, their solution is typically based on pathology; when social service providers gather, the solution is inextricably informed by their role as professional helpers. If the project’s goal was simply to educate service providers regarding the connections between disability and domestic violence, a task force composed of service providers would be a good fit. But the purpose of the project was to create opportunities for leadership for persons who have not previously come to the table, persons with disabilities. At ATVP, we learned that asking people what they need and listening to their experiences is the best way to guide our advocacy practices, remove barriers to our services and support the self-determination of survivors. It is by bringing together the collective knowledge of persons with disabilities and survivors of domestic violence that we can ultimately construct the most focused and pertinent solutions for disability communities.

Marshall’s experience was essential in connecting with people with disabilities in the recruitment phase of the project. It seemed like he knew everyone who was anyone in the disability communities in our region. In Gretta and Marshall’s first meeting together, they came up with a list of community members who were leaders in their own right – people with lived experience as persons with disabilities, survivors of domestic violence and sexual assault, persons who had something personal and professional to offer.

After about three weeks of calling prospective task force members, chatting with them over the phone and exchanging e-mails galore, Marshall and Gretta eventually wooed ten people to join the task force. When recruitment was done, Gretta was the *only* person on the task force without a disability and nearly everyone had some sort of personal experience with domestic and/or sexual violence. In ATVP’s experience, this group of individuals was already looking quite unlike most other task forces they had worked with. Hope (and a bit of trepidation) filled the air as the co-leaders embarked on this new venture with no road map to guide them.

It became clear early on that without a map or forced goals you can really get lost. Not lost in a bad way; not lost in the traditional sense of the term, but lost in relationship to what you thought you knew about facilitating professional meetings. Coming to the table and actually meeting with our task force membership, the co-leaders quickly learned that domestic violence agencies have a lot to learn from people with disabilities and that nothing that is done “for” them

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should be done without their direct feedback and support. James Charlton's seminal text, *Nothing About Us Without Us*,¹ is right on when it comes to explaining the absolute necessity of partnering with persons with disabilities when seeking to improve services for them. The task force was actually putting this concept into action!

Getting Started

"What is it that we are doing here?" task force member Susan Myers famously asked during the first several task force meetings. As co-facilitators, it was sometimes challenging for Gretta and Marshall to answer this question. Initially, it wasn't so clear, and for good reason. We were supposed to be coming up with that answer ourselves. Sure, we knew that our goals needed to be linked to enhancing accessibility at domestic violence programs for persons with disabilities, but it was up to us to define what that would look like. Exciting and frightening at the same time, we were tasked to chart our own pathway, and so we began.

Logistics

Food brings people together, breaks the ice and (in our case) can even break down barriers. When selecting a site for meeting it was important that it was accessible, comfortable, friendly and offered some tasty food choices. We found what we were looking for in the locally owned and operated Pullman Grill and Bar. Initially, we planned for meetings to last for an hour and a half, but the members asked if we could meet longer because we weren't getting enough accomplished. That was a sign that they were interested in the project, because it is rare for committee members to ask to meet longer than they have to! Following that request, we met once a month for two hours to discuss the issues of access, disability and domestic violence and share a nice meal together.

Between meetings, the task force stayed in touch with one another over the phone and over the email listserv that Marshall created. The listserv not only provided us with a vehicle for transmitting information about the task force, agendas, and meeting times, it also served as a venue for updates about other area happenings that related to our goals and vision as a team. As the time went by, task force members used the listserv more and more, and it became clear that we all really wanted to work together in new and creative ways. Staying in regular contact was of definite value to us all.

In total, the task force met ten times over the course of the year of the pilot project. The first meeting was an opportunity for us to meet and

¹ James Charlton, *Nothing About Us Without Us*, University of California Press, 1998.

introduce ourselves and our personal/professional interest in the task force. Marshall and Gretta facilitated icebreakers and reviewed the general goals of the project at the first several meetings. As the domestic violence agency representative, Gretta clarified the sometimes mysterious work that domestic violence agencies engage in and answered people's questions.

The purpose of the second meeting was a training to get folks on the same page regarding the co-occurring issues of disability and domestic violence. The Project Partners made the trek from Seattle to the rural Palouse region to provide a day-long training opportunity where domestic violence and disability advocacy was the focus. Sharon Johnson, a task force member with a cognitive disability referred by People First of Clarkston, WA, explained that the role play the Project Partners did was especially helpful in establishing an understanding of how domestic violence might look in the life of a person with a disability.

Charting The Pathway To Change

Marshall and Gretta came together to plan agendas for each meeting in advance. Some task force members required alternate formats in order to read the agenda and other materials that were sent out to them, so it was very important to not only ask them what format was the most accessible to them (audio, visual, on-line, large print or via a reader), but also to get the information out early so all task force members had the opportunity to review materials before meeting together. Our agendas always included time for check-in, identification of goals for the day, review of outstanding questions, group activity/discussion, breaks and a check-out.

As a task force, we spent time identifying barriers for persons with disabilities seeking domestic violence services, linking proposed activities to help alleviate the barriers we identified. As a tool for ourselves in this process, we also created a "resources" list. This list contained both formal and informal resources that could potentially be utilized when developing an action plan of proposed activities. When proposed activities were identified and resources were linked, the task force then began tackling these activities one by one in a collaborative manner.

Though this process was lengthy, it was integral to making the project meaningful to our specific region with its unique assets and challenges. Alternatives to Violence is situated in rural Eastern Washington, an area that matches beautiful scenery with a lack of resources; its harsh winters and scarce public transportation make isolation an ever-present reality. ATVP serves communities in both Washington state and Northern Idaho.

That was a sign that they were interested in the project, because it is rare for committee members to ask to meet longer than they have to.

Identifying Barriers

Barriers that task force members clearly identified included:

1. Lack of education about a variety of resources, including ATVP.
2. Lack of financial resources for survivors of domestic violence with disabilities.
3. Domestic violence agency policy stating that advocates do not go directly to survivors' homes.
4. Office/shelter locations of the domestic violence agency are not universally physically accessible.
5. Inaccessibility of emergency medications and equipment needed by persons with disabilities.
6. Persons with disabilities fear they will lose their children and or/housing, preventing them from accessing necessary resources.
7. Persons with disabilities fear loss of housing and placement in a more restrictive environment (like a nursing home or group home) "for their own safety" if they seek services or resources.
8. Domestic violence agencies use safety planning guides that are not tailored to fit the specific needs and experiences of persons with disabilities.
9. Accessible emergency transportation does not exist in our region.
10. Other service providers lack information about what domestic violence looks like in the lives of persons with disabilities.

Breaking Down The Barriers

Once we had identified these barriers, we worked to improve access to the domestic violence program in the following ways.

Improved physical access:

- ATVP's public office: ATVP staff located a new office space with greater accessibility potential and moved to this new site. Worked with our new landlord to ensure that an ADA compliant restroom would be added prior to moving in. Applied for and received a mini-grant from Pullman Rotary to install a wheelchair-accessible ramp in the main entrance of the public office. Budgeted for a bell for the entrance and signage in large print/Braille to be added to the main office entry point (to be installed by summer 2006).

- ATVP's confidential shelter: ATVP staff located a new shelter with greater potential for accessibility and plan to move to this new site in late June 2006. Plan on using funds to purchase supplies for Deaf shelter residents as recommended by ADWAS. Have received permission from our landlord to install a ramp and alter a restroom to make it accessible to persons with physical disabilities. Will complete these alterations to our new shelter site in summer 2006.

Changes to ATVP's agency forms, materials and some advocacy practices:

- Intake form:
 - Added the question: "Is there anything we need to know about you in order to provide you with the best services possible?" All program participants are either read or shown (depending on their personal preference) the "Service Accessibility Options" form, which lists a variety of ways in which ATVP advocates can make services accessible to the unique needs of each program participant [see "Service Accessibility Options" form in Appendix A, p. 61].
 - Removed the question: "What is your disability type?" Previously, we asked this question, but provided no follow-up regarding options. The focus on the question has now changed; the way we ask about disability has shifted away from categorization to an approach more concerned with providing the most accessible, best fit for all survivors of domestic and sexual violence. Federal anti-discrimination laws **do not** allow you to ask the person who is requesting services if s/he has a disability in most circumstances.
- All ATVP advocates are prepared to offer a description of the pathways of travel to the office or shelter, describe the inside of the shelter, and talk through what the physical and visual layout is of their office or shelter and possible access barriers (e.g., there isn't a bus to our office, identifying curb cuts and parking, if there is a slope to the sidewalk leading to the front door, or lack of sidewalks).
- ATVP is working on modifying their general Safety Planning Guide to include some safety planning questions from WSCADV's *Model Protocol on Safety Planning for Domestic Violence Victims with Disabilities*² on their form that they use with every survivor. The questions that are added relate to the specific ways persons with disabilities may have experienced abuse. The questions will strengthen the safety planning tool that ATVP has already been using. The updated edition will better equip advocates with a

² Cathy Hoog for the Washington State Coalition Against Domestic Violence, March 2003. This protocol is available at <http://www.wscadv.org/Resources>.

clear picture of the strengths and needs of each person seeking services.

The task force members from People First who noted that most of ATVP's old flyers are confusing to persons with cognitive disabilities.

Changes to ATVP agency materials for public use:

- ATVP reviewed their outreach handouts and removed pictures of people (as all of the pictures previously shown were of able-bodied persons).
- Created a new outreach flyer to be used to advertise ATVP services in a manner that is free of professional jargon and clear and concise in its presentation. This project was well-informed by the task force members from People First who noted that most of ATVP's old flyers are confusing to persons with cognitive disabilities.
- A new outreach route was identified by task force members which focused on formal and informal places where persons with disabilities may seek out information in our region. ATVP distributed the outreach flyers developed by the task force throughout Whitman County, WA and Latah County, Idaho at locations selected by task force members.

Gretta had never before spent so much time consciously thinking about creating an atmosphere of physicality and attitude that welcomed all who might participate.

TTY access:

- ATVP has added the phrase "V/TTY" to its written materials.
- ATVP staff and volunteers will receive ongoing annual training on the TTY from Disability Action Center Northwest (a local disability advocacy organization affiliated with Centers for Independent Living).
- ATVP is working on creating a procedure for publicizing the availability of interpretation services (sign and spoken language) and the hiring of interpreters. These procedures will be utilized agency wide in advertising of events, services and vacant positions within the agency.

Collaborations – new and for the future:

- ATVP's staff received training from the Palouse chapter of the National Alliance of Mental Illness. All direct service staff and supervisors were in attendance.
- ATVP presented to the Latah County-based Disability Action Center Northwest (a Center for Independent Living) on the issues of domestic and sexual violence in the lives of persons with disabilities.
- Project co-leader, Marshall Mitchell, has agreed to be a regular presenter at ATVP's annual new advocate trainings on disability and accessibility issues.
- The Latah County-based Co-Ad Protection and Advocacy System is seeking out Idaho-based funding to support the provision of

services of persons with disabilities who are victims of domestic violence.

A Face With A Name And Then Some

Many members expressed that they were surprised to have enjoyed the task force as much as they did. Participation felt as though it was truly linked to something real and tangible. Jane Pritchett of the Palouse Alliance on Mental Illness explained that she was surprised by the fact that people on the task force weren't already more acquainted with one another. "That's the myth about rural communities...that everyone is connected and aware of one another's business," she explained. "It's a misconception." It was clear that most people on the task force, though they may seem like natural partners, had never been too connected prior to this endeavor. Jane explained that getting to meet in person and connecting names to agencies and personal stories solidified relationships that are sure to last.

Since the task force began, cross-trainings between Alternatives to Violence and the other groups represented on the task force began happening for the first time. Agencies that had rarely ever contacted one another started coming together to discuss their services and the issues that drive their work. Suddenly agencies and people that were once so strapped for time and resources that they couldn't connect were prioritizing connecting with one another.

Reflections In Hindsight

Every member of the task force agreed that they would recommend other domestic violence agencies embark upon similar endeavors; however, in hindsight, certain changes would have been helpful. Many of the task force members expressed an interest in not only having enhanced training about domestic violence issues at the onset of the project, but also more comprehensive training regarding social/political/civil rights as they relate to disability issues. Dianne Millhollin, a task force member who is visually impaired and has diabetes, explained that while she is an expert on her own disability, she lacked information about other disabilities. Kathy Collins, a task force member who works as a disability rights advocate at Co-Ad in Latah County explained, "I would have no clue what would have benefited the blind community...Susan [a member who is blind] had excellent suggestions."

At times it took a while to get members the information they needed in a format that was the best fit for them. As a facilitator of many different types of work groups in the past, Gretta had never before spent so much time consciously thinking about creating an atmosphere

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It may be frightening to delve into an area where you have a lot to learn, but doing nothing is more frightening still.

Together, we had individual pieces of knowledge that, when brought together, formed a whole picture that was too powerful to ignore.

of physicality and attitude that welcomed all who might participate. Facilitating this task force gave Gretta and ATPV the opportunity to do just that. Preparing for this task force took longer than any other work group she had facilitated, but it was time well invested in the community on the issue of accessibility and its relationship to domestic violence. Task force members were making more and more referrals to the agency (more specifically, directly to Gretta). While being the “go-to” person is a good starting point, the future goals of the task force must include incorporating other ATPV staff so as to establish trusting relationships between multiple individuals.

Would we do this again? Everyone on the task force absolutely agreed that they would and that they would recommend that other domestic violence programs in the state of Washington (and beyond) do the same. Task force members also agreed to continue meeting to help remove the barriers that were identified. It may be frightening to delve into an area where you have a lot to learn, but doing nothing is more frightening still. Together, we had individual pieces of knowledge that, when brought together, formed a whole picture that was too powerful to ignore.

Potential Risk To Participants

The authenticity and integrity of this task force came in large part from having survivors who were also persons with disabilities included as members. However, task force participation caused some members to re-experience personal issues as survivors of domestic violence. Two of our members felt it was necessary for their health and well-being to discontinue their task force membership.

In the future, in an effort to provide a more supportive atmosphere that is informed by this experience, information about the potential emotional risks of participating in the task force should be discussed as early in the recruitment process as possible. And plans should be further developed to better structurally support task force members as potential survivors of domestic and/or sexual violence in order to facilitate their continued participation.

Task force members agreed that it is important to restate our task force’s confidentiality policy at the start of each session and to openly acknowledge the personal content of meetings. Task force members were in consensus that the need for self-care should be discussed and modeled by task force leadership to ensure healthy participation by all.

Members were provided with ongoing “check in” and support throughout their involvement with the task force. Additional efforts to

create opportunities for members who were having difficulties participating in task force membership could have potentially been service as “at-large” members or other ways as suggested by the members who chose not to continue participating.

Planning For The Future

Since the task force began, major changes have taken place at Alternatives to Violence. Both the Pullman-based office and the confidential shelter have moved to locations with greater potential for accessibility. Outreach efforts have been informed by the task force and have already started being implemented, and mini-grants have been written and funded to support ongoing efforts to achieve full access for all survivors of domestic and sexual violence.

Unlike many pilot site projects that begin and end according to their designated time frames, this is a project that will continue in our community. We have only begun to combat the barriers facing victims of domestic violence with disabilities. Rather than simply scratching the surface, we will continue this evolution as a community of people with like-minded concern and passion to delve deeper into the issues and carry on our work.

We recognize that this is a seed we have planted that needs to be nurtured to continue to grow. Together the task force agreed that staying in contact is necessary, as the work we have done has already impacted so much change at Alternatives to Violence. Task force members plan to remain in contact with one another from now on at quarterly check-in meetings to assess projects and develop new goals, and will remain in contact over the email listserv which proved so useful. New members are also in the wings as the group looks to the future and the benefits new voices can bring.

Unlike many pilot site projects that begin and end according to their designated time frames, this is a project that will continue in our community.

Chapter 2

Pilot Site Project Domestic Violence Center of Grays Harbor, Hoquiam

Finding Our Way Together

In The Beginning

When Nancy Eichenberger, Executive Director of the Domestic Violence Center of Grays Harbor, first received the disability pilot site proposal and application from the Washington State Coalition Against Domestic Violence (WSCADV), she believed that this project would be very important for her community. From her previous work experience at an organization that serves people with disabilities in finding employment, Nancy knew that there were many people with disabilities who had experienced abuse. She wanted to submit an application that demonstrated her initiative and enthusiasm – so, she started reaching out immediately.

Then DV Center of Grays Harbor was chosen as a pilot site. The Project Partners (WSCADV, ADWAS, WPAS) were impressed with Nancy's research and the proactive steps she had taken to find out if members of her community were interested in disability advocacy. As her understanding grew about what was needed to launch the pilot site project, Nancy realized that there wasn't any structure or concrete plan she could follow. This disability pilot site project was new, different and not entirely "crystal clear." Even for an optimist like Nancy, the goal of finding a person with a disability to be a co-leader and building a task force seemed somewhat daunting. In the end, taking on this pilot site work would take her on a new journey within her community.

Partnering

Project Partner David Lord of Washington Protection and Advocacy System provided the DV Center with the initial referral to a local disability advocate, Betty Beckett, which eventually led to finding the

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task force co-leader, Robin Sutherby. Betty is a member of People First, a volunteer organization led mainly by people with disabilities who are self-advocates, which has a vibrant chapter in Grays Harbor. Betty became a crucial guide to Nancy and helped identify individuals in the community who might participate in the project. Finding and partnering with Robin Sutherby as co-leader was vital in recruitment of individuals with disabilities and in guiding the work of the task force.

Robin was a student at Grays Harbor College and had already made connections with other disability self-advocates at the college. Born with a mild case of cerebral palsy, Robin's path as an advocate for herself and others seemed to be carved out for her from a young age.

Several years before, Robin had organized a seminar during Disability Awareness Week at the college to raise awareness about people with disabilities and dispel stereotypes. "It was a huge success," she happily recalls. "In the beginning, I never imagined that something born out of my desire to rid others of their misconceptions about people would turn into something so meaningful. In the end, I stood in awe of the impact one small group of people and one hour of people's time seemed to make."

Seeking Membership

When initially recruiting members for the pilot site task force, Nancy started with her contacts in the disability social services field. However, the goals of the disability pilot site proposal made it clear that a significant number of people with disabilities must make up the task force. And, most importantly, the task force had to be co-led by a person with a disability. Even though Nancy was building an effective list of disability social service providers, she had to reach beyond social service contacts and connect with members of the community to find people with disabilities who might be interested in participating in this project.

With the help of her co-leader, Nancy had to find self-advocates with a disability – and, obviously, there weren't any advocacy programs like that listed in the phone book or on the Internet. It became clear to Nancy and Robin that it was going to take longer than anticipated to find members for the task force. Nancy interviewed everyone she was recruiting in "face to face" meetings. This gave her a sense of what potential members were expecting and wanted to get out of their participation.

As Robin put it, "We have all heard the phrase 'It's not what you

know, it's who you know.” Her contacts for the task force came from old physical therapy buddies, former high school classmates, friends, professors and disability support personnel from Grays Harbor College. “As a member of Grays Harbor’s close-knit community, I was shocked to discover how difficult it was to uncover a diverse cross-section of people with disabilities here. That was one of the task force’s most difficult obstacles . . . finding a varying group of people with disabilities who had the time to participate in something like this.”

Robin reached out to individuals with a variety of disabilities to get broad representation on the task force. Even though it sometimes felt like trying to find a “needle in a haystack,” she was able to recruit three additional members who also lived with a disability. Once the task force began its work, fifty percent of the participants were people with disabilities.

Getting Started

At the beginning of the process, our group as a whole felt like we were not entirely sure we had a clear picture of where this task force was going to go. It was all new and uncharted territory. For the two co-leaders, we had to ask ourselves how we were going to facilitate the group and where it was all going to lead. Robin felt that she didn’t have a clear idea of what to expect from the task force in the beginning, much like Nancy and the rest of the members. “I just knew I would be doing something that would involve persons with disabilities in my community and invoke a sense of heightened awareness from others. Those two things alone were enough to prompt me to want to participate.”

Because Nancy and Robin talked with participants about their expectations of the project during the recruitment process, they had some “buy-in” from the beginning to build upon. Robin and Nancy would get together and plan the agendas for the task force meetings. Their organizational styles were different, but balanced out to make a good fit – one saw the big picture and the other kept an eye on the details.

The task force met a total of seven times over one year. The first meeting was an introduction of the members and a background of their experience with domestic violence and people with disabilities. Nancy and Robin used an “icebreaker” exercise that involved finding out how many years task force members had either lived with a disability themselves or worked with individuals with disabilities. This exercise helped to foster group unity and demonstrated to members where they had commonality, even though many came from very

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different backgrounds.

At the second meeting, the Project Partners visited the task force and conducted a cross-training on what domestic violence might look like in the lives of people with disabilities. The training provided an opportunity to spend time clarifying the members' ideas about domestic violence advocacy, as well as definitions and types of abuse. This gave the task force greater insight about the goals of the project and the shared values among domestic violence and disability advocates. By the third meeting, we were ready to get working on goals, and continued with discussion and refining our focus at each subsequent meeting.

At the onset of the project, a great deal of time was spent thinking together about what steps would be taken. We had no set path, but seemed to decide as a group what topics were most important to us and built our "road map" from there. Over time, one member's creativity easily became the answer to another's possible confusion and in no time at all we were a dynamic team.

Logistics

In preparing for the task force meetings, Robin and Nancy had to consider a wide range of access issues, such as: mobility needs (ensuring enough space in meeting rooms for chairs with large wheels to maneuver, accessible restrooms); special dietary needs, like food allergies, cultural or religious practices; serving pre-cut food for meals or snacks.

The task force started out meeting at a local church that was accessible for people with disabilities (recommended by Robin, who attends the church). The task force decided that the temperature at the church was uncomfortably cold, so we moved to the DV Center office. However, a new problem presented itself. We had to remove the meeting room door so task members who used wheelchairs could get into the room. This was, at best, an inconvenient solution, so we moved to the local Community Action Program agency and this became our ongoing meeting site.

Once we found a consistent and accessible meeting site, we had strong attendance by our task force members. If others are planning on creating a task force and having trouble with accessible locations to meet, they could work with their local Chamber of Commerce, library, WorkSource office, or faith-based facilities (churches, synagogues, mosques).

We always provided food for each task force meeting, which was

usually over lunch. In fact, Nancy's slogan was "no eating, no meeting!" We arranged to have a local restaurant cater all the lunches and deliver them to our meeting site. Food helps bring people together and gets them focused around a common goal. We all agreed it was a very important component of our meeting time together and we would not have skipped it.

We had to figure out how to effectively communicate with each other during meetings and in between. Some members did not use computers, some needed sign language interpreters and some preferred email only. We had to think about the pace of our meetings, how much information was reasonable to address in one meeting, learn to take turns and use the interpreters effectively. Nancy found she had to rethink her facilitation methods and check in with members (repeatedly) to make sure communication was effective over time. One task force member commented that she appreciated the way that Nancy facilitated the meetings and made sure everyone had enough time and room to share their thoughts.

We were lucky that the members using wheelchairs were able to obtain rides to meetings with relatives, friends or other task force participants, because public transportation for people with disabilities is very limited in our county. The local bus service is available for people with disabilities only by appointment with at least 24 hours notice, and is nearly nonexistent at night and on weekends. There are some accessible transit services, but they are restricted to those with medical coupons traveling to medical appointments or designated for individuals traveling exclusively to and from their work site.

An additional barrier in our community is the lack of sign language interpreters, who generally have to come from another county and require a lot of advance notice to reserve their time.

Charting The Pathway To Change

The task force was a small, hardworking group; everyone had the opportunity to contribute equally from his or her own experience. Having strong co-facilitation between Nancy and Robin helped the task force stay focused on figuring out how to improve access to the DV Center and in identifying community barriers.

Robin and Nancy had a clear passion for the project and they worked at building trust among the task force group from the beginning. This model of co-leadership of domestic violence advocate and disability advocate resulted in a powerful partnership. Participation by people with disabilities kept the task force focused on removing barriers that were most important for domestic violence survivors with disabilities.

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Even though some people on the task force knew each other before and were somewhat knowledgeable about services in our county, there were surprised to learn there were resources they previously knew nothing about. The task force offered an opportunity that encouraged new partnerships between organizations that hadn't previously worked together. For example, the connections that task force member Betty Beckett had to People First led to that organization conducting two trainings about the experience of living with a disability to the DV Center's staff and board. Additionally, one of the members brought up a new resource idea for the DV Center to apply for funds through a local matching grant program for community projects that Nancy was not aware of as a funding source.

Identifying Barriers

Our task force had lots of dialogue about barriers to access for people with disabilities when using DV Center services and throughout our community. Some of the barriers include:

1. The DV Center office and shelter are not universally accessible.
2. The DV Center advocacy practices do not allow domestic violence advocates to meet with survivors in their homes.
3. The DV Center has to develop a process to determine which agency materials need to be available in alternative formats for survivors and community members in general (e.g., on audio cassette, in large print, in clear language and much shorter in length, on video, by email/website).
4. Grays Harbor County lacks readily available transportation services for people with disabilities.
5. Grays Harbor County has limited public transportation services in general.
6. Other service providers in the county lack information about what domestic violence looks like in the lives of people with disabilities.
7. Local service providers have some resistance to receiving training about domestic violence and what it looks like in the lives of people with disabilities.
8. Adult Protective Services needs to improve their response to survivors who disclose their experience of intimate partner or personal assistant abuse, as well as their ability to hold abusers accountable.
9. Agencies that employ personal care assistants lack screening

and hiring practices that can identify potential abusers.

10. Lack of information for people with disabilities who want to hire personal care assistants regarding what kinds of questions to ask to protect their safety and to hire the most qualified individual.
11. Lack of education and information about the general legal rights for people with disabilities under the ADA and other laws.

Breaking Down The Barriers

What the task force accomplished, along with the DV Center, to improve access to the DV Center's services and to strengthen the DV Center's community partnerships:

Improved physical access:

- DV Center office: Restored wheelchair ramp to entrance (a volunteer reconditioned a previously unused ramp). Painted white strips on stairs to improve visibility and safety for sight-impaired people going to second floor (and will do at shelter as well).
- DV Center shelter: Altered lock on back gate, so a person using a wheelchair has better access to unlock it when using the ramp.

Changes to DV Center's agency forms, materials and some advocacy practices:

- Intake form:
 - Added the question: "Are there any accommodations that we should know about to help us serve you better?" If the client answers yes, there are additional questions at the back of the intake form to review [see "Service Accessibility Options" form in Appendix A, p. 61]. For example, the staff/volunteers describe communal living conditions and figure out what people need in this kind of residential setting.
 - **Removed** the following questions: "Do you have a diagnosable disability? If yes, what type? Do you have a mental disability? Do you have a physical disability?" The focus of the question has now changed; the way we ask about disability has shifted away from categorization to an approach more concerned with providing the most accessible, best fit for all survivors of domestic violence. Federal anti-discrimination laws **do not** allow you to ask the person who is requesting services if s/he has a disability in most circumstances.
- In practice, advocates will offer a description over the phone of the pathways of travel to the office or shelter, describe the inside

of the shelter, and talk through the physical and visual layout of their office or shelter and possible access barriers (e.g., there isn't a bus to our office, identifying curb cuts and parking, if there is a slope to the sidewalk leading to the front door, or lack of sidewalks).

- The DV Center provides ongoing staff /volunteer safety planning training – which includes staff and volunteers reviewing WSCADV's *Model Protocol on Safety Planning for Domestic Violence Victims with Disabilities*¹ on an ongoing basis. This safety planning information is now included in the agency's twice yearly training for new volunteers.
- The DV Center is also modifying their general Safety Planning Packet to include some safety planning questions from WSCADV's *Model Protocol on Safety Planning*² on the form that they use with every survivor. The questions will strengthen the safety planning tool that the DV Center has already been using. The updated edition will better equip advocates with a clear picture of the strengths and needs of each person seeking services.
- The DV Center reviewed their policy and procedures handbook and removed inappropriate language relating to persons with a disability. For example, "handicapped individual" was replaced with "person with a disability" to reflect "People First Language."

Changes to DV Center agency materials for public use:

- Agency brochure: Included statement that the DV Center provides "disability and accessibility advocacy" and included the wheelchair symbol. Will add TTY number in the future.
- Business cards: Added wheelchair symbol on back. Will add TTY number in the future.
- Outreach flyers or community event flyers: Include accessibility symbols indicating physical access and availability of ASL interpretation.

TTY access:

- The DV Center applied for and received a free reconditioned TTY machine for the DV Center office, and will be seeking funds for a second TTY to be housed in the shelter.
- The DV Center staff and volunteers will receive ongoing annual

¹ Cathy Hoog for the Washington State Coalition Against Domestic Violence, March 2003. This protocol is available at www.wscadv.org/Resources.

² In 1991, Kathie Snow wrote a groundbreaking commentary about the importance of using People First Language: "People First Language puts the person before the disability, and it describes what a person *has*, not who a person *is*." Read her complete commentary at <http://www.disabilityisnatural.com/peoplefirstlanguage.htm> (revised Sept. 2005).

training on the TTY from an outside source.

- The DV Center has developed procedures for publicizing the availability of interpretation services (ASL and spoken language) and the hiring of interpreters.

Collaborations – new and for the future:

- Cross-training opportunity for task force: At the last meeting of the task force, we had a “Disability 101” training conducted by Kathy Goldenberger, Disability Navigator at WorkSource for our five-county area of the state. This training gave our task force an awareness of how many more people have disabilities than are officially documented or recognized, and more knowledge about cognitive and physical disability issues.
- Raising visibility of disability advocacy in the community: To honor two individuals from People First, Nancy nominated them to receive a community award from Light Squared in April 2006. Light Squared is a non-profit organization that recognizes people annually in our county who are doing positive things in their community. Their motto is “What’s Working on the Two Harbors” (Grays Harbor and Pacific Counties).
- New referrals from disability social service provider: In April, the DV Center was asked by a case manager at Olympic Area on Aging Adults (O3A) to participate in a case staffing with a domestic violence victim with a disability. This is the first time the domestic violence agency has had such a request or had any referrals from this office. An Adult Protective Services worker was also at the staffing and was unaware of the range of services the DV Center could offer. This case turned out to be another way of educating other services providers in the community about how we can help people with disabilities in abusive situations.

In another recent referral situation, Catholic Community Services in a neighboring county called the DV Center to discuss another case involving a domestic violence victim with a disability. The social service agency provided financial support by paying for a personal assistant to help the victim while she stays in the DV Center shelter.

- Early in the disability project, we were asked if some individuals from People First could use our agency as a practice training site to present information concerning inclusion of people with disabilities in society. Four individuals presented their material, with assistance from a support person, to DV Center staff. The presentation was extremely successful. As a result, Nancy invited them back to present to the board of directors. Both trainings were very positive; the board was very impressed and had many questions for the group.

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Ask and ask again,
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participation.

- The DV Center and task force want to approach the Grays Harbor Transit System to negotiate developing emergency transportation services.
- The task force is interested in developing a co-advocacy educational outreach strategy in the community. The approach would be to pair a disability rights and domestic violence advocate to provide general legal rights information to people with disabilities in nursing homes, sheltered workshops or group homes.

Reflections In Hindsight

There are few things we could have done differently in the recruitment of task force members, and we will use these insights as we continue the work of the task force in some form in the future. We would have contacted the Quinault Indian Nation to recruit tribal members with disabilities who are self-advocates (as this is the largest Native tribe in our county). We would also like to include people with disabilities who are working in local businesses. Additionally, we would like to include a business that recruits and employs people with disabilities, and will use contacts at the local Chamber of Commerce to seek their advice and recommendations.

Robin would have liked more time to advertise for task force members in community calendars and other print media. Also, an opportunity to hold a big initial meeting with all potential task force participants could have been another strategy to gauge everyone's interest beforehand. Her advice to other communities thinking of using the task force model is to plan as far in advance as possible, recognizing that searching for potential members may take months.

From our experience, when recruiting members for the task force, it helps to explore each person's understanding of the connection between disability and domestic violence, even if they don't have previous knowledge of one of the two fields.

For other agencies and communities that may set up a task force structure in the future, effective communication and transportation issues could be barriers to member participation. Make sure that all of your task force members can attend and adequately participate before you set your first meeting. Ask and ask again, when trying to get information to help ensure everyone's full participation.

Planning For The Future

Our task force is committed to continuing to meet, and we will work on further development of co-advocacy strategies for survivors of

domestic violence who have a disability. About half of the current task force members have expressed interest in continuing to attend meetings. All have stated they want to stay informed and connected to our ongoing work. We will continue to think about who we will need to recruit to join our task force in order to broaden participation from survivors with disabilities.

We have plans to collaborate with the ARC of Grays Harbor on recruitment of potential task force members, funding sources for joint projects and also cross-training for both agencies. Through the pilot site experience, the task force members now have a passion for ending domestic violence and understand the complications that exist for people with disabilities experiencing violence.

The DV Center has been asked to present information about our joint disability and domestic violence work and the services we can provide to people with disabilities experiencing domestic violence to the Grays Harbor Public Health Department's Transition Council. This is a local task force involving disability service providers within the community to work with young adults with disabilities who are going from high school to work or college.

We continue to advertise the work of the task force at every DV Center sponsored meeting, training or any opportunity that arises. Nancy and one task force member were featured on three radio spots at one local station and one spot on another during Domestic Violence Awareness Month advertising the co-advocacy disability task force and information about the DV Center's services generally.

We are getting the word out in our community about domestic violence and disability work, but it will be slow. It would be a long-term goal to meaningfully change disability access in the wider community. One example is to use opportunities to educate law enforcement officers about people with disabilities and different communication styles and needs. We also have a new domestic violence roundtable in the county called the Prevent Violence Coalition. Membership in the Coalition is composed of diverse system and social service representatives (law enforcement, educators, sexual assault, children's advocacy, healthcare). We will have opportunities to use the roundtable to educate a broad range of agencies and fields by bringing up disability issues at those meetings.

Nancy believes that this project helped the DV Center build stronger community relationships and opportunities for collaboration. The DV Center has learned a great deal from task force members about the experience of living with a disability and we realize that we have much more to learn. The task force work has raised the profile of the

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You are your own
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be an ambassador for
change."

DV Center and domestic violence services in the wider community – and, in turn, the task force has highlighted the leadership of people with disabilities and their advocacy work in our community. In the words of the task force's disability advocate co-leader Robin: "I challenge all persons with disabilities to take a more active role in your community . . . You are your own biggest advocate, challenge yourself and be an ambassador for change."

Chapter 3

Discussion Series and Women with Disabilities Leadership Initiative

What We Did

In the fall of 2005, Communities Against Rape and Abuse organized a public discussion series attended by women survivors with disabilities in Seattle, Washington. Through this discussion series, the Disability Advocacy Project hoped to learn more about the impact of domestic violence in the lives of women with disabilities. We realized that survivors with disabilities were not making full use of the available community resources for survivors, and wanted to learn more about their strategies for finding support and surviving domestic violence. We wanted to identify informal ways that women find support from family and friends or others, navigate systemic barriers to safety, and otherwise increase their independence from an abuser and from institutions.

We learned that many survivors do not trust that needed services will be available for them, and often fear that things will be worse after attempting to use systems that others can take for granted. Given the general disregard of the ADA and other access-related laws that persists throughout society, many survivors believe that this resistance is blocking the removal of ubiquitous barriers to access.

Most importantly, the women survivors with disabilities talked about surviving abuse and coping with limited access as inseparable parts of their experience. In other words, survivors with disabilities could not talk about one issue without the other.

We recognized that identifying women with disabilities would be relatively easy, but identifying individuals within that group who were survivors would be difficult without compromising confidentiality. So we decided on the discussion series format as a way of identifying individuals who might engage in one-on-one conversations about the

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Integral to this project was the fact that women survivors with disabilities were consulted in the planning of the project and were also recruited to facilitate each public discussion.

details of their experiences as survivors. Also, by framing the discussion series as an event for the wider community of people with disabilities, we hoped to capture a larger potential pool of survivors than if the event was advertised as *solely for survivors of domestic violence*. This latter approach could have been alienating because many people do not see themselves as victims or survivors of domestic violence.

Eventually, we were able to identify six women survivors with disabilities who were willing to continue with an in-depth conversation with the project partners. Quotes from both the discussion group participants and the survivors who were participated in personal discussions can be found throughout the text and in the margins of this chapter. These quotes reveal only a narrow slice of their complex path to self-determination and safety.

The title of the discussion series was “What’s the Deal?: Sharing our personal experiences of the politics, tricks and skills of ‘dis’ability.” There were seven public discussions, with approximately 15 people in attendance at each; a different mix each time with newcomers at every meeting. The focus of the discussions was to introduce topics relevant to the unique experiences of female survivors with disabilities, and identify barriers and solutions to safety, support, autonomy, community and empowerment.

Integral to this project was the fact that women survivors with disabilities were consulted in the planning of the project and were also recruited to facilitate each public discussion.

Discussion topics were:

- What survivors with disabilities share in common
- Making connections between our different identities
- Grief and loss
- Economic barriers we experience
- Social lives
- Sexuality and relationships
- Creating community

Why It Worked

There was an excited community response to the discussion series from members of disability communities. The discussions were very honest and rich with individuals’ stories about encountering and overcoming barriers to healthy relationships, self-esteem and access. Many participants were distrustful of seeking support from crisis service organizations or law enforcement as a result of bad past experiences

and poor access, and instead shared experiences of operating outside of those systems to find support. Evaluations filled out by participants were very positive and requested that the series continue.

Some of the women identified themselves publicly as survivors in the group setting, and others identified as survivors on their evaluation sheet. Many participants commented that they had never before been in such a diverse group of people with disabilities. In attendance there were people with cognitive, mobility, visual, auditory, congenital, neurological, environmental, orthopedic and mental health disabilities represented. Some ideas presented in the discussion series have the potential for change in Seattle, such as a community forum for all organizations working with people with disabilities to meet and discuss larger strategies for community building and improving access.

How We Identified the Participants

We let people self-identify themselves as women survivors with disabilities in participating in the discussions.

“Woman:” We defined “women” in this project as people who identify themselves as having an identity as “female” or “woman.” It was particularly important to emphasize self-identification to welcome people with transgender identities into the group.

“Disabled:” This label is loosely used to define a wide range of people who experience some impact on their way of life based on their abilities and the barriers they experience in their environment. The word disabled is limiting because many people with disabilities don’t relate to this word, and it can be alienating to some who don’t want to think of themselves as disabled. Also, some people think the word disabled has negative connotations by focusing on a “lack” of ability. The word disabled in this context is meant to include people with mobility, cognitive, developmental, visual, aural, neural, mental, environmental, sensory and learning disabilities.

“Survivor:” A person who has experienced domestic violence, including emotional or psychological abuse, and/or sexual abuse, including coercive and forced sex acts.

In this process, common themes stood out that were unique to the experience of survivors with disabilities: disability identity, barriers to access, search for a shared community, grief and loss, safety concerns, poverty and job discrimination, sexuality issues, victim-blaming and denial of the abuse they experienced. This section of the report will highlight some of this rich discussion.

I have known women
with Multiple Chemical
Sensitivity who tried using
shelters and find they
can’t stay. They are
better off living in a car
than in the shelter – no
one will enforce the
accommodations we
need. Every time a
person ignores my
requirements and there is
a chemical exposure. . .
the worse it gets. “Oops!
I forgot!” is not helpful,
and there is no way to
“work with it” or ignore it.

Themes That Emerged

“People with disabilities are still very much at the edge of society, we’re still not in the center, we’re not even included.”

Disability Identity - People with disabilities have a shared history of difference, of being misunderstood, negative interactions with the medical system, the need for accommodations and exclusion from the wider community. For example, the eugenics movement in the United States in the 20th century was targeted towards people with all types of disabilities. For some in society, discussion of disabilities remains a “taboo subject.” Language can be empowering and also limiting. One woman talked in the group about how it is important to say “I have a disability, rather than I am disabled.” She did not want her disability to comprise her entire identity. Another in the group noted that some people with disabilities don’t call themselves disabled at all. One person who was born with cerebral palsy talked about how although she always used a wheelchair, she never thought of herself as disabled. But when she realized that her most precious possession was her wheelchair, that led her to understand how linked her identity was to disability, and also how dependent she was on this very expensive piece of equipment.

The participants agreed that self-perception about disability as an identity is changing among people with disabilities, and there is a growing solidarity among them. It was clear that the people in the group felt pride in having a disability, and were not ashamed of their disability.

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Poverty - The majority of people who attended the discussion series and participated in the private conversations were living below the poverty level. Some were homeless, and many were receiving welfare assistance and were unable to work. Economic barriers impacted every portion of their lives, and greatly impacted their choices for self-determination. There was a general sense of mistrust of governmental systems that decide who would get financial assistance, like local, federal and state agencies such as the Department of Vocational Rehabilitation and Department of Health and Human Services. Many participants expressed the belief that “the government is a barrier.” One person asked, “if you had to choose between getting the medicine you needed to stay alive, or paying your rent, what would you choose?”

Mental Health - Participants talk about how their experience of being bipolar and chronically depressed made them invisible as a person with a disability. Historically, a mental health-related disability has not always been included with other disabilities. Participants also discussed a societal stigma frequently associated with a mental health-related disability. Mental “illness” is a disability that is often characterized as “dangerous and out of control.”

Grief and Loss - Many participants agreed they were only able to show grief and loss in “safe places.” Constantly having to educate others about their unique experience as survivors and people with disabilities can be tiring and frustrating. If a disability came late in life, participants found it difficult to transition from being an active person to being isolated and perceived as not able to engage in as many activities. As one person explained, “grief doesn’t just happen once, then go away, instead it returns throughout life. There’s a cycle – the more nobody wants to listen to disability grief, the more I talk about it, the more freakish I seem for emphasizing it.”

Others described their process of coping with grief this way: “It’s harder to talk about grief it’s not as straightforward, as just a death. . . There’s a lot of pressure from other people to ‘move on,’ to look on the positive side. This can create a feeling that it is not okay to feel the way you do. Also, it prevents you from working through the feelings you are having. It ignores the problem.”

Sexuality - There was a general nervousness at the beginning of the discussion about disability and sexuality, as it is hard to overcome the stereotype of people with disabilities as non-sexual people. Participants expressed that their initial experiences with dating were very difficult, and years later they noted psychic wounds from bad sexual experiences at an earlier age. Many women with disabilities are struggling with their own expectations and understanding of sexuality. One person said that because of her disability, her family never asks if she intends to get married or have kids, while her siblings get asked those questions.

People found that socializing with non-disabled people was often hard, because they had misinformation or a lack of understanding about the lives of people with disabilities. Many participants stated that they had experienced responses conveying lowered expectations or assumptions about their ability to engage sexually. One person described their experience of “being in the closet” about their disability to their partner. This person did not feel comfortable disclosing their disability status because they were not confident that their partner would be accepting.

Several people talked about how their medications have affected their sex drive, either by increasing it or decreasing it. Certain sexual positions are difficult for some individuals. New partners do not always understand or support the needs of a person with a disability. Many participants stated that others assume that people with disabilities can be easily controlled in a sexual context. One woman with a spinal cord injury said, “I’ve been approached many times, for

“I think my major grief
is that I feel so
separated from other
people.”

“I’ve been approached
many times, for sexual
relations, by men who
are ‘curious’ about
having sex with a
person with a disability.”

Her non-disabled partner “throws my disability in my face” when he does not feel sexually satisfied with their relationship.

sexual relations, by men who are ‘curious’ about having sex with a person with a disability.” This same woman said that long-term sexual relationships have been difficult. Her non-disabled partner “throws my disability in my face” when he does not feel sexually satisfied with their relationship.

Past abusive experiences also affected the way some of the survivors with disabilities approached their relationships. As one person put it: “What sex life?” One woman described her history of family abuse and being isolated by her bipolar disorder as contributing factors to why she finds it difficult to be in a sexual relationship.

Some people have been so hurt by the ignorance of non-disabled partners that they have sworn off dating non-disabled people ever again. “It takes a long time to welcome people into my life because support is hard to get. I usually wait for the trust to develop, see if the person deals with their disability stuff.”

Having a positive sexual experience with a disability can require planning, as illustrated by one participant: “It’s hard to find mature people to have relationships with who can understand and handle loving a person in a way that includes their disability.”

Barriers to support and safety for survivors

“How much I decide to share with somebody depends on how much power they have over me and how much power I have in that situation.”

The participants were asked to identify what their barriers were to finding support for adequate accommodations, and maintaining their autonomy and safety from their abuser. One survivor clearly described the role of power for anyone in an abusive situation: “How much I decide to share with somebody depends on how much power they have over me and how much power I have in that situation.” She continues, “I was raised with deaf parents, and growing up sometimes we would sign to each other under the table, at a restaurant or something. It was a way of life for me to not say anything, to not get your needs met . . .”

Inadequate Accommodations and Restrictive Services - “We have a culture of isolating people with disabilities,” reported one participant. Many of the participants talked about the lack of accommodations and how that impacted their autonomy and safety. As one participant stated, “Accommodations for survivors with disabilities are an afterthought, rather than central to planning.” Many people in the group shared experiences of being unable to use existing services in the community. People with disabilities do not have the luxury of making assumptions that an available service is accessible. “Each time something is needed, we must check out the accommodations before feeling confident to go forward.” Additionally, more than one person said their own home was not fully accessible.

Frequently, participants stated, people with disabilities are not consulted in the planning of services or building design. One woman talked about how the disability student services office at her school was located in the basement in a corner of the school. “They don’t want people like us, with disabilities, mixed into the ‘normal’ environment.”

Participants shared that the amount of planning and money that is required to access services or resources restricts their decision making and choices. For example, one survivor explains that she “pays a lot of money to take cabs, because I am not eligible for Access services [accessible transit services] and Metro buses [county bus service] do not run late at night.” Additionally, survivors talked about the “important role adaptive equipment plays in our lives.” Necessary adaptive equipment is expensive and generally takes a long time to get authorized by insurance.

Participants described their experience of trying to access disability social services as “troublesome and often disempowering.” Several participants experienced frustration at being ineligible for many disability-related services. They found the criteria to be too stringent, and “not a good fit” when trying to describe their complicated lives and how their abuser would sabotage their attempts to get services. Participants said that they wanted a system that would honor all of the person’s individual needs while removing any barriers to accessibility.

One survivor, who received services at several domestic violence shelters and agencies, talked about how a lot more work needs to be done by these agencies to improve their accommodations for people with disabilities. She noticed a mindset that people with disabilities are “not doing enough to be self-sufficient.” It was clear to her that they viewed her as someone who was looking for sympathy. And it seemed that the staff attitude was “It’s not my job to help” if someone needed assistance based on their disability. Several others in the groups shared similar experiences, and knew other survivors with disabilities who did not even try to use advocacy services because they “knew” their needs could not be accommodated. Domestic violence advocacy programs have not done a good job of outreach in communities of people with disabilities.

Attitudinal Barriers - Participants shared the belief that many people in the community at large discount and ignore the experiences of people with disabilities. Participants critiqued the women’s liberation movement for excluding disability concerns: “The women’s movement has a lot of work to do to include disabilities issues and not separate them from the women’s movement.” In terms of individual bias, one

“He knows that if he
messed with disability
eligibility
documentation, it could
trap me much longer in
this homelessness cycle.
I can’t stay in homeless
shelters, they are scarier
than his house, so I
couch surf.”

"I worry a lot about hurting people's feelings or engendering anger, and it is so awkward to discuss most of the time. People don't take it seriously, and if they ignore me or respond in anger, it feels just like the other abuse I have experienced."

"The café works for me when other places fail. They are a 24-hour drop-in place. There is always someone there to chat with me and calm me down so I can focus."

participant described her experience this way, "When other people can't deal with the topic of disability and want you to say you're doing fine because they don't want to hear about it, it's quite an irritation." One woman talked about her sister's ongoing bipolar disorder, depression and schizophrenia, and her parents' choice "to ignore her experiences and pray. They don't respect her need for ongoing treatment."

Many survivors stated that if they tried to talk about the abuse they have experienced, they faced disbelief or even anger from others. "Sometimes support feels like denial, because the way that people support me as a survivor with a disability is to tell me that everything is fine and that I am normal. It makes me feel like they are not listening to me." Another stated, "I was raised in a family that thinks you should just deal with it and move on, if you acknowledge that you are having a hard time, they assume you are not trying to get over it. Then they don't want to deal with you anymore, it causes a chain of events that can negatively affect your self-esteem, your self worth."

Job Discrimination - Job discrimination towards people with disabilities restricted the economic choices of the survivors. Many of the participants said that they received only discouragement from job counselors and employers. Some were treated as being "lazy or difficult for being unwilling to do a job" that they could not do well because of their disability. Many employers don't understand their legal obligations under the Americans with Disabilities Act. Some of the survivors discussed that their abusive partners would remind them of their economic dependence and how hard it would be for them to find employment if they left the relationship.

Strategies And Solutions

We asked the participants to suggest what allies and domestic violence advocacy programs can do to support survivors' self-determination and safety. The participants also suggested strategies that could be employed by other survivors with disabilities. Listed below are suggested strategies and solutions offered by the participants in the discussion series and individual conversations.

What allies can do:

- Listen.
- Ask us if you can help, instead of assuming that we need assistance.
- Don't be afraid to talk about sexual abuse, domestic violence or disability.
- Be ready to accommodate an individual's needs.

- Plan in advance.
- Make survivors with disabilities central to your activity/project planning.
- Develop personal relationships with people with disabilities.
- Challenge your assumptions.
- Change the rules.
- Be willing to do what it takes to actually make an event or venue accessible.
- Share information and skills.
- Having spaces that are designated as non-smoking and non-fragrance areas.
- Acknowledge people's disability status.

What domestic violence advocacy programs can do:

- Ask to speak with the survivor in a private space.
- Ask the survivor if she is safe at home and what she needs to increase her safety at home.
- Don't question the survivor about the nature of their disability unless it is directly relevant to providing necessary services. Don't ask about their disability out of curiosity.
- Hire survivors with disabilities for staff positions.
- Recruit survivors with disabilities as volunteers.
- Recruit survivors with disabilities to join your board.
- Meet with local survivors with disabilities to learn about how to do effective outreach activities to people with disabilities.
- When doing community outreach, let survivors with disabilities know about your services.

What survivors with disabilities can do to support themselves:

- Create spaces for people with disabilities to make connections with each other beyond support groups.
- Let go of expectations about what we "should be" and instead focus on acceptance of where we are.
- Be clear about your needs and your boundaries.
- Talk to people about your experiences.
- Let allies know how they can help us. Include them in our lives.
- Listen to other people with disabilities. We need to educate ourselves about other people's experiences.
- Create a disability culture that promotes health, support and empowerment for all people.
- Don't be afraid to call people out about oppressive behaviors and terminology. Speaking up about racism or sexism creates an

"The best revenge is a
decent life."

"I value learning and working as a disability activist. It pushes me to value myself and . . . speak up for what I believe in . . . I am working hard with my friends to notice the good in people, and to own my space in the world."

environment where people will also speak up about able-ism and sexual abuse.

- Create a forum for local organizations that serve survivors with disabilities to meet together and discuss strategies for building community and meeting the needs of local survivors with disabilities.

Conclusion

A discussion series is a great way to bring people with different types of disabilities and people who may identify as survivors together to talk about shared experiences. Many people enjoyed connecting with a wide range of people with disabilities. Creating a public space that allowed women survivors with disabilities to tell their story and sometimes facilitate the discussion required ongoing trust building, flexibility with access needs, good food and a willingness to listen.

The experiences shared by survivors with disabilities gives our project direction in figuring out how to strengthen community partnerships between disability and domestic violence advocates and social services and resources. Additionally, the survivors' experiences can help us re-evaluate and create new outreach and education strategies for friends, family and allies who support people with disabilities who are being abused.

From the discussion series and individual conversations, we connected with survivors who described not only the ways their autonomy and safety were impacted by their abuser, but also the ways societal bias impacted their lives as a person with a disability. Their approaches to surviving abuse were drawn from the existing resourceful strategies survivors already employed to cope with the barriers they encounter in daily life as a person with a disability. We observed that people don't necessarily identify as survivors and don't name what they do as a "survival strategy." If survivors thought about separating, even temporarily, from an abusive situation, they had to figure out strategies to address fundamental dilemmas, such as "Can I find accessible housing, can I get enough money to survive on my own, who would hire me, is there accessible transportation, can I maintain medical care?" Survivors viewed concerns such as "Will the police help me, or should I tell my caseworker about the abuse?" as secondary issues. Survivors had to create plans and strategies to fill the gap that results from discriminatory system practices or individual bias towards people with disabilities.

All of the participants believed that people with disabilities are not seen as equal in society, and that these biases have shaped systems that are not responding to the needs of survivors with disabilities. In

listening to survivors with disabilities, it is easy to be overwhelmed by the scope of changes that are needed; however, survivors encouraged us to recognize that simple acts of respect could change their experience to one of inclusion, self-determination and increased safety.

Their approaches to surviving abuse were drawn from the existing resourceful strategies survivors already employed to cope with the barriers they encounter in daily life as a person with a disability.

Chapter 4

Disability Advocacy Project Survey Washington State Coalition Against Domestic Violence

In November 2005, the *Disability Advocacy Project* of the Washington State Coalition Against Domestic Violence (WSCADV) conducted a statewide survey to identify barriers that people with disabilities face and ask how these barriers impact survivors of domestic violence.¹ The partners of the *Disability Advocacy Project* – WSCADV, Abused Deaf Women's Advocacy Services (ADWAS) and Washington Protection and Advocacy System (WPAS) – sent the survey to fifty key constituents. These constituents represented people with disabilities (who may also be a disability advocate), disability advocates, domestic violence and sexual assault advocates and disability social service providers. The survey respondents are located in rural and urban areas throughout the state.

The project partners want our work to be guided by people with disabilities. There are several reasons why this makes good sense. Who can better describe how domestic violence affects people with disabilities than the people themselves? Who can better identify the barriers to accessing domestic violence advocacy and the accommodations to address these barriers? Survivors with disabilities can teach us about societal and individual barriers to autonomy and safety. Together, we can explore what this might mean for public policy and domestic violence advocacy practices.

We want our work to be
guided by people with
disabilities.

¹ See Appendix *Disability Advocacy Project Survey*, Appendix B, pg. 63 for complete list of survey questions.

Who responded to the survey?

We had a 74% response rate to our statewide survey, meaning that 37 out of the 50 surveys were returned.

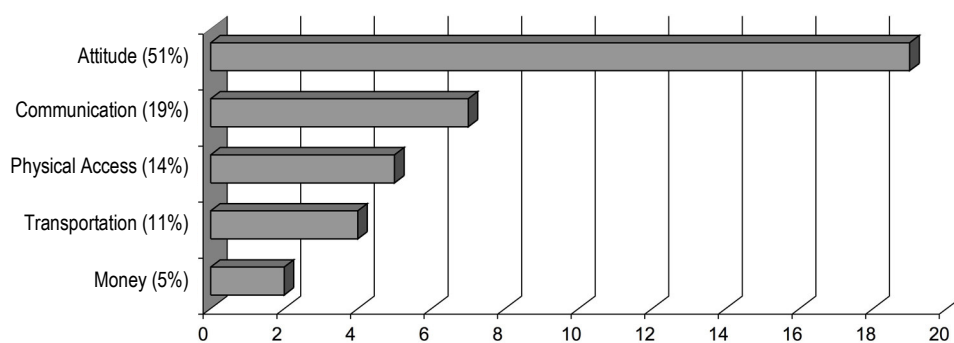
- 71% identified themselves as a disability advocate;
- 53% identified as a person with a disability;
- 29% identified as a domestic violence/sexual assault advocate;
- 24% identified as a disability social service provider.²



In our analysis of the survey responses, we identify themes that illustrate the beliefs and experiences of the respondents. For each theme, we provide examples and quotes from individual respondents.

What is the biggest barrier to access?

We asked the survey respondents to name the biggest barrier they faced as a person with a disability (or when working with a person with a disability). The five barrier themes that emerged were: attitudes, communication, physical access, money and transportation.



² The total percentages is greater than 100% because respondents could select more than one category.

51% of the respondents named “attitudes” as the biggest barrier. The survey responses described “attitudes” to mean beliefs that result in condescension, ignorance, misunderstanding or fear towards people with disabilities. For example, one participant stated that “condescending attitudes toward people with developmental disabilities are common” as well as “fear is a common reaction to people with mental illness.” Participants described beliefs that assumed people with disabilities don’t know what “is being said or done to them.” Other examples include: “fear of disclosure, not knowing who to trust, disclose information to about their abuse.” Another participant who identified as a person with a disability described the challenge of trying to discuss attitudes with service providers: “professionals treating you as if you are less competent, knowledgeable, smart . . . it is somewhat delicate to address because people don’t generally realize it, and get very defensive when you talk to them about it. ‘I was just trying to be nice,’ it is difficult to be taken seriously.”

The “communication” barrier was described by a lack of access to information that is clear and easy to understand. For example, one respondent stated “understanding what services and help are available, and knowing how to access it when you need it.” Additionally, communication barriers were characterized by a lack of interpretation services (ASL or other languages) or assistive equipment to facilitate communication (e.g., captioning, TTY machines, hearing aids, computer technology).

The “physical access” barrier was described by lack of access to buildings, bathrooms, and places where resources are available. For example, “the failure of courts to provide accommodations for people with disabilities.”

The “money” barrier was described by lack of affordable accessible housing and adequate medical care. Respondents described the impact of shrinking medical benefits: “many folks face hard choices and do without vital medications because of cuts in funding.”

Lastly, the “transportation” barrier was described by the lack of accessible public transportation. Without access to transportation, a survivor is literally unable to escape abuse without the assistance of the abuser. Respondents also discussed how the lack of transportation also prevents access to services and resources: “I have to notify transit at least a week ahead of time, and even then they are sometimes unable to fulfill my request. If this happens, I simply stay in, as I have few other options.”

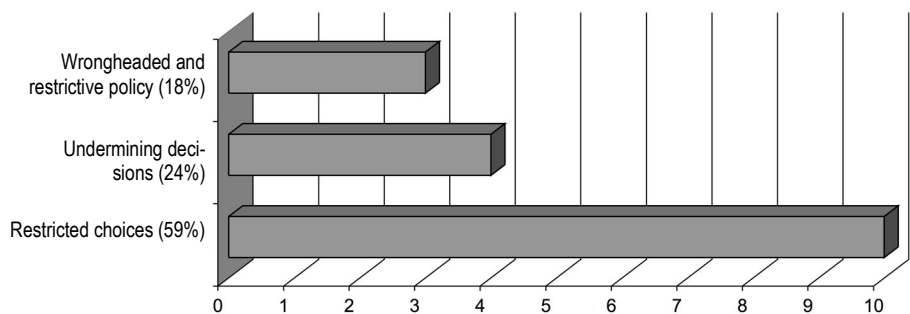
Caregivers,
professionals and even
family members often
dismiss verbal or
nonverbal reports of
incidents as fantasy,
exaggeration or
attention-getting ploys.

Focusing on the “attitude” barrier

The next two questions of survey asked the respondents to discuss how the “biggest barrier” (which turned out to be “attitudes”) impacted the independence and safety of survivors with disabilities. In the following paragraphs, we have provided some detailed analysis regarding how the attitude barrier affects survivors with disabilities and the programs that provide advocacy and service.

Restricting the choices of domestic violence survivors with disabilities

When asked how the attitude barrier affects the independence of survivors (using personal experiences or when working with a person with a disability), 59% revealed that prejudicial attitudes restricted the choices and undermined the decision-making of survivors. Additionally, respondents felt that prejudicial attitudes resulted in the development of ill-conceived and restrictive social policy. The themes that emerged were: “restricted choices,” “undermining decisions,” and “wrongheaded and restrictive policy.”



It often increases their dependence on abusers who fill multiple roles in their life.

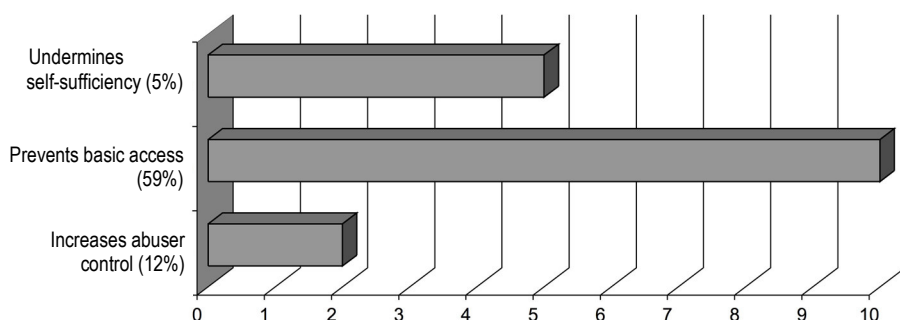
Restricted choices limit survivors’ ability to find out about and seek resources. Respondents commented that a survivor’s lack of access to information coupled with the experience that they may not be believed about the abuse increased the survivor’s dependence on their abuser. This dependence includes control of financial resources, help with physical and communication needs and emotional connection. One respondent described how restricted choices impact survivors of abuse: “it often increases their dependence on abusers who fill multiple roles in their life (friend, relative, caregiver, partner/spouse) and alienates them from potential resources . . . that fear of losing access to the minimal resources.”

The theme of “undermining decisions” was characterized by abusive tactics that dismissed or sabotaged a survivor’s decisions. Respondents stated that survivors were viewed as not capable or credible when talking about abuse they experienced or when asking for what they needed.

These prejudicial attitudes also led to the creation of “wrongheaded and restrictive policies” resulting in increasingly limited options for survivors with disabilities. Survey respondents’ examples of such policies included misguided healthcare policies that undermine a survivor’s attempt to maintain consistent healthcare, or “often lead to individuals being placed in unnecessarily restrictive environments (e.g., institutions, hospitals, nursing homes, family home when the person wants to live in his or her own home).” Isolation and withdrawal from the community only benefits the abuser and weakens the survivor’s attempts to assert her or his decisions and experience.

Preventing basic access to safety options for survivors of domestic violence with disabilities

When asked how the attitude barrier affects the safety of survivors (using personal or other experiences), 59% revealed that prejudicial attitudes prevent access to safety options. The themes that emerged were “prevents basic access,” “undermines self-sufficiency” and “increases abuser control.”



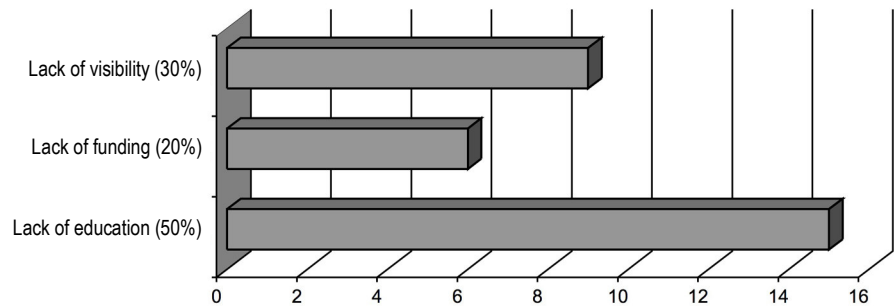
Safety depends on
being believed.

As stated by one respondent, “if the person cannot get the message across to people who can help them, the situation will eventually go from bad to worse.” Respondents described consequences such as denial of domestic violence services, increasing isolation and increasing abuser control over their partner. Preventing basic access to safety can also embolden the abuser to continue their tactics of abuse – if no one knows about it, no one can question their behavior. “It gives the abuser(s) added control and power over the survivor and creates a situation, often, where the survivor has no choice but to depend upon and believe the abuser.”

Why do barriers exist?

When asked why they think the barrier they identified exists, 50% of the respondents identified “lack of education.” As one respondent stated, “To deal with these issues takes more time and understanding than people are willing to, or capable of giving . . . professionals

seem to believe their formal education and training takes precedence over self-determination for the individual . . . People are viewed as a group with common needs; not as individuals.” The additional themes that emerged were “lack of visibility” and “lack of funding.”



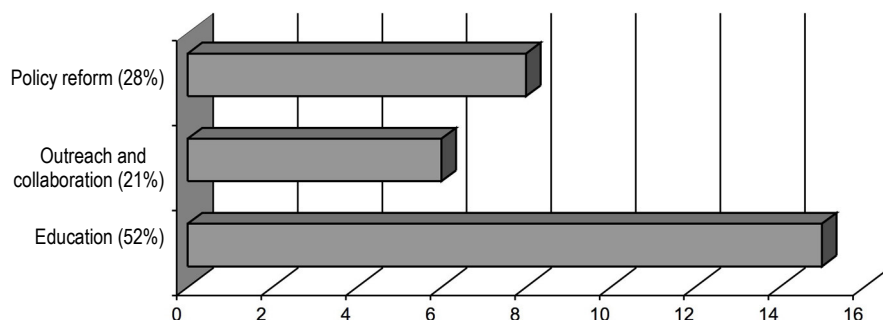
“Nothing about us without us.” What that means is that people with disabilities are essential in every discussion about meeting our needs.

People with disabilities may be “invisible” in communities that have few resources and limited public transportation. A respondent who lives in a rural area described the isolation of individuals with disabilities in this way: “people in our region are isolated in general. Individuals with disabilities lack the variety of resources they might have in larger, urban communities to create connections . . . they are so geographically isolated.” Respondents also noted that very few people with disabilities are employed by social service agencies. “There is a saying in the disability community: ‘Nothing about us without us.’ What that means is that people with disabilities are essential in every discussion about meeting our needs. If none of the people doing the planning have disabilities themselves, important perspectives are lost on what will truly be meaningful to people with disabilities.”

Respondents identified “lack of funding” as another reason that barriers to access still exist. Funding issues are often related to the belief that accommodations are too expensive, which can form an obstacle to finding out what an individual really needs. For example, “the cost of an ASL interpreter is expensive” may reflect budgetary reality, but also speaks to the need to resolve deeper issues of resource allocation and be more flexible in finding ways to meet individuals’ access needs.

How can we address these barriers?

When asked “Besides more funding, what are some ways that this barrier could be addressed,” respondents identified the following themes: education, policy reform and outreach and collaboration.



52% of the respondents reported that “education” about the experience of disability and abuse – for the general community and people with disabilities – was a necessary strategy to address barriers. As one respondent explained, “The education for the community should be a combination of disability awareness and anti-oppression, as well as making folks aware of the prevalence of abuse of people with disabilities.” Education about what domestic violence looks like in the lives of people with disabilities would improve cross-training between agencies that provide social services and agencies that are community based and provide advocacy or shelter services for survivors with disabilities.

Suggestions for policy reform strategies included: negotiation with transportation systems, working with the media and social systems to create policies that “address the additional and unique needs of people with disabilities.” For example, creating “an emergency pot of funding made available to people who are fleeing due to DV [domestic violence] so the can get needed medication, medical care and medical equipment and supplies.”

Respondents suggested that outreach and collaboration approaches include partnering between social service agencies, and disability advocacy agencies, and domestic violence advocacy agencies. In this context, social service agencies provide available state or federal medical or economic assistance and help individuals navigate the social service system. Employees are often in the role of case worker/manager, or supported employment worker.

Disability advocacy agencies are generally private non-profits directed by people with disabilities on behalf of people with disabilities and provide services such as advocacy with systems that people with disabilities use. Additionally, disability advocacy agencies provide

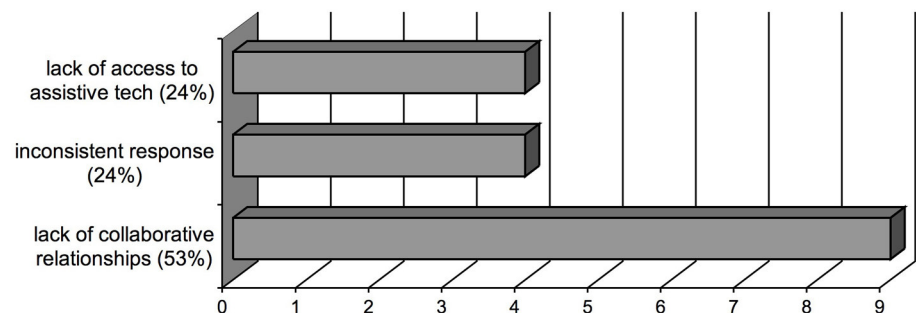
individual advocacy to support a person's ability to living independently in their community.

Community-based domestic violence agencies are private non profits who, like disability advocacy organizations, are guided by the experience of survivors and offer services that range from 24-hour crisis lines, emergency shelter, support groups and individual and system advocacy on behalf of survivors of domestic violence. Respondents suggested that domestic violence and disability advocacy agencies increase their outreach efforts to rural areas, and build ongoing relationships in local communities. One respondent advised: "Make major long-term sustained efforts to build bridges between the disability community and advocates or service providers."

"Make major long-term sustained efforts to build bridges between the disability community and advocates or service providers."

What existing barrier could be removed easily?

Survey participants were asked for an example of a barrier for people with disabilities that could be easily addressed. The themes that emerged were: "lack of collaborative relationships," "inconsistent response," and "lack of access to assistive technology."



53% of the respondents felt that a lack of collaborative relationships between people with disabilities, disability service providers, disability advocacy agencies and domestic violence providers could be easily addressed. Respondents suggested ideas for specific actions if collaborative relationships were present. One example cited was a need for disability service providers to be cross-trained by domestic violence agencies regarding ways to identify abuse if an individual uses non-verbal communication methods. Several others felt that collaboration was necessary to develop outreach materials that would be useful for survivors with cognitive disabilities.

It is interesting to note that quite a few people left this question blank, and three respondents stated there were "NO easily removed barriers left." One respondent explained, "I believe that most if not all the individuals would correct a barrier that was easy."

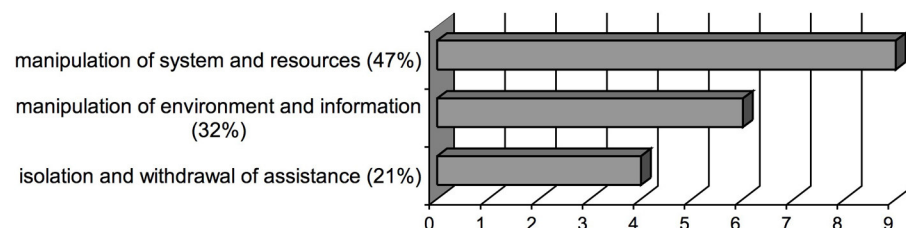
Some respondents cited inconsistent responses for people with disabilities in the delivery of services and in how buildings are designed for physical access. For example, respondents described inconsistent responses from crisis lines and first responders (e.g., domestic violence advocates, 911 operators, law enforcement and emergency medical technicians). Additionally, respondents talked about the lack of uniformity in the physical environment of public buildings. For example, “ramps are easily fixed yet still needed in many places.”

Respondents also noted that the lack of access to assistive technology created barriers, and that with funding and training many problems could be easily remedied, such as the purchase of TTYs and computer hardware and software.

“Imagine if women with disabilities, both physical and developmental, could be made welcome in shelters.”

How do abusers use a disability against survivors?

One of the things we have learned from survivors of domestic violence is an abuser will use the survivor’s disability against them. Survey participants were asked to give an example they knew about in this area. The themes that emerged were: “manipulation of system and resources,” “isolation and withdrawal of assistance” and “manipulation of environment and information.”



Most of the respondents (47%) described the ways an abuser would manipulate available systems and resources to limit a survivor’s choices. A wide variety of manipulative tactics that are used by abusers included:

- Targeting people for abuse who won’t be believed by system and social service providers (e.g., law enforcement, case workers).
- Using societal bias and misinformation about mental health disabilities or the experience of disabilities generally to discredit and undermine the credibility of the survivor’s experience of abuse – both to the survivor and others. For example, “the abuser stated a few things about the victim’s disability and tried to manipulate the court system to weigh in the abuser’s favor,” or “numerous news stories over the years where a person’s cognitive ability is used against them because an abuser does not think they will be believed by authorities.”
- Using the court’s bias against a Deaf victim to “malign the mother’s

“The abuser told her no one would believe her, as she had a developmental disability and he was correct. When she reported it at work she was called a trouble maker and soon fired.”

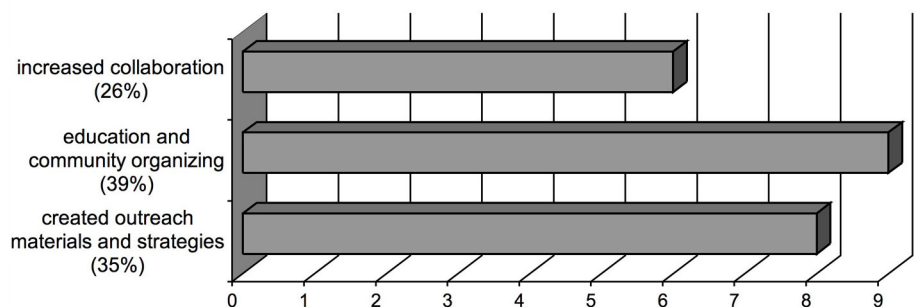
parenting skills because she was Deaf.” The court discounted the abuser’s behavior and awarded custody to the hearing father.

- Using the rationale that providing personal assistance results in “caregiver stress” as an excuse for abusive behavior.
- Using a system’s lack of access and community’s general lack of accessible services to entrap a survivor. For example, no one is available to assist survivor in filling out forms for needed services or a community lacks accessible public transportation.

Other responses indicated isolation of the survivor and withdrawal of assistance by the abuser. For example, one respondent stated “the survivor was a quadriplegic and personal assistant was her partner and abuser. He made sure that she had no other way to get up in the morning, go to the bathroom, get bathed, and go to bed at night.” Additionally, respondents described ways an abuser would manipulate a survivor’s environment to create barriers and block services or resources that would support survivors. For example, removing critical items or methods a survivor needs to communicate with other people (such as phone, TTY, computer, pager). Threats issued by abuser, such as “if you complain, you will have on one here to be able to assist you.”

What have local groups done?

The last question we asked was about the respondent’s knowledge of local groups that have addressed barriers for people with disabilities. The themes that emerged were: education and community organizing, creating outreach materials and strategies for increased collaboration.



“Strategies that educate and community organizing” was clearly the leading theme in the responses (cited by 39% of respondents) when talking about local group activities. Respondents suggested that community agencies needed to create outreach materials that are clear, concise and easy to understand and develop outreach strategies that come from listening to the experience of people with disabilities in the community. Also, respondents stated that collaboration efforts had

increased between social service agencies, disability advocacy agencies and domestic violence agencies.

Many community education strategies were given as successful examples, including:

- Educational forums sponsored by disability rights organizations
- Self-education and educational workshops for people with disabilities by people with disabilities (People First, TACID – Tacoma Area Coalition of Individuals with Disabilities)
- Forums on disability issues held at colleges and universities
- Disability rights organization (Washington Protection and Advocacy System) and the statewide domestic violence coalition (Washington State Coalition against Domestic Violence) working together and providing educational opportunities for disability rights and domestic and sexual violence community-based advocacy programs
- Educational workshops led by People First for friends and family of people with disabilities

Outreach strategies included:

- Creation of a website to identify available access in different neighborhoods
- Creation of a queer women with disabilities listserv
- Publication of articles by people with disabilities about their experiences in a local gay newspaper
- Communities Against Rape and Abuse, a community-based advocacy agency, sponsored an evening discussion series led by people with disabilities and open to people with disabilities and their allies. (see chapter 3, pg 37)

While there are growing efforts by people with disabilities and their allies to provide connection and education at the community level, most activities are small, under-funded and need organized support. As noted by one respondent, “Frankly, I am still wondering where all these things that I have been reading about are.” And another stated, “we have tried to watchdog currently subsidized housing and advocated for more, but no agency is championing this issue. We need further resources and more work in these important areas.”

Conclusion

Survey participants identified barriers primarily in five areas – attitudes, communication, physical access, money, and transportation. Respondents provided many specific examples of these barriers and the impact they have on people with disabilities. The barriers are famil-

"TACID (Tacoma Area Coalition of Individuals with Disabilities) have had 2 or 3 workshops for the disability community each year on disability and domestic violence/sexual assault, workshops are planned by a committee that includes people with disabilities, service providers and advocates."

ial to many advocates and people with disabilities.

Significantly, the participants had the most difficulty identifying barriers that could be removed *easily*. However, the survey results showed that survivors of domestic violence and advocates have considerable insight into why barriers exist, why abuse happens, and how abusers use disability against survivors.

When asked about addressing the most significant barrier – attitudes – the respondents focused on education, outreach and collaboration. These strategies are consistent with the direction of the Disability Advocacy Project and the pilot site projects. Survey participants offered both general advice and specific suggestions for reducing barriers.

The survey showed that survivors with disabilities and advocates can identify not only the difficulties and barriers they experience, but also strategies for increasing the safety and autonomy of survivors.

Appendix A

Service Accessibility Options

Created by the Alternatives to Violence of the Palouse

Please find following a list of options that may be of use to you as you access our services. If you have a need that is not listed here, please let us know and we will do our best to accommodate you.

Office

- Service Animals Allowed
 - Service animals are allowed to accompany any client to appointments
- Booklets on Audio Tape
- Booklets in Large Print Font
- Guided Tours of Office
 - Staff is available to provide guided tours of our offices
- Booklets Available in Braille
- TTY
- Real-time Captioning on Televisions
- Interpreters
 - Interpreters will be provided upon request
- Relay System for the Deaf and/or Hearing Impaired
- Hearing Aid Compatible Phones
 - All phones in the offices are hearing aid compatible
- Written communication
 - Includes brochures and pamphlets available in many different languages
 - All information can be provided to client in written format
- Sign Language
 - Sign language interpreters are available upon request
- Wheelchair Accessibility
 - Both offices have wheelchair ramps and accessible parking and restrooms
- Personalized Safety Planning
 - Safety planning designed to increase safety of all clients

- Access to Computer and Internet
 - Pullman office is equipped with a computer workstation that is wheelchair accessible. The computer also has large print font options. An advocate can assist in orienting clients to this service.

Shelter

- Shelter is NOT wheelchair accessible. If our shelter is unable to accommodate you, other options are available.
 - An advocate will assist you in locating other options such as hotel stays, other confidential shelters and other options. Clients staying at a hotel will be offered the same services as clients who reside in the shelter itself.
- Service Animals Allowed
 - Service animals are allowed to accompany a client during their shelter stay.
- Personal Assistants
 - Any approved personal assistants are allowed to stay within our shelter to provide support to our shelter clients.
- Bath Chair
- Interpreters
 - Available in different languages and sign language
- Booklets Available in Braille
- Booklets Available on Audio Tape
- Booklets Available in Large Print Font
- Guided Tour of Shelter
- Personalized Safety Planning
 - Safety planning designed to increase safety of all clients
- Hearing Aid Compatibility Phones
- Access to Medications
 - Clients have access to their medications through a locked box
- Access to Computer and Internet
 - Pullman office is equipped with a computer workstation that is wheelchair accessible. The computer also has large print font options. An advocate can assist in orienting clients to this service.

Appendix B

Disability Advocacy Project Survey Questions

The Disability Advocacy Project of the Washington State Coalition Against Domestic Violence would like you to answer a few questions about the barriers people with disabilities face in your community and how these barriers may relate to domestic violence. Your answers will provide guidance on how we can BEGIN to address these barriers. Your answers to these questions will help direct the work of the Coalition statewide in developing advocacy for people with disabilities who have experienced domestic violence.

1. Your name:
2. Name of agency you work for (if applicable):
3. Phone number of where we can reach you for any follow-up questions:
4. Your email address:
5. Please identify your role below by placing an "X" beside your choice (you can select more than one choice):
 - Individual with disability
 - Disability advocate
 - Domestic violence/sexual assault community-based program advocate
 - Disability social service provider
6. Please give one example of the biggest barrier you have experienced as a person with disability? Or, if you don't have a disability, think about people you have worked with.
7. How does this kind of barrier affect the independence of domestic violence survivors? You can offer a story about how it affected you personally, someone else you know, or in your work experience.
8. How does this kind of barrier affect the safety of domestic violence survivors? (Again, you can relate this issue to your own experience or other people's experiences.)
9. Why do you think this barrier exists?

10. Besides more funding, what are some ways that this barrier could be addressed?
11. Please give another example of a barrier for people with disabilities that could be EASILY addressed (that you know about or have experienced).
12. One of the things we have learned from survivors of domestic violence is an abuser will use the survivor's disability against them. Please give an example that you know of where an abuser did that. (Examples: the abuser would not let the survivor make any decisions about her money; the abuser says that no one would ever believe a person with a cognitive disability; a social service agency does not have ASL interpreters available and the abuser knows it.)
13. To your knowledge, what have other local groups done to address any barrier for people with disabilities in your area? (For example, community meetings, educational forums and/or activist strategies such as civil disobedience or picketing.)

Appendix C

Pilot Site Task Force Members

Alternatives to Violence of the Palouse Pilot Site

Co-Advocacy Task Force, Pullman, WA

- Gretta Fiske Jarolimek, Co-Leader, Alternatives to Violence of the Palouse
- Marshall Mitchell, Co-Leader, Disability advocate, Washington State University
- Kathy Collins, Disability rights advocate, Co-Ad, Inc.
- Sharon Johnson, People First, Lewiston/Clarkston
- Mel Leviton, Disability rights advocate, Co-Ad, Inc.
- Dianne Milhollin, Self-advocate
- Gina Morris, Advocate, Disability Action Center Northwest (a Center for Independent Living)
- Susan Myer, Self-advocate
- Jane Pritchett, Self-advocate, Palouse Alliance for the Mentally Ill
- Don Wade, community member

DV Center of Grays Harbor Pilot Site

Co-Advocacy Task Force, Hoquaim, WA

- Nancy Eichenberger, Co-leader, DV Center of Grays Harbor
- Robin Sutherby, Co-leader, Self-advocate
- Betty Beckett, Disability advocate, People First
- Gloria Callaghan, Supported Employment Manager
- Brenda Carlstrom, Self-advocate
- Marisa Chatt, Self-advocate
- Dee Dee Garmen, Disability advocate, ARC of Grays Harbor
- Carlin Marlow, Self-advocate
- Dr. Donna Smith, Psychological Services of Elma
- Chuck Sundberg, WorkSource Grays Harbor

