The Challenges We Face

About this Issue
This issue of the A-Files, asks us, as domestic violence advocates, to completely rethink the way we advocate for survivors of domestic violence who have a disability. And, as a result of that process, to rethink advocacy for all survivors of domestic violence.

We can be proud of our incredible success over the past three decades in creating safe havens for battered women and their children, reforming legislation and institutional policies and practices to improve battered women’s safety and access to justice, and changing public attitudes about battering. However, it is no secret that we have a long way to go before no one suffers from humiliation, abuse and fear. In fact, researchers repeatedly find very high levels of abuse (including forced sex, assault, withholding medical care, extreme neglect, confinement and financial exploitation) among persons with disabilities. If there is such a high rate of violence against persons with disabilities, why are so few of them seeking or receiving services from domestic violence programs, and what can we do to start changing that reality?

It has only been 30 short years since the passage of federal laws to protect the rights of people with disabilities and improve their access to employment, transportation, education and public institutions. While people with disabilities are a part of every community, societal beliefs and practices generally render people with disabilities invisible and perpetuate misinformation and stereotypes. In “Why Disability Isn’t Sexy To The Feminist Anti-Violence Movement,” the author asks us, “How can domestic violence advocates reach people with disabilities when we don’t know how and where they live?” We have much to learn about the struggles of people with disabilities for basic human rights, and have the opportunity to learn from the experts – that is, survivors of violence who also have a disability.

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Why Disability Isn’t Sexy To The Feminist Anti-Violence Movement

By Joelle Brouner

Do you remember Linda David? David is the Snohomish County woman with multiple disabilities, found covered in dog feces, with numerous broken bones that had mended without being set, pinned in the hull of the sailboat where she endured seventeen years of abuse and neglect at the hand of her husband Victor. Linda David was “liberated” from the filthy boat and sent to a nursing home. This egregious case illustrates a number of systemic failures. It also points to a notable difference between the perceptions of domestic violence advocates and members of the disability community. Local domestic violence advocates were taken aback by the David case. On one hand, the experience of Linda David illustrates the critical importance of our work; on the other hand, it became all too clear that Linda David is a woman who stretches our model of what the “domestic” in domestic violence can look like. The perception of the case within the disability community is different. Many people with disabilities were not surprised to learn what happened. We wondered why a woman who had been so traumatized was not receiving many of the services available to other survivors of domestic violence. We were puzzled: What made able-bodied people so certain that David would not become the victim of further abuse at the nursing home?

People with disabilities are simultaneously rendered invisible and hyper-visible by people without disabilities. Case in point, Linda David languished on that boat for seventeen years and nobody gave a damn. Print media told the story in the “look-at-this-vulnerable-cripple” vernacular for their own financial gain. Do we as domestic violence advocates think that a nursing home is the best place for a survivor to live? Did anyone ever question that?

Domestic violence advocates can help subvert the invisibility of people with disabilities by acknowledging their lack of understanding of the loving options available. The domestic lives of many people with disabilities have additional strategies to overcome individual, institutional and social obstacles to safety and self-determination. If we are to be “effective partners in advocacy,” then our task is to apply our advocacy skills and knowledge in ways that stretch the boundaries of our work practices. Doing this work will help us think expansively about what self-determination — a core goal of Advocacy-Based Counseling — really means, when working to end all forms of violence.

For those of us who are able-bodied (however temporarily), working with survivors with disabilities offers us the opportunity to build new alliances with another social change movement — the disability rights movement. We have much to learn from each other as advocates working for self-determination, safety and justice.
layers of complexity that we must understand if we are going to be effective partners in advocacy. There are a variety of living arrangements for people with disabilities that the social service infrastructure supports. For generations, institutionalization was the only living arrangement for people with disabilities. This fact looms large in the collective history of people with disabilities and continues to this day. There are five developmental disability institutions and countless nursing homes across the state of Washington. People with disabilities living in institutions and nursing homes are patient inmates rather than tenants. These people live in a hospital-like setting and have few if any choices about their lives.

Another common living arrangement is the group home. Group homes are not designed to accommodate the level of freedom that most adults expect at home. Twenty-four hour personal attendant services are available to residents. Partners may not be allowed to participate in consensual sexual activity or even sleep in the same bed if they live in a group home. When venturing into the community, group home residents are expected to let the staff know where they’re going. An additional approach to domestic sphere within the disability community is a menu of services referred to as Intensive Tenant Support (ITS). ITS includes personal attendant services, chore services, budgeting, and grocery shopping. Still other people with disabilities make individual arrangements with independent providers of personal attendant services or other services to meet their needs based on the availability and structure of their service dollars.

This socially engineered cattle car approach to the domestic lives of people with disabilities limits our self-determination, especially regarding issues like personal relationships, sexuality, and reproduction. There are a number of reasons why fewer people with disabilities are parents than the general population of survivors we work with. Living arrangements available to people with disabilities do not accommodate children. Parents of people with disabilities, social service professionals, and society at large are ill-equipped to address the fears and stereotypes they have about disability and sexuality. These fears and stereotypes have also led to forced sterilization and coercive efforts to direct women with disabilities to use harmful forms of contraception like Depo Provera or Norplant. Is it a forgone conclusion that people with disabilities are less capable of making these decisions? No. The systems that we’ve designed and support, including domestic violence advocacy, are infused with our values and reflect our distorted understanding of people with disabilities.

What prevents domestic violence advocates from understanding and responding to Linda David as a survivor? In a word, pathology. The vast majority of domestic violence advocates are able-bodied. Able-bodied people have the power and privilege to define the experience of people with disabilities from their worldview. The definition of disability that emerges from this powerful and privileged worldview is the pathological understanding of disability. Getting a handle on the pathological understanding of disability requires some appreciation for the roots of the word pathology itself.

Pathology is the study of disease in the mind and body. That definition seems benign until one considers the word’s Greek root pathos. Pathos translates to evoking suffering and pity. The word pathology has more depth and consequence when the meaning of the Greek root is not lost. A more accurate definition of pathology reflects the hybrid meaning: the study of disease in the mind and body through a lens of suffering and pity.
The pathological understanding of disability is value laden and it interprets disability as a negative experience that results in suffering. The pathological understanding of disability has greatly influenced many aspects of our societal infrastructure, including medical service models and social service models. Medical professionals have a long history of promoting cures and preventative measures. The race for various cures has spawned the lucrative pharmaceutical industry. The effort to prevent our disabilities too often prevents us from ever being. It’s hard not to take that personally.

The pathological understanding of disability extends to the way we approach violence against people with disabilities. The widely accepted analysis of domestic violence as it relates to people with disabilities is as follows: perpetrators target their victims, people with disabilities are “vulnerable” targets, and therefore the abuse of people with disabilities is unfortunate but unavoidable. This analysis is limited, inaccurate and fatalistic. Are people with disabilities really such “vulnerable targets” or is there a more complex analysis worth examining?

All people, including those with disabilities, are vulnerable to some degree. The perception that we are more vulnerable is not an objective truth. Domestic violence in the lives of people with disabilities is not fated. It’s worth examining why these assumptions have gone widely unquestioned. The values underlying these assumptions undermine the integrity of our work as domestic violence advocates.

How can domestic violence advocates reach people with disabilities when we don’t know how and where they live? How do we reconcile our pathological understanding of disability? How can we advocate for survivors with disabilities when our programmatic services are steeped in pathology? Clearly there are no easy answers, but we must rise to the occasion or we will continue to sacrifice survivors with disabilities. Not to mention our integrity.

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The A-Files Publication and Reprinting

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There are concrete actions domestic violence advocates and agencies can take to demonstrate a commitment to changing course. First of all, we must examine the way that able-bodied supremacy manifests in our personal life and in our work. What kind of personal and professional transformation would result if we considered a social model of disability? The social model of disability recognizes and celebrates the experience of people with disabilities as a natural and complex reality in human history.

In the 1970s, the origins of the social model of disability emerged in the United States. With the passage of hard-won minimal civil rights for people with disabilities (such as the right to a public education in 1975), radical disability activists, like Ed Roberts and Judy Hueman, birthed the independent living movement for people with disabilities. The independent living movement simply demanded that people with disabilities are fully human and have the fundamental right to live in the community – not separate from the community. This movement is helping the social model become a reality as opposed to intellectual theory. These advances are rooted in a belief system that challenges the socially constructed definitions of beauty and value for all people. The isolation that is imposed upon people with disabilities prevents us from envisioning a place for people with disabilities in our community or at our dinner table.

Everyone is responsible for her own education. Most of the work requires a generous dose of common sense. Learn about the history of people with disabilities. Consider the parallels between the feminist anti-violence movement and the struggle of people with disabilities to attain basic civil rights. Make connections with people with disabilities and the organizations that work with us. Apply what is learned. There is no excuse for inaccessibility in 2002. If our programs and services are still inaccessible, we must make and implement a plan of action with a timeline. Anything less is old-fashioned discrimination.

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ARE YOUR SERVICES AND PROGRAMS ACCESSIBLE?

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- Do you have a policy stating what kind of care your staff can reasonably expect to provide? Feeding assistance? Dressing? Toileting? Assistance in and out of bed? Does your staff know when to call for home health aides and where to find such services?

- How much assistance can you give a woman who cannot use the telephone or public transportation independently?

- Will you move meetings, counseling sessions or any other social contacts to an accessible location?

- Will you provide meetings for women trying to remain sober? Are your written materials in Braille or on tape? Is there a reader available? Someone to assist in filling out forms?

- Does your staff know your policy on using interpreters and know how to get an interpreter? Would you consider adding the requirement of being able to communicate fluently in Sign Language to one of your agency positions the next time it becomes vacant?

- Do your agency's medication policies distinguish between prescribed drugs and other drugs in determining whether a client has direct access to their medications?

- Do you routinely advertise your facilities and services as accessible? Is your accessibility noted on all outreach materials and in the phone book?

- Is your staff trained and comfortable working with women with disabilities? Disability awareness training is essential to the success of your program.

- Do you provide ongoing training on various disabilities, their medical aspects and functional limitations? Have speakers with various disabilities come in so that staff can ask questions of someone who is not in a crisis state? All of the literature in the disability/rehabilitation field states that negative attitudes toward persons with disabilities can be overcome through information and exposure to persons with disabilities.

- Are staff members aware of the policies concerning how services are to be provided to persons with disabilities?

- Have you included women with disabilities from your community in the process of developing policies and evaluating your facilities and programs for accessibility?
And, Now What?

What can you do now? What can you and your agency do now to increase your knowledge, accessibility and response to survivors with disabilities?

- **Connect with local resources.** Find out about your local resources, start by calling the Center for Independent Living in your area.

- **Evaluate agency accessibility.** To learn more about the disability advocacy community, resources for survivors with disabilities and how you can help evaluate your agency’s physical accessibility and policies, contact the following organizations: Abused Deaf Women’s Advocacy Services (ADWAS): (206) 726-0093 TTY; Communities Against Rape and Abuse (CARA): (206) 322-4856; ARC of Washington (888) 754-8798 and Washington Protection and Advocacy Services: (206) (425) 776-1199.

- **Learn about state resources.** To become familiar with state agencies that provide services to people with disabilities in Washington state, contact: Washington state disability coordinators in the county health department; Aging and Adult Services Administration (www.aasa.dshs.wa.gov); Economic Services Division, Community Services Division: 1-800-865-7801; Division of Developmental Disabilities (www.wa.gov/dshs/ddd/); Mental Health Division: 1-888-713-6010; Office of Deaf and Hard of Hearing: 1-800-422-7930 voice, 1-800-422-7941 TTY; Division of Vocational Rehabilitation: 1-800-637-5627.

- **Learn about state law.** Become familiar with Washington state RCWs that address accessibility and rights for people with disabilities, such as Chapter 2.42 RCW Interpreters in Legal Proceeding, Chapter 49.60 Discrimination – Human Rights Commission, and Chapter 74.34 RCW Abuse of Vulnerable Adults.


- **Check out some websites.** http://www.disabilityresources.org/A.html (Resources for All People with Disabilities); http://cosmos.ot.buffalo.edu/aztech/ (Technical & Adaptive Equipment); http://www.disabilityhistory.org/dshp.html (disability culture and history sites); http://www.sexualhealth.com/content/index.cfm?Topic=Disability%20or%20Illness (positive sexuality for people with disabilities).
Resources


