

CAREGIVER ABUSE  
AND  
DOMESTIC  
VIOLENCE  
IN THE LIVES OF  
WOMEN WITH  
DISABILITIES

**Meeting the Needs of Women  
With Disabilities:  
A Blueprint for Change**

**A Project of Berkeley Policy Associates**  
[formerly Berkeley Planning Associates]

by  
**Marlene F. Strong  
Ann Cupolo Freeman  
Susan Haight-Liotta**

REPRODUCED BY  
THE CALIFORNIA COALITION AGAINST SEXUAL ASSAULT  
WITH PERMISSION FROM BERKELEY POLICY ASSOCIATES

This publication was funded by the National Institute on Disability and Rehabilitation Research as part of the Field Initiated Research grant (No. H133G40077), "Meeting the Needs of Women with Disabilities: A Blueprint for Change." The opinions expressed are those of the authors and do not represent the policy of the federal government.

## STAFF OF THE PROJECT

**Ann Cupolo Freeman**, Project Director  
**Linda Toms Barker**, Principal Analyst  
**Marlene Strong**, Principal Analyst  
**Susan Haight-Liotta**, Research Assistant

## ADVISORY BOARD

<b>Adrienne Asch</b>	<b>Kathy Martinez</b>
<b>Tanis Doe</b>	<b>Margaret A. Nosek</b>
<b>Laurie Drabble</b>	<b>Bonnie O'Day</b>
<b>Jamie Lee Evans</b>	<b>Ruth Ricker</b>
<b>Nancy Ferreyra</b>	<b>Harilyn Rousso</b>
<b>Carol Gill</b>	<b>Marsha Saxton</b>
<b>Margaret Jakobson</b>	<b>Lorelee Stewart</b>
<b>Edna Johnson</b>	<b>Sara Watson</b>
<b>Erica Jones</b>	<b>Barbara Waxman Fiduccia</b>
<b>Megan Kirshbaum</b>	<b>Lucy Wong-Hernandez</b>

Additional copies of this publication are available from:

Berkeley Planning Associates  
440 Grand Avenue, Suite 500  
Oakland, CA 94610

Voice: (510) 465-7884 • TDD: 465-4493 • Fax: 465-7885  
e-mail: pat@bpacal.com

---

## ACKNOWLEDGEMENTS:

The staff of the project would like to thank all the women who told us their stories so that this booklet would reflect the real experiences of disabled women who had experienced domestic violence and caregiver abuse. Although they are anonymous here, they are very real members of the study team.

We also thank our Advisory Board for their invaluable support and assistance to the entire project with networking, reviewing outlines and drafts, sharing ideas, and for suggesting readings.

We wish to express appreciation to the following women for reviewing drafts and contributing information and ideas for this booklet:

Tanis Doe, Jamie Lee Evans, Carol Gill,  
Barbara Waxman Fiduccia.



## TABLE OF CONTENTS

I. INTRODUCTION	1
Why We Wrote This Booklet	1
Overview	3
What Do We Mean by “Domestic Violence” and “Caregiver Abuse”?	5
- <i>Domestic Violence</i>	6
- <i>Caregiver Abuse</i>	9
- <i>The Role of Society</i>	11
Examples of Domestic Violence and Caregiver Abuse	11
II. DISABILITY: THE ADDED DIMENSION	15
III. BARRIERS TO ENDING THE ABUSE AND VIOLENCE	25
Women with Disabilities Need Better Information	25
Escaping is Harder for Women with Disabilities	29
Programs and Services Aren’t Accessible	33
Disability Service Providers Are Not Educated About Abuse and Violence Issues	37
IV. FIGHTING BACK -- WHAT TO DO	40
What Women with Disabilities Can Do	40
What Service Providers, Agencies, and Law Enforcement Can Do	47
What Policy Makers/Funders Can Do	51
V. CONCLUSION	56
REFERENCES	57

---

APPENDIX A: RESOURCES	61
Hotlines	61
Internet Resources	61
Organizations	62
Suggested Readings	66
How to Find Your Local Independent Living Center	68
Information about the Americans with Disabilities Act (ADA)	68
APPENDIX B: KNOW YOUR RIGHTS!	70
What Is Mandated by the ADA?	71
- <i>Program Accessibility</i>	71
- <i>Readily Achievable</i>	72
Modification of Policies, Practices, and Procedures	72
What Is Meant by "Readily Achievable" or "Undue Burden"?	73
Fundamentally Alters	74
How is the ADA Enforced?	74
ABOUT THE PROJECT	76

## I. INTRODUCTION

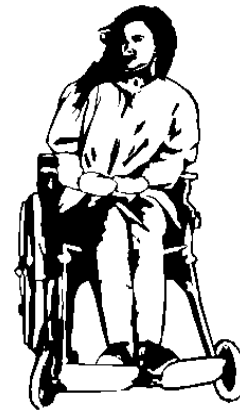
### WHY WE WROTE THIS BOOKLET

Violence against women with disabilities is a topic that is seldom discussed openly, but often comes up when we get together to share stories about our lives. Much as domestic violence in general was not a focus of public attention until the O.J. Simpson trial, until recently (Seelman and Sweeney, 1995) domestic violence and caregiver abuse against women with disabilities have been seen as “private” issues, not a focus of policy makers.

But keeping it private doesn’t mean it doesn’t exist. In spite of the lack of formal research, we know that violence and abuse affect the lives of women with disabilities (see, e.g., Panzarino, 1994). In 1995, Berkeley Planning Associates (BPA) set out to identify which social service systems were of highest priority for future research on access by women with disabilities. As part of a federal grant, we conducted a survey of women with disabilities to ask them to rank-order systems, such as child care, aging services, youth services, welfare, adoption, reproductive health services, and alcohol and drug treatment. To our surprise, domestic violence services were rated the highest priority. Within that broad topic area, women pointed to violence both by intimate partners and

caregivers<sup>1</sup> as important issues. They felt that it was necessary to educate women with disabilities and service providers about these issues, and to emphasize the need for access to services such as domestic violence shelters and sexual assault programs (BPA, 1996).

This booklet is the outcome of that survey process. We developed it by asking women with disabilities to share their personal stories of abuse and violence, as well as reviewing available research and interviewing experts in the field. Our primary audience is women with disabilities themselves, but we also hope it will be useful to service providers wishing to educate themselves about the issues, and to policy makers who seek background for improving public policy in the areas of abuse and violence. By writing about the latest research in this area, we hope to break the silence about abuse and violence in the lives of women with disabilities.



---

<sup>1</sup> Many people with disabilities shun the term “caregiver,” believing it to express the patronizing concept that disabled people need someone to “take care of” them. However, we decided to use the word caregiver in this booklet (in addition to “personal assistant”), first, because it is a widely used term. In addition, although most literature about caregiver abuse of disabled women has been about paid personal assistants, we wanted to highlight the fact that unpaid caregivers -- such as partners, relatives, or friends -- also abuse women with disabilities.

## OVERVIEW

Violence against persons with disabilities has been going on for as long as recorded history, and continues to be a problem in our time. The violence occurs in the home, in the form of child abuse, domestic violence, and sexual assault by partners, relatives or caregivers, or outside the home in nursing homes, hospitals, and other institutions, as well as crimes committed by strangers. People with disabilities were the first group to be experimented on and then systematically executed by the Nazis, before they attacked Jews, gypsies, homosexuals, and other people considered inferior (Gallagher, 1990). Research has shown that people with disabilities continue to be more likely than others of the same age or sex to be victimized, that the abuse is often more prolonged and severe, and that the effects may be more serious and chronic (Sobsey, 1994). Worse, abuse by caregivers in institutions or in homes is often not recognized as such because the actions of the abusers toward the persons with disabilities are supposedly “for their own good.”

For women with disabilities, the risks are increased, just as all women have a higher risk of being victimized than men. One study alone found that among a sample of 85 adult women with a variety of disabilities, 73% had been the victims of violent sexual assault at some point in their lives (Stimpson and Best, 1991). Physical assault is also more likely for girls and women with disabilities (Doucette,

1986). Because many people view women with disabilities as asexual and do not think of them as being in intimate relationships (Fine and Asch, 1988), there has been little attention paid to the fact that these women are at risk of being abused by their intimate partners. It has been estimated that 90% of the offenders are known to the women with disabilities they abuse (Eastcott, 1994).

Being an older woman doesn't make you exempt. A study conducted with 20 Massachusetts elder protective services workers about 28 cases of elder sexual abuse revealed that all 28 of the victims were disabled women who had been raped in their own homes or the homes of family members, mostly by husbands and sons (Worth,



1991). The most common type of sexual assault was repeated vaginal rape, and other types included fondling and molestation, forcing the victim to view pornography against her will, anal rape, and ritualistic abuse in which one woman was being tied and burned. The women had severe psychiatric impairments, Alzheimer's Disease, or mental retardation; several were bedridden and one had had a stroke and was unable to speak.

## WHAT DO WE MEAN BY “DOMESTIC VIOLENCE” AND “CAREGIVER ABUSE”?

**D**omestic violence is abuse by an intimate partner -- male or female, married or not -- and includes physical or emotional abuse, and sexual assault. Caregiver abuse is abuse by someone providing personal assistance or homemaker help, who may or may not be the same as one's intimate partner -- it could be a paid personal assistant (PA), a parent or another relative, or an unpaid friend.<sup>2</sup> Caregiver abuse can overlap with domestic violence because it is often committed by the same person, although caregiver abuse can also include other criminal acts such as theft. Therefore, these two kinds of violence against disabled women are often intertwined, and for most of this booklet, we will talk about both together, although the dynamics may be different and in many cases the ways of stopping the abuse are different. We will not discuss abuse by doctors and other

---

<sup>2</sup>Disabled women are vulnerable to abuse outside of their homes as well, by doctors, nurses, therapists, and teachers in nursing homes, schools, treatment centers and hospitals (institutional abuse), and by strangers as a result of their being part of a minority group (hate crimes -- i.e., crimes that are motivated by bigotry and bias). The federal crime bill signed into law in September 1995 orders the Justice Department to collect statistics on crimes against people with disabilities for the first time. Before this crime bill was signed, only three states (California, Connecticut, and Oklahoma) included disability as a risk category (Waxman, 1991). However, this booklet will not discuss these kinds of violence against women with disabilities. We will concentrate on violence that happens in the private realm of home and relationships.

professionals in this booklet, because we consider that kind of abuse to be more like the abuse that happens in institutional settings such as nursing homes and hospitals.

### *Domestic Violence*

A woman is battered in this country every 15 seconds, according to the National Coalition Against Domestic Violence, and about a third of all women experience domestic violence. We do not know the actual numbers of women with disabilities who experience domestic violence, because statistics are kept about the race, age and marital status of abused women, but not about their disability status. Since studies have shown that disabled girls are about twice as likely to be sexually abused as non-disabled girls, some have estimated that as many as 60% of women with disabilities may experience domestic violence (Russell, 1995). One study of physically disabled women found that the same percentage (62%) of women with and without disabilities had experienced emotional, physical, or sexual abuse, but women with disabilities experienced abuse for longer periods of time (Nosek, et al., 1997).

Domestic violence against women with disabilities is both similar to and different from domestic violence against non-disabled women. For all women, the abusers are

primarily men who dominate and control their partners.<sup>3</sup> Women are perceived as easy targets, and women with disabilities are viewed as additionally vulnerable and helpless by such men. The goal of the abusing partner is to control and dominate through whatever means necessary. Domestic violence can take several forms:

- ▼ **physical abuse:** hitting, shoving, punching, kicking, grabbing, slapping, choking, pulling hair, twisting arms, beating, using a weapon against her;
- ▼ **emotional abuse:** demeaning, ridiculing, putting her down, calling her names, making her think she's crazy;
- ▼ **sexual abuse:** making her do sexual things against her will, physically attacking the sexual parts of her body, treating her like a sex object;
- ▼ **intimidation:** raising a hand or using other looks, actions, or gestures to create fear, destroying property, hurting or threatening to hurt her children, abusing pets or service animals, displaying weapons;
- ▼ **making threats:** threatening to hurt her, to leave her unattended, to take the children, to commit suicide, to report her to authorities;
- ▼ **using "male privilege":** treating her like a servant or a child, making all the decisions, acting like "the master of the castle;"

---

<sup>3</sup>Woman-on-woman violence also exists, but in this booklet we are talking about the most common domestic violence scenario, which is committed by men against women.

- ▼ **isolation:** controlling what she does, who she sees and talks to, where she goes, what she reads, denying access to TV, radio, or telephone;
- ▼ **economic abuse:** taking her money, preventing her from getting or keeping a job or attending job training, making all the financial decisions, refusing access to jointly held funds or information about finances.

While issues of control and domination are similar, women with disabilities are subject to additional types of domestic violence that are not issues for women without disabilities, such as denial of medication, personal assistance services or assistive devices. Both anecdotal evidence and published literature give examples of situations where wheelchairs were removed and dismantled, phones were disconnected, and food was withheld. These stories illustrate horrible situations where women with disabilities were essentially held prisoner in their beds.

The psychological abuse experienced by women with disabilities has an additional disability-related component. Some women have felt that they need to submit to domestic violence as a trade-off for personal assistance and/or financial



support provided by the intimate partner. Batterers tell their victims that if it wasn't for them, the women would be in nursing homes or other institutions. They threaten that

they'll get custody of the children if the woman leaves them. They tell women that because they're disabled, no one else will want or desire them, so they should consider themselves lucky to have these abusing men in their lives. The emotional battering may focus on the woman's disability: "You'd be better off dead," or "You're an ugly gimp."

Certain disabilities prevent the victim from verbally reporting domestic violence, or running from or fighting their batterer, or being able to leave. For instance, police may not know how to communicate with a woman with a traumatic brain injury, or a woman who is paralyzed may be unable to get away from the perpetrator. Many physically disabled women are dependent on van services for transportation, which may not be available in emergencies, leaving the woman with no way to get away. If she cannot use or reach a phone without help, she may not be able to report the domestic violence. And if the battering partner also provides personal assistance services, she may not be able to leave if she has no emergency system to call on. Therefore, even disabled women who are psychologically prepared to leave an abusive situation may be unable to do so.

### ***Caregiver Abuse***

Research has shown that caregivers commit at least one fourth of all crimes against people with disabilities (Samuels, 1994). Although we are not discussing

institutional abuse in this booklet, research has also shown that persons who live in institutions are more likely to be abused than those who live in their own homes (Sobsey, 1994). In this booklet, we define caregivers to be persons who provide personal or homemaking assistance to women in their homes -- paid or not. Abusive caregivers have very intimate relationships with their victims -- when they provide personal assistance, they are in close contact with the women's bodies as they provide help with toileting, bathing, dressing, and feeding.

Caregiver abuse is the exertion of the caregiver's will over the woman with a disability, and thus can take forms similar to the kinds of domestic violence described above. It can include humiliation, intentional neglect, telling someone what they should or should not eat or wear, withholding food or medically necessary treatment, mistreating or refusing to feed service animals, stealing money and personal belongings, isolating the woman from friends and family, sexual abuse, physical abuse, and even murder. There is extensive literature about child abuse and elder abuse by the full range of caregivers, but less is known about abuse of working-age disabled women. One study of independent living center consumers who used hired personal assistant services found that 40% reported an instance of theft by those caregivers, and 10% reported being physically abused (Ulicny, 1991). Though there is little in the literature about caregiver abuse of disabled women, in the disability community where we live, there is a lot of anecdotal

evidence and discussion about it, pointing to the seriousness of this problem.

**The Role of Society**

Domestic violence and caregiver abuse are not issues that are restricted to the relationship between the victim and the abuser. They are also broader issues reflective of the values and prejudices of the society we live in. The interactions between the offender and victim are characterized by an inequity of power, but this inequity can only be understood by considering the environment in which they interact and the cultural milieu in which they exist. When people with disabilities are perceived as worthless or devalued, or seen as defenseless and less likely to complain to the police, they become more attractive to perpetrators (Sobsey and Doe, 1991). Women with disabilities suffer from double devaluation due to both their gender and their disability. Women with disabilities who are lesbians or women of color suffer additional prejudice.

**EXAMPLES OF DOMESTIC VIOLENCE AND CAREGIVER ABUSE**

Women with all kinds of disabilities -- physical, sensory, psychiatric, and cognitive -- experience domestic violence



and caregiver abuse. They may be young or old, heterosexual or homosexual, working or not, with children or not. Many disabled women came forward to share their experiences with us for this booklet. Here are some of their stories:

▼ *Suzanna,<sup>4</sup> a woman in her 30s, has cerebral palsy and uses a motorized wheelchair. For five years, her husband, who is also disabled and a wheelchair user, would hit her, pull her hair, and disconnect her wheelchair so that she couldn't get away from him. When she called the police, rather than making her husband leave, they wanted to take her to the local domestic violence shelter. However, the shelter wasn't accessible, so the police instead took her to a homeless shelter where she had to sleep on the floor. Another time, she had to stay in a friend's apartment, which was up a flight of stairs.*

▼ *Suzanna also had \$1250 stolen from her checking account by her personal assistant. She filed a police report and told the*



<sup>4</sup>All of the names in this document have been changed to protect the privacy of the women involved. Stories are based on interviews with individual women as well as on printed reports, and in some cases have been compiled from numerous accounts.

*agency that funded the personal assistance services, who acted like it was no big deal.*

- ▼ *Rachel, a woman in her 20s with a physical impairment, uses a wheelchair and personal assistants. She was very friendly with a female PA, who sometimes spent the night. One night she awoke to find the PA in her bed, touching her sexually. Rachel couldn't get out of bed or get to the phone.*
  
- ▼ *Daisy, a woman in her 30s with a developmental disability and a psychiatric disability, was physically abused by her boyfriend for six months before she was brave enough to call the police. She refused to go to the domestic violence shelter, however, when they said that her case worker could not work with her there. She got an emergency placement at a group home for a few months, and now lives in her own apartment. Daisy was also sexually abused in her family of origin by her father and brothers.*
  
- ▼ *Angie is a blind woman in her 40s. In a previous relationship she moved to a rural area with her controlling boyfriend, who became abusive and intimidating. He would stop talking to her for hours at a time, so that she had no idea what he was doing or thinking. She couldn't leave because it was winter and the snow made it impossible for her*

*to find her way around a strange area. In addition to being emotionally abusive, he would stand by while she was in physical danger from others and refused to put a railing on the basement stairs so that she had to carry the laundry up and down without protection from falling.*



## II. DISABILITY: THE ADDED DIMENSION

The kinds of abuse experienced by women with disabilities can be different from that experienced by non-disabled women. Withholding medication or using medication to sedate the woman for the caregiver's convenience, disconnecting a wheelchair's power supply, breaking or hiding crutches, refusing to attach a ventilator, or putting something dangerous in the path of a blind woman are all examples of unique abuse experiences of disabled women. Paratransit or school van drivers -- who are "caregivers" while you are in the van -- have been known to molest many disabled women and girls. The fact that many women with disabilities need assistance in activities of daily living can make them more physically vulnerable to battering partners or abusive caregivers. But beyond these kinds of differences, having a disability and needing personal assistance can add a layer of complexity to relationships with abusers.



*Josette sustained a head and back injury in a car accident at age 40, and uses a motorized wheelchair and personal assistance services. She hired a couple to live in her home and provide personal assistance. The couple stole most of her possessions while she had a short hospitalization, ran drugs and a prostitution ring out of her home, and sold her prescription drugs on the street. On another occasion, she was raped by a male personal assistant, who then moved her phone away so she couldn't call anyone for days, and begged her not to report him to the police.*

As discussed above, disabled women are more devalued than other women. Several authors have written about the devaluation of women with disabilities in society. Barbara Waxman (1991) wrote about how being both female and disabled increases the risk of violence against woman with disabilities because of the double prejudice they experience. Michelle Fine and Adrienne Asch (1988) point out how women with disabilities are devalued because they are not seen as capable of fulfilling the traditional female roles of wife, mother or homemaker, or as career women. Whereas most women have been placed on a "pedestal" by society because they fulfill these roles, women with disabilities are often seen as asexual. Sandra Cole (1988) also writes about society's inability to understand how physically disabled women could be

sexual: “It seems difficult for society to perceive sexuality in any other context than among ‘pretty people’: the domain of the healthy and beautiful.”

Prejudice against women with disabilities results in their being less likely to be in relationships with significant others: one study found that nearly half of the women with disabilities stated that they were not in a marriage or serious relationship because no one had asked them, compared to only a quarter of non-disabled women (Nosek, et al., 1997). Women with disabilities often internalize these prejudices, and feel grateful when they are in relationships with significant others, even when their partners are abusive. “He told me no one else would want me” is a common story.

*Carmen, a woman in her 40s, has a visual impairment. Before she found a way to leave, her husband terrorized her by beating her up and choking her, and then would do something to the phone so she couldn't call the police. They lived in a rural area so there were no pay phones, and her neighbors were far away. Once he drove her someplace and let her out of the car in the middle of the street after telling her she was at the sidewalk. She stayed in the relationship for about six years.*

Most non-disabled people assume that the dependency on caregivers is a one-way street, but there is another dimension to this relationship. Often, the caregivers end

up being dependent on the disabled woman -- because they need the job, because they are related, because they feel emotionally cared for by the disabled woman, or because they are so invested in the caregiver role. Elderly women are particularly reluctant to turn in their abusive caregiver children, whom they partially support with their disability checks (Pillemer, 1985). Other women feel that the caregiver would be lost without the job: “What would s/he do? Who would hire this person?” It is often hard for women with disabilities to push away people who seem to depend on them, or to take the ultimate step of reporting them to the police for their crimes.

*After she left her parents' house to live on her own, Kelly was abandoned by one of her first personal assistants, who just didn't show up one evening. The phone had been left out of reach by the previous PA. A person hired to read her college assignments to her let her urinate in her wheelchair rather than help her go to the bathroom, saying that personal assistance was not part of her job. In both of these cases, Kelly had to wait without assistance, cold, wet, and hungry, until the next time someone was scheduled to show up. Kelly hates conflict, and hates to fire people and to have to find new caregivers.*

Another difference between disabled and non-disabled women is that women with disabilities have often grown up in a highly protected atmosphere, where most things are done for them by parents, teachers (sometimes in special

schools), or paid staff. Girls with physical disabilities especially can miss out on normal developmental activities, due to their extensive therapy appointments and often needing extra time to do simple tasks. Disabled girls can be isolated when their families fail to include them in regular activities (for instance, when parents of deaf girls refuse to learn sign language, leaving the girl to try to follow conversations on her own) or to address the prejudicial attitudes that keep them from being included in normal childhood social situations, such as birthday parties, religious activities, sports, clubs, or after-school play.

*Kelly, a woman with a physical disability who uses a wheelchair, had never crossed the street on her own until she was 19 years old, when she got her first power wheelchair. Because of her lack of experience in getting around on her own, when she started college she asked her personal assistant to accompany her to class. The PA made fun of her for wanting this assistance.*

The overprotectiveness and isolation experienced by disabled girls can produce “learned helplessness” in many adult disabled women, who do not believe in their own ability to get out of a bad situation, or the converse, a learned “need to please” due to the family not including the disabled child in normal activities (Merkin and Smith, 1995). Young women who have missed normal dating experiences in adolescence due to their peers’ perceptions that they are different and asexual may be confused about

drawing the line when as adults they experience abusive sexual behavior (Womendez and Schneiderman, 1991). Rather than believing that they would be better off on their own, often women with physical disabilities have very real fears of being institutionalized if they fire an abusive caregiver or leave a battering partner who also provides personal assistance. For deaf or blind women, their partners may be their interpreters and readers, their link to the hearing or sighted world. “As disabled women with sensory disabilities, we substitute someone’s willingness to describe something to us or otherwise make up for a lack in sight or hearing and think that’s what love is,” said Angie, a blind woman in her 40s.



Women with invisible disabilities, such as learning disabilities, can also experience isolation, abuse, and neglect based on their disabilities. This can start in childhood and continue into adulthood. For many persons with learning disabilities, psychological abuse happens when they hear things like: “You’re lazy -- if you would just try harder, you could do it.” As children, they are often shamed in class because the teacher assumes they are not paying attention. There are many types of learning disabilities that affect a wide range of activities, from reading to verbal communication. When a woman’s learning disabilities are not diagnosed, people often think that she’s not paying attention, or that she’s stupid. This

can lead to deterioration of self esteem, learned helplessness, and abuse.

In many communities, women with disabilities are very isolated. They don't know others like themselves, and have not seen role models of strong, independent disabled women. They believe they must put up with what they have, even if it is abusive. And, as we discuss below, the services that might help them are usually not accessible to them.

*Mary, a woman in her 40s, has learning disabilities that were not diagnosed until she was in her late 20s. Growing up, she constantly dealt with the frustration of her teachers and parents telling her that she needed to try harder in school, but she believed she was doing her best. Mary always knew something "wasn't right" when she compared herself to classmates and saw how much quicker they finished their exams and homework. In addition, there was a frustrating gap between her ability to verbalize her knowledge and her ability to demonstrate her knowledge on an exam. At home, constant abusive screaming arguments often led to physical abuse and seemed to dominate her childhood. As an adult looking back, she now understands that her mother, who also had undiagnosed learning disabilities, was having a difficult time managing her own frustration. The cycle fed itself. As her mother would take out her frustrations on both her children, Mary would in turn take out her frustration by physically fighting back and inappropriately hitting her sister. She thought this violent response to frustration was "normal." After diagnosis, she realized that the continual criticism by others relating to her difficulty in school was perfect fuel for feeding the cycle of physical violence and psychological abuse. Mary is now able to understand that the miscommunication and shame experienced with an undiagnosed learning disability, combined with how she was treated, contributed to her being in violent relationships with her mother and later on, with a lover.*

Eventually, many women with disabilities in abusive situations *do* get out. “I felt like my spirit was dying and I didn’t want that,” said Suzanna. She finally sought assistance from a legal agency specializing in domestic violence in her community and asked for help from friends, and now lives on her own.



## BECOMING DISABLED FROM DOMESTIC VIOLENCE

*While there has been evidence for some time that women with disabilities are more likely to be abused than non-disabled women, only recently is more attention being focused on the issue of the kinds of disabilities **caused** by abuse and violence, and the particular rehabilitation needs of the women disabled in this way. The Domestic Violence Initiative for Women with Disabilities in Denver reports that during a two year period, 60% of the women seen in their program were disabled before they were abused, and 40% were disabled as a result of the abuse. Women may acquire physical, sensory, and cognitive disabilities as a result of abuse, incurring permanent back, neck, and joint injuries, vision and hearing problems, traumatic brain injuries, and seizure disorders. However, perhaps the largest category of disability caused by domestic violence and sexual assault is psychiatric disability, in the form of Post-Traumatic Stress Disorder (PTSD), which can affect functioning for years after the woman has left the abusive situation (Murphy, 1992, 1995).*

*Because the battered women’s movement has little connection to the disability community and service system, survivors of abuse may not identify as disabled or even attribute their functional limitations and vocational impairments to the domestic violence they suffered. Unpublished data indicate that women receiving welfare spontaneously identify abuse and its after-effects as their biggest barrier to employment.*



### III. BARRIERS TO ENDING THE ABUSE AND VIOLENCE

**A**buse and violence is not just about the relationship between two people. They are about the place of disabled women in society, and there are many levels of barriers to ending domestic violence and caregiver abuse. Below, we discuss some of the barriers at the individual level and the societal level.

#### WOMEN WITH DISABILITIES NEED BETTER INFORMATION

**S**ometimes women accept abusive treatment because it is all they have known. Like non-disabled women, women with disabilities who were abused as children or who grew up in households where they witnessed domestic violence tend to think of it as inevitable when it happens to them as adults. They may have never thought of what was happening to them as “abuse” or “violence.” Sometimes women believe that only physical abuse “counts” as domestic violence, discounting the emotional abuse, neglect, or forced sexual activity that can be equally damaging. Or they reason that the abuse is not really that bad. Suzanna, whose disabled husband physically battered her, initially felt that because he was disabled, “he couldn’t hurt me that badly.”

#### Cycle of Violence

**Build up of tension,  
anger, blaming and arguing.**

**Acute battering incident:  
e.g., hitting, choking,  
use of objects or weapons,  
sexual abuse,  
verbal threats and abuse,  
intentional neglect.**

**Contrition/Honeymoon period,  
with remorse, apologies, denial.  
Batterer says he’s sorry and promises  
it will never happen again.  
Flowers, candy, jewelry, and gifts are given.  
Batterer is actually trying his best  
to reconnect victim to the relationship.**

Other women with disabilities lack knowledge about how to get help. As we discuss in the section below, most often help that is available to non-disabled women is in fact inaccessible to women with disabilities. Women with disabilities may not understand that they are entitled to ask for restraining orders, to obtain accessible domestic violence or rape crisis counseling, or to have the police remove a batterer, just like other women.

Women with disabilities, like non-disabled women, are often caught in the cycle of violence (see figure). They believe the batterer when he says that he won't do it again during the "honeymoon" period after a violent episode. But inevitably, the tension builds and the woman is battered again, and the batterer usually makes her feel that she has provoked it! Just learning about the cycle of violence can help women with disabilities understand that they will not be able to make it stop by changing their behavior. It is the batterer who must change. If that won't happen, the best thing she can do is find a safe way to remove herself from the relationship.

Batterers often threaten to take the couple's children if a woman leaves an abusive situation, and women with disabilities receive this threat as well. One study of physically disabled women found that they were

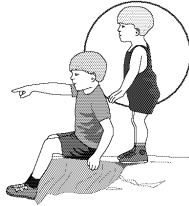


significantly more likely than those without disabilities to stay in a bad marriage for fear of losing custody of their children (Nosek, et al., 1997). Disabled women fear that a judge would not award them custody of their children if they were not living with a non-disabled spouse. This fear has some basis in fact, but judges can be educated about the capabilities of the mother with a disability (DeAngelis, 1995). Through the Looking Glass is an organization that assists disabled parents to keep custody of their children (see "Resources" section at the end of this booklet). With the right support and competent legal counsel, women with disabilities can and do raise their children as single parents. A recent national survey of parents with disabilities estimates that 36% of disabled mothers are single parents (Toms Barker, et al., 1997).

Another very real fear on the part of women with disabilities is that they will lose their personal assistance services (PAS) or family support and end up in institutions if they report abusive caretaking. It is true that there are often bureaucratic barriers to obtaining PAS quickly (e.g., if one leaves or throws out an abusive partner who also provides PAS). And very few communities have any kind of emergency personal assistance system, where women with disabilities can obtain help if they have to fire an abusive caregiver. Below, we discuss some system-level and individual-level approaches to address these issues.

## ESCAPING IS HARDER FOR WOMEN WITH DISABILITIES

Disabled women often face greater barriers to getting help because of inaccessible support services. They may lack knowledge precisely because the disability community and service system does not yet know how to recognize abuse or make referrals to domestic violence programs. The disability community has worked so hard at showing the general public that we can have partners, marry, have children and participate in other activities once forbidden to us, that there is often denial that abuse and violence happens in our community (Hickman, 1996).



This denial is especially strong when the abuser is also disabled. We don't want to splinter our small community by telling on one of our own. The fact that the disabled community is usually quite small in any given area means that if we do tell, we may not be supported or may be actively shunned for breaking the silence. The community may split as people feel that they must side with the batterer or the victim. When an abused woman talks about something that happened to her, the story often gets turned around to imply that it was her fault. Batterers often look like model citizens in public and can even have leadership positions within the community. It may be hard for the battered woman to find new friends and supporters.

*Connie, a deaf woman in her 30s, was battered for 10 years by her deaf husband. She was afraid to report him because the deaf community is a small, close-knit one and everyone would know. It was only after another deaf man murdered his wife that she had the courage to speak out.*

*Rachel, a physically disabled woman in her 20s who was sexually assaulted by her female personal assistant, discovered that the PA was saying that Rachel had initiated the sexual activity. Rachel found that many people in the small disability community believed her PA's version of the story. When the PA eventually left town, so did some of Rachel's checks.*

Not only is telling hard, but leaving home and setting up in a new one elsewhere may be very difficult. Some women are entirely dependent on their partners for financial support and health insurance. If a disabled woman depends on SSI for financial support, it is unlikely that she can save for first and last month's rent and a security deposit for an apartment. Another barrier to moving is the expense of modifications needed (e.g., ramps and grab bars for physically disabled women, TTYs and light flashers for deaf women, etc.). Non-disabled women can crash on a friend's couch without worrying about the stairs to the house, the narrow doorways, or the lack of a ramp to the bathroom. "I felt like I was in prison," said one woman who uses a wheelchair when she ended up at a friend's inaccessible house after the police refused to

remove her battering husband from their home. Other women have discovered that they couldn't leave after an abusive episode because the van services they depended on for transportation required reservations weeks in advance, and policies prohibit "priority treatment," even in emergencies (Aiello, 1986). And some women being abused by caregivers may wonder whether the next situation will be any better than the one they are in now. A known situation has a certain comfort, even if it has problems.

*Marie, who is blind, was sent an eviction notice for nonpayment of rent, because her personal assistant who was supposed to write her checks stole the money instead.*

Beyond the need for adaptive devices, there is the fact that the loss of assistance can be life-threatening for women with disabilities. Women who rely on respirators, for example, cannot just leave without knowing that someone else will be able to help them. Women with cognitive disabilities may not have the ability to negotiate a legal system that requires them to defend themselves against partners with greater cognitive skills. A woman who goes into hiding at a domestic violence shelter may be required to protect the anonymity of the shelter by giving up contact with the very people she depends on for support in her life -- her caseworkers, personal assistants, family members.

*Philly is a 50 year-old psychotherapist who has a neuromuscular disability and is ventilator-dependent. She requires 24-hour personal assistance services and uses live-in assistants. She often has a difficult time convincing new PAs that suctioning phlegm from her trachea is a priority, not something they can do after they finish a phone call or a TV show. Other PAs have been physically rough with her, even after being trained about how to move her. The abuse she experiences now reminds her of the abusive treatment by her mother when she was a child.*

Like most women, women with disabilities would like to believe that our partners are our friends and have our best interests at heart. We don't want to be in the position of pushing them away and appearing ungrateful for the good things they have done for us (hardly anyone is abusive all the time). Relationships with caregivers are sometimes very formal employer-employee relationships, but for some women the unpaid help provided by family, partners, and friends is less formal. Our real disability-related needs can put us in a "one-down" position with respect to these people, because of the lack of affordable and accessible alternatives. We must remember that we are entitled to respectful treatment.

## PROGRAMS AND SERVICES AREN'T ACCESSIBLE

Even if a woman with a disability decides to leave an abusive relationship, there are many barriers to her obtaining the help she needs. The domestic violence and sexual assault systems are usually not accessible to women with disabilities. One barrier is attitudinal: for the most part, disabled women are invisible to these service providers, who often share the common belief that disabled women are not in relationships, and thus will not need services. Other barriers exist because the service providers do not understand what it means to make their programs accessible to women with all kinds of disabilities. They may not understand that accessibility is important in many aspects of programming, for instance:

- ▼ **physical accessibility** (e.g., making entries, bathrooms, residential and therapy rooms accessible to those with mobility impairments; prohibiting the use of perfumes to accommodate those with environmental illness);
- ▼ **phone accessibility** (e.g., making sure that TTY-users have access to hotlines; training staff to understand that the woman with the slurred voice may have a speech impairment and is not on drugs or drunk);

- ▼ **outreach activities** (e.g., if they advertise only by print, most blind women will be unaware of their presence; making sure their materials are understandable to women with cognitive disabilities or learning disabilities).

Domestic violence services are often not accessible, especially shelters which have to move often to conceal their whereabouts and run on very limited budgets. Shelter staff may say that they never see or hear from women with disabilities, and so may not see them as having a need for services (Corin, 1986). There is circular reasoning going on here: one reason shelters don't see women with disabilities is because they're not accessible, and because they're not accessible, women with disabilities don't attempt to obtain services (Hickman, 1996). Another reason why domestic violence programs do not perceive that women with disabilities need their services is that women with hidden disabilities that often carry stigma (such as epilepsy, AIDS, learning disabilities, or psychiatric disabilities) may not be disclosing their disabilities. Even when shelters are physically accessible, they may not provide personal assistants or even allow PAs to be in residence, or have strict rules (e.g., requiring a certain number of hours of a certain kind of work) that exclude women with certain disabilities. The California Women's Law Center surveyed domestic violence programs in that state and found that only 25% had some accessibility, and that of those, many had little

understanding about what access entailed (California Women's Law Center, 1994).

Even if women with disabilities have someplace to go when they leave, they may not fare well in the legal system. Anecdotal evidence abounds that police often don't take complaints seriously when they're made by a disabled person. They tend to believe the caregivers over disabled persons, assuming that the non-disabled person has best interests of disabled person at heart and is always right. Sometimes the police don't even take a report when they see the victim is disabled. Women with communication or cognitive disabilities experience additional reporting problems as they may not be viewed as credible by law enforcement agencies or social service programs. Police are not trained to deal with persons with communication problems, and although many police departments have routine access to language interpreters, there are numerous reports of 911 operators hanging up on TTY calls or police not providing sign language interpreters when taking reports from women who are deaf (Goldman and Hoog, 1995). There is anecdotal evidence that this has even resulted in deaf women being themselves arrested when they tried to report their battering hearing partners! The police believed the hearing men who claimed that the women were the ones doing the battering.

Prosecutors often don't consider women with cognitive, sensory, psychiatric or communication disabilities credible witnesses, because their reports may be incomplete or inconsistent, they may not be able to see to identify a suspect in a lineup, or they have trouble communicating on the witness stand. Defense lawyers may imply that women with psychiatric or cognitive disabilities are habitual liars who tell stories just to get attention (Longo and Gochenour, 1981). In one case, a father was convicted of sexually abusing his stepdaughters, but not his 24-year-old mentally retarded daughter, who told the same story about the abuse (Allen & Savvides, 1992).



Punishment of the abusers is also a problem. A disturbing study of law students found that crimes were perceived to be less serious when the victims were disabled (Waxman, 1991). Many believe that judges tend to be more lax when victims are disabled people. In several publicized cases of abuse and murder of people with developmental disabilities in this country, judges have given more lenient sentences than would normally be expected for the crime committed.

## **DISABILITY SERVICE PROVIDERS ARE NOT EDUCATED ABOUT ABUSE AND VIOLENCE ISSUES**

**W**omen with disabilities may find themselves in abusive situations for reasons over which they have no control. The disability “system” (which is only a loose network of service agencies) has not always been on guard against the possibility of abuse and violence. In the past, disabled girls in special education or special schools were excluded from educational programs about what constitutes abuse and how to protect themselves. Schools that ran assemblies or classes about these issues had no requirement to include the children with developmental or learning disabilities who need to have the information presented in a different way, or may not have had sign language interpreters available for deaf girls. These girls grew up into women who were not educated about abuse and violence issues, and the service providers were not educated, either.

Women with disabilities have numerous stories about PAS agencies that seem to assume that abuse will happen and not much can be done about it. In the case of agency-provided PAs, women with disabilities who complain about the actions of a particular caregiver are often assigned another one, and the abusive PA is simply assigned to someone else. Rather than taking the complaint of

abusive behavior seriously, there was an assumption on the part of the agency that maybe the woman didn't know how to manage her caregiver. This is blaming the victim with a vengeance!

When women hire and fire their own personal assistants, there is no screening mechanism, and they still have little recourse when the reason for firing is because of abuse. In fact, the woman may be so intimidated by the abusive PA that she will avoid mentioning the reason for firing, deciding instead to couch the dismissal in other terms (e.g., the times didn't work out). There is no centralized listing of personal assistants where complaints can be registered, and the PA could go on to abuse the next person who hires him or her. If the woman did use a referral agency such as an independent living center to locate the PA, she may fear retaliation if she reports the abuse back to the referral agency, in the form of being “blacklisted” as a difficult employer for whom PAs won't want to work.

Personal assistants, whether provided by an agency or hired directly by a disabled woman who has a grant from a social services agency for that purpose, are typically paid minimum wage. They receive no benefits, and there is no opportunity to advance or get a pay increase. While many personal assistants are responsible people who genuinely want to provide good service, many people who take these low-paid, dead end jobs are those who cannot get better than minimum wage elsewhere, who cannot keep a steady

job, or who intend to leave as soon as something better comes along. Policy-makers in the disability service system close their eyes to the abuse potential of hiring low-paid personal assistants who will have high turnover.<sup>5</sup> Consumer groups have called for reforms of the system, to no avail (Center for Disability Rights, 1993).

The disability system has also been slow to establish emergency personal assistance systems. Whether PAs actively abuse disabled women or neglect them by showing up late or not at all, the woman has no place to call for a quick replacement, which leads to her putting up with the abuse. Women with disabilities are afraid to fire their attendants for fear that they will end up in nursing homes or hospitals; an outcome that punishes them if they report the abuse. Given how hard we have fought to be able to live independently in the community, many disabled women put up with a certain amount of abuse or neglect as the price we pay to stay out of an institution. But this price is too high -- no one should "have to" put up with abuse.



---

<sup>5</sup>We are not saying that low pay leads to abuse. Highly-paid doctors, therapists, and teachers abuse women with disabilities, too. But many people who would be good personal assistants would not consider doing the work because the pay is so low. Raising the pay scale would allow us to attract better people into the job.

## IV. FIGHTING BACK -- WHAT TO DO

The first step in fighting the epidemic of violence against women with disabilities is to break the silence and raise awareness of the issue, through talking about it, writing about it, and educating others. Reading this booklet and sharing it with other disabled women, service providers, and our allies in the fight for accessible services are good first steps.

Action is needed at all levels to address the issues of domestic violence and caregiver abuse of women with disabilities. Disabled women can take steps to protect themselves and help others. But because violence and abuse are embedded in the larger social system, there are steps that must be taken at the societal level to address these issues. In order for change to take place, disability service systems must acknowledge the issues, non-disability service systems must become more accessible, police and prosecutors must change the way they treat disabled women who finally gain access to the criminal justice system, and policy makers must increase funding and information collection.

### WHAT WOMEN WITH DISABILITIES CAN DO

The disabled women who told us their stories for this study also had advice for others who might be currently

experiencing abuse. Below are some of their recommendations.

- ▼ ***Women with disabilities can educate themselves and each other about what constitutes abuse, how the cycle of violence works, and that they are not at fault.***

Many of the women who responded to a survey about abuse felt that their disabilities made them burdens on others and that they were to blame for the abuse (Nosek, 1995). Women with disabilities must come to understand that *their disabilities have nothing to do with the violence or abuse they experience*. A culture of violence against women exists in our society, for non-disabled and disabled women. There is also tremendous prejudice against people with disabilities. Needing personal assistance can make us more vulnerable to abuse by individuals who want to control and to dominate. But the desire to control and dominate is the problem, not our disability.

Speaking out is educational and empowering, both for those who spread the knowledge and those who receive it. Often those who experience violence feel that they are the only ones. Silence equals shame, and it perpetuates the myth that this issue doesn't exist in the disability community. By speaking out, shame is dissipated, isolation is ended, and action is possible.

It is hard to admit that abuse is happening. Sometimes women can't admit it until the violent partner or caregiver is

gone for a few days or the woman herself goes away and gets some perspective on what is happening. When you find you're putting all your energy into placating your partner or personal assistant for fear of another emotional or physical attack, it's time to admit that the relationship is not working. Look carefully at your situation, your fears, and your options, and then do something.

- ▼ ***Join with others in a circle of support.***

Women who experience domestic violence and caregiver abuse for long periods are often those who have little support outside of their relationship with their abusers -- and isolation is often a tactic of abusers, to keep the victim



under control. The more that women with disabilities have relationships with co-workers, friends, family, and religious or community organization members, the more potential allies they can call on when something is going wrong. Don't let one person -- partner, relative, or paid personal assistant -- provide all your personal assistance or support. Plan ahead of time who you would call if you had to get away, what you would take with you (e.g., birth

certificate or passport, driver's license, address book, prescriptions, insurance information, other important financial records), and where you would go. Think about it carefully when your controlling partner wants you to move with him or her to a strange area where you don't know anyone. Angie, a blind woman who moved with her abusive boyfriend and then regretted it, said, "Ask yourself if you really want to live in an isolated rural area."

Women with disabilities must understand that they can be support for each other, because they understand each other's issues. If there isn't an active disabled women's group in your community, maybe you can start one. Talk to your local independent living center or a local woman's group. (For information on finding your local independent living center, see the "Resources" section at the end of this booklet.)

**If you are currently being abused and you have no circle of support to call on, call the police, a domestic violence program, a suicide prevention hotline, a rape crisis line, or other crisis line -- or tell your doctor or clergy person. Look under "Crisis Services" in the front of your phone book, or call the national hotline number in the "Resources" section of this book. Don't keep the silence any longer, and don't let others minimize what is happening to you. Domestic violence and caregiver abuse can be fatal.**

▼ ***Be systematic about hiring personal assistants.***

Personal assistants (PAs) often have our lives in their hands. It is important to select them carefully, and to protect ourselves from the potential for abuse. Check references on potential PAs. Interview potential PAs away from your home, in a coffeeshop or park, so that they won't know where you live if you decide not to hire them. Ask them what personal assistance services they've provided before, why they do this work, and how they handle frustration. Don't make an instant decision -- say you will think about it and call. Interview several potential PAs before making a decision, and be clear about your criteria for hiring. Keep the list of people you don't hire as possible backups. Treat the whole relationship as a professional employer-employee relationship, not a friendship.

Trust your instincts! If something tells you there's something wrong with a potential PA, there probably is. Don't discount that little voice in the back of your head.

▼ ***Be on guard with current PAs and have an emergency backup plan.***

When you feel that something has deteriorated about a current PA relationship, don't just assume that you have to put up with it. Make an emergency backup plan in advance -- if you have to find another PA quickly, how will you go about it? Is there an emergency PAS system in your community? (If not, lobby for one! See below.) Can you call another disabled friend and ask her PA to cover

for a few days while you hire a new one? (Make a mutual support pact that you will ask any PA you hire whether they'd be willing to do this in an emergency.) Is there someplace you can go if you have to stay in a different place for a while? Can you hire more than one PA for your everyday needs, so that they can be backups for each other?

If you feel that you are being mistreated by a current PA, invite another disabled friend to come observe and confirm your suspicions. One woman was reluctant to fire her PA who was exhibiting strange behavior that turned out to be initial symptoms of schizophrenia. Another let herself be talked into not reporting a sexual assault, because the PA promised he would go to therapy and never do it again. When something like this happens, you might not believe that something harmful is really happening, and having another point of view can be helpful. But don't give someone the benefit of the doubt if you feel like you're in danger.

When your PA is becoming more neglectful, is not following your directions, or is becoming more controlling, you can try and talk about it and resolve the issue rather than just severing the relationship. But keep it professional -- make an appointment to talk when the PA is not on duty. If you fear their anger, talk away from home in a public place like a coffeeshop or park. If you have made a decision to fire a PA, be prepared to ease out of the relationship if the person could do you harm.

▼ **Know your rights.**

Women with disabilities can educate themselves and each other about their rights to accessible services under the Americans with Disabilities Act (ADA). We have included basic information about the ADA at the end of this booklet (see the "Know Your Rights" section), as well as numbers to call to get further information (see the "Resources" section).

▼ **Advocate!**

If you're not in a crisis situation right now, you might want to get involved so that other disabled women who are experiencing domestic violence or caregiver abuse will have the help they need -- it's hard to change the system when you're in crisis and afraid for your life. Find out who



your local domestic violence service providers are, and let them know that violence and abuse of women with disabilities is an important issue. Educate them about accessibility and the ADA. Contact state and local legislators and encourage them to establish emergency backup personal assistance systems and criminal background checks for potential PAs (see below). Work with your local independent living center and other disability service providers to raise their awareness of

abuse and violence issues. Fight for a system to record abusive episodes in the local PA referral system.

Get involved in public education efforts. Every area has its own needs. What are the needs in your area? In a city with a large number of deaf students, you might focus on the needs of deaf girls, and help local agencies develop educational programs with sign language interpreters. If there are many minority disabled women in your area who don't speak English as their first language, maybe materials must be translated and made culturally appropriate for the disabled women in those cultures. The more we speak out, the less likely it is that the system would continue to ignore the needs of disabled women.

Advocating is hard work, and many women will not have the time or energy. If all you do is find ways to protect yourself, that's enough.

## WHAT SERVICE PROVIDERS, AGENCIES, AND LAW ENFORCEMENT CAN DO

- ▼ ***Domestic violence and sexual assault providers must increase access to existing programs.***

**S**adly, it is almost understandable why women with disabilities don't report abuse -- because they have so few options. Many agencies serving battered women throughout the country fail to provide programming and

services that include and respond to the needs of women with disabilities.

Many people, not only domestic violence program staff, think that "improving access" means building a ramp. However, accessibility is a broad concept that means much more, since women might have many different kinds of disabilities. True access can also include providing sign language interpreters, having information printed in alternative formats for visually disabled women, training hotline staff to answer TTY calls, or providing a safe environment for women with chemical sensitivities. It also means abolishing policies and procedures that discriminate on the basis of disability, such as not allowing someone to use personal assistants in a shelter. And it includes training staff about their attitudes toward women with disabilities.

Access is a good idea -- and it's the law. The Americans with Disabilities Act (ADA) became effective in 1992, which



means that programs have a legal responsibility to become accessible. There are resources available to help programs become more accessible, including excellent technical assistance manuals produced by the National Coalition Against Domestic Violence and the DisAbled

Women's Network (see "Resources" section of this booklet). But becoming accessible requires more than buying a manual -- it requires that the boards of directors and staff of programs make a commitment to serving *all* women in their communities.

Domestic violence and sexual assault programs can also reach out to the disability communities in their areas and invite women with disabilities to be on their boards or serve as staff or volunteers. They can offer to write joint funding proposals with disability service providers to increase access to services, or -- in rare cases where the community agrees that this is the best solution -- to develop programs especially for women with disabilities. There are differing opinions about whether specialized programs should be developed. The specialized programs that exist, such as the Domestic Violence Initiative in Denver or Abused Deaf Women's Advocacy Services in Seattle (see "Resources" section for contact information), also work to improve access to mainstream services in their communities.

▼ ***Disability programs should acknowledge that abuse/violence happens.***

The disability community has been in denial for too long about abuse and violence issues. Independent living centers (ILCs), which are the largest network of services provided by and for people with disabilities, can take the lead in this area, by improving screening for their personal assistant referral listings, encouraging consumers to report

on abusive episodes about particular PAs (anonymously, to prevent liability issues -- see below), and sponsoring support groups for women who are dealing with the after effects of domestic violence and caregiver abuse. Disability organizations can take the lead in joining with local domestic violence programs to increase access for women with disabilities, and can join with them to secure funding for increased access.

▼ ***Rehabilitation professionals and other counselors must be trained about abuse/violence issues.***

Rehabilitation workers serve many women with disabilities. In most cases, however, they have not been trained in recognizing signs of abuse, how to ask about abuse, or to be on the lookout for suicidal feelings that can result from abuse. In a study of nearly 400 Canadian women with disabilities, 61% had thought about suicide and 45% had attempted suicide. Those who experienced abuse were much more likely to have felt suicidal, and the more kinds of abuse a woman had experienced, the more likely it was that she had had suicidal thoughts (Masuda, 1995). Rehabilitation workers must also be aware of the fact that abuse can cause disabilities, and to help the woman deal with the trauma of the past abuse.

▼ ***Judicial systems should offer training to staff.***

Many police officers have undergone special training about domestic violence in recent years. However, it is important that police -- and judges and prosecutors -- learn about how abuse can be different for women with disabilities

(Chapman, 1996). The Justic Institute of British Columbia and the DisAbled Women's Network (DAWN) in Ontario have developed specialized training for the Canadian judicial system to raise awareness about the needs of women with disabilities, but little has been done in the United States. (See "Resources" section at the end of this booklet for contact information.) It is only through increased awareness that the practice of lesser prosecution and punishment of abusers of disabled victims can be halted.

## WHAT POLICY MAKERS/FUNDERS CAN DO

**T**here is no "magic bullet" that will stop domestic violence and caregiver abuse against women with disabilities. However, in addition to increasing general efforts to reduce violence against women in our society and seeing that the perpetrators are punished, policy makers and funders (e.g., state and federal legislators, foundations) can take steps to address some of the dimensions of the problem that are specific to women with disabilities.



- ▼ ***Fund emergency personal assistance systems.***

Many women with disabilities fear being placed in nursing homes if they lose their personal assistance services, and this fear is well warranted. It happens -- and will continue to happen until we have systems in place to guard against

this loss of freedom. We have only been able to identify one community (Berkeley, California) that funds an emergency backup system -- a registry of on-call personal assistants. Having emergency backup available (not only for cases of abuse, but when a PA simply doesn't show up or gets sick) is less costly than institutionalization, and much less costly than the human costs of violence. Since such backup systems are not in place in most areas, women with disabilities must piece together their own emergency plans, which, while better than nothing, are no substitute for a system.

- ▼ ***Increase funding for personal assistance services to allow higher pay.***

There is general agreement in the disability community that low pay leads to unreliable people taking personal assistance jobs, high turnover of good personal assistants, and a higher potential for abusive behavior. Agency-based programs may offer higher pay and better training, but less control of personal assistance by the consumer (the person with the disability). In areas where consumers can hire their own personal assistants, they are usually allowed a certain number of hours at minimum wage or just above. In order to hire higher-quality PAs, women with disabilities often offer a higher wage and settle for fewer hours of personal assistance than they really need -- a practice that is illegal and puts them in danger of losing their benefits if they are found out. Either approach places their health and quality of life in jeopardy.

Even with higher pay, personal assistance services are still very economical compared to institutionalization. In addition, a well-funded PAS system allows people with disabilities to live with dignity and work in the community, thus respecting their rights as human beings. This could also decrease the amount of abuse against women with disabilities, which adds to the arguments for a well-funded system of personal assistance services.

▼ ***Allow women to request criminal background checks of potential personal assistants, and make them happen promptly.***

In most cases, there is no way to check on the background of PAs hired by individuals. Women with disabilities have later discovered that the people they had hired had previously been convicted of drug dealing, robbery, child molestation, or rape. It is outrageous that we can run criminal checks on soccer coaches, who operate in public in full view of other adults, but can't check on the people who have intimate contact with us in our homes. A system must be developed to allow criminal background checks of potential PAs, and to make it happen quickly -- when someone has to hire a new personal assistant, she may need to make a decision in a few days. (Women with disabilities can call their local law enforcement agencies to find out if it is possible to request criminal background checks on potential PAs in their areas.)

▼ ***Develop systems to keep track of abuse complaints.***

Women with disabilities who have been abused by caregivers are often alarmed to find out that the person they fired was subsequently hired by a different woman. Presently, there are very few systems available to keep track of complaints (or praise, for that matter) about personal assistants. While this is understandable from a legal standpoint (we can't have a system that asserts that someone has done something criminal when this has not been proven in a court of law), there should be a way to anonymously register one's experience with a particular PA. One system that has been used is for the referral agency to maintain a loose-leaf binder with a sheet assigned to each person in their PA registry, so that people could write comments (good and bad) about their experiences. People who were hiring could read those comments and take them into account when deciding who to interview. Other local registries could adopt this approach, and could also make policies about dropping PAs from registries when a certain number of negative comments had been posted. This system does not prohibit anyone from becoming a PA or prevent anyone from hiring someone they choose to (because it is all voluntary), but it does give a venue for information for those who would like to take advantage of it.

▼ ***Facilitate increased data collection about the extent of the problem.***

As domestic violence becomes a more pressing social issue, there is more and more information becoming available about the demographic characteristics of battered women (e.g., age, race, marital status), but no information about their disabilities. Without data about the extent of the problem, most policy makers and programs will continue to assume that abuse and violence are not problems for disabled women. However, simple changes to standard intake forms, police reports, and other data collection instruments would enable researchers and others to document the extent to which disabled women are battered, and whether women are made disabled by abuse. This would allow the disability community to show the need for services, define the kinds of services needed, and advocate for greater funding for services for women with disabilities.



## V. CONCLUSION

Women with disabilities can and do get out of abusive situations. Sometimes it is not easy, and change does not happen all at once. Angie, a blind woman who left her abusive boyfriend ten years ago, after a six-year relationship, put it this way:

*T*ell the readers to have compassion for themselves. It's like when you're trying to get physically fit. If you hit it like gangbusters you're probably going to fail. The difficulty was having compassion for what I had accomplished. It's the only way to make things go forward. I am still hard on myself about my lack of progress [with leaving the relationship], but if I look at this piece that I did, and that piece that I did, I could say, damn, given everything, what I knew, how I felt, given the relationship, I really did make strides. But [at the time] it felt like 15 minutes on a bike on low speed with no tension. That's the part I keep hearing about strengthening exercises, doing something is better than doing nothing. Yes, I backslid, I had difficulties, but I kept struggling and kept going.

Violence against women, disabled or not, is wrong -- period. Together, we can work to reduce that violence.

## REFERENCES

- Aiello, Denise (1986). "Issues and Concerns Confronting Disabled Assault Victims: Strategies for Treatment and Prevention," *Sexuality and Disability*, Vol. 7, No. 3/4.
- Allen, Carrie, and Nick Savvides (1992). "'Child' adults suffer sexual abuse." *The Observer*, November 11, p. 10.
- Berkeley Planning Associates (1996). *Priorities for Future Research: Results of BPA's Delphi Survey of Disabled Women*. Oakland, California: Author.
- California Women's Law Center (1994). *Domestic Violence Resources in California: Shelters and Hotline Programs*. Los Angeles, California: Author.
- Center for Disability Rights, Inc. (1993). *Early to Bed/Late to Rise: An Analysis of Community-Based Personal Assistance Services in Monroe County and New York State*. Hilton, NY: Author.
- Chapman, Connie (1996). *Charting New Waters: Responding to Violence Against Women with Disabilities*. Justice Institute of British Columbia.
- Cole, Sandra (1988). "Women, Sexuality, and Disabilities," *Women and Therapy*, Vol. 7, No. 2/3.
- Corin, Leslie (1986). "Sexual Assault of the Disabled: A Survey of Human Service Providers," *Sexuality and Disability*, Vol. 7, No. 3/4.
- DeAngelis, T. (1995). "Custody battles challenging for parents with disabilities," *American Psychological Association Monitor*, January.
- Doucette, J. (1986). *Violent Acts Against Disabled Women*. Toronto: DisAbled Women's Network.
- Eastcott, Doris Rajan (1994). *We Are Those Women! A Training Manual for Working with Women with Disabilities in Shelters and Sexual Assault Centres*. Ontario, Canada: DisAbled Women's Network.
- Fine and Asch (1988). "Introduction: Beyond Pedestals." In Fine and Asch, Eds., *Women with Disabilities: Essays in Psychology, Culture and Politics*. Philadelphia, PA: Temple University Press.
- Goldman, Linda, and Cathy Hoog (1995). "A Light at the End of the Tunnel?" *ADWAS Newsletter*, Summer.
- Hickman, Sharon (1996). Founder/Director, Domestic Violence Initiative for Women with Disabilities, Denver, Colorado. Interview.
- Longo, Robert E., and Claude Gochenour (1981). "Sexual Assault of Handicapped Individuals," *Journal of Rehabilitation*, Vol. 47, No. 3, pp. 24-27.
- Masuda, Shirley (1995). *Don't Tell Me to Take a Hot Bath: Resource Manual for Crisis Workers*. Ontario, Canada: DisAbled Women's Network.
- Merkin, Lewis and Marilyn J. Smith (1995). "A Community-Based Model Providing Services for Deaf and Deaf-Blind Victims of Sexual Assault and Domestic Violence," *Sexuality and Disability*, Vol. 13, No. 2.

- Murphy, Patricia A. (1992). "Taking an Abuse History in the Initial Evaluation," *NARPPS Journal and News*, Vol. 7, No. 5, pp. 187-191.
- Murphy, Patricia A. (1995). *Making the Connections: Women, Work, and Abuse*. Delray Beach, FL: St. Lucie Press.
- Nosek, M., et al. (1997). "National Study of Women with Physical Disabilities: Special Summary," Center for Research on Women with Disabilities, Baylor College of Medicine, Houston, Texas.
- Nosek, M., et al. (1996). "Abuse Experiences of Women with Disabilities Compared to Women without Disabilities: Fact Sheet," Center for Research on Women with Disabilities, Baylor College of Medicine, Houston, Texas.
- Nosek, Margaret (1995). Director, Center for Research on Women with Disabilities, Houston, Texas. Interview.
- Panzarino, Connie (1994). *The Me in the Mirror*. Seattle, Washington: Seal Press.
- Pillemer, Karl (1985). "The Dangers of Dependency: New Findings on Domestic Violence Against the Elderly," *Social Problems*, Vol. 33, No. 2.
- Russell, Marta (1995). "Piercing the Veil of Silence: Domestic Violence and Disability," *New Mobility*, November.
- Samuels, Robert (1994). "Crime and Disability: Assessing the Risk," *New Mobility*, November/December.
- Seelman, Katherine and Sean Sweeney (1995). "The Changing Universe of Disability," *American Rehabilitation*, Autumn/Winter.

- Sobsey, Dick (1994). *Violence and Abuse in the Lives of People with Disabilities*. Baltimore: Paul Brookes.
- Sobsey, Dick and Tanis Doe (1991). "Patterns of Sexual Abuse and Assault," *Sexuality and Disability*, Vol.9, No.3.
- Stimpson, L. and M.C. Best (1991) *Courage Above All: Sexual Assault Against Women with Disabilities*. Toronto: DisAbled Women's Network.
- Toms Barker, L., et al. (1997). *Challenges and Strategies of Disabled Parents: Findings From a National Survey of Parents with Disabilities*. Berkeley, CA: Research and Training Center on Families of Adults with Disabilities.
- Ulicny, G. (1991). "Consumer Exploitation by Attendants: How Often Does It Happen and Can Anything Be Done About It?" *Rehabilitation Counseling Bulletin*, Vol. 33, No. 3.
- Waxman, Barbara (1991). "Hatred: The Unacknowledged Dimension in Violence Against Disabled People," *Sexuality and Disability*, Vol 9, No.3.
- Womendez, Chris and Karen Schneiderman (1991). "Escaping from Abuse: Unique Issues for Women with Disabilities," *Sexuality and Disability*, Vol. 9, No. 3.
- Worth,  
Vonne
- (1991). "Disabled raped by caretakers, family." *Different TIMES*, March.

## APPENDIX A: RESOURCES

### HOTLINES

- **National Domestic Violence Hotline**

**1-800-799-SAFE (7233) (voice)**

**1-800-787-3224 (TTY)**

The National Domestic Violence Hotline is staffed 24 hours a day by trained counselors who can provide crisis assistance and information about shelters, legal advocacy, health care centers, and counseling.

- **Rape, Abuse, and Incest National Network (RAINN)**

**1-800-656-HOPE (4673) (voice only; TTY access expected in early 1998)**

RAINN operates the nation's only toll-free hotline for survivors of sexual assault. The hotline is operated 24 hours a day, and routes each call instantaneously to the rape crisis center nearest the caller by reading the area code and prefix of the caller's telephone number. All centers on the network provide counseling and support, and each call is confidential.

### INTERNET RESOURCES

The Feminist Majority Foundation maintains a Web site that lists all the state Coalitions on Domestic Violence, as well as other resources about domestic violence and sexual assault. Access it at:

**<http://www.feminist.org/911>.**

You can read the story of a Canadian disabled woman survivor, as well as find links to resources and articles, at her Web site:

**<http://www.geocities.com/HotSprings/2891>.**

To join the International Coalition on Abuse and Disability, founded in Canada by researcher Dick Sobsey, visit their Web site:

**<http://www.quasar.ualberta.ca/ddc/ICAD/icad.html>.**

### ORGANIZATIONS

- **National Coalition Against Domestic Violence**

**P.O. Box 18749**

**Denver, CO 80218**

**303-839-1852 (voice)**

**303-831-9251 (fax)**

NCADV is a grassroots, membership-based organization, which has been working at the national level since 1978 to address the issue of domestic violence through information, referrals, technical assistance, product and publication development, public policy and community awareness activities. NCADV's membership is a diverse network of individuals and organizations which represent both rural and urban communities, and women of all races, sexual orientations, ages, cultures, religions, and lifestyles. One of NCADV's key goals is to ensure that services are responsive and available to all women who need them.

NCADV, together with the Domestic Violence Initiative for Women with Disabilities, has produced a **Technical Assistance Manual** for programs, entitled *Open Minds, Open Doors*, that can assist them to become physically and attitudinally accessible to women with disabilities. It is available for \$35 plus \$5 shipping and handling (\$1 additional S/H for more than one manual) from the address above.

■ **Domestic Violence Initiative for Women with Disabilities**

**P.O. Box 300535  
Denver, CO 80203  
303-839-5510 (voice/TTY)**

DVI was founded in 1985 by the current director, Ms. Sharon Hickman. DVI provides services to women with disabilities who are victims of domestic violence or caregiver abuse and works with shelters and the criminal justice system to advocate and ensure that needed services are accessible. DVI has provided advocacy, training and direct services at the local level. DVI's materials and approach serve as a national model for addressing the issue of domestic violence as it affects women with disabilities.

■ **Finex House**

**P.O. Box 1154  
Jamaica Plains, MA 02130  
617-436-2002 (voice - administration)  
617-288-1054 (voice/TTY - hotline)  
617-287-0553 (fax)**

Finex House is an accessible shelter serving the Boston area. They publish *Escape, A Handbook for Battered Women Who Have Disabilities*. Chris Womendez is the Executive Director.

■ **Abused Deaf Women's Advocacy Services**

**2366 Eastlake Avenue East, Suite 201  
Seattle, WA 98102-3366  
206-726-0093 (TTY)  
206-726-0017 (fax)**

ADWAS has been providing services to Deaf and Deaf-blind victims of sexual assault and domestic violence since 1986. It is the only agency of its kind in the United States. ADWAS publishes a newsletter and other publications.

■ **DisAbled Women's Network (DAWN)**

**123 Edward Street, Suite 1112  
Toronto, Ontario M5G 1E2  
Canada  
416-598-2488 (voice/TTY)  
416-598-2433 (fax)  
800-561-4727 (outside Toronto only)**

DAWN Ontario is a province-wide organization for women with all types of disabilities. They are a feminist organization controlled by women with disabilities. In addition to domestic violence and caregiver abuse, this organization also focusses on issues such as employment, advocacy, training, education, transportation, housing, health care, and resources for girls with disabilities.

DAWN has published several **resource manuals** for shelters and other programs to assist them to become more accessible to women with disabilities. A publication list is available from the address above.

■ **Justice Institute of British Columbia**

**Career and Community Studies Division  
715 McBride Boulevard  
New Westminster, B.C. V3L 5T4  
Canada**

**604-525-5422 (voice)**  
**604-528-5640 (fax)**

In response to a study by DAWN, this organization produced a **training package** (including a video and curriculum) for police and prosecutors, entitled: *Charting New Waters: Responding to Violence Against Women with Disabilities*.

■ **National Association for Protection and Advocacy Systems**

**900 2nd Street, NE, Suite 211**  
**Washington, DC 20002**  
**202-408-9514 (voice)**  
**202-408-9521 (TTY)**

This is a voluntary membership organization of federally-mandated programs advocating for the rights of people with disabilities, especially those with developmental disabilities and psychiatric disabilities. It offers referrals to programs in each state and territory. You can also find a list of state contacts at their Web site:

**<http://www.protectionandadvocacy.com>**.

**Adult Protective Services**

Every state has an agency (similar to Child Protective Services) that investigates allegations of abuse against the elderly. In some states, there are also agencies that will investigate abuse against persons with disabilities aged 18-65, but usually only people who are “dependent” on caregivers, and in some cases limited only to persons with developmental or psychiatric disabilities and served by state systems.

If you are concerned that someone is being abused by a caregiver and will not or cannot find help on her own, you may be able to make a report and a social worker will

investigate. The services vary by state. You can look in the government section of the phone book for “Adult Services” in the Social Services agency, or call your state Protection and Advocacy program to find out about the reporting process in your state.

■ **Through the Looking Glass**

**2198 Sixth Street, Suite 100**  
**Berkeley, CA 94710**  
**800-644-2666 (voice/TTY)**  
**510-848-1112 (voice/TTY)**  
**510-848-4445 (fax)**

Through the Looking Glass is a community non-profit agency that offers clinical and support services to families in which one or more members has a disability. They publish a newsletter called “Parenting with a Disability,” and offer consultation about adaptive equipment for parenting, and custody issues.

**SUGGESTED READINGS**

Browne, S., D. Connors and N. Stern. (1985). *With the Power of Each Breath: A Disabled Women’s Anthology*. Pittsburgh, PA and San Francisco, CA: Cleis Press.

Deegan, M. J. and N. Brooks, eds. (1985). *Women and Disability: The Double Handicap*. New Brunswick, NJ: Transaction Books.

Fine, M. and A. Asch (1988). “Introduction: Beyond Pedestals.” In Fine and Asch, eds., *Women with Disabilities: Essays in Psychology, Culture and Politics*. Philadelphia, PA: Temple University Press.

- Humphries, T. and C. Padden (1988). *Deaf in America: Voices from A Culture*. Cambridge, MA: Harvard University Press.
- Lonsdale, S. (1990). *Women and Disability: The Experience of Physical Disability Among Women*. New York, NY: St. Martin's Press.
- Morris, J. (1991). *Pride Against Prejudice: Transforming Attitudes to Disability*. Philadelphia, PA: New Society Publishers.
- Morris, J., ed. (1989). *Able Lives: Women's Experience of Paralysis*. London: The Women's Press Limited.
- Panzarino, C. (1994). *The Me in the Mirror*. Seattle, WA: Seal Press.
- Rousso, H. (1993). *Disabled, Female, and Proud! Exceptional Parent Press*. Wesport, CT: Bergin & Garvey.
- Saxton, M. and F. Howe, eds. (1987). *With Wings: An Anthology of Literature by and about Women with Disabilities*. New York: The Feminist Press at The City University of New York.
- Willmuth, M. and L. Holcomb, eds. (1993). *Women with Disabilities: Found Voices*. Binghamton, NY: Harrington Park Press.

## HOW TO FIND YOUR LOCAL INDEPENDENT LIVING CENTER

Several organizations maintain directories of Independent Living Centers, including:

- National Council on Independent Living (NCIL)  
2111 Wilson Blvd., Suite 405  
Arlington, VA 22201  
703-525-3406 (voice)  
703-525-3407 (TTY)
- World Institute on Disability, Oakland, CA  
510-763-4100 (voice)  
510-208-9493 (TTY)  
510-763-4109 (fax)
- Independent Living Research Utilization (ILRU) Institute, Houston, TX  
713-520-0232 (voice/TTY)  
713-520-5784 (fax)

## INFORMATION ABOUT THE AMERICANS WITH DISABILITIES ACT (ADA)

Programs and individuals can greatly benefit from the excellent informational sources available to the public for free, including:

- **Department of Justice ADA Home Page:**  
Information is available at:  
<http://www.usdoj.gov/crt/ada/adahom1.htm>. Or call the

Department of Justice's ADA Information Line at 800-514-0301 (voice), 800-514-0383 (TTY).

- **Disability and Business Technical Assistance Centers:** 800-949-4232 (voice/TTY). The National Institute for Disability and Rehabilitation Research funds ten regional technical assistance centers to assist businesses, governmental entities, and persons with disabilities. This national number automatically connects you to the center in your region. These centers have written materials, answer questions by phone, and provide training sessions on the ADA.
- **Americans with Disabilities Information Hot Line:** 800-466-4232 (voice); 800-644-2555 (TTY). The Disability Rights Education and Defense Fund (DREDF) operates an ADA information line funded by the Department of Justice.



## APPENDIX B: KNOW YOUR RIGHTS!

### Basic Information About the ADA

As a woman with a disability, it is very important to know your legal rights before you are in a crisis situation. Below you will find basic information about your rights as provided by the Americans with Disabilities Act (ADA). Please keep in mind that this is *basic* information. For information regarding your specific situation contact one of the resource information numbers at the end of this section.

The ADA is a civil rights law that provides protection to individuals with disabilities. Under the ADA, a person with a disability is defined using three prongs. The first prong is: (1) those with “a physical or mental impairment that substantially limits one or more major life activity” (like walking, seeing, hearing, learning, breathing, caring for oneself, etc); (2) those with “a record of having such a condition (such as persons who have had cancer that has gone into remission or a history of a mental disability); and (3) those “regarded as having” such a condition, even if it doesn’t limit a major life activity (such as persons with facial disfigurements). The ADA also protects persons based on *association* with persons with disability. For instance, suppose a woman was denied admission to a shelter program based on the fear she poses a significant

risk to others because her partner has AIDS. This action could be in violation of the ADA.

The ADA covers many aspects of daily living. The different sections are called Titles. Title I of the ADA law offers protection related to employment. Title II outlines the requirements for state and local governments to ensure their services or programs do not discriminate based on disability. Title III sets forth the actions private businesses must take to make certain they do not discriminate based on disability in the sale of goods or services to the public. The ADA also covers transportation, requiring that transportation services be accessible and available to persons with disabilities.

If a domestic violence program is offered through a governmental entity the coverage would then fall under Title II. If the program is offered by private entities, including private non-profit organizations, then the program is covered under Title III.

## **WHAT IS MANDATED BY THE ADA?**

### ***Program Accessibility***

Title II programs must make their programs “accessible to and useable by individuals with disabilities” unless doing so would cause an undue burden or fundamentally alter

the program. This duty is known as “program accessibility.” Program accessibility includes not only physical accessibility (no steps, wide doors, accessible restrooms, etc.), but also, removal of communication barriers—for instance, spoken information must be made available to persons with hearing impairments; or printed information must be made available to persons with visual or cognitive impairments.

### ***Readily Achievable***

A Title III entity has a “readily achievable” duty to make its services accessible, unless doing so would cause an undue burden or fundamentally alters the program. This may mean installing a ramp into a facility that is used for counseling or holding meetings at an alternative location. The level of duty will change from business to business based on the funds that are available to the entity.

## **MODIFICATION OF POLICIES, PRACTICES, AND PROCEDURES**

The ADA requires Title II (State and Local Government) programs and Title III (Public Accommodations) entities to modify their policies, practices and procedures to ensure access for people with disabilities. This may mean that a domestic violence shelter would allow a disabled woman who needs physical assistance the use of a personal

assistant when their policy is not to let anyone know the location except those who are being housed. However, the entity has the right to hold the personal assistant to the same confidentiality standards as the women with a disability.

## **WHAT IS MEANT BY "READILY ACHIEVABLE" OR "UNDUE BURDEN"?**

The same criteria are used in the ADA regulations for determining whether or not a requested modification is readily achievable or an undue burden. The following criteria are considered:

- (1)the nature and cost of the action to be taken;
- (2)the overall financial resources of the site or sites involved, including the number of persons employed at the site, the effect of the requested action on a site's expenses and resources, legitimate safety requirements;
- (3)the fiscal relationship of a local affiliate with its parent organization;
- (4)if the fiscal relationship is present, the overall financial resources of the parent corporation is taken into account; and

- (5)the type of organization or operations of any corporation or entity, including the composition, structure and functions of the workforce of the parent corporation.

## **FUNDAMENTALLY ALTERS**

A fundamental alteration is a modification that is so significant that it alters the essential nature of the goods, services, facilities, privileges, advantages or accommodations offered. It is common for domestic violence programs to operate "safe houses." It may be a fundamental alteration to allow a disabled women pass out the address to paratransit to be picked up directly from the location. It may be sufficient for a staff person to go with the woman to public area like a nearby mall to have the paratransit vehicle pick her up.

## **HOW IS THE ADA ENFORCED?**

The ADA is a complaint driven law. This means that no consultants or government agency can certify that a program meets ADA requirements.

Most times, organizations will find that workable solutions can be achieved. The purpose of the ADA is not to bankrupt programs but to safeguard the rights of persons

with disabilities to participate in all aspects of society. If there is a disagreement between the women with a disability (or her family members) and a program regarding a modification request, the disabled person has the right to file a private lawsuit or to file a complaint with the Department of Justice, which is the ADA enforcement agency for Titles II and III. At that point, the Department of Justice or courts will make a decision regarding whether or not the modification requested is "readily achievable" by the program. It is important to be aware that steps taken to become accessible can be used to show a good faith effort in the event of a law suit.



## ABOUT THE PROJECT

**“Meeting the Needs of Women with Disabilities: A Blueprint for Change”** was designed to promote increased access for women and girls with disabilities to services that meet their needs. We focused on access to nine different mainstream (non-disability) service systems that provide services to women and girls and have barriers to effectively serving women and girls with disabilities: Adoption, AFDC Benefits and Services, Aging Services, Child Care, Child Protective Services, Reproductive Health Services, Substance Abuse Services, Violence and Abuse Services and Youth Programs. Since this was a knowledge dissemination project, we conducted extensive reviews of the literature, consulted with knowledgeable women with disabilities in our areas of study, and interviewed program staff and administrators about barriers to access and levels of disability awareness.

As part of our grant activities, we have developed materials designed to promote accessibility and inclusion about these service systems for women with disabilities, mainstream program operators, and policy makers. We also conducted a national survey of women with disabilities to identify which of these service systems have the greatest priorities for further research and dissemination efforts.

Titles available from this project include:

- *Including Girls with Disabilities in Youth Programs*
- *Including Older Women with Disabilities in Senior Programs*
- *You May Be Able to Adopt! A Guide to the Adoption Option for Women with Disabilities and Their Partners*
- *Serving Mothers with Disabilities in Your Child Care Program*
- *Multiplying Choices: Improving Access to Sexual and Reproductive Services for Women with Disabilities*
- *Fostering Recovery for Women with Disabilities: Addressing Barriers to Alcohol and Other Drug Services*

- *When a Mother Has a Disability: Dealing with Disability in the AFDC and CPS Systems*
- *Caregiver Abuse and Domestic Violence in the Lives of Women with Disabilities*
- *Open Minds, Open Doors: Technical Assistance Manual to Assist Domestic Violence Service Providers Become Physically and Attitudinally Accessible to Women with Disabilities [produced by the National Coalition Against Domestic Violence]*
- *Priorities for Future Research: Results of Berkeley Planning Associates' Delphi Survey of Disabled Women*
- *Information about Women with Disabilities in the United States*
- *Meeting the Needs of Women with Disabilities: A Blueprint for Change Bibliography*

---

For further descriptions of the materials listed above, visit our Web page at: [www.bpacal.com](http://www.bpacal.com).

To receive an order form giving more information about the titles and their prices (bulk discounts available, and all are available in alternative formats), you can call, fax, or e-mail a request to:

**Patricia Spikes-Calvin**  
**Publications Coordinator**  
**Berkeley Policy Associates**  
**Voice: (510) 465-7884 or TDD: (510) 465-4493**  
**Fax: 465-7885**  
**e-mail: [info@bpacal.com](mailto:info@bpacal.com)**

Berkeley Policy Associates (BPA) is an independent, 100% employee-owned firm dedicated to providing the highest quality research and information to facilitate decision-making in public policy. For 25 years BPA's research and technical assistance have helped to make publicly-funded programs more responsive to clients and more accountable to sponsors.

---

### **Berkeley Policy Associates**

440 Grand Avenue, Suite 500  
Oakland, California 94610

Voice: (510) 465-7884

TDD: (510) 465-4493

Fax: (510) 465-7885

E-mail: [info@bpacal.com](mailto:info@bpacal.com)

[www.berkeleypolicyassociates.com](http://www.berkeleypolicyassociates.com)

