



Alberta Committee of Citizens with Disabilities

# Violence Against Women with Disabilities

*Break the Silence!*

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*We dedicate this research to all women who have been victims of violence and abuse.*

## ***Violence Against Women with Disabilities***

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## Foreword

Early in 1999, the Alberta Committee of Citizens with Disabilities (ACCD) received a phone call asking if we could assist a woman with a disability who was being abused in her home. The caller had received a request from a neighbour of the woman being abused. The neighbour believed that the victim, who was in a wheelchair, was being repeatedly abused by her caregivers. The police had been called and had visited the home, but the woman remained in her home and the abuse continued. When ACCD asked the caller about her role in the situation, she said she was calling from Social Services, that she received these types of calls “all the time,” and that she didn’t know where to turn for assistance.

To us at ACCD, the implications of this call were shocking and frightening. The safeguards and precautions that we had assumed were in place for persons in situations of high vulnerability were either ineffective or non-existent. A woman with a disability was in a dangerous situation and, apparently, neither a concerned neighbour, the police, nor Social Services could do anything to assist her. Moreover, according to the caller from Social Services, situations such as this were not uncommon. When reflecting on this call, Bev Matthiessen, Executive Director of ACCD, said, “In Canada, we tend to think we live in a society where people will be taken care of. But cuts to social services and reductions in funding for persons with disabilities mean that many people suffer. . . . We are working hard to have women with disabilities live independently, but I worry that we may be putting them in vulnerable situations.”<sup>1</sup>

Shortly after receiving this phone call from Social Services, ACCD met with Status of Women Canada to propose a project that would examine the issue of violence against women with disabilities. Through this project we hope to address the specific safety needs of women with disabilities who live independently in Alberta. We also want to equip ourselves to be leaders in the support of organizations and individuals that address this serious issue.

*In Canada, we tend to think we live in a society where people will be taken care of. But cuts to social services and reductions in funding for persons with disabilities mean that many people suffer.*

# Introduction

## a) Background

In Canada, widespread interest in violence against women emerged in the late 1970s. Grassroots collectives and consciousness-raising groups identified violence as a pervasive, systemic issue, not simply a domestic problem. Through the efforts of these groups, transition houses and crisis centres were established for women and their children. At the time, there was little public or professional awareness of the issue and “no understanding of the magnitude and extent of violence against women. Abused women were treated individually for emotional and psychological problems or abuse was treated within the context of ‘family problems’” (Denham, 1999, p. 3).

*Although violence and abuse in general have burgeoned into areas of concern in social policy and government spending and programs, only a very few studies have investigated the incidence of violence and abuse among people with disabilities.*

In the 1980s, however, public awareness grew and with it came an increased commitment at all levels of government to address the issue. Funding for shelters, an emphasis on the criminal nature of wife assault, public education campaigns, and an increase in the number of organizations involved in work to end the violence indicated Canada’s growing commitment to assisting women who experience abuse.

This commitment, however, has only recently been extended to include the particular circumstances of women with disabilities. The Canadian Panel On Violence Against Women (1993) notes, “Current research is . . . limited by its exclusion of many Canadian women. In particular, very little has specifically focused on the experiences of . . . women with disabilities” (p. 8). The Roeher Institute (1995) reiterates this view: “Although violence and abuse in general have burgeoned into areas of concern in social policy and government spending and programs, only a very few studies have investigated the incidence of violence and abuse among people with disabilities” (p. viii). The research that does exist suggests that women with disabilities are at a higher risk of experiencing violence than are women without disabilities. Statistics concerning violence against women with disabilities paint a grim picture:

» 40% of women with developmental and/or learning disabilities will be victims of sexual abuse before eighteen years of age. (Morin and Biosvert, 1992)

- » The risk of only a single incident of abuse for people with disabilities appears to be at least one-and-a-half times as great as the risk for other people of similar age or gender. (Sobsey, 1994)
- » 39% of women with disabilities have experienced physical or sexual abuse perpetrated by their husbands. (Statistics Canada, 1994c)
- » 83% of women with disabilities will be sexually assaulted in their lifetime. (Stimpson and Best, 1991)

*The purpose of this research project is to identify and address the specific safety needs of women with disabilities who live independently in Alberta.*

While researchers agree that it is difficult to obtain accurate and recent incidence statistics about violence and disability, “an accumulation of independent findings . . . suggests that there is a problem of considerable magnitude” (Roehrer, 1994, p. vi). The DisAbled Women’s Network (DAWN) Canada, the University of Alberta Violence and Disability Project, the Roehrer Institute, and Canadian Independent Living Resource Centres, along with many other organizations and individuals, are tackling this alarming issue through research, programs, and lobbying intended to increase awareness and to end the abuse.

## **b) Purpose and Objectives**

The purpose of this research project is to identify and address the specific safety needs of women with disabilities who live independently in Alberta.

To fulfil our purpose, this project will:

- » Outline the extent and nature of the problem
- » Raise awareness and understanding of the safety concerns faced by women with disabilities through community consultation and individual meetings
- » Recommend policy and program guidelines to address the issue
- » Position ACCD to play a leadership role in promoting and establishing safer communities for women with disabilities

## **c) Definitions**

### **Disability**

For the purposes of this project, we will use the same definition of the term disability as used by the Roehrer Institute (1993).

Any limitation that significantly affects a person's mobility, agility, sight, hearing, verbal communication or intellectual functioning. It also includes limitations arising from the difficulties in the psychological, emotional or mental health domain.

*This report uses the terms consumer directed and consumer driven based on the premise that we, as people with disabilities, are best equipped to articulate and define our own needs and find creative solutions to meet them.*

### **Violence and Abuse**

For the purposes of this project, the terms violence and abuse will be used interchangeably. A composite definition of the terms has been derived from the Roeher Institute (1995) and from the Alberta Family and Social Services Abuse Reporting and Investigation Protocol for Adults with Disabilities (1997).

Public or private acts that seriously violate the principle that persons with disabilities, like all other persons, are to be equally valued and protected as human beings. Abuse occurs in any situation where a more powerful person takes advantage of a less powerful one. Types of abuse may include, but are not limited to, financial, physical, sexual, verbal or emotional abuse, neglect, and exploitation.

### **Consumer-directed/Consumer-driven**

ACCD embraces a consumer-driven philosophy that actively promotes the full participation of persons with disabilities within the social, economic, and political life of our communities. This philosophy shapes all of our programs and projects, including the research we conduct. This report uses the terms consumer directed and consumer driven based on the premise that we, as people with disabilities, are best equipped to articulate and define our own needs and find creative solutions to meet them.

### **Living Independently**

In recent years, provincial governments and disabilities organizations have taken positive steps to promote the advantages of independent living for citizens with disabilities. This movement has empowered persons with disabilities to "take progressively more responsibility for the development and management of personal and community services" (Independent Living Fact Sheet). One outcome of this trend has been the increase of women with disabilities living independently in the community. As a matter of fact, Statistics Canada (1995)

reports, “In 1991, 92% of women with disabilities aged 15 and over were living in a private household, while 8% lived in a health-related institution” (p. 163).

For the purposes of this paper, the phrase living independently in the community will refer to any living situation in which care is provided by a licensed home care agency, by friends or family members, by the consumer herself, or through independent funding agreements (formerly self-managed care).<sup>2</sup>

## **d) Methodology**

Strategies and activities for carrying out this study are both research-based and community-based. Consumer input plays a key role in our research. ACCD is a consumer-directed organization, and we believe the thoughts, opinions, experiences, and ideas of women with disabilities are an integral part of this research. This consumer-directed philosophy forms the basis of all ACCD undertakings and echoes Dick Sobsey’s (1994) conviction that “Failing to include people with disabilities in these processes can only perpetuate the very power inequities and paternalistic systems that have left people with disabilities vulnerable in the past” (p. 355). Our research strategy includes a literature review, focus groups, community consultations, one-on-one interviews, and follow-up meetings.

### **Literature Review**

A literature review was undertaken to identify significant findings (e.g. the nature and prevalence of violence against women with disabilities) and to determine the types of systems in place in Alberta and elsewhere designed to protect women with disabilities from violence and abuse in independent-living situations. We focused our literature review primarily, although not solely, on Canadian studies and statistics.

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### **Focus Groups**

Two focus groups were held in four different centres: Edmonton, Calgary, Grande Prairie, and Milk River. These centres provided urban, rural, southern, and northern perspectives. Altogether, forty-four women and one man (a family caregiver) participated in the sessions. They brought a variety of perspectives to the table, including those of

*At these meetings, participants identified key issues that concern violence against women with disabilities and provided direction for the project.*

consumers, women's shelters, independent-living resource centres, victim services units, paid and family caregivers, and other professionals who work for and with women with disabilities.

The initial meetings took place in late November and early December 2001. At these meetings, participants identified key issues that concern violence against women with disabilities and provided direction for the project. Following these meetings, ACCD developed a draft document reflecting the focus groups' ideas. Participants had the opportunity to review the draft before the second round of meetings. At these meetings, which took place in late February and early March 2002, participants were given the opportunity to comment on the draft. As well, participants brainstormed the strategies and solutions that shaped the recommendations that are included in this final version of the document.

### **Community Consultations**

The focus group sessions raised questions that led us to consult with a variety of organizations that work with and for women with disabilities. Some of the individuals we interviewed had taken part in the focus groups, while others were contacts whose names had been provided at the sessions. As well, ACCD partnerships provide us with a variety of organizational and individual contacts whose expertise contributed to this aspect of our research. We believe the information gathered through community consultations ensures our research is current and relevant.

### **One-on-one Interviews**

One-on-one interviews were conducted in several locales with women with disabilities who have survived violence or abuse. The interviews were developed in consultation with Dick Sobsey from the University of Alberta's J. P. Das Developmental Disabilities Centre, and are based on interview frameworks used by DAWN Canada (1993) and Teresa Andreychuk (1995). The women we interviewed pursued a variety of traditional and non-traditional paths in addressing the violence in their lives. Interviews provided us with actual consumer experiences that personalized our research, making it relevant to women with disabilities in Alberta who are dealing with violence in their lives. (See interview questions: Appendix One)

## **Follow-up Meetings**

We will present our findings to groups who have the power to impact change concerning the issue of violence and women with disabilities. We will offer to take a leading or supporting role in initiatives that address the concerns we raise in our recommendations. Meetings have already been planned with Persons with Developmental Disabilities Partners, the Alberta Council of Women Shelters, and the Abuse Prevention and Protocol Committee. Through these meetings, we will fulfil this project's objective of positioning ACCD to play a leadership role in promoting and establishing safer communities for women with disabilities.

## **Nature of the Problem**

Women with disabilities in Canada “face both the threat and the reality of all the forms of violence confronting non-disabled women, but their disability compounds, alters and increases their vulnerability” (Canadian Panel, 1993, p. 67). This increased vulnerability is not solely linked to the physical, sensory, or cognitive limitations a woman may experience because of her disability. Research indicates that a disability itself plays a smaller role in increasing vulnerability than do the societal biases that influence the lives of people with disabilities. Sobsey (1991) notes, “Many of the factors that increase vulnerability . . . are not caused by the disability itself, but rather, they are a result of society's responses to [them]” (p. 4). The Roeher Institute (1995) reiterates this view: “For people with disabilities, challenges result not [only] from the disability but also from the accompanying marginalization, discrimination, disregard and neglect . . . they face in society” (p. vii).

*Women with disabilities in Canada “face both the threat and the reality of all the forms of violence confronting non-disabled women, but their disability compounds, alters and increases their vulnerability.”*

Our focus group discussions emphasized the significance of four factors that increase the risk of violence against women with disabilities. These are:

- » The Disability Itself
- » Myths and Stereotypes
- » Dependence on Others
- » Isolation



*I was living with somebody who had problems with his temper. One day, when things didn't go his way, he became very agitated. Later that afternoon, he hit me on the forehead. It was very scary because, being disabled, I was afraid that if I had to leave, I could not do it fast enough. That night he slept in the second bedroom and was saying all sorts of things like, "You know, I can come through your door anytime." I went into the bedroom that we had been using and shut the door and parked the wheelchair across the door. I had the portable phone in there, but I didn't really know who I would call at that point.*

*I was surprised at how powerless I felt in relation to my disability. I knew that to leave the apartment I needed to use the wheelchair. I felt powerless. Even though I put contingencies in place there still was the feeling that I could not get myself out fast enough if anything should happen. I was amazed that I would feel that much fear and be that helpless.*

A brief look at these factors provides important background information that is key to understanding the unique situation of women with disabilities in Alberta as they experience and address violence, as well as the risk of violence, in their lives.

### **a) The Disability Itself**

Violence and abuse, as outlined in our definition, are concepts that are closely associated with issues of power. With this in mind, a starting point for examining the incidence of abuse among women with disabilities is the role the disability itself plays in making a person more vulnerable. Nosek and Howland (1998) state,

For each disability type, different dynamics of abuse come into play. For women with physical disabilities, limitations in physically escaping violent situations are in sharp contrast to women with hearing impairments, who may be able to escape but face communication barriers in most settings designed to help battered women ([www.vaw.umn.edu](http://www.vaw.umn.edu)).

One of our focus group participants who uses a wheelchair was mugged. She was going to an appointment and had her wallet stolen out of her hand. As she was about to enter an elevator, a man ran toward her from a nearby entrance, grabbed the wallet, and ran out of the building. Her disability made her an "easy target" for the thief. Another focus group participant, also in a wheelchair, commented, "Before I was in this chair, I was the gutsiest thing going. This chair makes me very, very, very vulnerable." In most cases, the nature of a woman's disability will determine her vulnerability to abuse.

### **b) Myths and Stereotypes**

For women with disabilities, the stereotypical views that shape society's perceptions of gender are accompanied by another set of assumptions regarding disabilities. Societal stereotypes encourage women to be "nice, polite and submissive"; women with disabilities are further socialized to be "compliant, passive and grateful for any help they receive" (Canadian Panel, 1993, p. 68). These stereotypes, along with others regarding sexuality, capability, and credibility, make women with disabilities more susceptible to acts of violence.

The Canadian Association of Independent Living Centres (CAILC) (1996) argues that understanding the issue of violence as it relates to people with disabilities begins with understanding these stereotypes. They outline six myths that they believe “affect our actions, our laws, our social programs and policies” (p. 30) and that lead to an increase in vulnerability to violence. These myths range from “People with disabilities are not human” to “People with disabilities are helpless and need our pity.” (See Appendix Three for a complete list of the myths identified by CAILC.) Each of these stereotypes denies people with disabilities—especially women—the freedom to make choices, to be independent, to participate fully in society, and to be accountable for their own decisions. Viewed as helpless, asexual, and inhuman, individuals become increasingly vulnerable to abuse (CAILC, 1996).

### **c) Dependency**

Many women with disabilities who live independently in the community rely on others for care. Caregivers may be family members or paid caregivers.<sup>3</sup> Their involvement may range from providing homemaking services such as meal preparation and light housekeeping, to personal care services such as bathing and getting dressed, and to health-maintenance care such as administering medication and hygiene routines. Caregivers may be a relatively constant presence in the lives and homes of women with disabilities, or they may only be present for a few hours once or twice a week. Regardless of the type and frequency of care provided, research shows that more than half the abuse experienced by people with disabilities is perpetrated by family members, paid caregivers, and other people with disabilities, especially those living in service settings with their victims (Sobsey, 1991).

While women in general are “expected” to be submissive and polite, dependency on others for their care increases the expectation of these qualities in women with disabilities. Dependence on caregivers can create a culture of compliance that makes women with disabilities more vulnerable to abuse. Taught to acquiesce to their caregivers’ directives, women with disabilities are more prone to accept their situations, no matter how bad they become. This state of “learned helplessness” suggests that the women themselves have internalized the

*While women in general are “expected” to be submissive and polite, dependency on others for their care increases the expectation of these qualities in women with disabilities.*



*I'm in a wheelchair now, and I have friends who have known me all my life. They know I have many problems, but when they first saw me with a wheelchair, they started crying, "Oh my God, oh my God."*

*Here I am, getting around better now than before, but they are looking at me as if something terrible has happened. Now they can actually see one of my invisible disabilities. The chair changed many things. If I was to stand up, which I have the ability to do, or take a few steps, and act like I'm normal, you would never know there was something wrong with me. Unfortunately, when other people realize I have a disability, everything changes. They don't see that I'm still the same person, doing the same things.*

negative attitudes of caregivers and society. One focus group participant shared, "When we're brought up as a female and being disabled, we're supposed to be kind and polite and grateful. It affects your ability to resist. I grew up disabled and those expectations have been on me since I was a child." CAILC (1996) notes that dependent relationships result in low self-esteem, learned helplessness, and compliance—factors which increase a woman's vulnerability to abuse (p. 37).

## **d) Isolation**

Faced with cultural and social stereotypes, many women with disabilities find themselves on the fringes of society. They are often ignored by others who do not know how to act or interact with people with disabilities. Several of our focus group participants commented on feeling "invisible."<sup>4</sup> When people are socially isolated, the ordinary checks and balances that can detect, address, and discourage violence are not as effective as they are in the lives of others (Roehrer, 1995, p. 29).

Social isolation is often even more pronounced for women with disabilities who live in rural areas. In general, our rural participants felt that smaller centres do tend to have "a real sense of community" that includes visiting and caring for friends and neighbours with disabilities. However, women with disabilities living on farms often experience long stretches of time with little or no social interaction. As one focus group participant noted, "Women on farms can be extremely isolated. If abuse is occurring, it may be weeks or even months before it is detected."

Social isolation goes hand-in-hand with the physical isolation that many women with disabilities encounter. Buildings and transportation are often physically inaccessible, services do not provide alternative modes of communication, and programs don't provide disability-related supports. These barriers may mean that women with disabilities do not have the opportunity to socialize, work, go to school, or even run their own errands. One focus group participant said, "Usually, it feels easier to stay home than it does to go out." Yet, participating in society increases independence and reduces isolation and vulnerability.

## Barriers To Addressing Violence

### a) Availability of Information/Awareness of Situation by Women with Disabilities

Through community consultations, focus group sessions, and one-on-one interviews, ACCD learned that consumers and service providers alike consider inadequate access to education and information a significant barrier to addressing violence against women with disabilities. As one focus group participant said, “We want to live independently and safely. But there are so many things we haven’t been taught about being independent.” Focus group participants felt that in order for women with disabilities to take an active role in addressing the violence in their lives, they need to be able to:

- » Recognize the Abuse
- » Take Steps to End It
- » Access Resources that Provide Guidance, Aid, and Support

For this to happen, women with disabilities must receive adequate education about their bodies, about physical and sexual assault, and about the services available to them.

### i) Recognizing the Abuse

In this paper’s definition of abuse, we refer to acts that “violate the principle that persons with disabilities, like all other persons, are to be equally valued and protected as human beings.” If a woman with a disability does not know what it means to be “valued and protected,” she is less likely to recognize abuse when it occurs. CAILC (1996) points out that the biases and stereotypes that shape society’s views of women with disabilities keep victims in the dark about their rights, about what constitutes respectful care, about personal boundaries, and even about their sexual and emotional identities.

For example, the assumption that women with disabilities are “not sexual” limits access to sex education. It even “discourages and sometimes stops people from being sexual.” Similarly, the assumption that women with disabilities are “helpless and need our pity . . . supports the negative belief that [they] cannot make decisions for themselves or exercise any kind of control” (p. 31). Together, these views contribute to an environment that



*I would get a lot of emotional abuse from my husband. Sometimes, I would ask him to read the mail, and he would say, “I’m your husband not your slave. Hire somebody or get home care.” He was also very jealous over my guide dog. If I wanted to go somewhere with my husband, I had to leave my dog at home, which left me totally dependent on him.*

*There was sexual abuse going on in the relationship as well. I knew that I had to get out, but I had no way of getting out. I had no money. I had no income. I had no transportation. It took me a while, but with support from friends I managed to get away. I learned some things from that experience. Now I live by three rules: never hit me; never cheat on me; and never ever make me choose between you and my dog. Because it will be the dog. The dog has been more loyal to me than anyone, so she rules.*

denies women with disabilities the opportunity to learn about themselves, their bodies, and their sexuality.

Traditionally, people with disabilities have had very little choice or control over their sexuality or over their bodies... Often, people with disabilities receive no sex education or sexuality awareness. Without this very basic sexual information and awareness, and without a feeling of ownership or control over their bodies, people with disabilities are at a greater risk of sexual abuse.<sup>5</sup> (p. 38)

According to several focus group participants, students with disabilities in Alberta's public schools do not receive the same information regarding sex and sexuality as children without disabilities. One mother noted,

I had a child with a disability who attended special education classes and another child who was in "regular classes". The child in the "regular classes" received sex ed, but the other didn't. I think they need that type of training even more so in a special ed classroom.

*According to several focus group participants, students with disabilities in Alberta's public schools do not receive the same information regarding sex and sexuality as children without disabilities.*

Her views were echoed by a mother in another focus group, in addition to a young consumer with a developmental disability who said, "I had sex ed in school, but I think it was because I was in the same classes as all the other kids. They didn't put me in a different classroom."

If women with disabilities are not taught about their sexuality and about healthy sexual relationships, they will not be able to recognize sexual abuse when it occurs. This also holds true for other types of abuse. One woman who took part in our one-on-one interviews said, "If we are not taught what is right and wrong, we will not know what is right and wrong. If we are never treated with respect, we won't expect respectful treatment." Chenoweth (1996) points out, "Ultimately, women come into contact with the real world, where their overprotection actually increases their vulnerability. Without the survival tools necessary for women to learn to avoid potentially dangerous situations, women with disabilities face higher risks"(p. 399). If a woman who experiences violence does not perceive the incident as significant, she will not choose to report it. Learned

helplessness and the lack of awareness and education work together to silence women with disabilities who are being abused.

Even when an organization or individual recognizes the importance of education, sensitive and appropriate materials are scarce. Nancy Madsen, Community Rehabilitation Worker at the Independent Living Society in Grande Prairie, noted,

Most of the materials I use to educate our clients about sexuality focus on the situations of teenagers or school-age children without disabilities, and the scenarios take place in school settings. But I need information that is geared towards adults with varying degrees of education and different disabilities. It would also be helpful to have different materials for men and women that deal with abuse and sexuality.

Lack of funding to create or provide appropriate training materials creates another barrier. A women's shelter director who took part in our focus group sessions states, "The public education programs that our women's shelter runs or wants to run are not a funded part of our services."

## **ii) Taking Steps to End the Abuse**

Women with disabilities who live independently in the community often rely on caregivers. This reliance can create a culture of compliance and dependency that hinders the development of confidence, assertiveness, and self-reliance. Yet these traits are needed for a woman with a disability to escape an abusive situation. The Roeher Institute (1995) reports,

Whether survivors with disabilities disclose incidents of violence and confront their perpetrators can hinge on self-confidence and personal resilience. However, there are innumerable social barriers and negative social attitudes towards people with disabilities (and, particularly, women with disabilities) that inhibit the development of self-esteem and confidence. (p. 83)

We found this view to be consistently supported by our focus group discussions. One woman said, "In the prevention of



*We lived on a farm. We would see a neighbour maybe once a week. My life as a child was pretty lonely. I never discussed things with my parents. They didn't want to hear it. Even being disabled, I couldn't discuss my disability problems with them. My mom didn't see me as ever having a relationship because I was disabled. And sex, heavens sakes, people with disabilities didn't have sex! I never went home with any of those issues.*

*I have 2 brothers so there was not another girl in the family. I didn't have a sister to go to. There was a lot of crying periods. Where do I go, how do I release it? I never got counselling of any sort. I bottled up and I either had a good cry or would get angry and stay in my room for days. I didn't socialize. I felt it wasn't worth it.*

*In my first 16 years I spent 9 years in the hospital. Most of my hospital stays were not near family. I was 500 miles from home. So they were my family. And if you are not treated right where do you go? Back then they controlled you and you did what you were told.*

violence and abuse, the mindset of the individual needs to be considered. Those who were taught to be compliant are not able to be assertive and to express their needs. Consequently, they are vulnerable.”

### **iii) Accessing Resources that Provide Guidance, Aid, and Support**

When a woman with a disability recognizes she is in an abusive situation, and she is determined to end the violence, she needs to know where to turn for assistance. However, information and support are not always readily available. The Roeher study (1995) states, “Given the social isolation of many people with disabilities, it is reasonable to assume that many would have less knowledge than others about agencies in the community that assist with disclosures of violence” (p. 87). This finding was supported by a focus group participant who commented, “If I feel frightened or threatened, I don’t know who to call.” Another consumer found, “Once I started work, I learned about all kinds of supports in the community that I had no idea existed. By getting out into the community, I was able to learn more.”<sup>6</sup>

*In general, women with disabilities who took part in our interviews and focus groups felt they did not have sufficient access to information about the supports and services available to them to address violence in their lives.*

In general, women with disabilities who took part in our interviews and focus groups felt they did not have sufficient access to information about the supports and services available to them to address violence in their lives. This did not always mean the services weren’t in place, simply that consumers are not always in a situation to find out about them. One service provider noted, “It is not enough just to offer a program. Service providers need to ask themselves, ‘How can I make information available to consumers?’” Andreychuk (1995) comments, “Women with disabilities need information about the resources available to them. They also need to know that the reason the resources are available is because the violence or abuse they are experiencing is wrong” (p. 258).

This issue is even more pressing in rural areas. Many smaller communities do not have the resources that are available in larger centres, and cities may not have the resources or motivation to promote their services in surrounding towns and villages. Two different participants in our one-on-one interviews felt forced to move from rural areas so they could access supports. As well, through our community consultations we learned, “Isolation creates special challenges to educators. We

have to think differently in rural communities about getting our information out there. Informal networks need to be used: churches, the farm network on the radio, local television.” If these networks are not used, women with disabilities who live in rural settings are left with little or no information or support.

## Strategies/Solutions

- » Ensure awareness training is available from an early age. As with the general population, girls and young women with disabilities require sensitively delivered, thorough information about sex and sexuality in order to develop a healthy and confident self-image. Ideally, this information will be a part of the public/private school curriculum. If this is not the case, another group (perhaps a disability organization, consumer organization, government department, or parent group) must take responsibility for the education.
- » Establish an advocacy/educator program that explains issues and raises awareness among women with disabilities. This outreach program would involve advocates visiting the homes of women with disabilities who live independently in the community. At these visits, the advocate would answer questions and provide information regarding abuse issues. The advocate would emphasize the rights of the consumer, an awareness of the boundaries inherent in receiving care from others, and the availability of assistance through crisis lines and consumer organizations. As well, advocates would explain legislation, protocols and procedures that are in place to support women with disabilities should they experience abuse. Print or alternate format information would be left with the consumer. Ideally, the advocate would be a woman with a disability. The advocate would also inform the consumer of various training/awareness raising opportunities in the community and facilitate her participation in the training.
- » Develop an intervention and support model that links the provision of information to support and advocacy. This integrated support centre may house the educator/advocate described above. It would also coordinate services from a



*When I started school, children were always beating me up and calling me names, defeating my self-esteem. They were taking it all away. I didn't go to my family because I didn't know how to explain myself and how to express myself about the physical abuse and the sexual abuse. I found that I wasn't able to understand things as quickly as other women were. That's due to my disability of being slow and not being able to grasp things as quickly.*

*As I grew up it kept getting worse, it was not only kids at school, it started becoming adults, starting to date and things like that. I didn't know much about social skills and what's supposed to happen between a girl and a boy or a man and a woman as you get older. I didn't know what was happening and how to talk about it, who to talk to. I didn't know about the male/female physical relationship, about what's supposed to happen between a man and woman, the biological part. I didn't know what happens when you don't feel right and can say "no." I needed to learn how to say "no" sooner and tell when something's right and something's wrong.*

variety of sectors: health care, legal, law enforcement, social services, etc. Doctors' offices often provide a first point of contact for women with disabilities who have experienced abuse. These professionals are key in providing support and information to assist and educate women with disabilities in addressing violence.<sup>7</sup>

» Create a provincial resource guide that lists the relevant training materials available at organizations, libraries, and schools throughout the province. The list would include print, audio, video, and web-based training materials on issues such as sexuality, abuse, body image, consumer rights, and reporting and disclosing information. The list should be annotated and include pertinent details about the materials. It would be distributed to all organizations that work for and with women with disabilities.<sup>8</sup>

» Identify gaps in available material and create new materials to address these gaps. Some points to consider in the development of new materials include a range of literacy levels; plain, easy-to-read language; different learning styles (e.g. visual, tactile, aural); audience age, and gender. Consumer input is key to the successful development of new materials. Ideally, a provincial body should be responsible for the development of the materials.

*The lack of information, sensitivity, and training among paid caregivers means that negative stereotypes and attitudes persist.*

» Raise public awareness and understanding of the abuse experienced by women with disabilities. The media, the National Film Board, church and other community groups, and school curricula can all play a role in raising awareness. Specific strategies that have been used in the United States and Canada are outlined by Podnieks and Baillie (1995). Since “many of a person’s most persistent attitudes develop early in life” (Sobsey, 1994), the earlier this type of general awareness is introduced to students the better.

## b) Caregiver Training and Awareness Raising

### i) Paid Caregivers

When a woman with a disability relies on someone else for her care, the “physical and emotional contact involved with the care provider greatly increases the risk of abuse” (Rivers-Moore, 1992). The abuse, however, is not necessarily intentional. In some instances, the care provider’s lack of education and training regarding women with disabilities leads to abusive situations. As the Roeher Institute (1995) discovered, “The lack of information, sensitivity, and training among paid caregivers means that negative stereotypes and attitudes persist” (p. 17). If caregivers do not receive training that dispels the myths concerning women and people with disabilities, they will not be able to provide sensitive, informed care.<sup>9</sup> One woman who participated in our one-on-one interviews also worked as a care provider. She said,

When I took my course, it was like a bell went off in my head. Giving the consumer choice was something I never thought of. Maybe they want to brush their teeth before putting on makeup. We were taught how important it is to give someone choice.

In Alberta, most women with disabilities who live independently in the community receive care through licensed home care agencies. These agencies determine their own guidelines regarding worker qualifications and training. We interviewed home care agency representatives from the four health regions that provide services to the consumers who took part in our focus group sessions. For the most part, the agencies required their home care workers to possess a Personal Care Attendant (PCA) certificate or the equivalent.<sup>10</sup>

All agencies we contacted encouraged workers to participate in a variety of on-going training opportunities. For example, Bay Shore Home Care in Edmonton offers monthly inservices, and Lethbridge Family Services provides training in “back care, non-violent crisis intervention, abuse protocols, and first aid.” A caregiver at one of our focus groups took part in several optional training opportunities to improve her skills. She said, “In the abuse protocol inservice, we were trained to recognize abnormal



*My first experiences with abuse happened when my mother got together with my stepfather. He was an alcoholic and a very abusive man. He was very mean. He physically abused my mom and me. One time he said he didn't believe in children who were disabled. There was no such thing as disabled children, just lazy ones.*

*When I was in junior high there was a lot of pressure on my mom. She got very emotionally abusive. I think because she was protecting me from my stepfather. She wanted me to do everything right so I wouldn't be looked down on in his eyes. It was really hard.*

*While women in this situation have the ability to release someone whose care they find threatening or abusive, the overall shortage of workers in the system makes it difficult to find and maintain qualified care.*

behaviour, including behaviours that could be related to sexual abuse. We learned what to look for.”

Consumers who want to have more control over their care arrangements than is available through licensed agencies can apply for an Independent Funding Agreement (IFA), formerly known as self managed care. If they are eligible for and receive IFA, they take on the responsibility of hiring, firing, and managing their own caregivers. In these arrangements, expectations regarding caregiver qualifications will vary from individual to individual. While women in this situation have the ability to release someone whose care they find threatening or abusive, the overall shortage of workers in the system makes it difficult to find and maintain qualified care. A woman with a disability who has been on IFA for fifteen years shared, “I am constantly training and re-training workers so that my needs are met. It is difficult to get people to stay. Once I finally have them trained, they may decide to move on. It’s especially difficult to find someone who will work on the weekend.”

In spite of agency requirements and the control given to consumers with IFA, the anecdotes shared in our focus group sessions clearly reveal the need for improved caregiver sensitivity and training. One participant reported, “Care providers in our building will do anything from call you a ‘stupid retard’ to leave you in dirty diapers.” Another revealed, “I’ve had caregivers who lack the proper caring skills. They did not seem to be in the profession because they cared, but because there is a shortage of workers and they needed a job. They had no idea how to address my needs.”<sup>11</sup>

With 98–100% of PCA certificate students able to find employment, the door is definitely open for ill-suited workers in the field. One consumer felt, “Some people look at care giving as a transitional job. If care attendants are not in the job for the right reasons, they can lack the proper caring skills, especially if they haven’t received the appropriate training.” Another focus group participant added,

You are more likely to be abused if they don’t care about the job they are doing. To do a good job, you must care. For

example, a caring person will ask me what I would like to wear rather than deciding for me; and they won't give me a hard time about asking to lie down when it's not the right time.

## **ii) Family Caregivers**

Lack of training and awareness are also issues for caregivers who are family members. Sobsey (1994) states, "In-home care with natural families is typically the safest living alternative" (p. 240) for a woman with a disability who relies on others for care. However, family members are susceptible to the same myths and assumptions that affect society's view of people with disabilities. As well, they cannot be expected to know instinctively how to care for a family member with a disability.

One rural focus group member, who provided care for her mother, said, "We need more information about how to provide care in the home. When I was caring for my mother who has Alzheimer's, I didn't know she would try to run away." When the woman sought information on her mother's condition, her doctor suggested she attend a support group in the nearest city. She believes she should have been able to access support locally. She said, "It should be compulsory for family caregivers to have training. I wish somebody had made me go. The doctor said I could go to the nearest city to learn about my mother's Alzheimer's, but that would take me an hour each way. I didn't have the time to do that."

Family members who provide care are given minimal (if any) training regarding their new responsibilities. This lack of training increases the risk of abuse. One focus group participant who had undertaken provision of care for her aging parents said, "When my parents were discharged from the hospital, it just happened to be on a weekend. That meant that no one was available to tell me how to prepare for their return home. I was given no information on how to care for them." The Roeher Institute (1995) states, "Relying on family members . . . who may be ill-equipped for the task of care giving indirectly increases a person's vulnerability" (p. 18).

*Family members who provide care are given minimal (if any) training regarding their new responsibilities. This lack of training increases the risk of abuse.*

*All family members who become caregivers need to have training in and support for their new role. The training will involve all aspects of the care that are “new territory” for the caregiver.*

## **Strategies/Solutions**

- » Ensure consumer-directed training modules are mandatory in all care attendant training programs offered by private companies, health authorities, home care agencies, and post-secondary institutions. Agencies seem to have high expectations about worker training and qualifications, but ACCD believes the stories shared by our focus group participants and interviewees indicate this training needs a consumer-directed element. These elements need to be developed in consultation with consumers and delivered by women/people with disabilities. Three areas will be addressed by these modules: consumer perspectives, myths and stereotypes about people with disabilities, and violence and abuse.
  
- » All family members who become caregivers need to have training in and support for their new role. The training will involve all aspects of the care that are “new territory” for the caregiver. This may include training in practical skills, awareness raising, consumer perspectives, myths and stereotypes about people with disabilities, and violence and abuse. Ideally, this training should be provided by Public Health Units and take the form of a community outreach program (similar to the Capital Health Region’s Healthy Beginnings program).

### **c) Home Care System Increases Consumer Vulnerability**

When paid caregivers enter a woman’s home, they are, in a sense, given permission to become familiar with her daily routines, her lifestyle, and her physical and social needs. Reciprocal familiarity is generally not cultivated and thus creates a power imbalance in the relationship. If the caregiver takes advantage of this imbalance, abuse and violence ensue. The very nature of the home care arrangement, therefore, contributes to the possibility of abuse occurring. Sobsey (1991) notes,

[A]buse of disabled persons most often occurs at the hands of people society hired . . . to care for and protect them. This fact should not be viewed as disparagement of caregivers as there are many well-motivated and often

dedicated care providers who provide a valuable service to society and the individuals they assist. However, a minority of abusers can produce a multitude of victims, and one abusive caregiver typically has a large number of victims. (p. 4)

If proper safeguards and protocols are in place, the opportunity for abuse can be curbed. Participants in our focus groups felt improvements in the current system needed to focus on

- » System Inflexibility
- » Abuse Reporting and Investigating Protocols
- » Support for Family Caregivers

### **i) System Inflexibility**

Through our literature review, ACCD learned that when a woman is not given the opportunity to make her own decisions, she becomes increasingly reliant on her caregiver. We also learned that this dependence increases her susceptibility to violence. Yet, health authorities emphasize the importance of increased accountability through stringent guidelines. As a result, the home care system encourages increased consumer dependence. As one consumer noted, “It used to be up to us to negotiate our needs. Now we are assessed by a home care manager who decides what we need. Our power to decide has been taken away.” Another woman agreed, stating, “Our independence is slowly being eroded by decisions being made by the health authorities.”

The changes in home care reflect the government’s push toward government accountability. “These changes,” one consumer noted, “give us less power to decide anything. We only have the freedom to choose, as long as we choose what they want us to.” While this shift to a more accountable system may have been put in place to ensure consumers receive consistent care, this consistency has, according to one of our focus group participants, “led to neglect [of] and frustration on the part of the consumer.” Workers seem governed by agency expectations, not consumer need. She explained, “The system has become so hooked on accountability that the consumer’s ability and right to choose has been taken away.” For example, “With some agencies, you are booked one bath a week. If you miss your time slot because of a doctor’s appointment, you’ve missed your time slot altogether. There is a fine line between caring and ruling.”

*It seems strange to me they can’t change a band-aid. A caregiver’s actions need to be guided by common sense not by fear of being sued. But the system forces them to be this way. It is a systemic barrier.*



*When I had my own personal caregiver, she was working for me full time. She was very manipulative and very clever with words. She convinced me, without me even realizing it, that she could work for me full time as well as go to school full time. So she wasn't there as much as she should have been.*

*The first day of classes she was just going like mad, in a hurry because she had to go to school. It finally got to the point where I wasn't getting the care that I needed. So I said, "This isn't working, I have to let you go." We ended up getting in a real fight. My girlfriend, who is also a social worker, told her she had agreed to a full time arrangement so she had to do it. But the caregiver said I didn't need full time help anyway. She threatened to call up social services or home care and tell them I didn't need the hours. So I decided to keep her on. (continued...)*

In another scenario, a woman recalled how she needed assistance to put a band-aid on her cut finger. However, this task was not a part of her caregiver's responsibilities, so she was unwilling to help her client. While the consumer was frustrated and puzzled by the response, she also knew that the caregiver was adhering to a particular system. She said, "It seems strange to me they can't change a band-aid. A caregiver's actions need to be guided by common sense not by fear of being sued. But the system forces them to be this way. It is a systemic barrier."

#### **ii) Abuse Reporting and Investigating Protocols**

All home care agencies require abuse reporting and investigation protocols. However, our focus group participants were not convinced that these protocols served the consumers. Most of the women in our focus group sessions believed that, "once abusive caregivers are in the system, it's hard to get rid of them." This belief reflects, in part, the perception that home care agencies are unwilling to charge caregivers who are accused of violence. One consumer pointed out, "Agencies are afraid of being sued. The people who do the hiring make excuses to get rid of anyone who has been abusive, but that person is able to go to another place of work." The Roeher Institute (1995) supports this view. They found that some caregivers

who had been reported to administrators as perpetrators of violence and abuse against people with disabilities, were not terminated from their employment but were instead assigned to jobs where they were in a position to commit similar offences. . . . Police respondents indicated that administrators may have been saving face rather than taking appropriate action. (p. 102)

Interestingly, most home care agencies do not ask clients to provide a reason should they request to change their caregivers. On the surface, this policy appears to sensitively grant a consumer control over her care. However, focus group participants were divided on the usefulness of this policy. One woman, who is both a consumer and a service provider, said, "This is good because you are not forced to explain yourself, but bad because people don't tell when they are being violated. This makes it easier for repeat offenders to move through the system because they are not confronted with the abuse."

Even though agency-directed protocols are in place to support women with disabilities who want to report abuse, many consumers choose not to. Fear of retaliation or of reduction in services often impedes one's ability to disclose or report a harmful situation. Retaliation can take many forms. As the Canadian Panel on Violence Against Women reports, "Threats of withdrawing support can become a prime means of controlling a woman with a disability. It may prevent her from revealing abuse and leaving a situation where physical or sexual abuse may also be happening" (p. 69). One focus group participant said, "I am just grateful for the service I do receive. I sometimes sacrifice my expectations about what I think 'good' care is, just because I want some care." Another woman concurred, noting, "Because we are afraid of losing care, we are afraid to report abuse."

Ironically, choosing to disclose or report violence can also threaten a woman's independence. As the CAILC (1996) notes, a victim may choose not to report abuse because they fear being institutionalized: "If [the] survivor is living in the community when [the] abuse incident takes place, family or professionals may decide it's safer for them to live in an institution" (p. 43).

### **iii) Support for Family Caregivers**

Family members often find themselves assuming the role of caregiver. In Canada, 82.7% of adults who require assistance with intimate personal care live with nuclear or extended family members, and most of them (71.8%) receive assistance exclusively from family members" (Roehrer, 1995). However, these family caregivers often find themselves overworked, inadequately supported, and experiencing high levels of stress. Each of these factors creates a climate in which abuse or violence is more likely to occur. A woman who took part in our one-on-one interviews observed, "A child with a disability is a lot of work for a parent. The level of frustration is higher because you're doing a lot more than you have to do for a regular child. That can put the child at risk."

Family caregivers who attended our focus group sessions felt they needed to be better informed about services and supports available to them. In rural areas in particular, family caregivers were not aware that they could be supported by home care. One woman noted, "My own lack of awareness of possible services can lead to negligence and abuse. I don't know what services I'm entitled to."

*It's so hard to get funding to get a caregiver to come in anyway, that the very thought of having it taken away is very scary. She got away with doing next to nothing. I was getting friends to come in and help me out. I couldn't fire her because I had the bad experience of the big argument with her. When I did try to fire her, she turned the situation all around. She said "Come on, you're always playing the victim, you're not the victim."*

*She was so controlling, right down to when I ate. She would have me eating my supper at 3 o'clock in the afternoon if she could have gotten away with it. She would come and go whenever she felt like it. You can eat this; you don't need this, that kind of thing. She was able to manipulate me and get what she wanted.*

## Strategies/Solutions

*By enabling a consumer to select and direct her own care, the system will be less rigid and more responsive.*

- » Promote and expand Individual Funding Agreement options. By enabling a consumer to select and direct her own care, the system will be less rigid and more responsive. Dunn (1998) believes this approach is the most pragmatic and practical in developing individualized (rather than inflexible) systems and has the added benefit of being “significantly less expensive than traditional agency-based services” (p. 188).
- » Establish an advocacy/educator program for women with disabilities who receive home care. The advocate/educator would provide a neutral body to address and investigate complaints regarding violence and abuse. As well, the advocate/educator would meet with new clients to explain abuse systems and protocols and to raise awareness about violence and disability issues. This outreach program would involve advocates visiting the homes of women with disabilities who live independently in the community. The advocate would emphasize the rights of the consumer, an awareness of the boundaries inherent in receiving care from others, and the availability of assistance through crisis lines and consumer organizations. Print or alternate-format information would be left with the consumer. The advocate would also inform the consumer of various training/awareness-raising opportunities in the community and facilitate her participation in the training.
- » Promote the availability of respite, support, and home care options to family caregivers.
- » Include women/people with disabilities when creating and/or amending abuse protocols. If a consumer voice has not been included in current protocols, a review of the protocols needs to take place.
- » Create standard caregiver hiring practices. When care attendants move between agencies, former clients should be used as references, not the agency administration.

## **d) Transportation**

Of all the barriers identified at our focus group sessions, transportation issues elicited the most emotional response, especially from our urban participants. A sense of frustration and hopelessness surrounded these discussions. Many women had been fighting transportation battles for years and felt “able-bodied people have no concept of the impact of not being able to go where you want when you want.”<sup>12</sup> In our discussions, transportation systems were linked with abuse and violence in three key areas:

- » Increased Vulnerability
- » Driver Insensitivity/Verbal and Emotional Abuse
- » Inadequate/Non-Existent Services in Rural Areas

### **i) Increased Vulnerability**

Because women with disabilities often depend on parallel transportation and taxi services, our focus group participants felt more vulnerable to abuse perpetrated by drivers. Drivers pick women up at their homes, work places, and the homes of acquaintances. As a result, they become familiar with women’s schedules and routines, increasing a woman’s susceptibility to violence. As one consumer said, “If drivers want to perpetrate violence, they know where you are.”

A study conducted in Calgary validates these fears. Breaking the Barriers (Cooper, Younie, Farrar, & Guyn, 1995) examines personal safety issues for women with disabilities using public transportation. The study found that 65% of the women who took part in their survey “felt very or somewhat worried about their personal safety” (p. 17) when using public or parallel transportation services. The study also cites Sobsey (1994) who reports that 5% of perpetrators of sexual assault on persons with disabilities are transportation providers.

Focus group participants also felt vulnerable while waiting for buses to pick them up. Long, irregular, and unanticipated wait times accompany public and parallel transportation usage, and services on demand are seldom available. This means a woman with a disability can be waiting, alone, at a bus stop or other location for long periods of time. As one focus group participant

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*Last Christmas Eve, I was doing my last-minute Christmas shopping. I was going to take the bus home but because it was late in the afternoon on the Saturday before Christmas the schedule was limited. So I decided, instead of transferring and waiting, I would take a taxi. There were two taxis sitting right there. I asked a girl to help me. She went over to the taxi and approached on the driver's side and asked if it was free. The driver said, "No problem, get in." She told me it was free, but as I walked towards the car, he saw the dog and said, "I can't take you, I have another trip."*

*(continued...)*

said, "Handibus is not available on demand. You have to wait a long time. Sometimes they forget you, and if you don't have access to a phone you can't find out what's going on." These wait times are fraught with fears for women whose disabilities make them more vulnerable to abuse and violence. If a woman with a disability is threatened in any way, her disability may make it impossible to escape. One woman from our focus group who uses a wheelchair found herself in a very frightening situation. She told the group,

I was released from the hospital at 1:00 in the morning and told there was no room for me. Buses weren't running and I didn't have the money for a cab. I had to find my own way home. When I called social services to ask for an emergency-use taxi, they told me they couldn't provide one since I was on AISH.

With no other options, she journeyed from the hospital to downtown, "scared and tired." About four hours later, she arrived at an all night diner and waited there for the first public transit bus to take her home.

#### **ii) Driver Insensitivity/Verbal and Emotional Abuse**

Consumers shared many stories about the verbal abuse inflicted on them by drivers, especially when using the public transit system. In some instances they were called names, chastised for slowing down the buses, ridiculed for not being able to use the safety belts provided for chair users, and ignored during busy schedules. One woman recalled being told not to use the bus during rush hour. Another had a driver say to her, "You're retarded. You can't come on this bus!" When we spoke to an Edmonton Transit System representative, we learned that their drivers "are given general disability awareness information and instructions on using ramps if required." As with the general public, biases seemed to shape the attitudes of some drivers toward passengers with disabilities.

#### **iii) Services in Rural Areas**

Consumers in rural areas possess little, if any, public or parallel transportation at all. Women with disabilities rely almost solely on the help of family and friends in order to get around. According to the participants at the rural focus group sessions, this system works relatively well for most consumers. One

caregiver said, “Because family and friends want to bring you places, they will not be mean to you or call you names.” However, a lack of transportation, as one service provider noted, was “particularly threatening when in a crisis situation.” In one rural area, the Victim Services Program van could be used in these circumstances, but it was not adapted to transport a wheelchair. The executive director of a victim services program in a somewhat isolated area said,

There is no late night transportation available for people with disabilities in our community who may need emergency transportation. The victim services unit does have a van, but it is not wheelchair accessible. There needs to be a way of transporting women with disabilities who use wheelchairs and are trying to flee an abusive situation.

In this particular community, the victim services unit van provides many women with disabilities with a means of emergency transportation. However, many women with disabilities in rural communities do not have access to transportation at all.

## Strategies/Solutions

- » Ensure consumer-directed training modules are mandatory in all public and parallel transit driver-training programs.<sup>13</sup> These components need to be developed in consultation with consumers and delivered by women/people with disabilities. Three areas will be addressed by these modules: consumer perspectives, myths and stereotypes about people with disabilities, and violence and abuse.
- » Ensure that community transportation systems have formal complaint systems in place. An impartial ombudsman/advocate needs to be available to follow up on transportation concerns for women/people with disabilities.
- » Develop partnerships between parallel transportation services and victim services units/RCMP stations to ensure 24-hour availability of accessible transportation to assist women with disabilities who are attempting to

*It was obvious that he changed his mind because of the dog. I said OK and went to the next taxi. The girl who was helping me walked up to it first again, and I was following behind. I wasn't attempting to hide the fact that I have a dog, but she went first. She opened the back door of the next car and asked if he was free. He said yes. She opened the door, and I sat down and dropped my bags and he looked back, saw the dog and said, "Nope, no dog, no dog."*

*I just wanted to go home. I said, "I have to, I'm blind, it's a guide dog." I explained the situation, but he still wouldn't take me. So I got out of the car, thinking, "How in God's name am I going to get home?" I don't know what type of abuse this is. But it is wrong. I guess it is discrimination because it affects you emotionally and psychologically and lowers your self-esteem.*

escape an abusive situation. Community organizations (Lion's clubs, Rotary clubs, churches, etc.) could be asked to sponsor the use of the accessible transportation should it be needed.

- » Include on-going consumer input and consultation at all levels of parallel and public transportation development and assessment.

## **e) Accessibility**

The term accessibility is most often associated with accommodations that meet the physical or sensory needs of persons with disabilities so they can access buildings, events, and services. These accommodations are varied and can include wheelchair accessible doorways and washrooms, alternate-format documents, accessible public transportation, TTY phone service, etc. However, our focus groups felt accessibility went beyond the provision of physical and sensory supports. They identified three criteria that must be in place for services to be fully accessible. Services must

*The shelter is constantly full. Many women at the shelter have mental health issues, and the staff is not trained to deal with these individuals.*

- » Address the physical and sensory needs of individuals
- » Possess a community outreach component, i.e. be promoted in the disability community
- » Be staffed by personnel who are aware of and trained in addressing the unique needs of consumers

Unfortunately, the experiences of our focus group participants suggest that many of these criteria are absent from the systems and programs that respond to violence against women with disabilities. Consumers and service providers alike raised concerns regarding the accessibility of

- » Women's Shelters
- » Law Enforcement Services
- » Victim Services Units
- » The Legal System

## **i) Women's Shelters**

One focus group participant, who directs a women's shelter in a smaller centre, acknowledged the shelter's inaccessibility. She said,

Our community's women's shelter is not accessible. We assist women with disabilities, but it is difficult to do and there are many inconveniences for them. The shelter is constantly full. Many women at the shelter have mental health issues, and the staff is not trained to deal with these individuals.

This service provider, while sensitive to the needs of women with disabilities, was frustrated by a lack of resources to address the situation. Her story is a common one. Public funding for women's services and organizations has decreased significantly since the 1980s. Health Canada (1999) reports,

Funding cutbacks have had a major impact on services. Many feel that the "more for less" philosophy of many governments translates in practice into more work for shelter workers and less service for abused women and children. (Denham, p. 24)

In Alberta over the past several years, the number of women using shelters has increased drastically. However, financial and human resources to address these increases have not. Jan Reimer, Provincial Coordinator of the Alberta Council of Women's Shelters (ACWS), reported that 19,191 women and children were turned away from Alberta's women's shelters in 2000, an increase of 9.5% from the previous year. In a press release, ACWS stated,

Basic operating [budgets] for women's shelters have not increased since 1986. . . . Shelters continue to operate on a 'Survival Mode,' and this is simply not acceptable. ACWS continues to stress the need for adequate ongoing funding and a long-term plan that addresses strategies to reduce domestic violence. (November 29, 2001)

Some shelters, especially those in urban areas, do have accessible rooms for women with disabilities. However, if a woman without a disability needs assistance, shelter staff, understandably, will not turn her away given the possibility that a woman with a disability may need the room. Focus group participants understood these decisions, but also felt frustrated by them. One consumer said, "Sometimes accessible rooms in shelters are used for other women, so we can't access them.

One woman who is blind had her computer stolen while she was in the airport. When she reported the theft to the airport police, one of the first questions they asked her was "Are you sure you had the computer with you?"

## ONE WOMAN'S



## T O R Y

*I clipped out a newspaper article about a program for all the people who fall through the cracks. They said to come in, and we will help you with whatever you require education wise. We'll help you get a job; we'll help you down the road.*

*I looked at it every day for two months and I kept thinking, "OK, I'm going to phone these guys." But I had zero self-confidence, zero self-worth, zero self-esteem. Finally, I phoned and the man who answered said, "Yeah, we would like to meet you." Then he asked me about my disability. I thought, "Oh wow, I don't have one, but I have multi disabilities." I told him I have diabetes, I have rheumatoid arthritis, fibromyalgia and a few other disabilities.*

*(continued...)*

There should always be an accessible space open for women with disabilities."

### ii) Law Enforcement Services

Several women from our focus group sessions had reported violent or abusive situations to the police. Those who had an "invisible disability" felt they were treated differently once they disclosed their situation. One woman said,

When I had to go to the police, I found that once the people helping me found out I had a disability I had to wait a long time before they helped me. I felt that my disability meant I was "put on the back shelf" by people who were supposed to be assisting me.

Another consumer had a similar experience: "If you acknowledge your disability," she felt, "the police will serve the 'normal' person before serving you."

These perceptions of the police reflect a Roeher Institute (1993) study that examined police responses to abuse of persons with disabilities by their families and caregivers. The research found that people with disabilities generally felt they were not listened to by the police or that the listener was dismissive (p. 47). These feelings are partially rooted in a distrust of authority figures. The study states, "The perception of power relations on the part of the disabled community may include a wariness of the police. . . . It will likely take considerable effort to convince members of the disability community that the police are attempting to forge creative alliances with disempowered groups" (pp. 16,17).

Other consumers wondered if their disabilities raised doubts about the credibility of their reports. One woman who is blind had her computer stolen while she was in the airport. When she reported the theft to the airport police, one of the first questions they asked her was "Are you sure you had the computer with you?" Although trying to understand the officer's position, she felt quite taken aback by the response: "I don't particularly like to view myself as having been victimized. [But] I find it amazing that the police would think that I didn't know whether I had the computer in the first place." A one-on-one interview participant,

who uses a wheelchair, reported to the police after she'd been mugged:

When I first went to the police I thought they were pretty good, but then I started to wonder if the reason they kept on repeating questions was because they didn't believe me. It felt like they had me repeat my story because they were trying to catch me on things. They did not seem concerned with providing emotional support until much later.

Each of these situations focuses on accessibility in terms of the awareness and sensitivity of police officers' responses to women with disabilities. However, inadequate physical accessibility to police stations also has a significant impact on consumers' experiences in disclosing and reporting abuse.<sup>14</sup> For example, one service provider reported,

The RCMP office in our town is not accessible. There are six steps at the front door. There was a woman who used a wheelchair who wanted to report an abusive situation, and she had to be carried up the stairs by a police officer.

In rural areas, accessibility is closely linked with availability. RCMP detachments in sparsely populated regions are often responsible for large areas. If an officer is patrolling the area or is investigating another situation, calls to the office are rerouted to the closest city. This may lead to delays in the response to an emergency situation.

### **iii) Victim Services Units**

Women in the focus groups who received assistance from victim services programs appreciated the sensitive, compassionate follow-up support they received. Victim services programs, which are generally housed within police facilities, provide support to victims of crime. The Alberta Solicitor General web page describes these services: "A network of Victim Service Units has been established . . . to follow up the initial police response and provide assistance to victims as their cases proceed through the criminal justice system."

However, even these services lack the resources to effectively address the needs of women with disabilities. One victim

*He immediately said, "Oh well, I guess you're at the bottom of the gene pool. I don't think we can help you." I thought I was going to get some help, and he totally dashed me on the rocks. I hung up the phone and immediately wanted to commit suicide. This guy was telling me that I had nothing, knew nothing, and there was nothing that could be done. It took me four months before I could even approach that subject to talk about it because it was so painful. And it still is very painful today to think that someone has the authority to say, "C'mon I'll help you," and then be so mean.*

services program director explained,

Currently, our program finds it hard to train our volunteers and staff in a number of areas, including the provision of services to women/people with disabilities. The Alberta Police Based Victim Services Association in conjunction with the Alberta Solicitor General has developed a training module that will be available soon, but even when it is ready who will deliver it? We struggle with appropriate funding of staff resources and facilitators, which result in limited time to do ongoing training and training of new staff and volunteers.

*Intimidation and power imbalances are created between RCMP officers and clients, between social workers and clients, between doctors and clients, and between paraprofessionals and clients.*

#### **iv) Legal System**

Women in our focus groups who had used the legal system felt cynical about their experiences. They found it to be an expensive and troublesome process. One consumer reported, “Dealing with a lawyer was very difficult for me. I felt like he was taking advantage of me because I didn’t have much money. Maybe an advocate would have made a difference. I was very unhappy with the experience and with the cost.”

One reason this consumer gave for her frustration was that she never felt the process had been explained properly. The legal system did not seem accessible because it was difficult to understand. A service provider at the same focus group session commented, “Problems in the legal system often centre around language and process. It’s hard to know what’s going on.” In general, consumers felt this was true with many of their support systems. One focus group participant said,

Intimidation and power imbalances are created between RCMP officers and clients, between social workers and clients, between doctors and clients, and between paraprofessionals and clients. They don’t sit down and explain the situation to the people they are serving. They use their power and authority to shoot others down.

Women who are deaf or hard of hearing struggle with access to alternative communication in the legal system. Connect Society (2000), an organization that “exists to help deaf and hard-of-hearing individuals and their families to fully participate in

society,” critiques services for the deaf community in a series of position papers. In assessing the legal system’s accessibility,<sup>15</sup> they note,

In spite of directives established [by the Alberta government] in 1995, alternative communication services in Alberta courtrooms remain inconsistent and, in some cases, inadequate. For example, deaf Albertans may arrive at a court appointment to find that no interpreter is available.

## **Strategies/Solutions**

- » Investigate the potential for women’s shelters in urban areas that are specifically for women with disabilities. These shelters would address the physical and sensory needs of its clients and be staffed by people who have received awareness and sensitivity training. A shelter specifically for women with disabilities would require fewer resources to develop than would the conversion of rooms and training of staff in all existing shelters.
- » Investigate the possibility of safe houses for women with disabilities who live in smaller centres. Utilizing families that have experience with disabilities and homes that are already accessible would eliminate the need for training shelter staff or converting existing buildings to address the needs of these women. The volunteers who operate the houses would receive the training required by women’s shelter staff.
- » Assess the physical and sensory accessibility of police stations throughout the province and address the gaps in accessibility. Women/people with disabilities need to be a part of the assessment process.
- » Increase resources to ensure that the legal system, law enforcement officers, victim services staff and volunteers, and women’s shelter staff and volunteers receive adequate training regarding the unique needs of women/people with disabilities.<sup>16</sup> These training modules need to be developed in consultation with consumers and delivered by women/people with disabilities. The modules will address

*These training modules need to be developed in consultation with consumers and delivered by women/people with disabilities.*



*I was with this guy, and he abused me emotionally and physically. He didn't understand my disability. He was always asking questions: "How come you have cerebral palsy? Why can't you do anything like a normal person, like go out and look for a job, get hired?" He works, he comes home and complains, "I'm working and you're not, why aren't you working?" I feel like saying, "Excuse me, I was born with cerebral palsy, and I can't work." When he first beat me up I was so afraid to phone the police. I had bruises on my body. I was pretty scared and shaken up. I couldn't defend myself. I had to do something. He couldn't care less. I couldn't earn a living and was dependent on him.*

the myths and stereotypes about people with disabilities and the accommodations needed by women with disabilities when they seek to address violence in their lives.

- » Provide specialized training to some law enforcement officers. Sobsey (1994) states, "Some law enforcement personnel require comprehensive training in investigating cases that involve people with disabilities. They should understand the physical, social, and psychological aspects of disability and be prepared to interact with people with a variety of individual needs. These specialists might provide consultation to other police officers and respond to referrals of cases that require their expertise" (p. 274).
- » Establish an advocate/educator position for women/people with disabilities who utilize the legal system. The advocate/educator would provide plain-language explanations of the system and provide support to the consumer throughout the process.
- » Pay interpreters from victim services programs and use the same interpreters throughout law enforcement/legal interactions. Currently, many victim services programs rely on volunteer interpreters. These interpreters have work and other commitments outside of the victim services unit and are not always available to provide on-going assistance.
- » Coordinate efforts between police, protection agencies, social services, etc. This integration can protect the abused individual from further abuse and secondary trauma associated with the investigation (Sobsey, 1994, p. 350).

## **f) Poverty and Abuse**

The Canadian Panel on Violence Against Women (1993) reports, "Poverty and its direct impact on a woman's ability to control her life enhances her vulnerability to violence" (p. 68). When our focus groups discussed the link between poverty and abuse, they were interested primarily in the limitations imposed on them by the Assured Income for the Severely Handicapped

(AISH) program. In Alberta, many women with disabilities rely on the income support provided through AISH.<sup>17</sup> Consumers, service providers, and caregivers identified three aspects of AISH that they believed to be abusive or that contributed to the likelihood of abuse occurring. These aspects are:

- » AISH Amount
- » Funded Medications
- » Disincentive to Work

**i) AISH Amount**

Currently, AISH allots Albertans with disabilities \$850.00/month to meet daily costs of living. These benefits yield annual incomes substantially lower than the Canadian Council on Social Development Income Lines, the Senate Committee Poverty Lines, the Toronto Social Planning Council Budget Lines, and the B.C. Social Planning Council Poverty Lines. In her study *Living with disability in Canada: An economic portrait*, Gail Fawcett (1996) found “Women with disabilities are especially disadvantaged when it comes to the economic resources available to them. One quarter of all adult women with disabilities (aged 15 years and older) were poor in 1991” (p. 131).

*Women with disabilities are especially disadvantaged when it comes to the economic resources available to them.*

One focus group participant explained how the limited AISH amount makes women with disabilities more susceptible to violence. She said, “AISH is not enough to keep us independent, so many of us rely on others for basic needs. This dependency makes it difficult to leave if we are being abused by a spouse or a roommate.” Since the financial support that AISH provides a woman is affected by her spouse’s income, her dependence on him is magnified.<sup>18</sup> Statistics Canada (1995) reports that “81% of ever-married women who experienced wife assault in a past relationship reported no further violence after they separated from their partner” (p. 105). The system fosters women’s financial dependence on spouses and decreases the likelihood of their leaving abusive situations.

**ii) Funded Medications**

Along with cost-of-living benefits, AISH provides medical supports for individuals. However, restrictions are placed on the amounts and types of medications that an individual is eligible

*On Saturday, I went to get the drugs I need to function normally but the prescription had been changed and the new drugs weren't covered by AISH. What will I do?*

for. If her coverage period has expired or if a medication is not covered, a woman with a disability has to cover the cost of the drug herself.

If a person must make ends meet on \$850.00/month, nothing remains for the often exorbitant cost of medication. A few days before one of our focus group meetings, a participant, who has epilepsy, had been unable to fill a prescription. She told the group, "On Saturday, I went to get the drugs I need to function normally but the prescription had been changed and the new drugs weren't covered by AISH. What will I do?" The woman's doctor had changed her prescription to a more effective drug, but when she went to the pharmacy, the new drug wasn't covered. Because it was a weekend, she was unable to have the prescription changed. A caregiver at the session commented: "If there isn't enough money to provide pills, and the pharmacy won't provide them, then that is abuse."

### **iii) Disincentive to Work**

Women who rely on AISH but who are able to manage some form of gainful employment are neither suitably encouraged or supported in their efforts to become involved in the workforce. Because only a small amount of an individual's employment income is exempt from an AISH adjustment, the motivation for seeking and obtaining employment is negligible. Currently, single adults can keep the first \$200 they earn each month, plus 25% of any amount over \$200. This means an individual who works 20 hours/week for \$10.00/hour would only be able to retain \$366.67 of the \$866.67 she would earn.

When the considerable cost (transportation, clothing, and/or childcare for example) and energy involved in joining the work force are considered, the "rational choice is to withdraw from the labour market" (Fawcett, 2000, p. 15). And yet, the benefits of working are significant.

For a woman with a disability, the self-confidence, community involvement, and financial independence gained through work play important roles in decreasing her susceptibility to violence. As one consumer said, "AISH is a degrading system that penalizes work. But work is such a positive and important thing. Through work I've felt included in the community, and I've

learned about the supports that are available to me.” As Fawcett (2000) discovered in her study, “Women with disabilities are often those most adversely affected by the present system of linked disability-related supports and income programs”(p. 29).

## **Strategies/Solutions**

- » Increase AISH amounts to reflect current market realities. The basic AISH benefit needs to be aligned with current market costs of rent, transportation, utilities, food, etc. This amount needs to be indexed to reflect the actual cost of living.
- » Increase the allowable earnings for AISH recipients who enter the workforce. If individuals can retain more of their earnings while continuing to receive the full AISH benefit, the incentive to work will be increased.
- » Separate medical and health supports that help AISH recipients overcome any barriers directly related to their disability from income supports. If this were to happen, AISH recipients who are able to obtain employment would not risk losing the medical/health supports required to work or to live independently in the community.
- » Dissolve the link between the AISH benefit and spousal income. AISH needs to be considered an income entitlement program for persons with disabilities. Our society no longer sees women as dependent on their husbands, so AISH support amounts should not be calculated based on this assumption. Even within a marriage or common law relationship, persons with disabilities are independent men and women who should not be denied their AISH supports.

*For a woman with a disability, the self-confidence, community involvement, and financial independence gained through work play important roles in decreasing her susceptibility to violence.*

## Recommendations

This research paper has outlined a number of significant reasons why women with disabilities are more vulnerable to abuse and violence than other segments of society. The Strategies/ Solutions sections of the document deal with the primary issues in the following broad categories:

*Our society no longer sees women as dependent on their husbands, so AISH support amounts should not be calculated based on this assumption.*

- » Promote awareness and disseminate relevant information relating to violence and abuse to the following groups: women with disabilities, family members, women and disability organizations, private and public caregiver agencies, law enforcement and justice departments, medical and counselling professionals agencies, and all levels of government services departments. Education and awareness are vital components in affecting change at both societal and systemic levels.
- » Provide consumer-directed, caregiver training and support to family members, private caregivers, and public agencies.
- » Provide access to local transportation, women's shelters and alternate housing, medical services, counselling, attendant care, and law enforcement and justice services.
- » Provide income supports that allow women with disabilities the financial stability and independence they need to remove themselves from abusive situations.

Implementation of the following recommendations will address many of the above issues and drastically lower the incidents of violence against women with disabilities in Alberta.

1. ACCD will continue to develop brochures and other presentation materials relevant to the many stakeholder perspectives on violence against women with disabilities. This information will be disseminated to the various target groups listed above to promote awareness of the severity and pervasiveness of this problem.
2. Status of Women Canada should make information contained in this document available through its library and links on its web site to all funded women's organizations and other

federal and provincial affiliated project funding departments, for dissemination to their partners and funding recipients.

3. Disability organizations must develop and make available a consumer-focused training module for individual and agency caregivers and families of women with disabilities.
4. Disability organizations must promote funding agreements which will allow women with disabilities and their families to make their own choices (e.g. Individual Funding Agreements and Self Managed Care).
5. As neutral parties, disability and women's organizations must position themselves to advocate for women who experience abuse when using public services including transportation.
6. Transportation and other public service agencies must have an independent appeal process to investigate complaints lodged by clients or their advocates.
7. All levels of government should provide funding for law enforcement and justice services to partner with disability organizations in providing training and in developing resource information for their staff concerning women with disabilities.
8. When providing funding to women's shelters and related services, all levels of government must include funding to support accessibility requirements.
9. Governments at all levels must fund and publicize emergency accessible transportation services for women with disabilities who are victims of abuse.
10. All provincial and federal income support programs for people with disabilities must reflect indexed cost of living amounts. Financial assistance must not be linked to spousal income. Employment earnings must not negatively affect access to income support. Medical coverage must be separated from income supports.

*Governments at all levels must fund and publicize emergency accessible transportation services for women with disabilities who are victims of abuse.*

## Conclusion

Creating this document has proven to be both a difficult and rewarding task for ACCD. The bleak statistics and shocking stories concerning violence against women with disabilities are difficult to accept and even more difficult to understand. Why do our care systems contribute to the exploitation of individuals with disabilities? Why don't women with disabilities have equal access to the services and programs intended to address the issue of violence? What can we do to make Alberta a safer place for women with disabilities? Chapman (1996) succinctly outlines the problem:

Women with disabilities are vulnerable to the same forms of gender-based violence and abuse faced by all women, but they do so within the context of limited access to resources, dependency on others for their care, and culturally based assumptions regarding their sexuality, capability, and credibility. (p. 4)

*Through the stories of these women and their service providers, barriers to addressing violence against women with disabilities were identified and strategies to break down these barriers put forward.*

This document is unique in that it reflects both the experiences and views of women with disabilities who have survived abuse in some form and the experiences and views of those who provide services related to the disability community. Focus group participants disclosed their respective disabilities and discussed barriers, which they saw as factors that increased the risk of abuse in their lives. Key points included societal myths and stereotypes, dependence on others, and isolation. Through the stories of these women and their service providers, barriers to addressing violence against women with disabilities were identified and strategies to break down these barriers put forward. These strategies emphasize the need for information and education relating to abuse by both those with disabilities and their service providers, appropriate attendant care training and support, availability of accessible transportation and safe housing, and financial supports which will enable women to leave an abusive situation and manage the costs related to living with a disability independently. The recommendations that have come out of this project identify ways to break down barriers and increase the control and security women with disabilities have in their lives.

In spite of many challenges, ACCD feels confident that change is achievable. This confidence is rooted in the spirit and determination of the women with disabilities who have so generously shared their time and experiences with us in creating this document. Our interactions with them have been extremely rewarding. Already, recommendations made in this document are beginning to be implemented. For example, the Milk River town web page has a disabilities link that explains training and education opportunities for caregivers, and ACCD is creating a series of awareness-raising brochures directed at women with disabilities, their caregivers, and the general public.

We are inspired by the words of the women whose lives have been affected by violence and reinforce the importance of including women with disabilities at all levels of policy and program development. One of our interviewees reminds us,

People with disabilities wear different colours. We are, no matter how you look at it, unique individuals. We all have different strengths, just like people without disabilities have different strengths. We are no different than them. If we learn to concentrate on our abilities not our disabilities, we will find out we can do all these different things. I can have a hope or a dream—and I can fulfil it, too!

*In spite of many challenges, ACCD feels confident that change is achievable. This confidence is rooted in the spirit and determination of the women with disabilities who have so generously shared their time and experiences with us in creating this document.*



*Together, We Hold The Power!*

## Footnotes

<sup>1</sup> This anecdote is in no way meant to be critical of the work being done by Social Services. We are grateful that someone took the time to contact ACCD and alert us to the abuse that is occurring against women with disabilities. Funding cutbacks are making it difficult for non-profit organizations and government departments alike to assist the individuals they are mandated to support. An overview of initiatives to end woman abuse produced by the federal government (1999) notes, “The economic cutbacks that have shaped every government’s policies for the latter part of the 90’s have affected most Canadians. For many abused women and children, the impact of the cuts may be forcing particularly difficult choices” (Denham, p. 12).

<sup>2</sup> The women with disabilities who live independently in the community are protected by the Protection Against Family Violence Act and individual home care agency protocols. Women with disabilities who live in provincially funded institutions and residences are protected by the Protection for Persons in Care Act and by provincial Abuse Reporting and Investigation Protocols.

<sup>3</sup> Family caregivers might be relatives such as children, parents, siblings, grandparents, in-laws, etc. However, our definition also includes friends or roommates who provide care but who are not paid for their support.

<sup>4</sup> An aboriginal woman in one focus group session commented on the additional isolation she felt as a native woman. She told the group, “The racism and prejudice directed at me make me feel powerless. If you don’t have the language or the education you are ostracized, even from disabilities groups.”

<sup>5</sup> Men with disabilities experience higher incidence of abuse and violence than do men without disabilities. The CAILC (1996) and Roeher (1995) documents both discuss the threat and reality of violence against men and women with disabilities.

<sup>6</sup> Employment is a significant factor in creating independence and reducing vulnerability. In 2000, ACCD conducted a study that examined the employment barriers that affect women with disabilities. This study, *Working for change: An examination of employment barriers for women with disabilities in the prairie provinces* is accessible on-line under publications at <http://www.accd.net>.

<sup>7</sup> Similar integrated models exist for seniors. See McKenzie et al (1995). Also see DAWN’s handbook for health care professionals (1994).

<sup>8</sup> Such a resource guide would be similar to the *Prevention of the Abuse of Seniors-Canadian Training Guides* published by Health Canada.

<sup>9</sup> Several consumers and service providers commented that we would be remiss not to mention the abuse inflicted on caregivers by people with disabilities. While not as common as the abuse inflicted upon women/people with disabilities, caregiver abuse does happen. Appropriate training should be given to caregivers to ensure they can recognize and address this abuse, too.

<sup>10</sup> Several colleges throughout the province offer these certificate programs, but private companies, health authorities, and agencies also provide similar types of training. We spoke to program coordinators at four different campuses. By and large, the programs did not have mandatory, consumer-delivered modules, but they did express an interest in incorporating these types of modules into their programs. The Residential Aide Training program at Grant MacEwan College in Edmonton does have a consumer-directed module. This program also emphasizes an independent living model.

<sup>11</sup> Not all reports from our focus group members were negative. Some women were very pleased with the care they received.

<sup>12</sup> It was difficult in these discussions to stay focussed on the issue of transportation as it related to violence and abuse. For many consumers, the isolation caused by unavailable and inaccessible transportation posed such a significant threat to their independence that this is all they wanted to talk about. Focus group participants were clearly distrustful of and angry with the parallel and public transit systems in terms of their accessibility and availability.

<sup>13</sup> Drivers for parallel transit services undergo extensive training regarding disabilities and disability issues, while public transit drivers receive only very basic information. Training that involves a consumer perspective, while sometimes pursued, is not mandatory in either setting.

<sup>14</sup> Not all of the feedback we received regarding law enforcement services was negative. One woman reported that she received prompt and supportive attention when she had called the police to help her when a family member was drunk and abusing her. Another woman, with a developmental disability, reported that the police quickly found someone to help her communicate her situation.

<sup>15</sup> This position paper is based on a presentation made by Dr. Debra Russell, currently at David Peikoff Chair of Deafness Studies, University of Alberta.

<sup>16</sup> Some work has already been done in this area. Relevant materials need to be promoted in legal, law enforcement, and protection systems or used to develop further training. See the Roeher Institute (1992) *No more victims* series, the “reverse integration” workshops described by Stevens (1995), the *Charting new waters* video and guide developed by the Justice Institute of BC, CAILC’s (2000) on-line curriculum *Working effectively with persons with disabilities against crime*, and the *Double jeopardy* video developed by the Foundation on Independent Living (1996).

<sup>17</sup> In 2000, the provincial government undertook a review of its low-income programs, including AISH. They sought input from organizations and individuals, and ACCD responded with a paper that focused on six key points identified by its membership. This paper is accessible on-line under publications at <http://www.accd.net>.

<sup>18</sup> One focus group participant with a developmental disability felt that including spousal income in calculating AISH could also be considered abuse because it discouraged women with disabilities from seeking life partners. She said, “If you can’t have a husband this is a type of emotional abuse.”

## **Appendix One: Interview Questions**

### **Interview Questions for Violence Against Women with Disabilities Project**

#### ***Introductory comments:***

After introducing yourself, talk to the interviewee briefly about the project and ask her if she has any questions about the project in general. Let her know that the intent of the interview is to gather information/anecdotes to include in a written research document but not to provide counselling. However, let her know that we will provide follow-up assistance if she needs it to access counselling, etc.

The interview is meant to take approximately one hour.

Before beginning the interview, let the interviewee know that the discussion will be taped. However, once the tapes are transcribed they will be destroyed after three months. Information will be confidential, and the writer will not have access to the interviewee's name when using information from the interview. Ask if she has any questions about the tapes, issues of confidentiality, or the interview in general.

*(Have the interviewee sign the consent form [attached] at this time.)*

*(Start the tape recorder at this point.)*

In this introductory section, we would like you to obtain some information about the interviewee. This information could include her age, marital status, living situation, disability, relationship to abuser, etc. If you feel this information will come up as a matter of course throughout the interview, you do not have to ask the questions here. A checklist of the information we are looking for is provided at the end of the interview.

#### ***Interview Questions***

The comments provided in the brackets gives you an idea of the type of information we are looking for.

If you are taking notes, you can write directly on this page if you'd like.

1. Could you briefly tell me about your experience with abuse? (types, what happened, circumstances, could anything have been done to change what happened)

*(Note: If the interviewee is currently in an abusive situation, use your own judgment regarding the remaining questions. If we can gather some information, it would be useful, but safety issues, obviously, need to be our first concern.)*

2. How was it that you came to recognize the situation as abuse?
3. What effect did the abuse have on you at the time? How do you feel the abuse impacts you today? (if different)
4. Were you able to tell someone about the abuse? If yes, whom did you tell and what were the circumstances around your disclosure? (If the interviewee needs direction, ask her if she approached friends, family, a women's shelter, a disabilities organization, a counsellor, an advocate, etc.)

*(Note: If this is the first time the interviewee has disclosed her abuse, ask her why she chose to do so at this time. Let her know that at the end of the interview you can assist her in taking steps toward seeking counselling, etc.)*

5. Were you able to get help/healing? (explore helping/coping strategy, barriers to help, did disability affect help-seeking, do you feel like you are healed, better, or continuing?)
6. What would have made things easier for you in dealing with the abuse? (If she did not receive the assistance she needed, we would like to know why she feels the counsellors/advocates were unable to help her. What improvements could be made to the supports provided?)
7. Are you still associated with the individual/centre that you went to for help?
8. Do you think persons with disabilities are more or less likely to be abused than people without disabilities? Why? What about the differences between men and women?

*(Note: At this point the interview is almost over. If the interviewee has focused primarily on physical or sexual abuse and if you feel it is appropriate to shift the focus somewhat, ask her if she believes she has ever experienced financial or emotional abuse or if she has ever felt her needs have been neglected. If she answers yes, ask her to talk about the situation(s).)*

9. Is there anything else you'd like to share/say?

***Wrap Up***

- a) Review this brief checklist to see if we have the necessary details/demographic information. Provide any information that did not come up in the interview.
- b) Thank the interviewee for her time and let her know you will follow up with a phone call in a few days to see how she's doing. If you feel she needs assistance in linking up with a counsellor provide whatever assistance you can at this time. Give her the resource package at this time.

***Checklist:***

- Age:
- Marital Status:
- # of Children, if any:
- Urban or Rural Location:
- Living Situation:
- Nature of Disability:
- Relationship to Abuser:
- Source of Income:
- Financially Dependent or Independent:

***Consent Form***

I understand that the information gathered in the interview may be used to support the research conducted in ACCD's Violence Against Women with Disabilities Project. Names of interviewees will not be used in the study and confidentiality is ensured.

I also understand that after three months, the tapes will be destroyed. Transcribed interviews, without participant names, will be kept at ACCD to be used for further research as needed.

Date: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Signature of Interviewer: \_\_\_\_\_

## **Appendix Two: List of Community Contacts**

### **Abuse Prevention/Counselling**

Margie Graham, Training Consultant, Persons with Developmental Disabilities

Nancy Madsen, Community Rehabilitation Worker, Independent Living Society

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Judy Meadahl, Director of Clinical Services, Edmonton Home Services

Lynn Pack, Home Support Coordinator, Grande Prairie Family Community and Support Services, Home Support Program

Dalyce Greenslade, Director of Services, Calgary Family Services

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## **Appendix Three: CAILC Myths (1996)**

1. People with disabilities are not human.
2. People with disabilities are not sexual.
3. People with disabilities are like children.
4. People with disabilities are helpless and need our pity.
5. People with disabilities are worthless.
6. People with disabilities need special treatment.

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Alberta Committee of Citizens with Disabilities

## **Mission Statement**

The Alberta Committee of Citizens with Disabilities is a consumer-directed organization that actively promotes full participation in society for Albertans with disabilities.

## **Who We Are**

ACCD is a charitable non-profit organization active on behalf of citizens with disabilities. We are Alberta's only cross-disability organization, bringing together the concerns and interests of many individuals and community groups. We are the provincial affiliate of the national organization, the Council of Canadians with Disabilities.

## **Our Five Guiding Principles**

Accountability  
Individuality  
Equality  
Integration  
Full Participation

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