
No Longer Silent: Persons with Disabilities who have been Abused Identify their Service Needs



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Chapter One: Disabilities Defined and the Abuse of Children with Disabilities

This research is the second phase of a project conducted by RESOLVE Alberta in partnership with the Action Committee on Disabilities and Abuse. The first report, entitled “Persons with Disabilities across the Lifespan: Program Scan and Community Stakeholder Needs Assessment,” was authored by Tutty, Moorey, LeDrew, Jesso, Ondejko and Tenzin. It comprised an environmental scan of services specific to individuals with disabilities who have been abused in some manner; and qualitative interviews with Calgary service representatives from both the disabilities and the family violence sectors.

The second phase of the research presents the analysis of interviews with a small number of individuals who have disabilities and have experienced abuse, to gather their experiences and impressions about the services they did or did not receive to assist them in coping with the abuse. In conjunction with the input from the Calgary service providers, their important voices will be used to construct recommendations to improve services and better address their needs.

While a number of topics have received considerable attention in the field of domestic and sexual violence, relatively fewer resources focus on the abuse of individuals with disabilities. In the same way that the literature on different forms of family and sexual abuse are often separate (i.e. research on dating violence rarely addresses woman abuse or sexual assault), the resources on disabilities are also often focused on specific disabilities (hearing or visual impairments or mentally challenged). The project report focuses in a comprehensive manner on all of these topics

The document draws together resources on abuse across the lifespan. Children, youth and adults with intellectual challenges remain vulnerable to all forms of abuse for a much longer period than those without such problems. Older adults are a population that often develops disabilities and becomes vulnerable to abuse. Further, a focus on disabilities expands our notions of family and sexual violence and how to address these. An important difference in considering abuse in populations with disabilities is that such abuse is often perpetrated by caregivers other than family members.

The current report first presents research on the incidence, prevalence and core features of abuse to children, adults and seniors with disabilities. The project includes the results of comprehensive search of resources across various forms of violence and disabilities. This document provides information on the issues and successful projects across North America that could guide the development of an Alberta-made strategy to address disabilities and domestic and sexual assault. It also presents the result of in-depth qualitative interview with community representatives from both the disabilities and the violence field. The first chapter focuses on defining disabilities and examining the prevalence, nature and impact of abuse on children with disabilities.

Disabilities in Canada: Prevalence

First, an important question is how commonly Canadians across the lifespan experience disability? According to the Government of Canada (2002), the rate of disability among Canadians increases with age and, except for children/youth under age 15, is more prevalent in women. According to the Participation and Activity Limitation Survey (PLS, 2002, cited in Government of Canada, 2002), “one of every seven Canadians aged 15 and over has some level of disability – an estimated 3.4 million people, or 12.4 percent of the

Canadian population. Additional results of the 2002 Participation and Activity Limitation survey are summarized below:

Survey results confirm that the disability rate gradually increases with age. From 3.3% among children aged 0 to 14, it rises to nearly 10% among adults aged 15 to 64 and climbs to more than 40% among persons aged 65 and over. In fact, more than half (53.3%) of persons 75 and over report having a disability. Within the population aged 15 to 64, this gradual increase is reflected in a rate of about 4% among young adults 15 to 24 years of age, compared to 7.1% among persons aged 25 to 44 and 16.7% among those aged 45 to 64. (p. 8)

Defining Disability: A Social Model

Individuals with disabilities are an extremely marginalized group. For decades, members of this population have faced inaccessible, unaffordable, and unattainable environments and social degradation leading to the risk of both individual and systemic abuse and violence.

When asked to define disability, most people identify the various specific types based on lack of function or a medical diagnosis. The **medical model** of disability identifies people with disabilities as having specific illness or limitations based on a health condition (Human Resources and Social Development Canada, 2008). The inability to function is seen as existing internally and the individual is often considered unable, or handicapped in some manner simply by virtue of the fact that they have a particular difficulty. Given this definition, people with disabilities are often defined in terms of “**type**”. In no particular order of importance, types of disabilities include mobility, visual, deaf and hard of hearing, speech, physical (not necessarily mobility problems), cognitive, learning (not all individuals in this type have cognitive damage), hidden or hard to identify conditions fall under what is known as invisible disabilities.

Individuals with “hidden” disabilities are further misunderstood or ignored, without such visible props such as wheelchairs and white canes. Disabilities such as epilepsy, mental illness, lupus, cognitive or mental disabilities, including but not limited to bipolar (manic-depressive) disorder, anxiety disorders (phobias), some developmental disabilities, and health concerns such as diabetes, blood disorders like haemophilia, digestion problems, allergies, asthma and other breathing problems are not easily identifiable.

The World Health Organization (WHO) (2001) offered a definition in 1980 that is preferred by most disability groups. To summarize, an **impairment** resulting from injury, genetics, and/or birthing difficulties can result in **disability** or lack of function. Differing from the medical model, this definition suggests lack of function exists as a result of a **handicap** located within the environment. For example, John injures his eyes in a skiing accident. His disability is partial blindness. If offered accommodation (assistance to function) in various forms (large print, audio, Braille), John is minimally “disabled” as his functioning is less affected.

In 2001, the WHO upgraded this definition to be congruent with the International Classification of Functioning, Disability and Health (ICF), which considers disability as a universal probability such that all people can have disabilities in varying degrees. The ICF also notes that social issues (such as poverty) may affect an individual’s functioning (inability

to obtain financial support for technology/accommodation). It does not focus on disability or condition but rather on personal functioning and impact as a whole.

Our thoughts regarding people with disabilities, amongst other “marginalized” communities, have been influenced by myths for many years. “Plato urged that ‘inferiors’ should refrain from mating ... and ... that the children of such ‘inferiors’ and even of ‘superiors’ if they were deformed be ‘put away’” (Sobsey, Donnellan, & Wolbring, 1994, p 121). These sorts of belief systems have led to permanent institutionalization, sterilization and the eugenics of people who are considered “different”. For example, the Sexual Sterilization Act was introduced in 1928 (Gavel, 1999) and resulted in the 1996 precedence case where Leilani Muir was awarded \$750,000 in damages for the fact that she had been sterilized at age 14. Although this example depicts a victory, it also demonstrates how societal belief transcends historical times and remains ingrained in our culture today.

From 1960 to 1980, the Independent Living Movement, a grass-roots disability group starting in Berkley, California, became an alternative to living without choice and independence. Using this now international model, people with disabilities gained more control of service delivery and have greater involvement in their lives and the community.

The Independent Living philosophy is closely related to the “social model” of disability wherein “disability” is seen as existing outside of the body, contingent on context (health care, social treatment, poverty, gender, race and ethnicity, national priorities, immediate social context, family resources, and levels of experiencing discrimination *credo*) (Milberger, Israel, LeRoy, Martin, Potter, & Patchak-Schuster, 2003). In essence, this highlights the context of abuse where isolation and limited economic resources appear to place all individuals and women in particular, at increased risk for experience abuse. The context of disability and limited opportunity to find additional sources of social support may serve to prolong their experience of abuse.

The social model of disability suggests that “disability” is not located within a person but is dependent upon physical, social, economic, political, attitudinal and cultural barriers within society (Ballan, 2008). An individual’s knowledge about his or her world is built through interaction within his or her context/environment and social connection with others (De Koster, Devisé, Flament, & Loots, 2004).

The social model of disability emerged from social constructionism, in which the interaction between people and groups of people is considered central in constructing reality. The way that individuals with disabilities are socially defined is based largely on how they are publicly acknowledged. Language and other symbols are the means to communicate and define (De Koster, et al., 2004). When people with disabilities are defined as “retarded,” as only one example, they are deemed to be less valuable than others, and unworthy of appropriate treatment. As another example, it is frequently assumed that people with cognitive disabilities are asexual and so, they are seldom provided with education on sexuality. Such a lack of education does not allow opportunities to learn the different types of touch and individuals may be at greater risk of sexual abuse.

Social constructionists emphasize the importance of language, as all knowledge is the result of negotiation through interaction. Language or discourse constructs a social framework around which people define others. This suggests that “disability” exists only insofar as it is socially constructed and imposed. The social model declares disability to be a

complex collection of conditions, many of which are created by the social environment where other models consider it an attribute or problem occurring within an individual.

People's lives and relationships are shaped by the stories that they tell and engage in to give meaning to their experiences. We construct certain habits and relationships that make up ways of life by staying true to both internalized and socially imposed stories. Applying the social model in treatment for people with disabilities means defining psychological problems as part of "the disabling environment" not as individual impairments. Representatives from the Roehrer Institute of Canada in 1995 and Dick Sobsey (1994) of the University of Alberta Violence and Disability Project were some of the first researchers on disability and abuse that identified how external barriers negatively affected the safety of people with disabilities. Sobsey (1994) reported that approximately half of the perpetrators in this study made contact with the abuse survivor through services related to the survivor's disability. More recently, Powers, Curry, Oschwald, Maley, Saxton, and Eckels (2002) noted that, "assessing reliance on support services, poverty and isolation as critical for understanding people with disabilities' increased risk for abuse" (p. 4).

Few studies apply the social model to practice. Coles (2001) carried out a small-scale interpretive research study analyzing the effectiveness of the social model in terms of how it was demonstrated. Managers were asked to select individual employees and clients that evidenced 'good practice'. The workers were interviewed to evaluate their own professional roles, relationships with clients, and the attitudes and values that they adopted and brought to their work.

The results indicated the social model positively affected practice both directly and obliquely. For example, workers applying the social model assisted clients in advocating for themselves rather than taking over for the individual. Workers utilizing the model avoided categorizing clients as "impossible" and automatically assuming their "failure". Coles noted that many services adopt the medical model and use behavioral therapy to force change instead of providing clients with more opportunities to lead their own lives. This study represents an important springboard for further research using the social model in practice.

Child Abuse in Canada

The recently completed Canadian Incidence Study of Reported Child Abuse and Neglect (Trocmé & colleagues, 2005) documented an estimated 217,219 family maltreatment reports in the year 2003 were investigated because of alleged maltreatment. Of these, 47% were substantiated, 13% remained suspected and 40% were unsubstantiated... The study divided child maltreatment investigations into four primary categories: physical abuse (28% of all investigations), sexual abuse (3% of all investigations), neglect (30% of all investigations), and exposure to domestic violence (28%), which was previously subsumed under emotional maltreatment and emotional maltreatment (15% of all investigations). In substantiated cases of sexual abuse, 63% of the victims were girls and 54% were boys.

The Abuse of Children with Disabilities

A number of studies have demonstrated that children with disabilities are at an increased risk for maltreatment (Hershkowitz, Lamb, & Horowitz, 2007; Reiter, Bryen, & Shachar, 2007; Spencer, Devereux, Wallace, Sundrum, Shenoy, Bacchus, & Logan, 2005; Sullivan & Knutson, 2000a; 2000b). Embry and Grossman, (2006) investigated the risk for

maltreatment of children with disabilities examined a US nationally representative sample of substantiated child maltreatment cases. The authors reported that the incidence of maltreatment among children with disabilities was 1.7 times higher than the rate for children without disabilities. Sullivan and Knutson (2000a) estimated a 31% prevalence rate of maltreatment of disabled children compared to a 9% prevalence rate for non-disabled children. They also identified neglect as the most prevalent form of abuse.

Hershkowitz et al. (2007) reported that more children with disabilities than typically-developing children were allegedly victims of sexual rather than physical abuse. In addition, children with disabilities were more likely than typically-developing children to be abused by parent figures and to experience severe physical abuse resulting in injury or serious sexual offenses. Ammerman, Van Hasselt, and Hersen (1988) similarly reported that 35% of children with multiple disabilities admitted to a psychiatric hospital suffered from some form of maltreatment, the majority of which was physical abuse. In addition, the authors reported that children who were sexually abused were typically maltreated by more than one perpetrator. These findings, therefore, suggest a problem of considerable magnitude.

According to the Frazee and Seeley (2000), child abuse occurs when an adult (e.g., parent, family member, teacher, guardian, etc.) causes emotional, physical, psychological, or sexual harm to a child or places a child at risk for harm. The abuse of children, much like the abuse of women and other adults, involves the misuse of power (Ticoll, 1994). Because adults are more powerful than children, both physically and socially, they are able to help guide children in their development. However, this power can also be used in ways that are harmful and destructive to children, such as using harsh punishments, ignoring them, neglecting them, and abusing them physically or sexually (Frazee, & Seeley, 2000).

The usual risk factors for child abuse are intensified for children with disabilities. These children are vulnerable for a number of reasons: (1) the inability to complete tasks such as bathing, dressing, communicating, and toileting independently puts children with disabilities at risk for rough, careless, or intrusive personal care or neglect of their needs; (2) they are more vulnerable to low self-esteem; (3) they may be unable to participate in activities without the assistance of others, thus making them socially isolated; (4) children with disabilities may require help from non-family individuals; (5) parenting stress; (6) children with disabilities are often depersonalized because they are viewed only in terms of their disability; (7) they are often taught to be compliant with adults and may be unable to distinguish between legitimate and abusive demands from adults; (8) there are myths surrounding the sexuality of disabled children, which increase their risk; and (9) their opportunities to set their own personal boundaries are reduced (Ticoll, 1994). In addition, gender appears to be an important risk factor in child sexual abuse. Sobsey, Randall, and Parrila (1997) found that more disabled boys with disabilities were abused than girls with disabilities.

Benedict, White, Wulff, and Hall (1990) investigated whether factors such as functional, developmental, and perinatal influences could differentiate between children with disabilities that were reported and substantiated as maltreated as compared to children who were not reported as maltreated. The results indicated that there was no increased reporting for children in this population, and consistent with previous literature, demographic characteristics are associated with reports of maltreatment (e.g., having unmarried parents, parents with fewer years of formal education, and parents who are not regularly employed).

Interestingly, this study did not find that children with severe intellectual and developmental impairments were at a higher risk of reported maltreatment. Rather, children with marginal functioning were at a greater risk of reporting. The authors suggest that this may be the result of parents being subjected to considerable more frustration than the parents of children who are severely intellectually and developmentally disabled due to the unclear outcome of their child's functioning.

Reiter, et al. (2007) investigated the frequency and types of abuse of students with intellectual disabilities in a high school in Israel in comparison to the types and frequency of abuse experienced by a group of non-disabled students. A higher percentage of adolescents with disabilities were victims of abuse than non-disabled adolescents, with the majority of events taking place in social environments. Girls were more frequently abused in this population. The perpetrators were most often neighbours, school bus drivers, friends, or family members. Furthermore, sexual abuse was experienced more often than by disabled students than non-disabled students.

The clinical effects of abuse on children with disabilities appear to be more profound than for children without disabilities. For example, Reinke (2005) found that children with disabilities were identified for all the same clinical findings as non-disabled children, with behaviour problems being the most common for both groups. However, children with disabilities were significantly more likely to have at least one clinical finding. In addition, the differences between the proportion of children with or without disabilities increased with age.

Why are Children with Disabilities Vulnerable to Abuse?

Children with disabilities are hypothesized to be at risk for abuse and neglect by parents/caregivers because of factors such as increased care-taking demands, early separation, disrupted attachment, and disappointment. Parenting stress has been linked consistently with abusive parenting behaviours in a number of populations and high parenting stress appears to be especially prevalent in parents of children with disabilities (Rodriguez & Murphy, 1997).

In addition, Rodriguez and Murphy (1997) suggest that the degree of disability may influence the response of parents (and that additional challenges resulting from a child having a disability can create high levels of frustration and stress (Aniol, Mullins, Page, Boyd, & Chaney, 2004). For example, Cameron, Dobson, and Day (1991) found that specific characteristics of children with disabilities such as adaptability, distractibility, and demandingness appeared to increase the stress of mothers. In addition, both mothers and fathers reported similar levels of stress.

Further, Aniol et al. (2004) found a strong relationship between parenting stress, abuse potential and family relationships, thus suggesting that the possibility of maltreatment of children with disabilities is increased when families consist of poor relationships and parents are highly stressed. However, the study results indicated that respite care did not significantly reduce abuse potential among parents, nor did it improve the relationship among family members. The authors concluded that programs that target parenting stress and family functioning over time may be more likely to reduce the potential for abuse.

In contrast to these studies, Rodriguez and Murphy (1997) found that low-income African American mothers of children with disabilities suffered from high parenting stress

and displayed considerable physical abuse potential. In addition, parenting stress was strongly related to abuse potential. However, the results indicated that parenting stress and abuse potential were not significantly correlated with a child's adaptive or intellectual functioning. Therefore, it appears that cultural factors are important considerations. More research must be conducted in order to determine if parenting stress is a significant risk factor for the abuse of children with disabilities cross culturally.

Research on Children with Specific Vulnerability “Types”

Although the previous commentary recommended not stereotyping individuals with disabilities based on the nature of the disability, the research literature has tended to narrowly focus on abused specific to the various “types.” As such, the following sections report on research using this framework.

Vulnerability: Children with Communication Disabilities

Embry and Grossman's 2006 hospital based study concluded that children with communication disorders – including deaf and hard of hearing children – were twice as likely to be maltreated when compared to children without disabilities. In addition, deaf and hard of hearing children had twice the risk for neglect and emotional abuse, and almost four times the risk for physical abuse than their non-disabled counterparts (Kendall-Tackett, Lyon, Taliaferro & Little, 2005). These authors also reported that children with speech and language difficulties had five times the risk for neglect and physical abuse, and three times the risk for sexual abuse (Kendall-Tackett et al., 2005).

Sullivan, Vernon and Scanian (1987) summarized four research articles about deaf people and concluded that deaf children were more likely to be sexually abused than hearing children. There could be several reasons for this increased vulnerability to abuse. Most of the times the child frequently has limited abilities to communicate information about the abusive incident, and also the child's complaint may not be believed due to their inability to communicate effectively about the maltreatment (Mitchell, Turbiville, & Turnbull, 1999). Based on their inability and inadequacy to verbally describe incidents and offenders, maltreatment of this population is under-reported and it is difficult to arrest and prosecute the offenders (Tang & Lee, 1999). Without social and legal repercussions, the offenders are likely to repeat their offences with the same or similar target victims over protracted periods of time (Sobsey, 1994).

Vulnerability: Developmental Disabilities

The Administration on Developmental Disabilities has defined a developmental disability as a physical or mental impairment that begins before 22 years of age that alters or substantially inhibits a person's capacity to do at least three of the following: (a) take care of themselves; (b) speak and understand clearly; (c) learn; (d) walk/move around; (e) make decisions; (f) live independently; (g) earn and manage an income (Shannon & Agorastou, 2006).

Children who are developmentally delayed have four times the risk for physical abuse, neglect, sexual abuse and emotional abuse (Kendall-Tackett et al., 2005). There are many possible reasons why children with developmental disabilities experience higher rates of maltreatment. Sobsey (1994) speculated that American society devalues people with disabilities, and suggested that children with disabilities are dehumanized and treated as

property by their caretakers. Families sometimes view a child with developmental disability as a threat because the needs of the child disrupt family routines and family relationships (Shannon & Agorastou, 2006).

Also, parents may be forced to quit their jobs in order to look after the disabled child, which can affect the family income. Child factors such as impaired communication, poor self-defence abilities, and the potential for exhibiting problem behaviours have also been suggested as reasons for the higher rates of maltreatment of children with developmental disabilities (Sobsey, 1994). Family stress and the ability of the family to cope with stress may be associated with maltreatment of children with disabilities (Shannon & Agorastou, 2006).

Vulnerability: Children with Intellectual Impairments

Children with intellectual disabilities are more likely than typically developing children to be maltreated or victimized by crime (Sullivan & Knutson, 2000a). Bruhn (2003) found that children with less obvious disabilities such as learning disabilities are more likely to be mistreated and this being because the parents have higher expectations of children with less apparent disabilities, and when those expectations cannot be met, the resultant disharmony creates elevated stress. Additionally, the apparent “childishness” of many learning-disabled children may attract potential abusers (Westcott, 1991). Westcott argues that learning-disabled children’s problems in reasoning, lack of impulse, control and inability to predict the consequences of their actions also heighten vulnerability to maltreatment.

People with intellectual disability generally have substantially restricted access to appropriate sexual information (McCabe, Cummins, & Reid, 1994) and there is reference in the literature to the increased risks of sexual abuse experienced by this group of people. Most of the times there is frequently little knowledge of an individual’s sexual rights or of how to behave in a situation which involves decision making on whether to engage in sexual behaviour (McCabe et al., 1994). In such an environment, an individual is poorly prepared to resist sexual exploitation. McCabe et al. found that 36% of the people with intellectual disability believed that someone other than themselves made the decision on what sexual experiences they would have.

Given that a large proportion of the sexual abuse is by relatives and friends, and many intellectually disabled people are unsure how to handle sexually exploitative situations, they may be placed in the situation of relying on someone who assists them in their needs, but who also abuses them (McCabe et al., 1994). Another very disturbing finding from the study was that a significant proportion felt neutral or good about incest, unwanted sexual contact, rape and sexual abuse. The researchers felt that these feelings may stem from the fact that they are made to feel special and valued within these abusive relationships.

Vulnerability: Physically Impaired Children

Children who are physically impaired are vulnerable to maltreatment mainly because the child frequently has limited abilities to communicate information about abusive events and also professionals may have difficulties distinguishing behaviours or injuries that are a result of abuse and neglect from those that may be a manifestation of the physical disability itself (Mitchell et al., 1999). The stress of caring for children with extensive needs such as

proper medication, regular monitoring may also contribute to child maltreatment (Cowen & Reed, 2002).

A physical disability that causes difficulty in ambulation can place a child at risk for accidental falls. Therefore, close supervision responsibilities are required. Lack of respite or breaks in child care responsibilities can contribute to an increased risk of abuse and neglect (American Academy of Pediatrics, 2001). Physically impaired children are at an increased risk for sexual abuse because of their increased dependency on caregivers for their physical needs and they may be accustomed to having their bodies touched by adults on a regular basis (AAP, 2001).

Vulnerability: Children with Behavioural Problems

Children with behaviour disorders have a seven times higher risk for neglect, physical abuse and emotional abuse, and 5.5 times higher risk for sexual abuse than are children without disabilities (Kendall Tackett et al., 2005). It has been suggested that children with substantially deviant behavioural or temperamental characteristics might place extreme stress on otherwise competent parents who may engage in maltreating behaviour (Cowen & Reed, 2002). Dubowitz and Black (1994) contend that the “goodness of fit” between child and parent characteristics influences the child’s vulnerability to maltreatment. Cowen and Reed (2002) postulated that the child becomes the victim of maltreatment, not because of their own behaviour, but because their needs place added burdens upon their already stressed or incapable family system resulting in breakdown in the processes of good parenting.

Vulnerability: Children with Chronic Health Problems

Excessive care giving demands, lack of child responsiveness and unusual behaviour patterns have been closely associated with both increased stress levels and depression in parents of chronically disabled children (Seideman & Kleine, 1995). Family members who are tired, depressed, or in need of health care may turn to abusing the disabled child in order to relieve their frustration. Higher levels of parenting stress have consistently been associated with increased child abuse potential in mothers of children with chronic illnesses (Aniol, Mullins, Page, Boyd, & Chaney, 2004).

Best Practices in Addressing the Abuse of Children with Disabilities

There is a dearth of research on how to respond to the needs of children with disabilities who have been maltreated and the best practices required to serve them. According to Sobsey and Mansell (1990), information concerning the prevention and treatment of sexual abuse for disabled individuals, both children and adults, is scarce. However, a number of researchers provided recommendations on how to improve the current situation:

Orelove, Hollahan, and Myles (2000) found that parents, educators, and investigators did not have extensive knowledge in how to recognize and respond to maltreatment of children with disabilities. In addition, only a third of the educators and early interventionists, who are mandated reporters, indicated being very knowledgeable about the process to report child maltreatment to child protective services. However, the majority of respondents were receptive to becoming more effective partners by attending training that will close the gaps in the knowledge they possess.

Kendall-Tackett, et al. (2005) suggest that child welfare services need to include specialized assistance because a disproportionate number of abused children have disabilities. However, there is a critical shortage in knowledge and severe gaps in the provision of services to children with disabilities who have been maltreated. Therefore, according to Kendall-Tackett et al. (2005), it is increasingly important for disability status to be included in needs assessments and evaluation studies of maltreatment interventions.

According to Kapitanoff, Lutzker, and Bigelow (2000) it is important for services to have culturally sensitive programming for disabled children who have been maltreated and their parents. Service providers need to recognize that cultural factors such as the importance of the child to the society; cultural meanings of disability; and cultural views of the causes of illness and disability may affect the probability of abuse in many ways.

Sobsey and Mansell (1990) proposed that sex education programs for disabled individuals that are tailored to age, environment, and communication skills are important for risk reduction. In addition, assertiveness training, choice-making, and personal rights education are essential. It is also imperative that staff providing services be trained in the recognition of and response to signs of abuse. Furthermore, there should be staff screening, and service providers need to accept greater responsibility for their clients.

For those that are institutionalized, reduced isolation is important. Sobsey and Mansell (1990) also state that treatment for offenders is also important for the reduction of future offenses. Provisions that require that all reports of maltreatment go to authorities that are independent of the service delivery system that is involved are essential. Finally, treatment programs for children with disabilities who have been abused need to be more accessible (e.g., physical accessibility, alternative telephone devices, availability of translating services, non-print alternatives for reading materials).

Mitchell and Buchele-Ash (2000) propose that more uniform forms of reporting by those within the fields of mental health, social services, medicine, law, and education will result in more accurate data, which will in turn lead to more valid and reliable research from which new knowledge and policy reform can be based. "Connecting systems through prevention measures, the elimination of current policies that condone maltreatment, the provision of appropriate self-protection education, mandated training for reporters, legal reforms, and the enactment of uniform policies and reporting forms are promising prospects for preventing, or at least reducing, the maltreatment..." of individuals with disabilities.

Children with disabilities who have been abused have difficulty obtaining treatment services that are accessible and adapted to their needs (Mansell, Sobsey, Wilgosh, Zawallich, 1997). Treatments offered have been limited, inappropriate or unavailable. Mansell et al. stated that the components of therapy should include considerations of the specific social circumstances, heightened vulnerability to sexual abuse that children with developmental disabilities experience, and their cognitive and social limitations. Also, therapists need to work with the client's network of caregivers in order to obtain sources of information that may not be directly provided by the victim.

Vig and Kaminer (2002) recommended that professionals recognize subtle forms of maltreatment; clinicians, educators, day care providers, and other professionals working with children should routinely screen for developmental problems because there is a high incidence of developmental disability in maltreated children; refer children for

comprehensive multidisciplinary evaluation to identify and differentiate maltreatment and developmental disabilities, and determine the best kind of intervention; identify caregiver competency; become familiar with intervention resources; and monitor children's progress once maltreatment and developmental disability have been identified and intervention services have begun.

Aniol, Mullins, Page, Boyd, and Chaney (2004) concluded that programs that target parenting stress and family functioning over time may be more likely to reduce the potential for abuse.

Chapter Two: The Abuse of Adults with Disabilities

This chapter presents statistics with respect to the abuse of adults with disabilities and programs and strategies to more effectively address these. The following literature review regards the impact of these conditions on adults with disabilities and the resultant abuse. A great portion of the literature focuses on women with disabilities and/or specific disability types when adults in general are considered. Examining specific disability types is not the focus of this review except when researchers have used “type” to outline how characteristics of disability may directly relate to situations of abuse. Given these parameters, the following review examines the literature concerning domestic violence in general and people with disabilities (women more specifically), from a cross-disability perspective.

Abuse in Intimate Partner Relationships

The abuse of intimate partners, primarily women abused by men, is a serious problem in Canada (Tutty & Rothery, 2002). The prevalence of domestic violence varies according to different studies. The 2004 General Social Survey on Victimization (Statistics Canada, 2005) estimated that 7% of Canadian women and 6% of men are the victims of an act of violence from an intimate partner over a five year period.

While the self-reported rates of abuse appear to be equal, abuse against women by male partners occurs more often and tends to result in more serious consequences such as fear of death. In this national study, 44% of women reported being injured, compared to 19% of men: 13% versus 2% sought medical help. Women were almost twice as likely as men to report having been beaten (27 versus 15%), and three times more likely to report having been choked (25 versus 8%). Perhaps most informative is that women fear their partners’ violence to a significantly greater extent: 34% of women compared to 10% of men admitting being afraid for their lives (Statistics Canada, 2005). Nevertheless, although men are the primary perpetrators of serious violence against women partners (Johnson, 2006), women can both physically and emotionally abuse male partners and about 10% of arrests for spousal assault are against women as the sole perpetrator.

In comparison, the previously mentioned 1993 Violence Against Women Survey that focused solely on women, estimated that “three-in-ten women currently or previously married in Canada have experienced at least one incident of physical or sexual violence at the hands of a marital partner” (Rodgers, 1994, p. 1). Such differences in estimates of abuse occur because of the manner that violence is defined, for example, whether it includes forms of abuse other than physical, such as sexual assault or financial abuse. Nevertheless, the conclusion that from 7 to 30 percent of Canadian women have experienced violence from intimate partners is concerning.

Abused women face a number of serious and trauma-inducing stresses while living with or after leaving an assaultive partner (Tutty, 1998), which have been associated with symptoms in both their physical and psychological health (Follingstad, Brennan, Hause, Polek, & Rutledge, 1991). These stressors include significant physical assault, marital rape, murder, being stalked, and threats of kidnapping or taking legal custody of children. Given the severe and chronic stress endured by abused women, it should not be surprising that many experience symptoms such as depression, anxiety, sleep disorders and suicidal thoughts (Tutty, 1998). These common symptoms are consistent with a trauma response, similar to victims of child abuse and sexual assault.

Women who are abused physically by male intimate partners are often sexually assaulted by them as well, a little acknowledged dynamic (Mahoney & Williams, 1998). In a study of intimate partner violence in two Calgary shelters, approximately half of the residents reported marital rape in addition to their physical and psychological abuse (Tutty & Rothery, 2002). A 1995 Alberta study of high school students (Bagley, Bolitho & Bertrand) found that students with a higher number of unwanted sexual contacts in the previous six months suffered greater negative effects, including conduct disorders, somatic complaints, emotional distress and suicidal ideation.

Adult Sexual Assault

The most recent survey regarding adult women's experience with sexual assault was conducted by the Canadian Panel on Violence Against Women in 1993. This Violence Against Women survey measured the incidence of sexual assault as defined by the Criminal Code of Canada: "an assault committed for a sexual purpose or an assault of a sexual nature that violates the sexual integrity of the victim". There are three levels of charges, based on the degree of force used and the severity of the offence. Included in the charges are: sexual assault; sexual assault with a weapon, threats to a third party or causing bodily harm; and aggravated sexual assault.

The 1993 Violence Against Women study estimated that 39% of adult Canadian women have experienced at least one incident of sexual assault since the age of sixteen. Alberta had the second highest rate of violence against women in Canada with 58% of adult Albertan women having experienced at least one incident of physical or sexual violence since the age of sixteen. The report estimated that only 6% of female sexual assault/abuse survivors report to the police.

Although the report is fifteen years old, this research remains the latest and only national study that examines the life-time prevalence of a broad range of forms of violence against Canadian women. Also the dynamics and the impact of violence and abuse do not change dramatically over such relatively short time periods. The immediate and long-term effects of sexual assault include rape trauma, depression, anxiety and suicidal thoughts and attempts (Tomlinson, 2000).

The Abuse of Women with Disabilities

Adults and children who are disabled are vulnerable to a number of forms of family violence in equal, if not increased rates, to that of the majority population. According to Ridington's 1989 position paper for the Disabled Women's Network, an estimated 42% of women with disabilities have been or are in abusive intimate partner relationships. Women with disabilities face the same system difficulties such as service fragmentation and being forced to reiterate their traumatic experiences as other assault victims. In addition, they must deal with the existing myths and stereotypes about their disabilities, and barriers such as communication problems, physical access, and intellectual gaps such as access to information when attempting to disclose their abusive/neglectful situations.

According to the Canadian national Participation and Activity Limitation Survey (Government of Canada, 2002), "one out of every seven Canadians aged 15 and over has some level of disability – an estimated 3.4 million people, or 12.4 percent of the Canadian population. In exploring the literature on the extent of violence against women with

disabilities, the most striking feature is the dearth of research on this issue. “Research into the incidence of violence is extremely limited and fragmented; often it does not distinguish either the nature of the disability, gender differences and differences between children and adults. Research into the extent of violence is also limited by the lack of data collected on disability by law enforcement agencies and service providers” (Howe 2000).

Researchers highlight the pervasive nature of violence against women with disabilities. A convincing body of Canadian and international research mostly conducted in the middle of the 1990’s demonstrated that people with disabilities generally are 1.5 times as likely to deal with crime, violence and abuse as their able-bodied counterparts and are 1.5 to 2 times as likely to suffer from crime, violence and/or abuse as their able-bodied counterparts (Sobsey, 1994). The risk of being sexually abused in institutions is 2-4 times as high as the risk for being sexually abused in the community (Sobsey & Mansell, 1992). Despite this increased level of vulnerability, the number of domestic violence related complaints involving persons with disabilities remains very low.

Violence against women with disabilities has been identified as not only more extensive than amongst the general population but also more diverse in nature than for women in general. Womendez and Schneiderman (1991) identify the nature of domestic violence against women with disabilities which may include abuse common to all women such as incest, rape and assault and in addition be particular to a woman’s disability including such as withholding of medication, removing a wheelchair, a ramp or a white cane. Despite the significant number of persons with disabilities and their increased vulnerability, many crisis services still do not report a high percentage of service usage by clients with disabilities.

Adults with Disabilities who are Abused

Adults with disabilities are particularly susceptible to abuse and violence. Jacobson (1989), for example reported that 68% of psychiatric outpatients were victimized by physical or sexual assault, and Jacobson and Richardson (1987) found that 81% of psychiatric inpatients were victimized by physical or sexual assault. In a study conducted by Ulincy and White (1990), 40% of consumers of attendant care services reported theft by attendants and 10% reported being physically abused by an attendant. Sobsey (1994) estimated that those with disabilities are 1.5 times at greater risk for abuse than their non-disabled peers. These findings, therefore, suggest a problem that is of considerable magnitude (Ticoll, 1994).

According to Ticoll (1994), violence against disabled persons can be characterized as occurring due to an imbalance of power in the context of discrimination against people with disabilities, and includes both subtle and overt forms of abuse that are not necessarily considered criminal acts. In addition to being susceptible to the same forms of violence as the general population including physical, psychological and sexual abuse, people with disabilities may find themselves in circumstances that make them more vulnerable to certain types of abuse, such as neglect or withholding of the necessities of life (Ticoll, 1994). Furthermore, Ticoll purports that a number of cultural, social and psychological factors contribute to the environment in which abuse and violence against persons with disabilities occurs including the marginalization of persons with disabilities; myths and stereotypes surrounding disability; lack of support for care-givers; negative attitudes towards individuals

with disabilities; the nature of the disability; reliance on other people for care; and ineffective safeguards (Horne, Merz, & Merz, 2001; Ticoll, 1994).

Social, physical, financial, communicational, and disability-specific barriers are compounded by problematic societal attitudes that often leave people with disabilities powerless and at greater risk for abuse than people without disabilities (Farrar, 1997; Ticoll 1994; Sobsey, 1994). Abusive care practices are frequently not detected or reported as people with disabilities fear loss of daily assistance, accommodation, emotional relationship, and fear of having no place to go are at major risk of further abuse especially if they cannot report the crime due to speech and/or cognitive difficulties (McPherson, 1991; Ticoll, 1994), may assume that only very violent acts are important enough to be reported (Ticoll, 1994), fear isolation and disclosure might make the person more vulnerable (Ticoll, 1994), fear retaliation (punishment or withdrawal of services) (McPherson, 1991), risk poverty, be institutionalized, lose children, not be able to access services, find the lack of options so small that suicide might seem like the only choice.

Of particular concern is the seeming tolerance of abuse toward women with disabilities that is widespread in our communities. Almost all of the literature examining the issue identified the failure of those responsible for providing protection and care to notice violence, believe the victim, protect against future violence or take legal action against the perpetrator (Carlson, 1997, McCarthy, 1993; Waxman, 1991; Crossmaker, 1991; McPherson, 1991; Sobsey & Doe, 1991). Sobsey and Doe reported that even though in 95.6% of cases the perpetrator was identified, the perpetrator was charged in only 22.2% of these.

It is frequently more difficult for a woman with disabilities to leave an abusive situation because of her dependency on her partner/caregiver for physical care and yet if she manages to leave may not be able to locate housing or support services that are accessible and responsive to her needs (Womendez & Schniederma, 1991; McPherson, 1991; Gill 1996). Several barriers block access to services in the community that could help individuals with disabilities. According to Andrews and Veronen (cited in Nosek & Howland, 1993), crisis interventions that are typically conducted when domestic violence occurs are not necessarily effective for people with disabilities.

As a result of the attitudes and perceptions of society, individuals who have disabilities are at an increased “risk of initial and ongoing physical and emotional abuse, which may result in trauma” (Horne, et al., 2001, p. 46). In addition to experiencing a range of sequelae, including compromised psychological health, physical trauma, and death that is common among those who have been maltreated in the general population, persons with disabilities who have been maltreated may develop secondary disabilities (Horner-Johnson & Drum, 2006); also known as double disabilities (Horne, et al., 2001), which result when an individual with disabilities suffers emotional or physical abuse over an extended period of time. Posttraumatic stress disorder or secondary mobility disabilities can be the result of such prolonged abuse and violence.

Systemic Abuse

Systemic abuse originates in or through a system (a larger more complex entity) such as the environment. Although systemic abuse can affect all individuals, it negatively and seriously affects vulnerable populations such as people with disabilities. A great deal of abuse and violence experienced by people with disabilities is systemic in nature.

Dick Sobsey (2000; 2002) is one of the first researchers to study the abuse and violence of people with disabilities from a systemic perspective. He incorporates an ecological model recognizing environmental aspects of abuse in the lives of people with disabilities (Sobsey & Doe, 1991). Apart from his ability to analyze the holistic nature of abuse and violence in the lives of people with disabilities, he continues to help researchers and service providers look beyond internal factors to the multidimensional and dynamic nature of abuse in this population.

It is generally believed that care facilities are one setting in which residents are “protected.” Organizations are thought to practice normalization and individualization; however, services can fail to emulate these vital goals (Moore, 2001). In the study conducted by Cramer, Gilson and Depoy (2003), participants identified three kinds of abuse, one of which is systemic consisting of, unresponsive, discriminatory and punitive services and legislation. Services are considered powerful and able to correct negative situations; however, this is not always possible. For-profit and non-profit organizations especially face limited budgets restricting the ability to serve a population facing complex needs both (violence and disability specific). For example, many shelters remain in older structures not accessible to wheelchairs, canes, or crutches. Funding to provide accommodations such as sign language interpreters, TDDs or materials that are in Braille or on tape is rare (Smith, 2009).

Beck-Massey (1999) noted ways in which the “system” could become a further threat to women with disabilities who have already been abused by (natural or hired) caregivers, partners, or both. If already dealing with domestic violence, a woman with a disability is suddenly threatened with changes such as living in a care facility and having her children removed because she is seen as unable to care for them. Often her credibility is questioned and she faces disbelief from authorities. Although males with disabilities face many of the same systemic barriers, women with disabilities also confront specific barriers related to the roles of mother/caregiver.

Sequeira and Halstead, (2001) studied how people with disabilities in care (systemic settings) were responded to when demonstrating negative behaviours such as acting out or becoming agitated. The researchers discovered that restraint was used more frequently on women and emergency tranquilization was more often applied following actual or threatened violence in women than men. When interviewed, many of the women described pain and discomfort in relation to the restraints, seclusion and rapid tranquilization. In addition, the women demonstrated “mental distress” in the forms of anxiety, fear, upset, or sadness. Women distrusted the nursing staff, and perceived the interventions as forms of punishment and control. The clients also perceived some behaviour of the nursing staff, such as laughing during the administration of interventions, as indicators of the desire on the part of these workers to punish and control them.

Sequeira and Halstead (2001) concluded that behavioural interventions such as rapid tranquilization are forms of invisible “control” over clients’ behaviour, where seclusion was more visible internally; yet both are forms of systemic abuse. The clients’ description of the agency functioning indicated how a care facility can easily become abusive in nature. The researchers made suggestions to check-in with the clients regarding their interpretation and reactions to intervention procedures, especially when individuals are survivors of trauma or sexual abuse. They further recommended that the staff take the role of facilitators in helping

people with disabilities express their issues and ensure they are heard. Gilson, Cramer and DePoy (2001) also indicated that the women with disabilities in their study considered restraint and control as forms of abuse more so than women without disabilities did. When people with disabilities are further limited in their functionality through reprimands, a fine line exists between what is purposeful and necessary intervention, and what is abuse.

Many violence services strive to develop programs that can serve a variety of client needs; however, women with disabilities face many obstacles, which require distinct forms of assistance. Zweig, Schlichter and Burt (2002) assessed programs from a larger group (Burt et al., 2000) serving historically underserved populations. The focus for this study was 20 agencies dealing with domestic violence, sexual assault or combinations of these two crimes and serving women dealing with substance abuse issues, mental health problems, cognitive disabilities, incarceration, and/or involvement in prostitution. The article notes a focus on programs increasing access to services for women with “multiple barriers.”

As a screening process, the program staff was asked whether the above-noted groups of women were served and, if so, whether programs offered specific services or special/different services for the group and/or whether they were increasing access to services for the group. Only programs answering yes to one of the latter questions were included in the survey. This screening process made it abundantly clear that programs serving multi-barriered women are scarce. More than one out of every two programs identifying as serving women with multiple barriers did not meet the basic criteria. Some of the barriers identified by respondents most specific to women with disabilities were:

- lack of transportation
- employment
- housing
- education
- poverty (no income independent separate from the perpetrator)
- lack of services for victims of violence in communities
- little information to make services known

Between 5% and 10% of respondents reported seven of the above barriers, and 25% of respondents reported a lack of services in communities. Using the term “multi-barriered client” identifies the problems as being within the person. The assumption is that if an individual has a cognitive disability, then changes must be made to her. As the social and feminist models indicate, the barriers exist in the environment and clients often respond well to assistance with overcoming them. Although many victim service programs have clients with a variety of needs, very few strive to make programs specific to these needs. “Women are dually traumatized—once by their perpetrator and again by the services” (Zweig et al., 2002).

Violence/Abuse and Women with Disabilities (Gender and Disability Status)

The Disabled Women's Network of Canada (DAWN) (Ridington, 1989), one of the first women's groups to look into the issue of violence in the lives of women with disabilities, distributed an abuse survey, obtaining responses from a population of 245 women. Findings indicated that 40% had been raped, abused, or assaulted, and 64% had been verbally abused. Few respondents had access to services for victims of violence, and the women with multiple

disabilities indicated being victims to several forms of abuse. A report is presented on the following website which documents the all information covered and obtained by this survey.

Compared to men and boys with disabilities, women with disabilities tend to be more at risk of discrimination and abuse due to the impact of both gender and disability status (Fairchild, 2002). This sociological reaction to disability devalues women with disabilities leading to greater barriers and further intensification of their vulnerabilities (Curry, Hassouneh-Phillips, & Johnston-Silverberg, 2001).

Since women with disabilities deal with such a complex grouping of issues, a wider lens is required to assess and understand their situations. Feminist researchers insist that applying the social model alone to understand the issues of women with disabilities excludes the gender implications in these women's lives. According to Mays (2006), the dominant approaches (psychological and sociological) and the social model of disability all fail to adequately address the complexity of domestic violence and women with disabilities. “the disadvantage and discrimination experienced by disabled people generally is simply exacerbated for disabled women” (Lloyd 1992, p 209).

Women frequently confront barriers similar to people with disabilities such as poverty inflexibility of employment structures, lack of supports for personal care issues. College-educated women with disabilities are less successful in obtaining employment than college educated men with disabilities or college-educated women without disabilities (Asch & Fine, 1988). The addition of a feminist perspective addresses gaps in all areas of working with this population. Lloyd (1992) stresses how women with disabilities are greatly affected by issues of sexuality and sexual identity, and deal daily with stereotypical views of childbearing, rearing and motherhood. Society expects women with disabilities be dependent, non-assertive and to go along with the status quo.

Although some forms of violence experienced by women with disabilities are identical to that of women without disabilities, there are types unique to the former group. Violence may occur in private living quarters and is frequently related to meeting basic needs such as; personal care, accessing (equipment, medication, finances and transportation) (Powers, Curry, Oswald, Maley, Saxton, & Eckels, 2002). Many women with disabilities deal with more intimate and personal forms of abuse from a partner or family caregiver, and/or from paid informal caregivers and systemically from certified structures providing care.

Women with disabilities face some completely different and unrecognizable forms of abuse than do women without disabilities. Service providers may not identify the removal of a battery to a wheelchair or omitting parts of a personal care regime as abuse (Beck-Massey, 1999; Hassouneh-Phillips & McNeff, 2005). Care-related abuse forms involve lack of proper care or abusive forms of care. Disability-related abuse consists of negative reactions to the existence of disability such as kicking a wheelchair in operation by a person with a disability.

According to Cramer, et al. (2003), people with disabilities deal with very complex forms of abuse. Their qualitative study with four focus groups of professionals and survivors with and without disabilities used a person-in-environment perspective to examine the complicated dynamics in the lives of women with disabilities that leave them more at risk for abuse. The following four open-ended questions were asked (in both written and oral formats, making these more accessible): (a) what forms of abuse occur most often among

women with disabilities? (b) How can the woman with a disability(s) protect herself and her children? (c) What could people and agencies in the community do to address the issue of abuse among women with disabilities and make reporting easier? (d) To conduct further research on abused women with disabilities, what could researchers do to gain access to the women, and what questions should researchers ask?

The results of Cramer, et al. (2003) indicated the following types of abuse: “active forms” such as not giving medication, “hidden forms” such as “intrusion” and “blurring” of physical and emotional types of abuse. Other forms were “abuse through image,” using stereotypes and “contextual abuse” coming from the inaccessibility of legislative and social systems. Many women indicated service providers had not believed abuse disclosures and social service and legislative systems had been unresponsive, discriminatory and punitive. However, these results may have been confounded using both professionals and survivors in the analysis.

Gilson et al. (2001) also employed focus group methodology to examine the experiences of women with physical disabilities and women without disabilities with a history of or interest in abuse. The women with disabilities experienced very specific types of abuse such as assault (emotional and/or physical battering), neglect (passive but intended harm), control or restraint (deliberate limitation of physical functioning and contact with others). In terms of their responses to the abuse, women with disabilities often felt responsible, felt caught in the situation and either believed it would never change or felt that something could happen to end the abusive relationship. Gilson et al. found it especially striking how repetitive emotional abuse severely affected this already systemically devalued and marginalized population. The women with disabilities classified “abuse” as restraint and control more often than did the women without disabilities.

Victim and Perpetrator Characteristics

Some of the literature focuses on perpetrator characteristics to the exclusion of victim issues (Nosek et al., 2006). Although responding to and treating victims of abuse are important, professionals in the field need to also focus on where the responsibility for this violence lies (with the perpetrator).

Researchers have suggested focusing on types of disability would help define more clearly why this population is at greater risk. For example, in a review of the literature regarding abuse and WWD conducted in the 2000s, Glover-Graf and Reed (2006) suggest that the focus on various disabilities (cognitive, sensory, physical, psychological, and substance dependence) prevents specific protective responses to abuse such as, positive identification of the abuser, believability of the victim, increased dependence on violent partners, lack of self-defense, reduced judgment, communication difficulties, and limitations to available service depending on specific needs.

Most researchers in this review claimed to identify victim-related characteristics in a non-blaming way. For example, knowing why a woman with a cognitive disability may not understand distinctions between “good touch” and abuse without opportunities to learn about such differences. Often victim characteristics attributed to disability features are immediately considered reasons why the individual is at greater risk without considering other environmental and social factors.

Brownridge (2006) documented how important it is to see beyond “victim vulnerabilities” “in assessing relationship characteristics (dependence and duration), perpetrator characteristics (sexual “proprietaryness” *men needing to control their sexual property*, (p. 809) and victim-related characteristics (socioeconomic status and age) to establish which variables were most influential on abuse of women with disabilities. Perpetrator characteristics such as patriarchal dominance and sexually proprietary behaviours were more indicative of an elevated risk of abuse against women with disabilities than were victim characteristics such as socioeconomic status (unemployment rate) and age. Male partners of women with disabilities tended to be 2.5 times more likely to behave in patriarchal dominating ways, prevented their female partner from knowing about or having access to the family income, tended to be sexually possessive and demonstrated sexual jealousy as compared with male partners of women without disabilities.

Brownridge (2006) concluded that women with disabilities experienced 40% more possibilities of violence throughout the five years preceding the interview. These women were at risk for severe forms of violence. The perpetrators did not evidence tendencies toward the misuse of substances in this study whereas, in a study conducted by Milberger et al. (2003), 50% of the women reported that their partners were using drugs and/or alcohol at the time.

Like Brownridge, Curry et al. (2001) stress the importance of avoiding a “victim blaming” approach and emphasize how both social and environmental factors increase the possibility of abuse. While these researchers achieve this; others are not careful enough to distinguish between internal and external reasons. When researchers document individual characteristics alone there is a huge risk of labelling/diagnosing the person.

Society portrays women with physical disabilities as less or non-desirable in comparison to their able-bodied counterparts, especially when the former has greater physical and dependency needs. This negative social construction encourages poor treatment; lack of support, and ultimately feelings of low self-esteem especially in women with acquired disabilities. Hassouneh-Phillips and McNeff (2005) explored how low sexual and body esteem might be connected to intimate partner abuse in women with varying degrees of physical disabilities. Using an interview format, 37 women (34 heterosexual) with physical disabilities responded to 72 individual in-depth interviews regarding their life stories from early childhood and the meaning of experiences of abuse.

The following themes were identified: *societal devaluation*, *low sexual and body esteem* (low due to negative social construction), *preference for non-disabled men* (athletic), *desire to be partnered* (feared being alone), and *relationship decision-making* (lower standards in choice of partners). The results suggest that women with a greater degree of physical impairment frequently see themselves as sexually inadequate and unattractive. These women indicated strong needs to find and remain in abusive relationships over time. Even though these negative responses are documented in the article as originating through social constructions, little regarding the environment is examined. Questions regarding accessibility, communication strategies, and proper safety planning for women with disabilities were not even considered. Some of the solutions can be found in an accurate exploration of the “real” problem.

According to Sobsey (1994), the four types of individuals who most abuse people with disabilities are, (in order of frequency); paid staff or volunteers who provide services to a person with a disability, neighbours and people that the person with the disability knows and interacts with at times, natural family members, peers with disabilities (especially those in the same programs or living in the same accommodation).

Young, Nosek, Howland, Chanpong, & Rintala (1997) also reported a higher number of health care workers and attendants as perpetrators. In many places, those providing care allowed by law to help the disabled woman but not allowed to help with her children. Obtaining another caregiver is too great an expense for most women with disabilities. Women are often labelled as the caregivers in a home, especially if married to a man with a disability, as often it is her responsibility to provide all of the care. Beck-Massey noted that many women with disabilities end up divorced within five years if the disabling condition occurs during the marriage. Without caregivers to assist her, the woman relies on family, friends and even strangers to help out, putting all involved in dangerous circumstances, especially if domestic violence exists. Systems designed to register and monitor caregivers do not exist and formal training for these workers is lacking.

The National Institutes of Health (NIH) funded the Center for Research on Women with Disabilities (CROWD) in 1992 to study the broad range of sexuality issues facing women with physical disabilities. From this initial study, Nosek, Foley, Hughes, and Howland (2001) examined if and how vulnerability to abuse is directly related to women's physical disabilities. The results indicated that perpetrators often; emotionally abandoned the victim because she had a disability, frequently confined physically and restrained women, handled women with disabilities poorly when providing care, and expected sexual payback for help given. The women reported being segregated in disability-related settings, facing high staff turnover rates, experiencing frequent encroaching of medical boundaries and those having increased physical limitations reported more incidents indicating an increased risk of their safety.

Incidence/Prevalence of Abuse for People with Disabilities

Incidence and/or prevalence rates of violence/abuse in the lives of people with disabilities are rarely or inconsistently documented in the literature. Brownridge suggests it is difficult to obtain clear prevalence rates based on the poor knowledge base regarding this population. Nevertheless the following section is a review of more current literature on rates of abuse and women with disabilities.

Similar to the National Research Council (1996), Powers et al., (2002) found the rates of physical and sexual abuse to be approximately twice those typically found for women without a disability. Powers et al. (2002) found women with physical and with physical and cognitive disabilities combined experience abuse by any type of perpetrator two times as much as women without disabilities.

Similarly to women without disabilities, women with disabilities are most often abused by their male partners but for a longer duration (Milberger et al. 2003; Young et al. 1997). Hassouneh-Phillips (2005) found that women with disabilities who needed essential personal care from an intimate partner tended to stay in abusive relationships longer. Intimate partners often "buy in" to dependency myths believing power over a situation, in

this case, the disability, is necessary. This power and control need creates responses that are abusive but “sanctioned”.

In a national study of 439 women with physical disabilities and 421 women who did not have disabilities, Young et al. (1997) found a comparable rate of abuse in an exploration of whether women with physical disabilities; experience more emotional, physical and sexual abuse, have certain types of perpetrators following onset of disability, and in terms of repeated abuse, is the duration longer than women without disabilities. Following application of a questionnaire, results indicated the following (p.36); more husbands abused women (both with and without physical disabilities) emotionally (25.5% versus 26.1%) and physically (17.3% versus 18.5%) than other perpetrators.

Mothers and fathers were the next most common perpetrators of emotional and physical abuse for both groups of women, male strangers were the most often cited perpetrators of sexual abuse for both groups (10.5% for women with physical disabilities versus 11.6% for women without physical disabilities), women with physical disabilities were significantly more likely than women without physical disabilities to experience emotional abuse by attendants, women with physical disabilities experienced abuse (emotional, physical, or sexual abuse categories combined) for significantly longer periods of time than women without physical disabilities (7.4 years versus 5.6 years), and women with physical disabilities also experienced physical or sexual abuse for significantly longer durations than women without physical disabilities (3.9 years versus 2.5 years).

McFarlane, Hughes, Nosek, Groff, Swedlund, and Dolan Mullen (2001) created the four-item “Abuse Assessment Screen-Disability (AAS-D),” to assess a multi-ethnic sample of 511 women, aged 18 to 64 years. The assessment of abuse toward women with physical disabilities using a specific tool had not occurred prior to this study. The results indicated that 9.8% of the women (50 of 511) reported abuse. However, when using only questions 1 and 2, only 7.8% of the sample of women (40 of 511) reported abuse. Following the addition of two disability-related questions, an additional 2% of the population (10 women) reported abuse. An intimate partner was the primary perpetrator of physical or sexual abuse. Disability-related abuse was attributed almost equally to an intimate partner, a care provider, or a health professional.

Milberger, et al. (2003) assessed the prevalence of violence in a sample of women with physical disabilities, the risk factors for violence against women with physical disabilities and how women with physical disabilities escape abusive situations. This is one of the only studies that defined disability as the result of a functional impairment. The interview questions were based on a protocol developed by Nosek, et al. in 1995.

The results showed that 89% of the reported abuse had occurred in the past (consistent with the idea that women with disabilities have an elevated risk for being abused). Of the 85 women who reported abuse and completed the follow-up 87% physical, 66% sexual, 35% refused help, 19% prevented from using assistive device. Eighty-nine reported multiple incidents of abuse and for almost half of the sample there were multiple perpetrators. Thirty-three percent of the women with disabilities tried to obtain help and half noted having good experiences with service providers. Four main themes were identified; lack of knowledge about accessibility of the shelters (21%), fear of interference or threats from abuser (10%),

trying to cope with shame and guilt regarding the abusive situation (10%), and looking for help from friends or relatives to escape (10%).

Differences in incidence rates can be a result of decreased reporting. Through surveying a population of 425 adult female survivors, The Disabled Women's Network of Canada (Ridington, 1989) discovered that fewer than half reported their abuse for fear they would lose services they could not do without. Given this low reporting rate, women with disabilities may experience abuse of longer duration (Nosek, et al., 1995). (Milberger et al, 2003). The inability to reduce and/or document degree of risk is directly linked to difficulties in reporting such as lack of training on indicators of abuse, legal definitions, credibility issues, protocol implementation,

Disability as a Consequence of Abuse

Abused women are at risk for developing permanent disabilities because of battering. Women with disabilities are at a heightened risk for obtaining additional health problems through abuse, especially if the perpetrator is also the caregiver. If a bedsore is not cared for, it could lead to major lesions and infection of the skin and possibly to death if not responded to properly (Curry et al., 2001).

The common effects of abuse for women without disabilities are substance abuse, low self-esteem, and depression, however, women with disabilities may also demonstrate these issues because of issues related to the disability such as lack of access and social support, so these factors are not always directly connected to possible abuse. However, the combination of these severely affects women with disabilities making it imperative for service providers to assess and respond accurately.

Hassouneh-Phillips (2005) documented the affects of abuse on women with disabilities in her study. The women reported stress, depression, anxiety, and suicidal ideation, worsening bowel and bladder control, poor nutrition, skin breakdown, and impaired mobility secondary to physical injury. Reported social problems included distrust of others, social isolation, and homelessness. The health of women with disabilities is often worse than women without disabilities, thus injuries have a greater affect on their functioning and health as a whole.

Milberger et al. (2003) noted that women with disabilities who were also dealing with abuse were often isolated and trapped. The stigma and social isolation that women with disabilities face reduce emotional defences and lower self-esteem. Without supports, protection from all forms of abuse is reduced dramatically. Although hired support might be the cheapest source available, it is often not the safest. Interestingly, these researchers found a positive relationship between histories of abuse and being laid off or unemployed compared to women without disabilities. Women with disabilities were often financially dependent on husbands and those with abuse histories were more likely divorced and less likely to be single compared to women who had not been abused. Women with disabilities who had been abused were more likely to have more than one disability.

Barriers to Reporting Abuse for Adults with Disabilities

People with disabilities face overwhelming odds of abuse living within their environments. The existing pressure in their lives often relates directly to confronting barriers including social, physical, personal (care, self-esteem and attitude), communication,

financial, and societal forms. A greater number of barriers increase the risk of abuse. "...the greater vulnerability; the greater the abuse. Abuse leads to disability, or exacerbates existing disability in a literally vicious cycle" (Klein, 1992).

Several issues can intensify the risk of abuse including the degree of support and education base, gender type, dependency issues and indirectly disability type (Ticoll, 1994). Andrews and Veronen (1993, cited in Nosek & Howland, 1993) also considered issues such as lower risk of perpetrator discovery, lower believability, and mainstreaming without considering issues of self-protection. These concerns often relate more to problems (barriers) existing in the environment than only within individuals with disabilities. For example, the impact of "socializing" persons with developmental disabilities toward "compliance", frequently leads to their victimization.

Barriers in the lives of persons with disabilities can take many forms and are frequently connected. Individuals with disabilities are often in situations where attaining a "normal" social life is impossible. For example, living inside group homes with the same roommates and support staff each day can lead to various degrees of isolation. According to, Nosek, Hughes, Taylor, and Taylor (2006), age, education, mobility, *social isolation*, and depression were used to identify with 84% accuracy whether or not a woman with a disability may have experienced physical, sexual, or disability-related violence or abuse within one year.

An individual's financial barriers are usually determined by social, educational, and employment-related issues. People with disabilities cannot typically afford services including but not limited to personal care, technological, and housing. Without these options, choices become "friends", hired strangers, and unrestricted services further increasing isolation and vulnerability. Should abuse occur, victims with disabilities might be unable to obtain help due to financial barriers. For this population, educational issues are not always related to employability. Some individuals may avoid abuse from gaining active living skills, sexuality education, and knowledge about self-care/esteem and protection.

Systemic financial issues both directly and indirectly affect persons with disabilities. Many disability-oriented programs frequently lose funding following a "pilot" phase. Such repetitive losses to eager agencies have the effect of lowering the commitment/morale regarding this vital issue and population. In addition cuts to individual needs-based services leave people with disabilities desperate for support.

Services of all types (medical, recreational, social) need to be "accessible" for persons with disabilities. "Access" can be defined as "the ability, right, or permission to approach, enter, speak with, or use; admittance "http Access is mainly dependent upon the environment and can be accomplished by physical changes (wheelchair ramps and grab bars connected to bathroom walls), removing barriers to communication such as providing TTYs, brailled information and plain language materials. In this regard, professionals and workers from a host of venues need to be educated about variations of accessibility based on personal needs and disability type. Community disability services both online and in person can offer such information.

Reporting abuse and the possibility(s) that the abuse may cause disability or further disability in a person's life are two extremely critical factors to situations of abuse within the lives of persons with disabilities. Often victims with disabilities will not report abuse for at

least the following reasons, the act is not identified as abusive by the victim, fear of losing support or services, fear of not being believed, justice system's hesitant response, fear of further disability (Sobsey & Mansell, 1992). Probably the largest fear is that of acquiring a disability from the abuse itself. This could occur in cases of physical, sexual, and emotional abuse/violence, and perhaps others.

Social, physical, financial, communicational, and disability-specific barriers are compounded by problematic societal attitudes, which often leave people with disabilities powerless and at greater risk for abuse than people without disabilities (Farrar, 1997; Ticoll, 1994; Sobsey, 1994). Abusive care practices are frequently not detected or reported, as people with disabilities fear loss of daily assistance, accommodation, emotional relationship, and fear of having no place to go are at major risk of further abuse especially if they cannot report the crime due to speech and/or cognitive difficulties (McPherson, 1991; Roeher Institute, 1995), may assume that only very violent acts are important enough to be reported (Roeher Institute, 1995), fear isolation and disclosure might make the person more vulnerable (Roeher Institute, 1995), fear retaliation (punishment or withdrawal of services) (McPherson, 1991), risk poverty, be institutionalized, lose children, not be able to access services, find the lack of options so small that suicide might seem like the only choice (Ticoll, 1994).

Of particular concern is the seeming tolerance of abuse toward women with disabilities that is widespread in our communities. Almost all of the literature examining the issue identified the failure of those responsible for providing protection and care to notice the violence, believe the victim, protect against future violence or take legal action against the perpetrator (Carlson, 1997, McCarthy, 1993; Waxman, 1991; Crossmaker, 1991; McPherson, 1991; Sobsey & Doe, 1991). Sobsey and Doe found that, even though in 95.6% of cases the perpetrator was identified, the perpetrator was charged in only 22.2% of cases.

It is frequently more difficult for a woman with a disability to leave an abusive situation because of her dependency on her partner/caregiver for physical care and yet if she manages to leave may not be able to locate housing or support services that are accessible and responsive to her needs (Womendez & Schniederma, 1991; McPherson, 1991; Gill 1996). Several barriers block access to services in the community that could help individuals with disabilities. According to Andrews and Veronen (cited in Nosek & Howland, 1993), crisis interventions that are typically conducted when domestic violence occurs are not necessarily effective for people with disabilities.

Further research is required to understand both the incidence of abuse and the nature of abuse in relation to gender and particular disabilities. The literature also suggests a failure of service providers in both the disability field and in the family violence field to take into account the needs of women with disabilities experiencing violence.

Prevention and Early Intervention of Abuse

Sobsey and Doe (1991) insist that staff and people with disabilities be taught to recognize abuse indicators. Sometimes symptoms of abuse are erroneously considered as part of the individual's disability. Dialogue between staff and those in care would help to reduce this confusion. Although prevention can occur through strong reporting systems, it is frequently a difficult process for individuals who have been abused. This is especially true

with persons with disabilities who may be relying on the abuser for care and/or financial security. Abuse by service providers can be hidden when disguised as providing service.

Moore (2001) suggests that prevention might be better achieved by focusing more on changing the attitudes, beliefs, value systems and philosophies of staff and how these come to be, instead of solely emphasizing organizational structures and processes.

Glover-Graf and Reed (2002) suggest that prevention can occur when people with disabilities learn forms of self-defense, or seeming capable of doing so. For example, being able to say the word “NO” is okay in cases whereas compliance is not always the best choice. Some prevention techniques can focus on working with women with disabilities themselves helping to teach them processes such as the following (Curry, et al., 2001):

- have a back up personal assistant
- help with screen care providers
- choosing their own
- access to emergency response
- info to assist with managing this relationship
- self-protection/preventative measures

Services/Responses to Individuals with Disabilities

In terms of providing services to people with disabilities, disability often becomes a social construction within the counselling process and what is focused on is the disability as “the problem”, instead of the problem of violence in the lives of people with disabilities (Swain, Griffiths, C., & Heyman, 2003, Galambos 2004). The notion of accepting people with disabilities are rarely evident in services studied and the medical model is often used (Coles, 2001). The professional response to the problem of domestic violence in the lives of women with disabilities becomes more prescriptive, offering rehabilitation and counselling and not studying how factors such as systemic abuse and social constructions negatively affects this population (Galambos, 2004).

Sometimes personal problems and the disability itself become a political issue. Mitchell and Amy Buchele-Ash (2000) noted that one of the biggest problems in reducing abuse in the lives of women with disabilities relates directly to agency reporting issues including: lack of training in agencies to identify abuse, understanding reporting laws, fears of reporting doing more damage to the family, lack of confidence in the child protective system and client credibility issues.

Assessments or audits of organizations providing service to women with disabilities, are rare, however, Chang, Martin, Moracco, Dulli, Scandlin, Loucks-Sorrel, Turner, Staroneck, Neal Dorian, and Bou-Saada (2003) found that 99% of the programs in North Carolina provide service to at least one woman with disabilities (physical or mental) within a year, 85% offered shelter services to women with physical or mental disabilities and 94 to 99% reported that their programs were either somewhat able or very able to provide effective services and care to women with disabilities. Problems in services delivery occurred due to a lack of funding, lack of training, and structural limitations of service facilities.

The methods used by the programs to overcome these challenges were networking and coordinating care with organizations serving women with disabilities. Providing service to “at least one” woman with a disability within a year does not seem satisfactory, however,

this may point out the inaccessibility of the facilities themselves. Collaboration between both disability and crisis services could create a more universally accessible and knowledgeable service system.

Knowing the specific needs of women with disabilities, mainstream service providers can attempt to provide more effective services. Zweig et al. (2002) found agencies seeking possible collaboration with others providing alternate services in order to meet the needs of women victims of violence experiencing multiple barriers. Zweig, et al. assessed the extent to which programs for victims of domestic violence, sexual assault, and/or stalking in nonprofit victim service agencies are available for women with learning disabilities and mental health issues facing multiple barriers to service.

In this study, Zweig et al. administered a telephone survey to 20 agencies with respect to what special issues face women using the programs. The responses included transportation, employment, housing, education, and/or poverty or income only accessible through the abuser. A lack of services in communities and awareness on the part of women needing service was also noted. Agencies could also benefit from adding direct services such as advocacy and outreach; provide training to staff and encouragement or hiring individuals with experience in other fields.

One of the difficulties in identifying and responding to violence in the lives of women with disabilities has been too narrowly defining the context of its occurrence. In terms of disability issues, terms such as “domestic violence” have sometimes compartmentalized violence as an occurrence within a “conventional” home. For this population, “home” might represent a variety of living situations and different relationship types. Using of the terms “domestic violence” hides abuse in familial roles (Beck-Massey).

Fairchild (2002) insists that services need to advocate against the isolation and marginalization many people with disabilities experience. Barriers cause marginalization at all levels of an ecological system excluding full participation of women with disabilities. Professionals must become effective advocates to bring about legislation that is effective, funded and focused on the needs of people with disabilities as a whole.

Intervention for Individuals with Disabilities

Few screening mechanisms exist to categorize forms of abuse directly related to the life experiences of women with disabilities. Many of the forms of abuse experienced by women with disabilities are not typical to able-bodied individuals. Older tools were designed to screen for physical, sexual and emotional forms of abuse. For example, the Abuse Assessment Screen (AAS) identifies both physical and sexual abuse and defines them as actions such as hitting and forcing sexual interaction. This tool fails to address issues such as neglect, and/or actions rendering victims with disabilities helpless such as removal of a wheelchair, lack of accommodation such as accessible transportation services, provision of ASL interpreters and direct access to safe emergency attendant services.

McFarlane, et al., (2001) created an assessment tool from the (AAS), finding the addition of questions 3 and 4 of the AAS-D to be helpful. These items read; “within the last year, has anyone prevented you from using a wheelchair, cane, respirator, or other assistive devices” and, “within the last year, has anyone you depend on refused to help you with an important personal need, such as taking your medicine, getting to the bathroom, getting out of

bed, bathing, getting dressed, or getting food or drink?” Following the addition of the two noted questions above, an additional 2% (10 women) of the population (511 women) reported abuse.

Curry, Powers and Oschwald (2003) conducted a study to further develop an abuse-screening tool specific to women with disabilities. The researchers outline previous and affiliated qualitative and quantitative studies conducted to identify types of abuse that women with disabilities experience and identify as being most hurtful. Focus groups and individual interviews were used to gather such information. Similar to women without disabilities, participants identified physical, sexual, emotional, and financial abuse. However, the financial abuse was often long lasting and specific to the participants’ with disabilities.

The study participants noted other disability-specific types of abuse such as interference with medication, ruining equipment, and refusing to provide essential care services. Findings from the qualitative research just described were used to conduct a quantitative survey study aimed at determining women with disabilities’ experience of, and perception of the harmfulness of, various forms of abuse behavior. Responses were used to devise survey questions for the development of the survey tool. The tool underwent various field tests including exploration of the wording. The researchers found that creating, using and conducting associated screening procedures facilitated the identification of abuse and risk factors (high rates and diverse forms of abuse experienced by women with disabilities).

Nosek, et al. (2006) conducted a survey to identify other variables that could put women with disabilities at a greater risk for abuse. A survey questionnaire was administered orally assessing demographic information including age, race, education level, household and personal income, marital status. The study identified women with disabilities who were *younger, more educated, less mobile, more socially isolated*, and who had *higher levels of depression* as those being more likely to have been abused in the year preceding the study. The model implemented, correctly recognized 84% of the abused women with disabilities. The researchers plan to add this information to the previous AAS-D developed in 2001 by McFarlane et al. This combined information could offer professionals better methods for identification of abuse in the lives of women with disabilities.

Best Practice Ideas and Future Work

Only two recent articles regarding women with disabilities abuse recommend or discuss fundamental changes from the policy level. The only way that barriers can be eliminated is by changing policies stipulating these measures. Glover-Graf and Reed (2006) suggest that policies could work toward creating accessible services, treatment and safety plans (how to escape a violent situation despite having a disability) for women with disabilities. These authors also discuss the importance of greater and consistent funding to disability programs, to ensure both program development and accessibility are maintained and improved.

Policies condoning maltreatment should be eliminated. Actions such as institutionalization, sterilization, overmedication, excessive restraint, aversive interventions, and denial of health and other care can be considered systemically abusive. In a study of women with developmental disabilities, comments regarding the types of services noted above were, physical discomfort, reports of anxiety and mental distress described as, bad, sad

or upset feelings. Patients perceived nursing staff's actions as attempts to control (Sequeira & Halstead, 2001).

Generally, domestic violence has been covered well in the literature and throughout services, however, as already indicated, fewer studies exist with respect to women with disabilities and fewer still regarding men with disabilities (Cramer et al., 2003). Theory is not informing education and practice with this neglected population of both genders. However, this review has discussed how a large number of women (both with and without disabilities) are subjected to abuse, and that many women become disabled because of abuse.

Education is imperative for students and professionals need to understand these issues. Entire courses, not just individual classes, need to become a mandatory process (Powers et al., 2002). Many educational systems and professional associations need to provide a comprehensive unit on disabilities. Teaching material must become less diagnostic in nature (Ballan, 2008). Moore (2001) suggests that professionals should be involved in what she terms, "Disability Equality Training", designed to consider society as the creation of problems in the lives of people with disabilities instead of labelling the person/disability this way. Glover-Graf and Reed note the importance of incorporating training related to violence against women with disabilities into the rehabilitation education curriculum.

More funding is imperative. Often lack of access is explained by "lack of funds" as the Canadian government insists little money exists for "social" programs. Most disabled programs in Canada have no core funding and Barile (2002) suggests women's organizations cannot accept this reality. This ends up leading back to institutional "system-based abuse" caused by inaction.

Research Limitations/Issues

Although research regarding violence/abuse of people with disabilities is sparse, the existing literature spans approximately three decades. Studies during (1980s to mid 1990s) focused on "**at risk**" groups including the elderly and those with cognitive disabilities (Calderbank, 2000; Curry, et al. 2001). Initially, persons with developmental disabilities and children were the most studied subgroups (Curry et al., 2001). This is largely because people from this disability grouping were often institutionalized and more easily accessible to researchers. Sobsey's research focus is on children and adults with developmental disabilities and specifically sexual abuse in these populations.

Prior to 2001, only three studies focused on physical disabilities (Curry et al., 2001). Now, a large percentage of the 20th Century research focuses on women with physical disabilities. Earlier literature has not considered a variety of disability types (cross-disability perspective). According to Calderbank, the only major piece of literature directly focusing on all disability types was from the Roehar Institute of Canada in 1995 and Rioux et al. (1997, cited in Calderbank, 2000).

A review by Curry et al. (2001) found that "there is practically no literature regarding the risk of abuse, women's experiences of abuse, and barriers to seeking help among women with disabilities" (p. 60), and that "the absence of attention to this issue from both disability and violence researchers has contributed to the 'invisibility' of the victimization of women with disabilities" (p. 68).

However, research is now starting to focus on the need for **theory** to define the issue of abuse and women with disabilities. Building from previous research and development of a new study, Hassouneh-Phillips (2005) developed the “Abuse Pathways Model” outlining what women with disabilities may experience from social implications leading to abuse, accessing intervention, and possibly exiting the abusive relationship. This model takes into consideration the implications of both disability and gender related factors. Interactive components of the phenomenon social context of the disability, women’s abuse trajectories and vulnerability factors for abuse. Research should locate problems regarding people with disabilities in the broader cultural and social contexts in which they occur and attend to the ways in which race, class, tender disability and the other social constructions shape experience (Hassouneh-Phillips, 2005).

Some writers have used the previous literature to analyse specific issues. For example, Calderbank’s goal was to establish whether the forms of abuse experienced by people with disabilities result from something intrinsic to self or because of imposed social standards and beliefs. She used a case study approach, but suggests that these represent common features of abusive situations not specific individuals. The case studies show that disabled people are vulnerable to disproportionate and complex levels of abuse, and that this abuse is fostered by assumptions prevalent in social attitudes. Consequently, the policies developed by society show contentment within welfare services and ignorance or denial by society at large, to the abuse experienced by disabled people.

Empirically sound studies regarding people with disabilities are few, however Nosek et al. (2006) are one of the first to use a more rigorous design implementing several measures specific to disability issues and disability and violence. Unfortunately the study failed to document its results in a comprehensible format. Perhaps the complexity of this study in and of itself highlights the numerous obstacles victims with disabilities face. The results indicated that younger, more educated, less mobile women with disabilities who experienced greater social isolation and had higher levels of depression were more likely to have experienced abuse during the year prior to the study. The model correctly identified 84% of the abused women with disabilities.

Some researchers examining the issue of women with disabilities and violence (Gilson et al. 2001, Cramer et al., 2003, Curry et al., 2003) used feminist methodology such as focus group interviews that encouraged the women participants to discuss and interpret their experiences in their own words. These authors stressed the importance of creating opportunities for women with disabilities to tell their stories, an account separate from empirical theory developed from studies of their non-disabled counterparts.

Earlier studies have been plagued by errors such as researchers failing to operationalize variables, using inaccurate measuring devices and ignoring variables impacting results such as cultural issues (Hassouneh-Phillips & Curry, 2002). Using convenience sampling versus random sampling has compromised applying data to external situations.

Studies likely underestimate the rate of partner abuse experienced by women with disabilities considering in many cases, partners were measured as the most frequently perpetrator. This could have to do with the way data is collected such as the survey method where women’s cognitive functioning prohibited them from understanding the survey. Often

studies used self-report data, with no standardized instrument for reporting abuse and no external validation of abuse such as police, medical, or social service reports. Thus the prevalence of abuse may be either underreported or over reported. Even different definitions of abuse and disability are used.

Brownridge stresses that some victim “characteristics” are difficult to change as these are often imposed systemically with failures to change several different policies. This is an example of a non-victim blaming stance as the focus for the “problem” is not individual attributes. He suggests it would be most important for research to focus on how such characteristics could direct prevention efforts toward formative changes in health and social policy.

Some of research conducted by women with disabilities themselves follows a social structural analysis of disability, which begins with evaluating the individual using “pathologizing constructions” (Lloyd, 1992). Research should empower women with disabilities to live healthier and safer lives, for example, more qualitative research examining the ways women with disabilities succeed in preventing or diminishing abuse in their lives (Curry et al., 2001). Research needs to be connected well to women’s experiences and the results must be given to women with disabilities in ways that will be helpful. The victimization of women with disabilities remains invisible as long as both violence and disability researchers fail to further investigate this problem. The limitations in research to date must be identified and new methods developed. In attempting to generate knowledge useful for education, assessment procedures and effective service development/ treatment provision regarding women with disabilities.

One of the greatest challenges for future work in the area of abuse and women with disabilities is researching and responding to the impact of factors such as neglect and limitation. Intentional or unintentional neglect are often omitted as abusive acts since both fail to fit under the mainstream definition of abuse/violence. Neglect is often overlooked as accidental or explained away as occurring because of caregiver stress or lack of finances.

Gilson et al. (2001) noted from their study that “limitation” in a person’s life can affect an individual turning very ordinary situations into damaging ones. For example, women with disabilities can become caught in cycles such as isolation and poverty making them more susceptible to abuse and more abuse as these develop and redevelop. It is imperative that professionals identify the variables that affect women with disabilities within the context within which they live. Personal characteristics do play a role such if a woman who has had a disability her entire life is more confident in dealing with abuse than a woman who suddenly faces changes of a disabling condition.

However, understanding this social problem must come from a holistic perspective. Milberger and colleagues (2003) write about the, “need for holistic perspectives including how the systemic and cumulative effects of culture and social implications such as race, class, gender, disability, and other social constructions shape experiences in these women’s lives.”

The literature covered thus far has explored violence in the lives of women with disabilities and to provide recommendations to deal effectively with this insidious social problem. More research and response from perspective of the social model and feminist approaches must occur for the purposes of knowledge raising and providing effective professional responses to women with disabilities. The issue of neglect and limitation in the

lives of vulnerable people must be examined more specifically. A conceptualization from Cramer et al. (2003) captures well the issue of abuse and women with disabilities, “<a>buse as a continuing social/cultural paradox between social sanctions of care giving based on functional incapacity and social devaluation of women with disabilities. Care is bestowed on socially and culturally devalued women with disabling conditions.”

Chapter Three: Disabilities and the Abuse of Older Persons

The abuse of older persons and the abuse of individuals with disabilities are issues of growing concern among those that work in the domestic violence field. Both populations are vulnerable to abuse by family members and caregivers, yet little literature and few programs consider the needs of individuals who are both older and abused and have a disability. This chapter provides an overview of the issues specific to the abuse of older persons with disabilities.

The Abuse of Older Persons with Disabilities

There is a paucity of research on older individuals with disabilities who have been abused. Because reports of abuse are limited and health care professionals often fail to recognize at-risk elderly individuals, the issue of elder abuse remains a hidden problem (Coyne, Reichman, Berbig, 1993).

McDonald and Collins (1998) have suggested that older adults who have suffered maltreatment often fail to report because of a fear of retaliation, fear of being placed in an institution, and feelings of stigma and shame. In addition, it is possible that limited reporting by victims and recognition by health care professions is due to older adults being less likely to participate in community events, thus making abuse even more difficult to detect (McDonald & Collins, 1998). Therefore, further research is required to fully understand the incidence of abuse and the nature of abuse in relation to the elderly population and particular disabilities.

The limited number of studies conducted indicates that this problem requires attention because abuse and violence is believed to result in harming the physical, material, and social well-being of many older adults, especially those who suffer from disability (Choi & Mayer, 2000). It is apparent from these few studies that disability is a risk factor for the maltreatment of the elderly. Lachs, Williams, O'Brien, Hurst, and Horwitz (1997) conducted a longitudinal study to determine the risk factors for elder abuse and neglect among a sample of older adults living in the community. Several factors emerged as predictors of elder abuse, including race, poverty, and living with someone. However, the results indicated that the most controversial predictor of elder abuse was functional status.

Lachs et al. (1997) found that cognitive impairment, higher functional impairment, and the number of impairments in activities of daily living were risk factors of elder mistreatment. In addition, deteriorating cognitive impairment was particularly predictive of maltreatment. The researchers concluded that professionals should be increasingly aware of high-risk circumstances in which an individual is suffering from functional and/or cognitive impairment, and this should be especially so in situations where violent behaviour was evident in the past (Lachs et al., 1997).

Similarly, Choi and Mayer (2000) investigated the complex nature of elder abuse, identifying a number of risk factors for the different types of maltreatment. On average, the researchers found that abused elders were in their late 70s, cognitively impaired, and frail, thus suggesting that disability is a significant risk factor for the abuse of elderly adults. Choi and Mayer also found that elders with more acute or chronic health problems were more susceptible to neglect and abuse by others, postulating that the burden and stress experienced by those providing care could have provoked neglect and abuse in some cases. In addition,

three risk factors were found for financial abuse: home ownership, being unable to manage one's own finances, and cognitive deficits. These results suggest that disability, including cognitive deficits and chronic health problems may contribute to the incidence of elder abuse among older adults.

Lundy and Grossman (2004) examined the experiences of 1057 elderly victims of abuse who had sought help through domestic violence programs, despite the uncommonness of older persons using such programs. The majority of the individuals who participated in this study were white females who had a mean age of 71.8 years old. Lundy and Grossman found that 12.2% of participants had a disability or specific special need at intake, including hearing and visual impairments, use of a wheelchair, developmental disabilities, and assistance required for feeding, dressing, or toileting, specialized diet, administration of medication, and immobility. These results suggest that it is important to take into account the special needs of individuals with disabilities when they seek services, and to incorporate ways to make such services more accessible to the disabled elderly who are victims of abuse.

More specifically, Coyne, et al. (1993) investigated the relationship between elder abuse and dementia using a sample of 342 caregivers recruited through a telephone helpline specializing in dementia. Results indicated that abuse of adults with cognitive impairments by their caregivers is associated with the psychological and physical demands placed on those who care for relatives with dementia. In particular, they found that abusive caregivers, in comparison to non-abusive caregivers, were providing care for more years and for longer periods during the day, and were also caring for patients that had functional impairments that were more severe. These findings suggest that, due to the greater demands of care-giving placed on them; the abusive caregivers were subject to greater levels of burden and experienced more symptoms of depression than caregivers who were not abusive. As a result, some caregivers may project, rather than internalize, feelings of helplessness, anger and dysphoria outwards in the form of verbal or physical abuse. Coyne and colleagues suggest that interventions should be designed to reduce levels of burden and depression experienced by caregivers. Therefore, caregiver stress and burden is another potential risk factor for elder abuse of individuals with disabilities.

Furthermore, Matsuda (2007) examined how attitudes toward abuse were affected by the presence of dementia in older adults. Studying 135 individuals between the ages of 18 and 86 who were not taking care of a relative with dementia at the time of the study, the participants were asked to rate how abusive they believed a number of behaviours to be. The results suggest an association between older adults with dementia, prior experience of caregiving, and the type of abuse. More specifically, abusive behaviours towards elderly patients with dementia were not considered to be as abusive as the same behaviours towards patients without dementia. The authors speculated that such attitudes may be another risk factor for elder abuse of individuals with such disabilities.

McDonald and Collins (1998) proposed a number of characteristics of the victims and perpetrators of elder abuse. First, the victims of physical and psychological abuse tend to suffer from psychological problems, but usually have good physical health. The perpetrators of physical and/or psychological abuse tend to suffer from substance abuse and/or psychiatric illness, and depend on and live with the victim. Second, elderly individuals with dementia are more likely to be victims of physical abuse, and their caregivers tend to suffer from low self-esteem and depression. In addition, when an elderly individual is dependent on their

abuser, they are at risk for more serious financial exploitation. Finally, the victims of neglect are usually very old, and suffer from cognitive and physical disabilities, which create a source of stress for the caregiver (McDonald & Collins, 1998).

With respect to sexual abuse, the literature review conducted by Ramsey-Klawnsnik and colleagues in 2007 indicates that women adults are the most common victims of sexual abuse, and that the abuser is most often male. It is important to note that both males and females can be both victims and perpetrators of sexual abuse. Ramsey-Klawnsnik, et al. concluded that victims of sexual abuse tended to be highly impaired due to communication, cognitive, and physical limitations and advanced age. Perpetrators included family members, fellow residents in facilities, and care providers. Furthermore, the sequelae experienced by victims of sexual abuse include sexually transmitted infections, psycho-social trauma, and physical injuries. The locations in which the sexual abuse of the elderly or disabled occurred included nursing homes, the community, and other care settings; and because these individuals are often dependent on others for their care, they are at high risk for sexual abuse.

Vida, Monks, and Des Rosiers (2002) investigated elder abuse among patients using a geriatric psychiatry service, concluding that elder abuse is common among geriatric psychiatric patients. Financial abuse was the most commonly identified, followed by neglect, emotional and physical abuse. Furthermore, living with friends, family (not including husband or wife), and others, as well as being divorced, separated, or widowed were significantly associated with elder abuse among this population. Vida and colleagues conclude that it is important to have multidisciplinary expertise within geriatric psychiatry services, as well as resources available for dealing with elder abuse. In addition, service providers should be aware of situations that may indicate a high risk for elder abuse.

Intervention Strategies for Elder Abuse

In addition to the paucity of research on the incidence of abuse and the risk factors of abuse among the disabled elderly population, there is also little research on the service needs of these individuals. More specifically, there is a lack of information regarding the prevention and treatment of the disabled who have been maltreated; what services work, for whom and in what context (McDonald & Collins, 1998; Sobsey & Mansell, 1990).

It has been suggested that service providers have failed to take into account the needs of elderly disabled persons who are experiencing maltreatment. Furthermore, this situation is further exacerbated by the social, physical, financial, communicational, and disability-specific reporting barriers that this population faces. Compounded by problematic societal attitudes, older individuals with disabilities are often left powerless, thus, as mentioned previous, making them more vulnerable to abuse. As a result, these abusive care practices are often undetected or not reported.

Another barrier to effective intervention is that professionals are often unclear of what constitutes neglect and abuse, lack knowledge about what services and resources are available and appropriate, and are sometimes unwilling to intervene (McDonald & Collins, 1998). Mitchell and Buchele-Ash (2000) proposed that there must be uniform standards applied across the United States, as well as across Canada, in order to make reporting procedures of abuse more consistent. By doing this, more accurate data will be available and thus more valid and reliable research will be able to proceed. As a result, knowledge about

abuse of disabled elderly persons will be more accurate and will contribute to future policy reform, as well as developing appropriate treatment and prevention strategies.

The limited literature available on the needs of elderly adults with disabilities provides some insight as to what can be done to improve the current situation. Cohen, Levin, Gagin, and Friedman (2007) examined the rates of identification of elder abuse with three different assessment tools: (1) direct questions that elicit disclosure of abuse; (2) identifying signs of psychological, physical, sexual, financial abuse, and neglect; and (3) a tool for assessment of high risk of abuse. The results indicated that it is necessary to use all three assessment tools in order to identify elder abuse; no single tool was optimal. Cohen et al. also emphasized the importance of routine screening of high-risk abuse situations. Therefore, the assessment of elder abuse should be well-rounded and include a number of assessment tools.

In addition to improving the assessment of abuse of the disabled elderly, it is also important to identify areas that need improvement among the services that are provided, such as domestic violence shelters. For example, an interagency collaboration formed in Florida with older residents in order to determine where the gaps in services exist for older victims of domestic violence. Vinton (2003) stated that the inability to meet the needs of elders is a potential barrier to serving elderly women in domestic violence shelters. Often, assistance with a variety of daily living tasks are not available at shelters, including help with bathing, taking medications, grooming, etc. By making improvements to domestic violence shelters, and other organizations that help victims of maltreatment, it will help make the services provided to victims more available to elderly persons with disabilities.

Furthermore, educating professionals is important for developing knowledge and skills, providing the foundation necessary to offer effective services for disabled elderly persons (McDonald & Collins, 1998). Education allows for consistent conceptualizations of neglect and abuse, and aids in the detection and reporting of abuse. It will also allow professionals, specifically clinicians, become more aware of the services offered to help victims of domestic violence and neglect.

Chapter Four: The Participant's Narratives

Ten research participants were involved in semi-structured interviews of approximately one to one and a half hour in length to discuss their experiences and perspectives on disability and abuse. With two exceptions, the interviews were conducted face to face at the University of Calgary or the participants' current residences. Two interviews were conducted on the phone due to the participants living out of Calgary at the time of interviewing. The interviews were audio-recorded and transcribed verbatim. The RESOLVE Alberta team conducted the data analysis using mainstream social work qualitative methodology (Tutty, Rothery & Grinnell, 1996) with the support of ATLAS-TI qualitative software.

This section presents results with respect to the background of the women interviewed for the current project and their challenges in terms of disability and abuse. It concludes with information about the services that they accessed or attempted to access, as well as their recommendations for better serving this distinct client group.

Study Respondent Demographics

The research participants were invited to be interviewed through posters placed in domestic violence-specific organizations and agencies serving persons with disabilities. While the intention was to interview individuals from both domestic violence and disability services avenues, it was extremely difficult to recruit individuals from the latter source, despite the efforts of agency staff. While some individuals using such agencies did express interest, this did not result in contact, despite the researcher's flexibility and willingness to conduct interviews with support persons and/or counsellors on site.

Nine women living in Alberta who were accessing abuse-specific services and had some form of disability agreed to be interviewed for this project. In addition, one woman who was her sister's caregiver was interviewed regarding her sister's experiences of abuse and her disability. Her sister was hospitalized at the time due to challenges because of chronic mental health.

The participants ranged in age from 23 to 50, with an average age of 31 years. Six respondents described their racial background as White/Caucasian, three as Aboriginal, and one as Filipino. Eight respondents had young children; the children of two of whom were in temporary care with Child and Family Services. Two respondents had adult children.

The participants all had substantial disabilities comprised of chronic mental and physical health conditions. Seven respondents described their challenges as multiple mental and physical health chronic conditions.

The women had all left their adult abusers at the time of the interviews. This fact was not surprising, given that violence against women shelters were the main venue that led to engaging the research participants. At the interview, six women lived in domestic violence emergency shelters, three in subsidized housing and one in private housing. Of the three respondents in subsidized housing, one had recently been hospitalized in emergency psychiatric care. Her experiences of disability and abuse were documented by her sister who was her caregiver at the time.

The Participants' Disabilities

This section presents the respondents' insights in terms of their difficulties related to chronic physical and mental health conditions that led to disability. Major aspects that were explored include the time and ways in which participants became aware of disabilities, their limited participation in employment and other financial opportunities, isolation, and their coping strategies.

Chronic Physical and Mental Health Conditions

Since experiencing a disability was a characteristic for recruitment into the study, the fact that all of the participants were dealing with at least one physical or mental health chronic condition is not surprising. However, the women's accounts regarding their struggles and their desires to overcome their challenges are compelling.

As documented in Table 1, seven women related that they were facing challenges generated by multiple mental and/or physical health conditions while three women commented on difficulties associated with a mental health condition and one woman dealt with a physical health condition.

Table 1: Chronic Physical and Mental Health Conditions

Type of Disability	Number of Interviewees
Single Mental Health Condition	2
Single Physical Condition	1
Multiple Mental Health Conditions	3
Multiple Mental Health & Physical Conditions	4

Three of the ten women mentioned a single mental health condition as a cause for their disability:

I'm considered mild to very severe developmentally disabled; so I'm in between these two categories. I accepted that.

My sister is mentally ill. She was on medication for depression and hallucinations.

I am brain injured. I was shot in the head. The bullet went inside my head and grazed my eye. I can't see you but I can see the corner edge of your shirt.

One woman mentioned multiple physical health conditions:

I have diabetes for a long time. I have rheumatoid arthritis and it's hard to walk. I have to use a walker and I'll have a scooter.

The women's accounts of their multiple chronic health conditions were compelling. Of the seven respondents, four mentioned multiple mental and physical health conditions:

I have a couple of disabilities: mental health as well as physical. I have a processing disorder and anxiety. I recently found out that I have Celiac disease. I have also a thyroid condition, so I have health concerns on top of everything.

Since I was born, I did not have 20/20 vision. Recently I was diagnosed with border line personality disorder.

I'm asthmatic and I've had very bad experiences because of it. I had a near death experience where I had died and I came back because of asthma. Another of my disabilities is major depression, which is fully understandable for what I've come through. Another part is what they call posttraumatic stress disorder, and it wasn't a onetime event. It's been repeated most of my childhood and even part of my married life. I have fibromyalgia, I have chronic fatigue, I have carpal tunnel syndrome. I've already had an operation on one of my hands for the carpal tunnel; now I have to get it on the other one.

I have Celiac disease and many dietary restrictions. I have to be gluten-free and wheat-free. I'm allergic to seafood and a few other things, so it really limits my food options. I also have depression, which I am in counselling for.

Of the seven women, two related challenges associated with multiple mental health conditions:

I have posttraumatic stress disorder, anxiety disorder, panic disorder and attachment disorder. I also have social disorder, agoraphobia and possible OCD [Obsessive-compulsive disorder]. I struggle with these every day.

I have a lot of problems concentrating. I get really hyper sometimes. When I was younger in school, and even when I was older and went back to school I had to take Ritalin because all of a sudden, I'd be walking around and people were looking at me. I would be weird and couldn't help it. I have to be on the go all the time. I have problems waking up because I have a sleeping disorder on top of everything else.

One of the important aspects explored was the age at which the participants became aware of some of their conditions and their initial thoughts about them. Three participants explained that their conditions were present from birth and that they had experienced the first signs of disability before or during elementary school:

I was born going blind. During my elementary school I had my eyes tested. I had stigmatism and what is called myopia, which affects your long or short vision. A few years ago I was classed as "low vision." I needed things like magnifying glasses, or writing stencil that helped me write in a straight line; specialized pens, which are basically really hard nylon, tipped felt pens. Even for low vision people it is hard to read normal ballpoint pen or pencil.

When I was younger, in school, I heard something was not okay and that I was mild developmental. Throughout the years I tried to use services to feel better.

I was prescribed Ritalin for ADHD when I was a child. I was 3 years old.

Seven respondents had developed physical and/or mental health conditions after birth. All recognize the impact of these conditions on their health as adults:

I didn't know I had the processing disorder until very recently when I had some testing. Even my mental health conditions weren't fully appropriately diagnosed until last year. It has taken me a year to get the correct diagnoses.)

I just started this processing work, to accept that I have disabilities. I started from the fact that I recently have received these mental diagnoses.

I've had diabetes practically 35 years, so it's the end stages. You don't die of diabetes; you die of the complications that come with it. The bones of my feet are eroding. It's called "carpal joint". The bones are eroded and they snap. I also have rheumatoid arthritis because my knees are supposed to be new knees, plastic knees.

A couple of years ago I was shot in my face. I felt the pain for 10 minutes and then blacked out. I woke up a week later and my skull was missing. I have an acrylic plate in my skull. I was married at the time but my husband is long gone. I don't remember who shot me or what happened. When I woke up I was trying to get acupuncture for the pain, but was told I couldn't. When I saw a doctor, he observed that I had pupils of different size. He was quick in guessing that I had a brain injury.

When I was at the women's shelter I didn't know that I had all the disabilities that I have today. I knew I had asthma. I was just learning what abuse was when I left. Through the years, that's when I started to learn that I had a real disability and I really fight with it.

Six or eight months ago I was told I have Celiac disease. While they were checking I initially was off work for a hernia. I had a hiatus hernia, which is up high. Everything I ate was affecting me.

In addition, three participants commented on the significant long-term effects of their chronic conditions on their physical health. The women highlighted that the physical or mental health conditions that led to their disability had left them vulnerable, which increased their need for proper care and resources:

I have to use the walker for life. But I could go back into a wheel chair at any time. It is unpredictable. It depends how the disease progresses. In 2004, I noticed a little snap in my foot and everything started from there. I got infection in my bones because of that. The infection spread into my whole body, they called it septicaemia. I went into a coma for a few days. I was on life support this year three or four times.

My asthma is so chronic and so bad and it triggers it (sexual abuse issues), so you either have to take your chance at triggering it or you don't eat. You go for weeks without milk or juice in the fridge but you are supposed to be trying to concentrate on the stuff that got you where you are with the sexual abuse.

Every day I am in constant pain. When I don't have the proper care I get the body shakes. Yesterday I was vibrating and I looked like a drug addict. I was shaking because I don't have proper nutrition. On top of that, I was exhausted. I walked a lot yesterday to get things done. I got so many blisters and it exhausts me. I am also anaemic, because I can't get the nutrition.

Six women highlighted the tremendous impact of disability on their mental health. These consequences include memory problems, confusion over treatment, suicidal ideation, and lack of predictability.

My memory is not as good, ever since I came out of life support. Each time I've lost a bit of memory because of the lack of oxygen. It's not that bad yet, but pretty bad. It's irritating and you have to re-learn everything, how to walk and breathe and everything each time.

I've been in and out of these different places, doctors giving me different medication and people telling me to go off all the medication. I think the mental health is the hardest to treat of all of them. As far as the chemical imbalance, needing psychiatric care because of that, I think that condition is the worst.

My sister did not look for help for her depression. She tried to hide it. That is probably one of the reasons why she got mentally ill. It's not just because of the drugs, most likely is her depression and that she has suicidal thoughts. Whenever she cannot handle things she would not eat, she would stay in the room for many days and not eat. We would just force her to eat.

I have seizures but I don't remember how often. I only started to have seizures when my acrylic plate was put in. They hit me suddenly. I can be relaxed and they'll hit me and then I don't know anything. It's not only when I'm overly stressed.

The medication made me nauseous. Sometimes I would be too focused. I'd forget where I was and then I'd snap out. "Where am I?" And I would realize I'm at school; time to go to my next class.

Several of the mental health challenges that the women described left them feeling unsafe, even in their homes. Without the social and professional supports that are essential to persons with chronic health conditions, they risked seriously harming themselves or placing their lives in danger. Two participants described such a risk. The woman who was the caregiver for her mentally-impaired sister related how her sister had almost set the house on fire:

A couple of times we called the police to get her [sister] to the hospital because she was hallucinating. The house could have ended up on fire. She put some oil on the stove late at night. My children and my friend were in the house. Luckily my son was awake, so he smelled something burning. Then he woke me up. In that moment, I thought that the house might catch fire and all of us woke up.

I've got no depth perception, so everything looks flat, even the type of paint on stairs. If it is a high gloss paint, that is very dangerous, depending on my footwear or if I've got wet shoes. I have fallen downstairs more than a few times. My knees are permanently bruised from running into the corners of my coffee table or the edges of kitchen chairs, or garbage cans. Lately, because I didn't have bump-up dots on my kitchen appliances, I wanted to shut the oven off. Because I am very short, my chest touched the top of the stove and I got burned right through. It melted my shirt.

Limited Ability to Generate Income

The participants all identified their limited incomes and the huge discrepancy between their financial resources and their special needs as one of the greatest difficulties. Seven women mentioned the impossibility of working due to their health problems and three provided detailed comments:

I racked up my credit cards as I was raising my children, so I ended up having to go bankrupt. I used to have very good credit. I used to be able to work. I was a good worker. Now my doctor says I have way too much going on. She doesn't want me working at all, so I can't even count on me to bring any more money in.

I've tried almost all areas to get extra financial help and every avenue is well closed. I hate having to just survive. It's the 4th of the month and I hardly have any money left. So you wonder, "How am I going to get by for gas, for food". I would really like help financially, as I go through the healing of this intense sexual abuse healing.

I am not cleared to go to work but I need to bring in more money. I'm sinking so badly. I need some finances to take care of myself. I can't choose the cheapest foods. Now I am living in a shelter and I've lost my routine. I can't follow the proper diet and treatment. My iron level is low but to improve that I need stability. For housing, my only hope is the Y [Mary Dover]. But if you get in, you pay them rent, and you don't know if it is shared or not. It is hard for me to share the room.

One participant described how challenging life was without being able to pay for basic social needs:

I tried living without a phone because they had cut it off for a couple of months. But with asthma, when you don't have a phone it's impossible; you have to be able to phone 911. It just makes you too tense. So definitely, finances are important for people going through this.

All the participants expressed frustration regarding difficulty finding employment. Except for two respondents, none of the other women were working at the time of the interview. They identified their disability as the major cause of their unemployment.

I need to bring in money but I don't want to start a job that I can't handle. I work for four hours and I'm exhausted. I'm no good to an employer. I need to try. I need to do something. I feel useless right now.

I am not working. I have been turned down by every business I have walked into and inquired about. The normal, the typical across the board phrase is, "We are sorry but we don't have anything to do for somebody like you"

Even the two women who were working commented on discrimination and a lack of understanding of their disabilities. Neither was working full time and both were afraid of losing their positions and/or not being able to find other jobs.

My bosses don't like me very much because they don't know what my problem is. Because I have an anxiety disorder I get anxious, especially when I'm under pressure. I freeze up and can't think at all. I don't know how to deal with the situation and sometimes I'll just make jokes to make things more relaxed. But when I'm doing that my bosses think that I'm being disobedient or immature. I'm afraid to talk about my problems at work. They probably think that I'm not a good enough worker or that I'm not smart. I'm afraid that I might not get a job because of it. I guess they'd know that I am slower than everyone else.

Lack of affordable, appropriate housing also was a result of these women's limited opportunities to earn income. Seven women were currently living in emergency shelters for abused women and had no stable housing yet established for when they needed to leave.

I want to get going on it and get rid of it. Instead, I've had to fight to stay where I am because I'm finally in a safe place with my children not around and I can deal with it

but it means that the depression will probably get worse before it gets better. A move is not what I need right now.

In addition, one participant explained how the financial compensation that she could receive for the disability and abuse was necessary as a moral aspect yet was not a substantial enough financial support:

I have a disability that I can be compensated for. If it is to do with being in an abusive relationship, I can be compensated for the physical damage to my body. I am coming forward and pressing charges against the people that have caused this physical harm to me. But, having been a victim of any sort of crime takes something from you that cannot be compensated. This financial program is not a means of support or not a closure by any means. It just gives me a small financial compensation. There is no word that I can find to name this. And that financial help is not going to compensate for any amount of pain or physical damage that somebody did to you. Not to mention the psychological damage.

Participants' Complex Needs Related to Disability

Four participants described how they have been forced to ignore their complex needs related to their disabilities. The major obstacles include the lack of professional supports, lack of daily routine and the difficulty in predicting their needs due to abuse:

My sister needs someone to take care of her all the time. That is something I can't do 100%. I have my two children. I've been telling the nurses in the hospital that she is not able to be on her own and that she puts herself and her children in danger.

Because I have seizures, I have to eat every three hours. Lots of times that is impossible. When the court support counsellor called and I told them about my husband's plans on going to a lawyer, she asked me to go to her office immediately. This was on the run, so all I thought of was protecting my daughter. It didn't occur to me that I needed food. I was in court the whole day and I was hungry and limping. I ended up buying food from the court building but it was very expensive.

I'm allergic to preservatives, not just because of the asthma, but I also have fibromyalgia. I'll be in bed for a week if I eat foods with preservatives. So people think, "Why should you eat organic." I'm told, "We're not paying for organic, beggars can't be choosers, take the muffins we are offering you and be happy". Fifteen loaves of bread another time and I would rather get half the amount because what am I going to do with a case of yogurt that expires in three days? How is that going to help me two weeks down the road?

I have a hard time with organizing. I have yet to get anybody to help me. My important papers are disorganized because I can't read them to put them in order or show me where to buy one of those accordion file folders, something so simple.

Participants' Accounts of Isolation

Four participants provided extensive comments with respect to the isolation that they experienced and the unwillingness of people to support their disability. For one respondent, this had a serious effect in terms of physical mobility:

A lot of places don't have ramps; I was with my bank for 12 years. They finally got a ramp. Some restaurants and other buildings downtown, to get into some of them it's impossible. There are stairs but no elevators. Before I was in a wheelchair, it was hard to find somebody to push me around. It was a manual wheelchair and I missed a lot of my appointments. I've got kidney failure problems and I'm diabetic and I have all kinds of other medical problems. I missed a lot of my appointments and ended up back in the hospital because of it.

Another three participants described how they had to adjust to what they could not do anymore. The lack of understanding and support from others, including family members, stands out.

It was hard for me to have phone conversations because of my memory problems. I need things written down before talking on the phone and I've accepted that. I would take a phone message and hang up the phone and say, "Who just called?" That was how bad I was; I could not remember who called.

I am assuming that is easier for sighted people to do recreation and de-stressing. But in my case, people in my family did not recognize that I'm not able to use a computer, play video games, watch T.V., or pick up a book, things like that. I ended up becoming very isolated to the point where I would just sit at the kitchen table because I got tired of listening to all these things. It becomes ambient noise because I can't put together what is what.

Mental and Physical Impairments as Non-visible Disabilities

Four respondents commented that their chronic health conditions were not visible, yet they were struggling with physical pain and feelings such as depression and anger. For some of the women, the invisibility of their condition resulted in being denied help, support and understanding.

The physical damage is not visible. But it is very upsetting and depressing. It angers me but I have to learn to live with it because it is not going to go away.

So many people don't see my struggles. I used to go to church and it helped a couple of times but they think that I should just be able to work, even though I tried to tell them that I can't. But I look like I am well. They can't see the pain when I don't get out of bed some days. They don't feel the depression, when sometimes you have suicidal thoughts. They don't see it, so that door is closed.

I come across as really high functioning, especially in school. I get really stressed out and crazy but get really high grades. I'm able to show what I know verbally but I'm not able to organize myself and put it into practice very well. So a lot of times my supervisor would be upset with me, thinking that I was lazy or goofing and not taking it seriously, or not trying as hard as I could.

I suffer discrimination because it's an invisible disability. I do not use a wheel chair but I'm disabled. When I go to a mall or in public areas I feel like I need to wear an "I'm blind" sign. I can't see the people around me, so they have to watch out for me.

The same participant highlighted that her visual impairment led to her being wrongfully accused of shoplifting:

When I ask store staff to help me I may be helped or may not. Some just walk away. They called security on me one time because I was looking on the bottom shelf for something and I was actually crawling on the floor with my face literally in the shelf because nobody would take the time to ask what I needed and help me get it.

Coping with Disabilities

Despite numerous difficulties, the respondents expressed their thoughts in terms of resilience and positive coping skills. The following quotations provide a snapshot of how participants use their strengths:

I try to push myself. I try to walk to some place every day, a little walk. I am really trying hard this time.

Saying, "Look, I have this disability, but how can I make it benefit me?" That is what I have to do; I have to figure that out myself. I have to overcome barriers, struggles, and fears, because it really depends on what your disability is. I try to look at struggles as a way to learn how to re-communicate with people.

When I lost the majority of my sight I was angry. After a while, I came to the conclusion that there are two ways I can deal with this. I can lock myself up in my house and feel sorry for myself, or I can take what I have been dealt and do the best I can with it. After that I developed the attitude that if anybody learns anything through me being blind, that's great because my disability becomes an educational tool. I have always been very upfront and honest. If people have questions, "Come and ask me". I would prefer you ask than make assumptions, because assumptions are usually wrong.

Life is not enjoyable for me, I don't have fun. I haven't been able to do much besides survive at this stage and I want it to get better and I'm trying so hard.

The Participants' Experiences of Violence and Abuse

Another important issue explored in this study was the respondents' experiences of abuse. Given that this was a requirement for the research, it was not surprising that all of the participants disclosed being abused at least once in their lifetime. However, the extent of the abuse and the numerous forms of abuse that most of the interviewees brought forward reflect great vulnerability, indicating complex relationships between traumatic experiences with both disability and abuse.

Four women disclosed having been abused during their childhoods; nine participants were victims of intimate partner violence, and three women commented on their experiences of abuse from extended family members. A further four women were abused or subject to being abused in public areas (see Table 2).

This section presents the participants' perspectives on the following issues: abuse during childhood, intimate partner violence, involving the police, abuse in extended family, abuse in public areas, emotional and physical safety, and the relationship between abuse and disability.

Table 2: Experiences of Violence and Abuse

Form of abuse	Number of Interviewees
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Child Abuse only	4 women
Intimate Partner Violence	9 women
Abuse from Extended Family	3 women
Abuse in Public and Institutions	4 women

The Women's Experiences of Child Abuse

Four interviewees had been abused during childhood by either their parents or other family members. The women commented that the abuse increased their vulnerability to being controlled in their adult lives, associating it with low self esteem and a lack of confidence in their capacity to stand out against abuse. The forms of childhood abuse that were inflicted on the participants included emotional, physical, sexual abuse and neglect:

I've experienced all kinds of abuse since childhood. My mom was mean. She's got a lot of my uncles' traits and it was hard. They'll give you "Tough love." When I was feeling really sorry for myself she didn't see I was in pain.

I was still in my crib when my dad started to sexually abuse me. I was nine months old. The abuse went on until I was 13. That's what I'm dealing with today. I just had a second surgery to fix problems from the abuse. It's amazing that I'm alive, that's how horrific my childhood was.

It was difficult at first but throughout my life, even my childhood, I grew up in a very abusive family. My mother was extremely abusive. I could have very easily been a completely different person than I am now, a much angrier, much bitterer person. However I chose not to be like that at a very early age. I love my mother but I don't like the way she treated me. That is the best way I can put that.

The same participant related being bullied in elementary school:

I had a mobility cane when I was in grade 12. I actually stopped using it because I had students take it away from me and beat me with it. People would purposely trip me with it; I was teased a lot, and I was called a freak. In spite of all those obstacles I did graduate high school.

Another woman spoke in detail about the abuse and its long-term impact on her life:

Trust is a big problem when you've been in an abusive relationship. For me, it stems back when I was a child and I had to develop those bonds that are supposed to be strong, like a mother daughter relationship. Those bonds and healthy communications is something I never got to see; only in a book or a fairy movie. I got to see the other side of things that was really scary. I never felt protected. I had to feel like I was the protector. Being a 4year-old and having to feel like you are the protector is not right. I grew up fast and learned a lot of good and bad things. I learned how to manipulate the situation, because I had been manipulated.

This woman also explained her perceptions of the interconnection between her childhood abuse trauma and the trauma of intimate partner violence:

If you have been in an abusive relationship and your parents are abusive to you that becomes the norm. After it happened in my relationship, I have been thinking that if a man doesn't abuse you, there is something wrong with him.

Women's Experiences of Intimate Partner Violence

Nine women disclosed being victims of domestic violence. While several of the participants related past traumas of intimate partner violence, others were currently in the process of separating from their abusive partners. Several women indicated the possibility of trying a temporary separation and returning to their partners on the long term.

Three respondents related how they had decided to leave their abusive partners in the past and how they became aware of the abusive patterns in these relationships:

I wouldn't have known that I was in an abusive relationship unless I talked to a counsellor. One of the counsellors at the second stage shelter I was living at before told me, "This is the cycle of abuse and this is what is happening" and I thought, "What?" I didn't know how bad it was until I got there.

I was in an abusive relationship and endured a lot of abuse and trauma. First, I wanted to escape. But I didn't feel safe with people, especially family members or people that were close to me, because those were the people who hurt me the most. I had started drinking and started into cocaine and crack and then I started prostituting to get that money. I really put myself at a high level of risk and did more damage to myself in the end. Now I have to repair myself because of the damage that somebody else inflicted on me without me wanting it; because nobody wants to be a victim.

I was in counselling and started to find out about abuse and that my husband was abusive and that I had grown up in it. My husband made death threats to me.

Six women were living apart from their abusive partners when interviewed for this project. Of these, five were housed in violence-against-women shelters. They described in detail the abuse their intimate partners had inflicted upon them:

The reason I'm in a women's shelter is that my husband has a brain injury too. He was fired from a good job and started working in other jobs. Lately he's been getting so frustrated that he verbally attacks me and the final straw was when he verbally attacked our daughter.

The person who abused me was a roommate, more or less. We were in some kind of relationship. They [home support counsellors] came into my house but he was around and would counter what's been said; made it look like everything was roses rather than accepting the reality. If I would make an analogy, he made it look as everything was normal and it wasn't normal. When the abuser was there, I didn't say much because I didn't want to rock the boat. I didn't want to expose myself.

My partner has left me in dangerous spots or places out in public where I have actually fallen and gotten hurt. Things like being asked to make phone calls during the day, home business type phone calls or appointments. He would ask me to make these phone calls but he would get very angry with me when I hadn't, in spite of me asking him to record the phone number on my tape recorder, what it is in regards to.

I am not able to read a phone book and there is only one Telephone Company that provides 411 for free with proof that you need it and that is TELUS.

We had broken up a few weeks before he beat me and raped me. I found out he cheated on me and was smoking crack and he chose the drugs over me. So after we broke up he begged me saying, "Please let me explain myself." I decided to give him the benefit of the doubt. One night we met and I went back to the house with him. He didn't even explain anything, he just got violent. He punched me in the face and when I finally came to I was trying to make sense of what happened to me. He was still there the next day when I woke up.

My ex-husband never touched me until near the end of our relationship. He started with little stuff, and then he was verbally abusive and then the pushing and it got worst. He hit me, pushed me, kicked me and did other things to me.

Of the six women who had left their abusive partners, one was hospitalized in emergency psychiatric care. The woman who was her sister's caregiver talked about the woman's challenges in terms of domestic abuse:

Every time my sister was with him he used drugs and got her into drugs. My sister didn't want to use the drugs. She was forced to in the sense that she thought that taking drugs was the only way she could please her man. Because she was trying her best to get her husband's attention, because her husband is always out of the house and she knew that he's always with some other girls.

Two women articulated thoughts regarding possibly returning to their intimate partners in future. One of the women explained that she intended to reconcile providing that her partner agreed to receive counselling assistance:

His problems with anger are difficulties we will have to face together. But I'm waiting for him to get the counselling for it, to be together. He said last week, "I need you to come back, so we can get counselling together." I said, "No, I need to get counselling by myself and you need to get counselling by yourself and only after that we could think of other ways."

The woman who was a caregiver for her sister related her fears that her sister would return to her partner and had not yet connected with any domestic violence supports:

My mother always cried. She wanted the best for my sister. She tried her best to help her get rid of the drugs and get away from the husband. But my sister would come to my mom's place for a couple of days and go back to her husband again. I tried to advise my sister to leave him because he was not doing nice things to her. But she didn't. Now I am looking for more help for her because I think after the hospital she'll go with him.

Emotional Control in Intimate Relationships

As an aspect of domestic violence, emotional abuse was a frequent strategy that the men used to control the women. The respondents provided several examples of such control that amplified their already-existing vulnerability and isolation:

My husband called my daughter a "bitch" and a "fucking piece of shit." I know in the past when he's had these spells or outbreaks I just clammed up and let him blow

up at me. Later on when he is normal again; he apologizes and he is okay. But this has been happening more in the last year than ever before.

One of the things with my partner is trying to enforce respecting my needs. Because I can't read newspapers and magazines, I always listen to the six o'clock news, like Global Calgary, so I can stay in touch with what is going on. But at home, my needs and my asking for that were not respected at all. More understanding and respect would definitely (laughing) make it easier on everybody. Things like the putting down and the lack of courtesy and support is a problem at home. It is bad enough in public, but these are a problem especially at home.

My ex partner was saying, "I don't want you to have friends" and I told him that this is my life. But when I don't go out, he's telling me I'm boring. When I go out he gets mad because I have friends. So it feels that I can't win. Now I have a No Contact Order. But as long as his friends harass me on the street and call me a bitch and a whore, the court papers do not mean anything. As they don't mention his name there is no proof that they are his friends except that I know they are his friends.

Financial Control in Intimate Relationships

Two participants commented on the financial abuse that they experienced while they were preparing to leave their partners. The women described how the financial control was initiated as a means to prevent or punish their decisions to leave the abuse:

I waited until he went to work and I got my daughter to write a note that we were going to grandma's for the weekend. He stole my truck keys and I drove the 20 year-old car here. If he stole the keys, I would have come by bus. I knew I was leaving.

The police said I had to leave. I only had twenty minutes to get everything ready and leave. My partner was so angry, he gave everything of the children's away to his brothers and their children. It was really very hard emotionally on my children. He [partner] gave away their comforters, their toys, and the things that were special to them. My daughter was angry at me for many years.

Multiple Forms of Intimate Partner Violence

The participants revealed that they were victims of multiple forms of abuse, indicating that they had struggled with severe control and violence that hurt them on emotional, financial, physical, and sexual levels. The interviewees also mentioned long histories of abuse, explaining how they were controlled during childhood and how they became victims of domestic violence.

When I was younger I was physically abused in my relationship. When I was even younger, in my childhood, I was sexually abused. I endured mental and emotional, and a bit of physical abuse.

He beat me after he knocked me out; he beat me with my mop. The pattern of the handle was imprinted in my back. I went unconscious around 1:30 in the morning and I didn't wake up again until 6:30, so he had all those hours to beat me and rape me. I shudder to think what else he might have done while I laid there.

I was abused physically, emotionally and sexually, and it all started as a child. I grew up in that whole atmosphere. I knew something was wrong but then everybody

said nothing was wrong, so I had a hard time to understand. I thought I must be wrong if everybody else is right. Later the abuse continued with my husband and boyfriends and with other people.

Two other respondents spoke about the severity of the sexual abuse that they had experienced. In response, the women dealt with several emotional and physical health problems:

The sexual abuse was with my dad, a lot of it. When I was at the women's shelter, that's when I learned what emotional and spiritual and financial and sexual abuse was. I tried to understand why I came across so many problems with my health. I was very ill for a while.

I am taking HIV medication in case - because this guy has been in and out of jail for a long time. There is a possibility that he contracted HIV and because the rape was so brutal, the doctors were worried.

Women's Experiences of Abuse by Extended Family Members

Three participants described their experiences of abuse from extended family members. Two of these women were currently fleeing not only their abusive partners, but also abuse or pressure from their relatives:

My stepson threatened to kill me. He threatened to have other people kill me. So protecting myself is a big issue. I can't run away from a threat because being blind and running does not mix. I have tried to run in response to one of my kids crying; but I have been very badly injured. So running away from a threat or seeing a threat coming for me is huge.

I have problems with my daughters and my boyfriend and I wasn't able to heal with them. They don't allow me to rest the way I should, so I had to come to the shelter [VAW shelter]. I just got out of the hospital and I need to take care of myself. But sometimes my daughters leave their girls who are babies with me. I don't mind, but it takes a lot out of me. I wish I was in better health to be able to run with them and play around. I try. But I basically live on antibiotics and painkillers.

The woman whose step-son had threatened her detailed the threatening statements. Her lack of support and the fact that her partner condoned such an abuse were heart-breaking:

He [step-son] told his father that he was going to curb stomp me and break every single one of my ribs individually, smash my face in and leave me to die. This was said in front of his father and there were no consequences for that, which really hurt. I was looking to his father [participant's partner] for support and I didn't get it. In fact I was told to stand up to the bully. My stepson has also said that he has a friend that will do any favour for him, including doing whatever it takes to kill me. So I have to watch over my shoulder all the time or be extra careful in public.

A third respondent explained that the abuse from her son had occurred in the past, as a consequence of intimate partner violence. The woman explained that, during childhood, her son had witnessed considerable abuse in the home:

My son was too angry and started to be abusive; that's why he had to leave my house. I had to tell him [son] that's not okay and if he doesn't deal with it, he's got to leave because violence is not okay. He moved out by his dad.

Women's Experiences of Abuse in Public Areas & Institutions

Four participants commented on their lack of safety in public areas and/or institutions. The women clarified that the abuse they endured was because of their chronic health conditions. They felt at risk of being attacked and by unknown persons that targeted them as vulnerable and unable to defend themselves:

Even going out is dangerous. It's not safe to venture out because I can't defend myself. I've had a few encounters, I was at Stampede and they wanted to steal my candy floss. I think they were drinking at the bus stop and this stranger gave me a big hug. I was with my daughter but she could not protect me. The stranger walked up to me, crying. I don't know what was wrong with him. He said, "I'm so sorry". But that hug hurt because I had a broken back, just healing from it. I had two cuts under my arms where I had tubes in my lungs. I don't understand why he did that.

I've actually had somebody come and push me right off a sidewalk on 17th Avenue. The guy said, "What are you carrying that stick for. You are not blind". I said, "How do you figure." He says, "Your eyes are open." I said, "Just because my eyes are open does not mean to say they work".

I was stuck in one of those little round doors. Someone else was pushing and then they left and it slowed down and I was stuck in it because I didn't have the strength to push the stupid door. I felt trapped and useless. I couldn't even push this door. I was weak that day. I used my whole body. Another guy comes through looking at me. He didn't help at all. That was annoying.

One of the four participants disclosed difficulties with teachers during elementary school:

When I started school, the teachers started telling my parents that I was retarded. It turned out I couldn't see anything on the board, so they moved me up to the front of the class. Later in school that wasn't working because my vision was changing so fast. It was changing every six months, it would plateau and then it would drop. By grade 3, I was coming home with chalk dust on my nose and the front of my shirt because I would literally have my face on the chalk board, trying to write the homework down that the teacher had written on the board. So it was really frustrating. There was no understanding.

Another participant related how she had received threats to harm her from another resident in the second stage shelter in which she was living:

One girl in the same housing [second stage housing] started harassing me. One day she told me bad words. The other day I'd come home and she had a big kitchen knife. She'd sit there tapping the knife in her hand. She'd follow me around the house.

While they related their experiences of discrimination and abuse in public areas, the respondents also reflected on how they could have protected themselves. The following quote provides insight into one woman's sense of helplessness:

I could carry spray mace with me. But what if it is a day when my hands aren't working, so I wouldn't be able to even press the spray bottle. What can I do to protect myself? I don't know. Just pray, that would be all I could do. I shouldn't go out unless I have somebody to go with me, I guess that is the answer for now; or I should get a protection dog.

Coping with Abuse

A number of the women commented on how they had gained an understanding of their own struggles related to the abuse. Most identified counselling and informal supports as essential resources in surviving the abuse trauma:

When you deal with abuse, there are layers you have to deal with. For example, taking counselling is one layer, your relationships is another. Under each level of abuse you have to explore very much in depth and deal with being dependent; even from the earliest childhood abuse, whether you know it or not, that is why you are reacting this way. So you would have to go inwards, backwards to your earliest childhood memory to really deal with it.

It took me a while to develop a support network. I was very standoffish, very aggressive, and defensive to the point where it really scared people. To get to that point scared me and that's when I knew I needed help. But to ask for help, and then to take the time to feel safe, to trust the people that I asked for help, was not easy. That was done by developing a healthy relationship and healthy communication. But that takes time, and I was so down and so hurt. That is something I have had to overcome instead of remaining aggressive.

I'm primarily here for Beth [daughter] but I'm here for myself as well, because I have to let her know that her mother stands up for herself.

Along with resilience and other strengths, women also expressed their helplessness and awareness that they will need more time as well as greater resources to go beyond survival mode:

My family wanted me out of the stressful situation I was in for years. After a while, I'm tired of what I'm going through. I looked into the process of getting what had to be done. I'm still going through that now and it hasn't even hit the bad part. I'm just coasting until it gets bad. It's not bad yet and I know that. I will not screw up this.

I had known about the sexual abuse and I started to deal with it when the children were younger. But I couldn't do everything; I had to put myself on the back burner, especially with deep issues like that. Now the children have grown and are living on their own. So now I am working on me. I want to pass something healthy and that's why I'm very persistent. I persevere because it will help me later on.

The thing that angers me most is that somebody else did this to me. I never got a chance to deal with my anger. I'm still pretty angry about what happened to me. I'm dealing with this with my psychologist.

The Relationship between Disability and Abuse

Another aspect explored in this study was the interrelation between disability and abuse. Participants were asked what they believed were some of the causes for either the

abuse or the challenges associated with disability. Three women commented on abuse as a risk factor for disability while four other women identified disabilities as a cause for the abuse they endured. Another three participants could not determine the causes for these circumstances.

Abuse Leading to Disability

Three respondents perceived the major cause of their disabilities as abuse during childhood or intimate partner violence. The women explained that their understanding of the interconnectedness between disability and abuse was confirmed by the professionals who assisted them in coping with their difficulties:

I'm new to accepting that I do have a disability, a mental disability as well as physical disabilities that stem from being abused.

You have so many things in your life and you just want to be left alone and concentrate on this sexual abuse so that I can get it out of me. But I'm learning that fibromyalgia can be a result of abuse, of sexual abuse especially.

I think she used drugs because she wants to not think of the problems with her husband. He made her mentally ill because he would always put her on drugs so that he could do bad things without anyone knowing. He often has relationships with other girls. My sister is depressed and suicidal. I believe she could end up dead because she cannot handle her husband. She tried to kill herself many times.

Disability Leading to Abuse

Three participants indicated that the chronic health problems increased their vulnerability to being abused. These women highlighted how they could be easily manipulated and abused because of their health issues such as short term memory problems as well as their limited capacity to defend themselves:

Due to my short-term memory problems I tend to forget the bad and concentrate on the good. There was a lot of good and love. But the abuse was just too much. I know now that when my partner treated me badly, called me a bitch and I let it go, then our daughter would think that was okay.

Near the end of our relationship, he would do stuff because he knew I was weak. He pinned me against the wall, that's all it took for me to get hurt. I couldn't fight; I'd push but I was exhausted. So that's what was scaring me; he knew that I'm weak and he was still pushing or holding me. He held me down once. He knew that I was weak and he knew about my problems.

I used to get myself in trouble with my boyfriend, because sometimes I fly off the handle and I can't control my rage when I get going. I know I need to stop but it's already gone. The Ritalin helps to control that too. Medication helps.

Stigma related to Abuse and Disability

All of the women in this study commented on the stigma and discrimination that they often face due to surviving abuse or/and coping with mental/physical impairments. The women talked about stigma directly related to abuse or to disability and also to a double stigma reflected in the society's judgemental thinking toward abused and disabled

individuals. The women highlighted how discrimination and judgemental thinking profoundly affected their self esteems and deepened their vulnerability to being controlled and abused:

To be vulnerable is another thing, because these women have gone through a tremendous amount of struggles. I'm not sure because I'm still trying to find out who I am but to not pass judgement is what I had to overcome, and hope that nobody passes judgement on me.

I don't think I would be able to do these appointments if I had to be on the transit. I would be way too vulnerable, because that is one sad thing about people that have been abused. It's almost like you have this big victim written on you and people can sense it and the vulture is there waiting. So I truly believe my car is a need. I've given up so many things; I don't have a computer, I don't have cable TV, I don't do entertainment. But I need my car.

Six participants voiced their concerns regarding people's discriminatory attitudes toward their limitations due to disability. Two women disclosed shame and helplessness, as they could not hide their health problems in public. They mentioned feeling labelled or unfairly judged as suffering from an addiction:

One day I was waiting for a bus and fell down. I was so tired and I can't really walk that well, so I fell right inside the bus when it got there. I had clogs on and it got stuck on a bolt. I went forward and couldn't stop myself and I was thinking "somebody should help me." One guy was helping me and made sure I sat down and was safe. I was glad he was there. But after that I wondered if they thought I was drunk because people are looking at me when they get on the bus.

There are times when if I can't keep food down. I shake and if I'm walking I get dizzy and it looks like I'm drunk. I'm sure people think I'm drunk. I have no energy.

Another three respondents pointed out that the general public have limited knowledge about physical and mental impairments, so there is a lot of room for assumptions and stigma:

About my anxiety disorder, there is still so much stigma around! I'm always nervous to tell anyone about it because, even being on medication, a lot of people don't understand it. I'm afraid and I am wondering if I will be able to handle a full life or if I will keep just crashing down, I'm really scared.

My disability is something that I don't blurt out because people are always so cruel. If I say it, there is something wrong with you. That is what they think. I don't say it to everybody. It's not a good thing. It can be frustrating. Some people can understand it, but some of them can use it in ways that it probably wouldn't be nice.

A lot of people out in public make fun of me, especially teenagers. Ignorance bred by a lot of ignorance, which is why I encourage people to not hide from me or ask questions. Young children ask, "Why does that lady have that stick." Parents don't know how to answer their kids.

One woman commented on her doctor's reaction that, at a more profound level, revealed people's worries about accepting their mental impairments:

My doctor was surprised that I was coming as an adult and asking for medication. Most adults don't want to admit they have that problem and can't control it.

Not surprisingly, stigma and discrimination amplifies women's low self esteem, diminishing their capacity to cope with challenges in a healthy way:

It is hard not to feel like a loser and incapable. No matter how hard I try, sometimes I just want to give up. But I keep going for my kids. I've got two daughters I have to set the example for. I have threatened to quit several times but by nature I'm not a quitter.

The participants also recognized that having to deal with both violence and disabilities amplified their vulnerability to be mistreated, judged and labelled:

Some people understand and other people will judge you. I haven't told too many people about my addiction and abuse; you don't really disclose that. There are all these things that people don't quite understand. It is hard. Sometimes you feel you are living in two different worlds. It's trying to fit into both worlds somehow.

I have always said that I do not need to apply for AISH or other programs that help people with disabilities because I looked at it as a weakness. You are less of a person or you were handicapped, either physically or mentally, so I had a hard time accepting that. I need to accept that I have these problems. It's upsetting because I didn't ask for these; they were because of the abuse. But I'm the one who has to learn how to deal with them to the best of my ability.

A friend supported me for a while. But because I had to deal with my sexual abuse and the pain from my health problems, my friend refused to see me. So that's another grieving of that relationship, another rejection because of my poverty and because of my sexual abuse and my disabilities.

Participant's Experiences with Agencies/Programs

This section presents the observations and options of the research interviewees with respect to their experiences with service providers, both with respect to domestic violence and disabilities and their suggestions to improve services.

The women accessed a variety of services. A number were specific to individuals with disabilities including: Access Calgary (1 interviewee), Assured Income for the Severely Handicapped (AISH) (3 interviewees), Brain Injury Rehabilitation Centre and the Southern Alberta Brain Injury Society (1 interviewee); Canadian National Institute for the Blind (1 interviewee), Trinity Services (1 individual); and McDougall House (Recovery residential program for women with addictions) (1 interviewee). Some services that address disability issues were mentioned but not yet accessed including as EmployAbilities (1 interviewee), and U.R.S.A. – Universal Rehabilitation Services (1 interviewee) and Connect Calgary Christian Society (1 individual).

A number of the women mentioned generic health and mental health care including hospital inpatient and outreach programs, nurses, psychiatrists and psychologists. The women had also used services for the general public, not specific to either individuals with disabilities or who had experienced abuse, including the Distress Centre (1 individual), the

Calgary Drop-in Centre (homeless shelter) (1 individual), the Food Bank (2 interviewees), Legal Aid (1 individual), and the Support Network (1 individual).

Likely because we were more successful in recruiting women from services specific to domestic violence and other forms of abuse, these services were mentioned more often. These included emergency shelters [Sheriff King (4); Calgary Women's Emergency Shelter (2), Awo Taan Healing Lodge (1)] and second stage shelters for women abused by intimate partners [Sonshine Center (1)], which were mentioned by a total of eight women. Two commented about Calgary Communities for Sexual Abuse (CCASA) and two had used the services of the HomeFront Domestic Violence Court Case Workers. Four women had contact with the police and three with Child and Family Services, primarily because of the domestic violence.

Positives about Domestic Violence Services in General

A number of the study respondents spoke about ways in which the service/agency or particular staff members assisted them.

(Did these DV services take into consideration your disabilities?) They have been very good with it. My husband made death threats and he was very angry that I took the children, so they [VAW shelter] had a special alert for him. I am very appreciative of what they are doing to help me. It is so affirming to be able to hear from my sexual abuse counsellor. She [CCASA counsellor] is able to validate me where I've not been validated.

Every agency I've contacted, there's at least one thing they are able to help me with. The counsellors here [VAW shelter] have been great. They are good listeners and there is a group. It is nice to talk to the other girls because, I know it sounds bad, but sometimes their stories are a little worse so it makes me feel I'm lucky, because I could have been a lot worse off. It's nice to know that those agencies are there. CCASA [counselling for sexually abused], at night, the number goes to a crisis line and they are volunteers. It's nice to know that people out there care. It makes it easier to deal with things.

She used to take me to my appointments and I really felt close to her. I don't feel close to anybody to really get into details and to express my feelings but there are a few workers and she's [Nurse Outreach worker] one of them.

The social worker helped me access different things. I've got all these wonderful counsellors working for me. I'm plugged in.

She [HomeFront court caseworker] called me at my mother's. It was miraculous that I was there. She took me to the court house at 11:00 and the judge heard the case. She [court support counsellor] explained that she was not a lawyer, she was the court support counsellor, and she led me through the legal system. I thought, "Thank God". She was there to meet another client, so she helped both of us.

Police and Children's Services Involvement in Domestic Violence Situations

While dealing with their abusive partners, four women had contact with the police at least once, seeking physical and legal protection. In three out of the four cases, the women perceived the police intervention as helpful.

He threatened me Saturday morning when I came here with charging me with kidnapping our daughter. A neighbour said, "Call the police; they will know what to do". I called the police and they said, "I strongly urge you to contact the Calgary Women's Emergency Shelter". I phoned and came in. Sunday night I told him [partner] I was in the emergency shelter and he threatened to go to a lawyer. This is how I met the court support counsellor [HomeFront].

I ended up phoning the police and child welfare and they came and helped me get out of the house because he [husband] wouldn't leave. So I left the house and him and everything besides my car and my children.

I called the police. The police caught him on the bus leaving my neighbourhood and arrested him and the guy [abuser] still got bail. This guy has pretty serious charges against him from the past and other domestic abuse charges that I didn't know about. He's got kidnapping charges and the judge let him go. I was stunned.

It was getting so rough at home that I had to leave. My youngest boy had to have open-heart surgery. He [son] didn't need the stress. The cops wouldn't take my ex [partner] away, so that was difficult. I left my boy when he had major surgery. I was going through enough emotion and I went living at a shelter.

Three women had been involved with Family and Children's Services in some way. In two cases, these interventions dictated the woman's actions or supports because of the agency's mandate to protect children living in situations that put them at risk such as domestic violence.

I arrived in the shelter on May 10th. Child Welfare [Child and Family Services Area] came to me on May 7th and said that I needed to go to a shelter in case this guy [abuser] gets out [of jail]. I told them that I didn't want to because I still had my home. I was scared that if he got out he would kill me. I'm pretty sure if he sees me he'll try. But they wanted me to go that week and I was saying there was no point as long as he was still in jail. Eventually I agreed that I would go to the shelter and I asked the worker, "Are you going to take my children?" She said, "Not if you go to the shelter". So I came to the shelter; found out the next day he [abuser] got bail. Wednesday I just wanted to go home and the worker said that I couldn't.

Somebody contacted her from Children's Social Services. They told her that my sister can no longer live there. She is not safe with the children of my friend and when she gets out of the hospital she should not keep her in that house. They say they are just protecting the children, not protecting my sister. They want my sister to stay away from people but not give her help. Maybe it's drugs, they so hate drugs. I told my friend, "How come they want you to kick out my sister and at the same time they don't want to give her help. Where is she going to live?"

Challenges Dealing with Agencies/Services

One of the greatest challenges mentioned by the participants was the lack of understanding about the effects and impacts of disabilities by domestic violence service workers and the effects and impact of abuse by disability services staff:

There are brain injury counsellors and there are family violence counsellors, and they are separate. The brain injury counsellors understand [my memory problems]

immediately but the family violence counsellors don't. They say, "You can't remember her dreams" but do not see how this is a challenge for me. I don't mean they are not helpful, the people here have been beautiful, but I told one counsellor that I had problems with short-term memory and she gave me sheets, physical pieces of paper where I can read and re-read again if necessary. It is information about second stage housing. But it is hard for me to read and really get the meaning of those papers. I've gotten a different counsellor every day. It means that I'm repeating myself every day (crying).

Difficulty accessing housing services, whether shelters for abused women or specialized housing for individuals with disabilities, was another key problem.

There is U.R.S.A [Universal Rehabilitation Services Agency, residential services for developmental and physical disabled]. They only accept people on AISH. If you are on AISH you or are handicapped or sick. This place gives you your medication, makes sure you take it. You have a nice big bedroom with your own bathroom and it's all on a main floor, so if you are in a wheelchair, they accommodate you. They take you to your appointments; make sure you get there. They don't have a wait list; they had a list before, but people's circumstances changed, they'd already moved on, so they stopped having a [waiting] list. I have to phone every month and she [worker] can't really tell me if there is going to be a vacancy. I imagine people living there wouldn't want to leave if it's that good.

I've been turned down by a few shelters because I am blind and shelters require independent living. I can understand the liability issues on their end. However, there is no way for them to understand how independent and capable I really am. I was turned down a few times before we got here [Sheriff King VAW shelter]. I felt discriminated against. I asked the other shelter, "Are you in any way prepared to deal with disabled women?" They said, "Unfortunately no." I think disabled women are at higher risk of some type of violence in their life because they are disabled.

They have a ramp for wheelchairs and stairs and an elevator but I couldn't go there, they said, because of fire regulations. I said I can get down the stairs, I just can't climb back up and why would I want to go back to a burning place? They said no.

Difficulty accessing services besides housing was mentioned by several respondents:

I found out about CCASA [counselling for sexually abused] through the hospital. They came and offered free counselling. I have a worker there and she's trying to get me into counselling. I don't know when yet. I expressed in May that I was interested in going to the counselling so it's a matter of when someone can see me. I keep calling her every other day or so, just to let her know that I still want to do this.

The only service in Calgary that assists me with being blind is the CNIB, the Canadian Institute for the Blind. I've been a client since 1992. I've had a really good experience. It has been hard to access at first, especially in outlying areas. A few years ago, I lived in northern Alberta and the closest agency was in Edmonton. They would send out a CNIB nurse to assess me, at that time I was classed as "low vision." I needed magnifying glasses or writing stencils that help you write in a

straight line, specialized pens, basically really hard nylon-tipped felt pens. After I moved to Calgary, this agency was very accessible for me.

It is frustrating. Different programs have different criteria for different disabilities. That's another frustration because you may have one or two, but you need to have three of the symptoms to qualify. So it is kind of "hit and miss" on certain things. You just have to make the best of it.

It is hard to find the information, unless you have someone that refers you. Looking in the phonebook is not a good way to find information, I don't have internet, I don't have a computer and that seems to be essential these days. When I ask, everybody tells me "check the computer." Even if you know of a resource, it's hard to find. When I started getting sick I looked in the phonebook but you don't know where to look. So trying to get avenues is hard. Once you get into programs, usually referred by a doctor, it's easier. However, on your own is frustrating. There are always little hoops that you have to follow and criteria you have to make. At first they were saying, "You belong here" and then they would say "No, you belong to a different one," so a little bit of shuffle before entering a program was a tad annoying.

Other women mentioned difficulties accessing benefits to which they are entitled:

My [disability] worker has been pretty good. I like her and she has been helpful, but it's all policies and her hands are tied. If you are going to have your electricity cut off that very day, they'll one time pay it for free. But that's been used. I've been on this for many years, so there is another onetime thing that they'll pay, but then you have to pay them back. So now it is totally shut there. This is how much you get and that's it. She [disability worker] does help with things, like the dentist is not covered. She'll tell me, "You have to send this in as a special request and be rejected 3 times and write letters to appeal it." She tells me the steps. She has been patient with all the stuff coming back and forth but to work on one tooth took two years. You have this tooth hurting for two years and you can't get anything done. She's way over-worked and probably underpaid. She can't even really take the time to go into those details. She knows some things but she is more the financial link, not emotional or mental.

I'm on AISH and CPPD [Canada Pension Plan Disability] is still in effect on AISH. So I thank God for her [disability worker's] help because now I'm getting \$700 a month for me and \$200 for [daughter]. But they didn't tell me about this before. I learned that there is thus financial help for [daughter] when she was 6 and half years old. I said "what about my child". She [daughter] was born in 2002. [Worker] said "You should have been getting money for her [daughter] all along. But now we can't go back that far." (I: Nobody told you about it?) That's the government and that's how they inform people.

Victims of Crime have a two year time limit, so I have to provide proper documentation as well as proof that the incidents and injuries occurred. I have to provide psychological assessments if it is psychological damage. I have to do prove that the damage occurred. They need a list of references to contact for additional information. They need a psychological assessment from my psychiatrist stating that

I've got post traumatic stress disorder and explaining what level is it. There are different types and different levels of the mental disabilities, so they would contact my psychiatrist and counsellors for that information. I have to provide a justifiable reason as to why I have exceeded the two-year time limit since the abuse. Most people don't know about this program, so they don't apply within the time limit.

Having to access multiple services to meet one's needs was also problematic.

I managed to find support through the Family Centre [Family intervention and home support in Edmonton], to help me learn skills to be organized because you have to go to a different agency for everything, so it just gets overwhelming. There is always a program you can do. So it is overwhelming. They want you to be functioning too (Laughs). I want to be functioning.

[How do you deal with so many workers, services?] After a while I became numb. I stopped opening up and that wasn't good. It made me more stagnant, not wanting to go anywhere. How did I gradually do it? I am connected to a service which is not in this area. I will access that. I know there are agencies out there that can help; it's just a matter of accessing them when it's needed. I don't want to overuse it, because I know there are other people that need it more than I do, even though I am in need. So I need the service right now but I'm thinking some other people are off services a little bit; they are the worse cases and they need it more than I do.

Sometimes the programs that the women did access did not live up to the promises:

I used Access Calgary, but only twice. The first time they went to the wrong address and the second time they were really late. It was too late. So I don't have much faith in them. But I've talked to other people and I might try again. I'm going to fill out papers again for that because I'll be able to go from place to place in the winter time with an electric chair.

Inappropriate interventions or unhelpful comment were noted by several women:

When I went to the other shelter about 8 years ago, the first thing the counsellor said was, "He couldn't have beaten you too bad." I said, "Excuse me?" She didn't see the bruises because some were already faded and she said, "He couldn't have beaten you too bad because you left your kids with him." That attitude was upsetting. She never offered me anything. I was never offered any housing options. When I left, they gave me a sheet that showed the Drop-in homeless shelter and those places. One lady commented, "I don't think you are trying. We didn't get a phone call." I said, "I'm leaving the phone number at work. I don't want to leave this number." So nobody asked me if I applied for housing or other things. I asked many times, "Can you help me with the computer; I don't know how to look." They didn't help me. So my experience the first time at the shelter was that they weren't there to be helpful.

I was thinking about that phone call to the Distress Centre. Maybe there should be a separate one for women in this situation, someone that has a little more empathy, because I threw everything at her, I'm going to be homeless, my health's not good. She didn't sound like she cared or wanted to talk to me. She made me feel like I was a piece of garbage and was wasting her time. I don't know if I got a certain person that

day. Not everybody can be pleasant all the time. It's sad. A couple of times I wanted to talk to someone, but I didn't call there.

In another situation, a disability service had assigned in-home support workers to assist a woman. Their lack of understanding of the dynamics of intimate partner violence interfered in the woman being able to safely disclose the abuse:

They knew something was wrong. They couldn't pin point it because I couldn't say anything. The abuser would just cover it up. They were saying, "How can we better understand" or they would try to be there for me but that was not enough. Because the abuser was there, I didn't say much to the workers; I didn't want to rock the boat. I didn't want to expose myself. I didn't want him [abuser] there. I just didn't do anything; I wasn't myself and it showed.

Participants' Suggestions to Improve Services

An important aspect of this research was eliciting the participants' suggestions about what services should be in place. Overall, the respondents spoke about services that might exist but they did not know about or they identified some services that were missing.

Five participants commented on their limited knowledge regarding services that addressed the challenges associated with their disabilities. They recommended more resource centers or networks that should provide outreach to the persons with special needs:

There should be outreach. Maybe there already is. Maybe there things I don't know about. But a place to go, like outreach; a meeting place to deal with things and people to show you where you can deal with things, or point you in the right directions, somebody that is trying to help you.

You have to let people know what is out there because the information is missing, so much that I started looking on my own. Even when I was leaving the last shelter, I sat there watching how they did not give me any resource.

Six participants highlighted that their biggest difficulty was dealing with their issues of abuse and disability separately. They suggested that the professionals assisting persons with disabilities who have also been abused should be trained in both areas. Additionally, the workers should be able to make referrals to address their basic needs. In this way, professionals could provide a holistic approach in services, minimizing the risk of inconsistency.

What would have been helpful for me is if I didn't have to go to so many different agencies, like one agency that could help me with a lot of my stuff. I found it stressful, always searching for a place and then sometimes having to go to three different places. It can be overwhelming. So it would be nice if you just had one person to go to and they could help you with the different things.

A brain injury counsellor who is also a family violence counsellor is what I need, but family violence counsellors are all I get. Even so, I'll make every use of them because I can't do this alone.

One thing I would like to see across the board is that every shelter is educated about disabled persons and has a better way of determining if disabled persons could adapt to living in the shelters. All I was told in the shelters [in which] I was refused was

about independent living; you are on your own. Disabled people should have somebody who can help them do what they can't do on their own. I am very independent but some things, as simple as they may be, I require assistance with, for example using the microwave.

Three participants commented on the need for more domestic violence counselling as well as better crisis counselling:

Regarding domestic abuse counselling, there is only the once a week session. I think they should have it more often, maybe twice or three times a week. Once a week for a few hours is not doing anything. They wonder why these women go back to their spouses; because it's not enough support.

When it comes to groups and counselling, there needs to be more than one day a week. There are seven days in a week, choose two, it's not hard. You have seven days; why can't there be two or three days? Other programs, such as anger management, AA [Alcoholic Anonymous], NA [Narcotics Anonymous], offer support more than once a week.

Maybe there should be a separate crisis line for women in this situation, someone that has more empathy. She didn't sound like she cared or wanted to talk to me. So have a line with someone that has more sympathy for people or is more able to deal with it.

Two participants recommended more flexibility, consistency and follow up in providing services for abused persons with special needs:

They would be followed up appropriately; because in the case of a person with mental health you can disappear off the face of the planet and they won't even really notice. If you stopped taking your medications or if no one is following up saying, "How are you doing" or "It's been six months so how are you doing?" There are short term services but nobody really follows you on the long term.

The policies don't have to be in stone. Somebody could have some more service without it taking a year because what good is it going to do you when you are in a different crisis by then. You have had to deal with that the best you could. So things that I could go to my worker and say, "This is where it is right now."

One participant suggested that counselling for abuse and disabilities should go beyond the support groups that were typically offered:

It's great to see that they have groups where people can support each other with their problems, but sometimes the government and agencies need to do more. They push everyone into support groups but they forget that we are all sick. We can help each other to an extent but we are all drowning, so they should not put the emphasis on us making ourselves better. Obviously we have to take responsibility for our part of it but when you have so much pressure, especially for people mental illness and abuse, then you also need another kind of help.

Three participants commented on the need for education to minimize the stigmas around disabilities and abuse:

Definitely the stigma would be addressed. A perfect city would be a place where people wouldn't have to feel bad or different or strange because they have a

challenge. Especially with abuse; abuse has a stigma also. People are more aware that it happens to some degree to everybody. We might not all have many problems but everyone has someone in their family that has at least one problem.

Education and sensitization is a really big issue for any disability. It would be nice if there was more than one service like the CNIB [Canadian National Institute for the Blind]. This is the only service that I'm aware of. There are other services but they are not easy to access; I find it lacking because the waiting lists are huge. For instance, the mobility instructor is the only one in all of southern Alberta. All public services should definitely have more education and more sensitivity and acceptance because some people just flat out don't accept it.

The biggest part is understanding what the disability is. Whether it is the person who is helping the individual with a disability or the person who has a disability. In the case of the disabled person, accepting and being aware of their disability is very important. Awareness is big when you have disabilities.

Several respondents commented on the need for resources or programs to address their basic needs. This was identified as their greatest challenge and the most important area for the study respondents. Six participants highlighted that the greatest help would consist of an in-home support worker who could assist them accomplish basic tasks and overcome isolation:

The one I haven't found is somebody helping you with tasks that are stressful. They have that help when a person has a physical disability, they might have someone drive them somewhere and help them get groceries. But if a person has a mental disability they can't really go and do things either, but you just can't see it.

What I like is casual connections in services. Have someone say, "Can I help you with anything?" If you tell them, to have them offer their help. Have services that are more flexible.

Better access to somebody coming into your home once or twice a week, to help with basics. Some areas of housecleaning I have a difficult time with. Dirt does not show up to me. I'm able to do my dishes, sweep, and mop the floors when I can; things like bathtubs are difficult. Somebody who is consistent and will be there every week, so that you can plan errands and have your mail read, go grocery shopping for the week. You will be able to stay in your budget.

Seven respondents also mentioned the lack of appropriate transportation resources:

Transportation for mentally disabled is a huge need. They [individuals mentally disabled] have many appointments. I didn't have a car. Until this year we did everything on the bus so sometimes it is difficult.

It would be useful to give me a bus pass to cover transportation. Why did they give me these numbers because I called them all and one was annoyed, "How did you get this number, we're not taking patients." Or they picked one place way across town. When I'm sick, the last thing I'm going to do is hop on a bus puking or being dizzy and going far away. To get things closer, convenient would be helpful for me.

The participants all mentioned that the financial support they received was not covering their basic needs. Two respondents commented extensively in this regard:

One of the biggest needs is housing. I don't know why they took off rent control. More housing needs to be available. I thought that the shelter staff might have had an apartment, some connections to allow me to stay there for a month. That's big, because not knowing where you are going is hard. I have stuff everywhere. I'm freaking out because it's going to be cold and I don't have all my clothes (crying). I have clothes at different people's houses and I feel like an inconvenience.

The biggest thing that could help somebody with a disability and sexual abuse issues, (would be) if I could find somebody even for six months to help me out a bit more financially. Whether it would be grocery cards or anything. Because my cheque just doesn't do it. Finances are important for people going through this.

The same participant explained that her first priority was addressing the trauma related to her history of sexual abuse. However, she believed that this could not be addressed until her basic needs were met:

I would really like help financially for a while, as I go through this intense sexual abuse healing. That should be hard enough. Then just function by getting to my doctor's appointments, my counsellor appointments, and daily getting by. That's one service that would be very helpful.

Another participant spoke about the need to allocate more government funds for programs in general:

Obviously, money is the key. They'd have to change the way money is spent. I'd choose the priorities but at the same time, when you see a social problem solved to a large degree. For example, 10 homeless people or 10 people with disabilities end up getting a life and becoming part of society.

Summary of the Themes from the Experiential Interviewees

This chapter described the participants' challenges related to their physical and mental impairments. An important factor that needs to be repeatedly mentioned is that most of the interviewees were dealing with multiple chronic health conditions that constituted complex disabilities. Thus, the professionals assisting persons with physical and mental health conditions need to take into consideration the complicated needs associated with these conditions.

Notably, the interviewees' discussions about services focused mainly on difficulties accessing such basic needs as finances, housing, food, transportation, employment and food. Given that six of the ten women were living in emergency shelters for abused women at the time they were interviewed, this should not be surprising. All were in transition when we spoke to them and were in the process of accessing services to meet such core needs.

A major difficulty identified by the participants was a lack of appropriate financial support. The participants identified their mental and physical health conditions as a significant barrier to their full or part-time access to income-generating activities. As examples, some respondent's job applications were rejected and several could not access career development programs tailored to their special needs.

Further, the women stressed that food bank programs did not take into consideration their needs determined by chronic physical conditions, which aggravated their physical and mental health. The government assisted income support programs proved to be insufficient in covering the participants' expenses when considering their special health assistance needs, medication, and housing. These challenges suggest the need to educate employers, career development programs, as well as greater financial assistance for persons with disabilities.

The participants disclosed complex histories of violence, abuse and control. The majority of the participants revealed having been the victims of multiple forms of abuse in addition to multiple abusers in intimate relationships, extended family, and in public. This was not surprising, given the vulnerability of persons with chronic mental and physical health conditions. However, this finding suggests the need for appropriate counselling and support that specifically addresses violence and abuse.

Seven participants acknowledged the interrelation of abuse and disability. Four respondents identified disabilities as a major cause for the abuse and three women disclosed that they had developed disabilities in reaction to the abuse and violence. The majority of the participants commented on the tremendous stigma and discrimination related to both disability and abuse. As such a more holistic approach to the issues of abuse and special needs must be developed and instituted by professional agencies.

Finally, the participants disclosed great isolation in their personal and professional life. They identified few informal supports and few professionals that could assist them in the long term. The women revealed that loneliness and lack of communication generated additional mental health problems worsened their health and their desire to survive.

This study offered the participants a safe and non-judgemental space to articulate their voices in terms of the challenges associated with disability and abuse, the coping strategies, and the respondents' suggestions for service improvement. Overall, the women described the research process as a necessary and positive interaction, appreciating that fact that their ideas were valued as unique insights that will be used to inform service providers.

Chapter Five: Discussion and Recommendations

This research is the second phase of a project conducted by RESOLVE Alberta in partnership with the Action Committee on Disabilities and Abuse under the auspices of Calgary's Alliance to End Violence. The first report, entitled "Persons with Disabilities across the Lifespan: Program Scan and Community Stakeholder Needs Assessment," was authored by Tutty, Moorey, LeDrew, Jesso, Ondejko and Tenzin. It comprised an environmental scan of services specific to individuals with disabilities who have been abused in some manner; and qualitative interviews with Calgary service representatives from both the disabilities and the family violence sectors.

The second phase of the research presented the analysis of interviews with a small number of individuals who have disabilities and have experienced abuse, to gather their experiences and impressions about the services they did or did not receive to assist them in coping with the abuse. In conjunction with the input from the Calgary service providers, their important voices will be used to construct recommendations to improve services and better address their needs. This chapter reintroduces the core findings from the community agency stakeholders, noting those that are congruent with the individuals with disabilities and presenting recommendations stemming from both sets of research respondents.

Summary of the Key Stakeholder's Research

The 20 interviews conducted for the previously completed needs assessment study were with key community professionals who worked either for organizations specific to abuse issues (8), or with agencies specific to disabilities (8) and four other community sectors neither specific to disabilities or abuse such as from health organizations or funders labelled as "community stakeholders" in the results. Congruent with the experiential interviewees, the community professionals agreed that persons with disabilities who experience abuse have a number of special needs that are, in many ways, not being met by the continuum of services in Calgary. At least half of the professional stakeholders were of the opinion that the Calgary community is not adequately addressing the complex needs of these individuals.

Consistent with the voices of the individuals with disabilities, the majority of the professional stakeholders agreed that persons with disabilities commonly experience physical, attitudinal, language and communication barriers that are exacerbated by the increasing population in Calgary. Among the physical barriers identified were inaccessibility to transportation and buildings and services such as shelters. Social barriers included attitudes against persons with disabilities such as sexual myths and assumptions, which were communicated through popular culture, reinforcing their marginalized position. One stakeholder noted the importance of considering persons with chronic mental health problems as within the definition of disabled.

Both the experiential and the professional key stakeholders recommended additional training and education for service providers, counselling professionals, emergency room staff, police and funders concerning abuse of persons with disabilities. Specialized mental health supports was identified as a need for clients at shelters living with a mental illness. Increased awareness around the need of persons with varying disabilities, particularly when they get older was suggested for the public.

Perhaps the strongest service need identified by the individuals with disabilities, the majority of whom were in the process of fleeing domestic violence, was access to basic needs such as housing, food, financial support and safety. Poverty and isolation were also identified by the professional stakeholders as barriers for persons with disabilities in accessing services and community activities. The professionals identified financial supports in serving the needs of abused persons with disabilities as inadequate. Limited affordable housing in the city was also noted as a barrier.

Congruent with the experiential interviewees, the professional key stakeholders suggested policy supports including enforcing universal designs for access for various disabilities, particularly in shelters.

Social, financial, educational, policy, training and education, community wide and research supports were identified by about one-third of the professional key stakeholders as needed for persons with disabilities who have experienced abuse. At its most basic, a number of professionals in the disabilities field need additional education about abuse and a number of professionals in the abuse field need more education about disabilities. As one avenue to accomplish this, agencies could use their combined resources to better meet needs of persons with disabilities experiencing abuse through cross-training and collaboration. Increased knowledge and communication was also identified as needed between domestic violence agencies and those serving persons with disabilities.

Even though the professional key informants did not perceive these needs as being met, almost half acknowledged attempts that have been made by local community agencies including the accessibility of interpreters through HomeFront and shelters such as the Kerby Rotary House, which provides shelter and services for older adults, however, only if the person can provide self-care. Funding barriers were also mentioned in terms of agency's ability to staff appropriately to meet these needs.

The smaller number of experiential interviewees, with a diversity of disabilities, could not speak to the broad range of backgrounds exhibited in the professionals who were interviewed for Phase I. As such, the professional key informants raised additional issues that are important to consider. The services providers identified language and communication barriers, particularly with immigrants and individuals living with mental illnesses. They identified individuals immigrating to Canada as vulnerable due to difficulties understanding English and cultural variations in responding to disabilities and abuse. The professional key respondents suggested that equipment meant to enable communication with persons with hearing disabilities needs to be regularly checked for functionality.

The professionals also discussed barriers to reporting, screening and responding to abuse, and expressed concerns that persons with disabilities whose caregiver was abusing them meant that reporting could result in a loss of supports. Congruent with the information presented in the literature review, universal screening tools were identified as needed along with a clear and consistent definition of abuse and coordinated community response. The professional stakeholders suggested mandatory reporting of abuse of persons with disabilities as it is for child abuse and all cases could be investigated thoroughly using a specialized response team. Additionally, stakeholders recommended neglect of persons with disabilities should be criminalized as it is under the *Child, Youth and Family Enhancement Act* for child abuse.

Recommendations

The following recommendations stem from the analysis of the 10 experiential and the 20 professional key stakeholder interviews with representatives from the disability and abuse sectors in Calgary. These suggestions are offered in light of the deep concerns expressed by all of the key stakeholders that, although some progress has been made, information about the complex and diverse needs of individuals with disabilities who have been abused by others needs to be brought forward to the professionals who work in agencies that provide services to this group as well as to the general public.

These are also offered acknowledging that the Alliance to End Violence Action Committee on Disabilities and Abuse team must negotiate the priorities in a manner that fits with the Calgary community and the resources necessary to proceed. The team has already initiated activities that address several of the recommendations, such as the January 2010 conference entitled, “Ending Abuse of Persons with Disabilities,” with guest speaker, Dr. Dick Sobsey from the University of Alberta, an internationally renowned researcher in the fields of disability and abuse.

Further, the group recently developed a list of TTY numbers for Calgary key resources and agencies and created a generic safety plan to assist individuals with disabilities to safely disclose abuse. The work of the Action Committee on Disabilities and Abuse is ongoing and conversations about next steps will undoubtedly have either touched on or begun to develop strategies that fit with the recommendations below. It is hoped that this document and the recommendations are perceived as supporting the initiatives already put into place by the action group.

Recommendation 1: Develop public awareness materials as an initial step in educating the general public, as well as professionals from all service sectors, about the importance of this issue. Such educational materials will form the foundation for developing other initiatives. Notably, the bulk of the research on sexual abuse is somewhat dated; many studies are from the 1980s and 1990s. Despite this shift of focus away from sexual abuse, the risk of sexual abuse victimization for those most vulnerable, children and adults with disabilities has not dissipated. Continuing to remind service providers, policy makers and the general public about these dangers is critical and a worthy focus for the Action Committee on Disabilities and Abuse.

Recommendation 2: Develop training and cross-training materials (disability to abuse sector as well as abuse to disability sector) as a way to raise awareness of the complex needs of this oft-ignored population. Such relatively simple training for professionals as how to broach the question of whether an individual has a disability or has been abused would be a useful initiative and could also be easily integrated into professional education and training. In addition, training focused on providing appropriate abuse and disability resources should be designed for child welfare and police services staffs.

Recommendation 3: In collaboration with the abuse and disability-specific agencies, investigate funding for innovative strategies to more holistically address the challenges of abused persons with disabilities. Some avenues could be to develop a disability liaison counsellor position in abuse-specific agencies and, respectively, an abuse/domestic violence liaison counsellor position in disability serving agencies. Another strategy would be to

develop outreach counselling designed to specifically address challenges associated with abuse and disability and, importantly, to address the individuals' basic needs.

Recommendation 4: Remind agencies of the need to diversify/expand affordable and high quality counselling opportunities for abused persons with disabilities. Individual and group counselling could offer greater flexibility and longer engagement with the clients. Crisis-counselling lines should more thoroughly train workers in addressing the multiple challenges of abused persons with disabilities.

Recommendation 5: Inform agencies and policy makers about the need for real access to in-home support workers. Paid or volunteer positions need to be developed so that in-home assistance could serve persons with disabilities in meeting their basic needs and overcoming the isolation that was identified as a significant barrier for persons with disabilities who have been abused.

Recommendation 6: Advocate for more education and support programs for the family members of the abused persons with disabilities. This could prove essential in situations when persons with disabilities face less observable forms of abuse such as threats of violence or emotional control in their homes. Through adequate education and support, family members could more easily acknowledge abusive situations and could help the victim to reach appropriate resources in a timely manner.

Recommendation 7: In collaboration with disability and abuse specific agencies, develop a strategy for greater access to long-term, affordable housing. Agencies providing housing services to various populations should be involved in community meetings and other events.

Recommendation 8: The environmental scan of programs identified a range of programs, policies and interventions to more adequately address the needs of individuals with disabilities who have been abused. If nothing else, the scan suggests numerous strategies to better provide for and acknowledge the complex and pressing needs of these persons.

As noted previously, no program or policy can simply be replicated in a different community. Each facet must be considered within the context of the unique needs, social agencies and laws and legislation of each site. The Action Committee on Disabilities and Abuse team must determine the priorities for Calgary and district.

Recommendation 9: Repeatedly remind agencies and services to examine the accessibility of their services for clients across the array of disability forms. Ongoing issues include the need to budget for interpreters (currently at about \$120 for deaf and hard of hearing interpretation) and to ensure that offices have the capacity to accommodate those with physical limitations such as wheelchairs.

Recommendation 10: Beginning in the mid-1990s, the Calgary Domestic Violence Committee developed and implemented domestic violence screening protocols in 64 Calgary community agencies. Although still utilized by a number of organizations such as hospital emergency rooms, in some agencies the protocol has been forgotten or misplaced. Specific instructions, including for example, who to ask to translate, have been developed for some and could be integrated into other agency screening. Reinstating the protocol project with updated considerations for persons with disabilities who have been abused would be timely.

Concluding Thoughts

In accordance with the literature on the prevalence, nature and needs of individuals with disabilities from across the life-span who have also been abused, the experiential and professional key community informants from the Calgary district highlighted the need for special services, responses and acknowledging the unique needs of persons with disabilities who have been abused. While the city has a number of excellent agencies specific to disabilities and specific to addressing violence in its many forms, seldom have these agencies collaborated in the service of individuals with these multiple and complex needs.

The development and ongoing work of the Action Committee on Disabilities and Abuse team is an excellent first step in raising awareness of these important and previously ignored issues. It is hoped that the resources in this document, from the literature review, environmental scan and comments from experiential and key community stakeholders provide support and additional direction to the team and its mission.

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Appendix I: Interview Guide

No Longer Silent: The Service Needs of Persons with Disabilities Who have Experienced Abuse and Sexual Violence Interview Guide – Persons with Disabilities October 2008

Script: My name is _____ and I work for RESOLVE Alberta, part of a tri-provincial research institute on violence and abuse based at the University of Calgary. RESOLVE Alberta has contracted with The Alliance to End Violence Persons with Disabilities Task Team to conduct this needs assessment to identify what could better assist persons with disabilities who are currently or who have experiencing abuse across the life span. The Person's with Disabilities Task team is a group of domestic and sexual violence service providers, disability service providers and researchers who came together out of a mutual concern for persons with disabilities who are experiencing abuse

1. What Calgary services assist people with your form of disability? Have you used these services?
2. Did you disclose your abuse to any of these disability services? What response did you receive? Was it helpful? How did the workers address your abuse?
3. Did you disclose your abuse to any family or sexual violence-specific services or agencies? What response did you receive? Was it helpful? In what ways did the workers take your disability into consideration?
4. What needs to happen to better serve people with disabilities who have also been abused?
5. If in the next five or ten years, Calgary was to become a model community in better addressing the needs of persons with disabilities who have been abused, what would need to be developed? How would things be better?
6. What needs to be in place to prevent such abuse from occurring in future?
7. Do you have any other comments or suggestions?

Just so that you know, the Alliance to End Violence Persons With Disabilities Task Group is developing an accountability group of individuals with disabilities to inform the work of this task team. If you might be interested I could give you the contact person's name: Kelli Moorey at (403) 283-3013 ext. 230.