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**Persons with Disabilities and Abuse Across the  
Lifespan: Environmental Program Scan and  
Community Stakeholder Needs Assessment**

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by

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

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 Law 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 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 sexuality education. 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 Roeher 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 impacted 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 impacted 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 reported and substantiated as maltreated and children who were not reported as maltreated. The results indicated that there was not an increased reporting risk 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 report of maltreatment. Rather, children with marginal functioning were at a greater risk of report. 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 found 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 have substantially restricted access to appropriate sexual issues (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. More people with disabilities should be served within the community rather than in institutions.

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 Shneiderman (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 Uliny 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 affects humans generally, it negatively and seriously impacts 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 were 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, et al., 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, Swedlend, 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 what women with physical disabilities do 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 89% reported abuse had occurred in the past (conclusion 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 impact 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://dictionary.reference.com/browse/access> 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, 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 is 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 impact 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, Bou-Saada (2003) found that 99% of the programs in North Carolina provide service to at least one women with disabilities (physical or mental) within a year, 85% offered shelter services to women with physical or mental disabilities and 94-99% reported 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 of 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 administrated 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, 2001; 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 20<sup>th</sup> 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 Roehrer 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 impact on 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 impact 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, 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 location 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 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 previously, 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: An Environmental Scan of Services for Disabilities and Abuse**

This chapter presents the results of a best-practices review/environmental scan of established programs that address those with disabilities. The environmental scan was considered an important element of this project for a number of reasons. First, while a number of topics have received considerable attention in the field of domestic and sexual violence, relatively fewer resources are available that focus on disabilities. In the same way that the literatures 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 environmental scan focused in a comprehensive manner on all of these topics, although it was not an exhaustive review.

The review draws together resources on abuse across the lifespan. 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 develop 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.

Thus, the review consisted of a comprehensive search of resources across various forms of violence and disabilities using the literature and the internet as the major sources. The results provide information on a range of successful projects across North America that may guide the development of Alberta-made strategies to address disabilities and domestic and sexual assault.

### **Overview of the Environmental Scan**

In general, the programs/services identified in the environmental scan (see Table 1) fit within the following nine categories. Nevertheless, a number of the programs presented in Table 1 focus on more than one activity. Each category is briefly described below.

- **Public Awareness Campaigns.** These programs provide information to the general public about the nature of the abuse in the hope of improving identification and disclosure. They include radio and television spots and other information strategies such as brochures or websites where the goal is to educate the general public as well as individuals that could be affected by abuse.
- **Identification:** These include services or venues that facilitate disclosing abuse such as telephone “hotlines” or websites.
- **Training & protocols.** Training programs are for professionals who work with those affected by abuse and disabilities. Protocols are agreed-upon mechanisms that organizations follow when an individual with a disability discloses abuse.
- **Counselling/support/advocacy.** Counselling services provides a range of interventions aimed at ameliorating the negative effects of the abuse either through in-depth therapy or support. The intervention approach could be offered in individual, family or group sessions or combinations of these.

- Legal services/advocacy: These programs provide specialized support to individuals with disabilities who have been abused, to safeguard and prosecute the criminal aspects of the abuse.
- Disability accommodation/shelter: This category refers to the extent to which services such as counselling agencies and shelters accommodate to the needs of individuals with a variety of disabilities.
- Legislation/Public policy: i.e. right to intervene/EPOs: This type of intervention is with respect to legislated strategies or public policies. Examples include legislation and policies that mandates the right to intervene and specific legislation that could address such issues such as emergency protection orders,
- Investigation/Criminal justice system intervention: police/Crown prosecutors: These interventions are specific to the police or criminal justice response to specific issues. Included are specialized police or Crown prosecutor units, or specialized teams of other professionals, such as social workers, that work from within the criminal justice system.
- Prevention. These primarily school-based programs for children teach about different forms of abuse, risk factors and strategies to disclose if abuse has taken place. The majority of the programs are labelled “universal” as they are targeted to entire populations rather than to groups that already have the problem. The prevention programs identified in the table are from a resource manual of school-based abuse prevention programs (Tutty et al., 2005).

### **Commentary on the Programs**

The programs presented provide an array of focuses from broad public awareness and prevention programs, to those dealing with identifying those affected by abuse, to the counselling approaches necessary after abuse has been disclosed. This breadth of focus provides a number of strategies that communities interested in enhancing their responses to the problems of the abuse of individuals with disabilities could address.

Several of the programs/policies are specific to one form of disability, particularly in the school-based prevention programs. Others address the range of disability forms, focusing on the generic needs of individuals with disabilities who have been abused. While there are a number of similarities across the various initiatives, whether in Canada, the United States or Australia, each developed in response to the unique needs and characteristics of their site. No program could be wholly replicated; each must be designed to fit the legislation, policies, services and the expressed concerns of these individuals and those who work with them.

Notably, few of the profiled programs have been evaluated; thus the term “best practices” is not appropriate. The programs are mostly at an early stage of evidentiary development, and are more aptly described as “promising practices.”

Table 1: Disabilities and Abuse Programs

Focus	Program	Contact Information	Program Description <sup>1</sup>
<p>-Public Awareness -Prevention -Training -Counselling</p>	<p>Disability Services ASAP (A Safety Awareness Program) Safe Place</p>	<p>PO Box 19454 Austin, TX 78760 USA Phone: 517-267-SAFE or TTY: 927-9616 <a href="mailto:Info@SafePlace.org">Info@SafePlace.org</a> <a href="http://www.safeplace.org/Page.aspx?pid=317">http://www.safeplace.org/Page.aspx?pid=317</a></p>	<p>Disability Services ASAP (A Safety Awareness Program) is an award-winning, statewide program in Texas designed to promote healthy and violence-free relationships for persons with disabilities. The program provides a comprehensive array of prevention and intervention services.</p> <p>The program’s services extend to children, youth, and adults with any type or severity of disability, including persons who have physical, sensory, cognitive, psychiatric, developmental, acquired, or multiple disabilities. It also targets loved ones and it targets professionals in the disability and/or domestic violence, sexual assault and other crisis fields. An advisory council of persons with disabilities and professionals guides current activities, program development, and expansion initiatives.</p> <p>Disability Services ASAP offers education for adults with disabilities to prevent sexual abuse, to increase awareness of domestic and caregiver violence dynamics, to plan for personal safety, and to promote healthy relationships.</p> <p>Training relating to sexual abuse, caregiver abuse, and domestic violence prevention as well as sexuality education is available for families and professionals. The education covers vulnerability factors related to abuse/violence faced by many individuals with disabilities, strategies for preventing abuse, techniques for providing abuse prevention and sexuality education, information on detecting and reporting abuse, and tactics to effectively support persons who are victimized.</p> <p>The continuum of services includes free individual and group counselling for persons who have experienced sexual abuse/assault, domestic violence, or abuse by a caregiver. Counseling is designed to promote healing and recovery, to provide education to reduce the risk of future abuse, and to offer information to explore safe options and access necessary community resources.</p>
<p>-Public Awareness -Training</p>	<p>Wisconsin Coalition Against Sexual Assault</p>	<p>Contact WCASA's Disabilities and Aging Program Coordinator for more information. <a href="mailto:tiffanyl@wcasa.org">tiffanyl@wcasa.org</a></p>	<p>The Wisconsin Coalition Against Sexual Assault works to bridge the gap between the systems that work with people with disabilities and older adults and those who are victims/survivors of sexual violence. This is achieved by:</p> <ul style="list-style-type: none"> <li>- Encouraging cross system collaboration</li> <li>- Providing technical assistance</li> <li>- Creating educational resources</li> </ul>
<p>-Public Awareness; -Training; -Counselling and Support</p>	<p>Communities Against Rape and Abuse: The Disability Pride Project</p>	<p>e-mail: <a href="mailto:info@cara-seattle.org">info@cara-seattle.org</a> phone: (206) 322-4856 tty/fax: (206) 323-4113 office: 801-23rd Ave S, Suite G-1 Seattle, WA 98144</p>	<p>The Disability Pride Project increases community capacity to support survivors of sexual violence and bolsters community efforts to promote safety, support and liberation in a manner that challenges rape and oppression by education, strengthening coalitions between people with disabilities and our allies, and by supporting community action that increases awareness of sexual violence, safety, and informed decision-making.</p>

		<a href="http://www.cara-seattle.org/disabled.html">http://www.cara-seattle.org/disabled.html</a>	<ul style="list-style-type: none"> <li>• Develop healthy sexuality workshops for people with disabilities.</li> <li>• Support groups for women with disabilities who are survivors of sexual assault.</li> <li>• Teach community specific peer advocacy and self-advocacy skills if they are assaulted or harassed.</li> <li>• Organize with activists with disabilities to compel the State of Washington to allow people with disabilities who are institutionalized against their will to live in community spaces.</li> <li>• Organize workshops for personal attendants and institutions about sexuality and sexual violence in the lives of people with disabilities.</li> <li>• Create opportunities for young women with disabilities to be mentored by older women with disabilities.</li> </ul>
-Public Awareness	ARCH: National Resource Center for Respite and Crisis Care Services	Disability, Abuse and Personal Rights Project SPECTRUM Institute, P.O. Box 65756, Los Angeles, CA 90065, (310) 391-2420, Ext. 333 <a href="http://www.archrespite.org/archfs36.htm">http://www.archrespite.org/archfs36.htm</a>	Produces annual national conference on abuse and persons with disability; conducts research and produces reports on abuse and disability; provides training and produces training materials for both abuse response service providers and disability related service providers. Provides advocacy services for persons with disabilities related to civil rights and abuse related issues.
		<b>National Center for Child Abuse and Neglect (NCCAN)</b> P.O. Box 1182, Washington, DC 20013, 1-800-394-3366.	Studies the incidence of maltreatment of children with disabilities.
		<b>National Coalition on Abuse and Disability</b> P.O. Box "T," Culver City, CA 90230-0090, (310) 391-2420, FAX (310) 390-6994	Quarterly newsletter and has approximately 250 members whose work includes or specializes in abuse and neglect of children with disabilities. There is no charge for membership. Annual meetings are held in conjunction with the NCPA Conference.
-Training	Springtide Resources Women with Disabilities and Deaf Women's Program	Suite 220, 215 Spadina Avenue Toronto, Ontario, Canada M5T 2C7 Phone: (416) 968-3422   TTY: (416) 968-7335   Fax: (416) 968-2026   Email: <a href="mailto:info@womanabuseprevention.com">info@womanabuseprevention.com</a> <a href="http://springtideresources.net/programs/show_prog.cfm?prog_id=2">http://springtideresources.net/programs/show_prog.cfm?prog_id=2</a>	In response to community-identified needs Springtide Resources set up this program to address barriers to service for abused women with disabilities and Deaf, deafened and hard of hearing women. This program is designed to meet the needs of a range of service providers including managers, counsellors, shelter and crisis workers, victim service workers, police, health care providers and advocates. We build on your group/organizations strengths to create a more accessible, disability and Deaf positive environment for staff, board, clients and volunteers. Specifically, we can offer: <ol style="list-style-type: none"> <li>1. Exploration of effective ways to improve access to services for women with disabilities and Deaf women (including modification of policies, practices and procedures)</li> <li>2. An understanding of the implications for your service of recent and pending legislation</li> <li>3. Training on how to work with visual language interpreters and deaf-blind intervenors</li> <li>4. Follow-up support in making change in your group/organization</li> <li>5. Networking/partnership opportunities with others working to improve access for all</li> </ol>

			women 6. A tailor-made training/consultation geared to your group/organization's needs.
-Policy -Protocol	Disability Services Queensland (DSQ)	GPO Box 806, Brisbane QLD 4001,Australia Toll-free: 1800 177 120 <sup>†</sup> TTY Toll-free: TTY 1800 010 222 <sup>†</sup> Fax: (07) 3224 8037 <a href="http://www.disability.qld.gov.au/publications/abuse-policy">http://www.disability.qld.gov.au/publications/abuse-policy</a>	Disability Services Queensland (DSQ) is committed to providing and funding high quality services for people with a disability. DSQ has introduced a policy to establish standard practices across all services operated or funded by DSQ, for preventing and responding to the abuse, assault and neglect of people with a disability. Through the policy and its accompanying resource booklet, disability service providers put procedures in place to ensure that people with a disability have safe, high quality services and are free from abuse and neglect. Under the policy, all services for people with a disability provided or funded by DSQ must develop, implement and regularly review procedures and strategies for prevention of and response to instances of abuse, assault and neglect.
-Legislation -Identification/ -Investigation	Boston's Commission for Persons with Disabilities	Disabled Persons Protection Commission 50 Ross Way Quincy, MA 02169 Phone: 617-727-6465 Hotline Number: 800-426-9009 Web: <a href="http://www.mass.gov/dppc">http://www.mass.gov/dppc</a>	Boston's Americans with Disability Act Transition Plan provides guidance in monitoring facilities, programs, and activities of the City. The Disabled Persons Protection Commission (DDPC) offers a hotline that is manned 24 hours a day for reporting incidents of suspected abuse involving adults with disabilities. The DDPC staff will review each report of abuse and determine the response needed to ensure the safety of the individuals involved. Information gathered is entered into a database for review each time a subsequent report is made. An investigator is assigned to each call that meets the jurisdictional criteria. A member of the State Police reviews every report made to the hotline to determine whether a criminal investigation is necessary. Suspected criminal activity is reported to the appropriated District Attorney's Office
-Legislation -Legal services/advoca cy	Virginia Office for Protection and Advocacy: Virginia's Protection and Advocacy System Serving Persons with Disabilities	1910 Byrd Avenue, Suite 5, Richmond, VA 23230 Telephone: 804-225-2042 (Voice/TTY) 1- 800-552-3962 (Voice/TTY) (Toll-Free in Virginia) E-mail: <a href="mailto:general.vopa@vopa.virginia.gov">general.vopa@vopa.virginia.gov</a> Web Address: <a href="http://www.vopa.state.va.us">www.vopa.state.va.us</a>	<b>Developmental Disabilities Program (DD):</b> The Developmental Disabilities Assistance and Bill of Rights Act funds this program to provide legal and advocacy services to assist children and adults with severe, lifelong disabilities who require special care, housing, treatment, and services and who have been abused, neglected, or discriminated against, due to their disability. Problems related to education, residential care, training centers, community rehabilitation programs, infant programs, and activity centers are handled under this program. The most common DD issues include: special education services; abuse and/or neglect of persons in special programs; the right to live, learn, and work in the most integrated setting; assistive technology and assistive technology services to support independence; freedom to make independent decisions whenever possible; and access to programs and services. <b>Protection and Advocacy for Individuals with Mental Illness Program (PAIMI):</b> The Protection and Advocacy for Individuals with Mental Illness Act funds this program to provide legal and advocacy services for people with mental illness who live in a hospital or other facility providing care and treatment for their illness. People who have problems while being taken to or from a facility, getting admitted to a facility, or within 90 days of

			leaving a facility may also be eligible for PAIMI services. Depending on federal funding levels, persons with mental illness who live in the community independently or with family or friends may also be eligible. PAIMI protects the right to: obtain appropriate services; make complaints about services or treatment; ask questions of anyone who is supposed to provide services or treatment; be safe from harm; make decisions about services received; keep records private; and have a written plan in place before leaving a mental health facility.
-Identification -Investigation	Adults with Disabilities Abuse Intervention	Illinois Department of Human Services Springfield Office 100 South Grand Avenue East Springfield, IL 627041-800-843-6154 1-800-447-6404 TTY <a href="http://www.dhs.state.il.us/page.aspx?item=30270">http://www.dhs.state.il.us/page.aspx?item=30270</a>	The Illinois Department of Human Services, Office of Inspector General provides a 24-hour hotline at 800-368-1463 (Voice or TTY). Conducts investigations of abuse, neglect, or exploitation of adults with disabilities in a private residence and connects the victims with needed protection and services. OIG coordinates with local law enforcement and with local and State social service entities to connect victims to needed services. OIG also has authority to pursue orders of protection, guardianship, or emergency placement in another setting. Who can receive these services? Individuals 18 to 59 years of age who have mental or physical disabilities, who live in a private home, and who are unable to seek or obtain help on their own. Anyone can ask on the person's behalf. OIG keeps confidential who called to report an allegation.
-Identification	Australian National Disability Abuse and Neglect Hotline	National Disability Abuse and Neglect Hotline Locked bag 2705, Strawberry Hills NSW, Australia 2012 1-800 880 052; TTY:1800 301 130NRS: 1800 555 677; TIS: 131 450 <a href="http://www.disabilityhotline.org/about.html">http://www.disabilityhotline.org/about.html</a>	The National Disability Abuse and Neglect Hotline is an Australia-wide telephone hotline for reporting abuse and neglect of people with disabilities using government funded services. Allegations are referred to the appropriate authority for investigation. Anyone can call the Hotline to report cases of abuse or neglect or to find out more about the service. The Hotline is open from 8am to 8pm across Australia, seven days a week.
-Counselling	The Butterfly Programme	Catholic Family Service of Calgary 250, 707 — 10 Avenue SW Calgary, AB T2R 0B3 email <a href="mailto:info@cfs-ab.org">info@cfs-ab.org</a> TTY number: (403) 205-5223 Phone: (403)233-2360 <a href="https://www.cfs-ab.org/our-services/counselling-and-community/the-butterfly/">https://www.cfs-ab.org/our-services/counselling-and-community/the-butterfly/</a>	The Butterfly programme provides counselling services and community support for children, adults, and families who are deaf or hard of hearing. Counsellors, who are fluent in American Sign Language (ASL) and sensitive to DEAF culture, provide support in education and life settings. The community support includes volunteer programs, facilitating parenting groups and offering community workshops
Counselling/legal advocacy			
Counselling/legal advocacy	Disability Abuse/Assault	1600 SW 4th Avenue, Suite 900, Portland OR, US, 97201	DART coordinates advocacy, co-advocacy, crime victim & independent living services for crime victims with disabilities. The Disability Assault/Abuse Response Team

	Response Team (DART)	503.725.4040 <a href="http://www.rri.pdx.edu/dart.php">http://www.rri.pdx.edu/dart.php</a>	provides comprehensive victim services for crime victims with disabilities in Portland. DART advocates provide direct services to people with disabilities at various sites, including Independent Living Resources office, and the DA's Offices Services include: -Advocacy within the criminal justice system -Peer counselling and support -Information, referral and advocacy within social service and benefit systems -Victim support groups -Independent living skills training -Safety awareness and crime awareness classes -Workshops on managing caregiver relationships and preventing/dealing with abuse from caregivers
-Counselling -Training -Prevention	Independence First: Accessing Safety Initiative, Milwaukee, WA	Title: Domestic Violence Specialist/Counsellor <a href="http://www.independencefirst.org/services/other/violence_prevention.asp">http://www.independencefirst.org/services/other/violence_prevention.asp</a>	This program is for people with disabilities who are victims of violence and victim service providers in Milwaukee, and area. Goals: -To eradicate violence against people with disabilities. -To teach persons with disabilities to identify violent and abusive behaviours in others and how to protect themselves. -To teach community organizations how to better serve people with disabilities. -To advocate for changes in the current systems that address violence. -Systems advocacy, education and technical assistance is provided statewide. For Individuals: -Domestic Violence Counseling , Individual advocacy, system advocacy, classes on self protection, assistance accessing victim services, information and referral For Domestic Abuse Programs: -Case management assistance, technical assistance, accessibility surveys, staff training Both individual and group abuse prevention classes are offered in addition to the above.
-Prevention	Promoting Alternative Thinking Strategies (PATHS)	Channing L. Bete Co., 200 State Road, South Deerfield, MA 01373; Phone 1-877-896-8532; Fax 1-800-499-6464; Email <a href="mailto:custsvcs@channing-bete.com">custsvcs@channing-bete.com</a> ; Website: <a href="http://www.nrcys.ou.edu/">http://www.nrcys.ou.edu/</a>	Kindergarten to Grade 6, teacher-offered classroom curriculum for deaf, hearing-impaired, learning disabled, emotionally disturbed, mildly mentally delayed, and gifted students. Strong research design-Unpublished: Grades 1 to 3 regular and special needs teachers primarily reported improvements in behaviour and socialization
-Prevention	Kid&TeenSAFE	National Resource Center on Domestic Violence (NRC DV), 6400 Flank Drive, Suite 1300, Harrisburg, PA 17112-2778 or phone 1-800-537-2238, fax at (717) 545-9456,. <a href="http://new.vawnet.org/category/Documents.php?docid=850&amp;category_id=10">http://new.vawnet.org/category/Documents.php?docid=850&amp;category_id=10</a>	Program on child sexual abuse, bullying, dating violence for Grades 1-12 Externally facilitated classroom instruction Suggestive Research Evidence-Unpublished: 21% of students increased their knowledge of personal safety strategies.

-Prevention	Circles II Stop Abuse	James Stanfield Publishing, P.O. Box 41058, Santa Barbara, CA 93140; phone 1-800-421-6534; fax (805) 897-1187; or website <a href="http://www.stanfield.com/">http://www.stanfield.com/</a>	Focuses on child sexual abuse for grades 2 through 6. A teacher-offered curriculum for children with mild to moderate developmental disabilities
-Prevention	LifeFacts 2 Sexual Abuse Prevention	James Stanfield Publishing, P.O. Box 41058, Santa Barbara, CA 93140; phone 1-800-421-6534; fax (805) 897-1187; or website <a href="http://www.stanfield.com/">http://www.stanfield.com/</a>	Focuses on child sexual abuse in students Grades 5 through 10 in a teacher-offered curriculum for adolescents and adults with mild to moderate developmental disabilities.
-Prevention	No-Go-Tell Protection Curriculum for Young Children with Special Needs	James Stanfield Publishing, P.O. Box 41058, Santa Barbara, CA 93140; phone 1-800-421-6534; fax (805) 897-1187; or website: <a href="http://www.stanfield.com/">http://www.stanfield.com/</a>	Child sexual, physical abuse & personal safety Kindergarten to Grade 3 teacher-offered curriculum for young children with special needs (e.g., Deaf and Hard of Hearing, other disabilities)
-Prevention	The Rappaport Curriculum for the Prevention of Child Sexual Abuse in Children	1997 book, Child Sexual Abuse Curriculum for the Developmentally Disabled, by Rappaport, Burkhardt & Rotatori contains the curriculum. Published by Charles C. Thomas Publishing for \$38.95 (US): website: <a href="http://www.ccthomas.com">www.ccthomas.com</a>	Child sexual abuse and sexuality education for children with developmental disabilities in a teacher-offered curriculum.
-Prevention	Making Waves	Partners For Youth Inc., 535 Beaverbrook Ct., Suite B-10 Fredericton, NB E3B 1X6 Phone: 506-462-0323; Toll Free: 1-888-739-1555 Email: <a href="mailto:pfy@nb.aibn.com">pfy@nb.aibn.com</a> <a href="http://www.partnersforyouth.ca/projects.html">http://www.partnersforyouth.ca/projects.html</a>	Focus on dating violence, gender and media stereotyping uses a teen leadership model for Grades 9 through 12 Translated into Braille. Program includes students in special classes. Evaluated
-Disability Accommodation	DAWN (DisAbled Women's Network)-RAFH Canada	110 Sainte-Thérèse Street, Suite 505, Montréal, QC H2Y 1E6 Phone: 514-396-0009(QC); Fax: (514) 396-6585 (QC); Toll free (Canada):1-866-396-0074 <a href="http://www.dawncanada.net/ENG/ENGwelcome.htm">http://www.dawncanada.net/ENG/ENGwelcome.htm</a>	Shelters or transition houses across Canada have been sent a survey to determine whether they are accessible to women with all types of disabilities. As shelters see on a daily basis, violence against women with disabilities is more frequent than violence against non-disabled women. For results see Smith, 2009.

## **Chapter Five: Community Stakeholder's Impressions of Disability and Abuse**

A second major phase of this project entailed conducting a needs assessment of key informants in Calgary who are knowledgeable about the service needs of individuals with disabilities that have been victims of family or sexual violence across the life span. A list of potential respondents was developed by the project research advisory team. The University of Calgary Conjoint Ethics Review committee approved the project.

The semi-structured interviews (see Appendix I for the interview guide) took place primarily over the telephone. However, if the respondents preferred, they had the option of participating in face-to-face interviews. The tape-recorded interviews were from 1 to 1.5 hours in length. The interviews were transcribed verbatim and analyzed using mainstream social work qualitative methods (Tutty, Rothery & Grinnell, 1996).

The 20 interviews conducted for the 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. Notably, though, a number of the respondents were well aware of the broader issues, as is perhaps illustrated by their willingness to be involved in the current needs assessment.

The majority of the stakeholders (80% or 16 of 20) were of the opinion that persons with disabilities who experienced violence have specific service needs. The stakeholders suggested a number of ways of reducing the barriers and increasing social and community supports for responding to abuse.

This chapter outlines the physical, attitudinal, language and communication barriers that persons with disabilities experience. Language and communication barriers are also discussed, particularly with respect to immigrants and individuals living with mental illnesses. Next, barriers to reporting, screening and responding to abuse are explored. Social, financial, educational, policy, training and education, community wide and research supports are identified as needed for persons with disabilities who have experienced abuse. Lastly, community wide and research supports are reviewed.

### **Meeting the Service Needs of Persons with Disabilities**

An overarching interview question was asking the key respondents, "How well does the current continuum of services in the Calgary community address these needs? What could be done to improve these services?" Half of the stakeholders (10) were of the opinion that the continuum of services to address abuse in the Calgary community is not adequately addressing the needs of persons with disabilities.

*The continuum of service doesn't do a great job serving the needs of persons with disabilities. Many times services are geared to, if you will, "well" clients. So anyone who has a disability, be it mobility, hearing impairment or otherwise, has a great deal of trouble accessing those services. At present, it's very difficult for persons with disabilities. (Abuse Sector)*

*Those needs have not been well met in this community; which is what has fuelled this project. (Abuse Sector)*

*I don't think their needs are being addressed by the community. The Kerby Centre, for example, is wonderful and they will take some people who have disabilities as long as the person is able to pretty much take care of themselves. But if the person's sicker than that, there's no place to go. I deal sometimes with people who are sixty plus but most are between forty and sixty. That [Kerby Centre] would be an appropriate place to go for them except, because of their health, they won't be accepted. So there are not those resources. (Community Stakeholder)*

*Sometimes it can be difficult because, specific to people with developmental disabilities, many mainstream don't know how to respond. (Disability Sector)*

*We did the best job in the country because we're pretty well the only game in the country; we're the only people working in this specific area. So for older adults, we're able to do some things but definitely not all things. (Abuse Sector)*

Two stakeholders commented that obtaining legal and counselling services was challenging for persons with disabilities who were victims of sexual abuse.

*It's hit and miss and some of that is really dependent upon existing relationships with the hospitals or the police or advocates. But, from our experience when we've tried to seek legal counsel or get affordable legal counsel for our clients or an advocate, sometimes that's really tough to find someone who can take that on. (Disability Sector)*

*There's no question that there are some skilled folks that do an awesome job around anger management and sexual health and some really fabulous work and they're specialized. But when you talk about specific to developmental disabilities, there's a few psychologists but I don't know if they had to go elsewhere to get that skill or if it's just from continuously working with the population, I don't know. (Abuse Sector)*

One respondent from the abuse sector commented on the long waitlists for services.

*The biggest thing would be access. Ideally you would have more knowledge, which would reduce risk. Increased access, god forbid, when it does happen because it will and it does, but that the supports and the services are there, not wait-listed, not having to wait a month or whatever to get in and that it's dealt with quickly. It is for safety but then it's the recovery, it's an opportunity for the individual to get in and get support and be dealt with well in order to get back into life in a healthy way. (Abuse sector)*

Another key informant noted that meeting the needs of persons with disabilities depends on organizational leadership and funders.

*It depends on the leadership at an organization and their understanding so that's not happening. Calgary Communities Against Sexual Abuse, and DDRCC and other community members put in a proposal to do capacity building in the organizations that provide services to adults with disabilities. We put it in three times and it was denied three times, so there's a lack of understanding on the funder's part as well. (Disability sector)*

In contrast, however, nine stakeholders (45%) commented that, from their perspectives, a number of services were attempting to serve the needs of persons with disabilities, mentioning, in particular, the Kerby Centre and HomeFront.

*We don't have a TTY system but we have phones that increase the volume. We have brail on our microwave and doors; we try to cater to the individual. (Abuse sector)*

*HomeFront has (the) flexibility to bring in sign language interpreters, contact whatever other supports are involved with those individuals so that they feel supported in the court process, so their voice is heard regardless of their ability to speak or to get to court or to not get to court. (Abuse Sector)*

*They have some great shelters and I know they try to accommodate as much as they can. It's not that they won't take these people if they had the room; it's just that they can't manage the people's health care and health needs. (Community Stakeholder)*

Three stakeholders emphasized that, despite barriers, agencies and service providers were doing their best to providing services to persons with disabilities.

*There's quite a bit of awareness out there. There's movement to put protections in place, procedures so that they are addressed. I don't think anything can 100% protect somebody but certainly they're trying. (Disability Sector)*

*I have communicated nationally with centres that are just starting to deal with crime/violence prevention with people with disabilities; I think in Calgary we're eons ahead of other centres. But, sadly, it's kind of like comparing Canada to Rwanda. We've got more human rights than Rwanda, but what does that say? So, Calgary is eons ahead of other centres across Canada but, there are a lot of Rwandans across Canada. We can advance a lot further yet. (Disability Sector)*

*I don't want to make judgements because some organizations are doing amazing things with really limited money. But, it could be improved. I heard from the disability community that, because services are very fragmented, there's a need to coordinate. (Community Stakeholder)*

One stakeholder from the disability sector emphasized that a collaborative risk management process involving clients works well in that organization.

*We have an extensive risk management planning, monitoring, approval process where we have teams and families and the client involved and, of course, it's monitored and approved by the psychologist trained in that area. We also have mandatory staff training. Then there's more training around specific client needs for teams or staff working with those individuals. We take risk management with the clients quite seriously and dedicate a fair bit of time to set those processes in place. (Disability Sector)*

Another key stakeholder from the abuse sector suggested that the increasing population of Calgary is challenging service providers.

*Calgary's probably overwhelmed with requests and finding it difficult to meet the needs of these clients as fully as they would like. When we collaborate, we see the huge amount of stress they are under to meet the needs. They do the best that they*

*can, just as every social service agency in this city tries to, with the resources that they have and the increased population accessing their services. (Abuse Sector)*

Further, another stakeholder from the disability sector suggested that legislation around persons with disabilities helps identify and deal with abuse.

*The Persons with Developmental Disabilities [task group] does a lot of work with abuse prevention protocols plus the Act to make sure that people know what abuse is, and how to report it when it does occur. (Disability Sector)*

Finally, an informant from the abuse sector described how their organization incorporates client feedback into program planning and quality improvement.

*We've got program evaluation in place for all of our programs to insure quality improvement. One piece that we really pride ourselves on is to continuously gather client feedback of their experience in accessing our programs. Those are the pieces that feed into us being able to provide specialized services to clients who need it. (Abuse Sector)*

### **Reduce the Barriers to Accessing Services**

Another central question in the needs assessment interview was “Do persons with disabilities easily access the available services or do they face barriers?” Ninety per cent of the stakeholders (18) commented that individuals with disabilities often experience barriers when accessing services in the community including physical, attitudinal, language and communication difficulties. They mentioned such issues as the lack of equitable access, social barriers, and language/communication barriers.

#### **Lack of Equitable Access**

The stakeholders expressed concern about the lack of equitable access to services for persons with disabilities, including shelters for woman abuse. Nine stakeholders (45%) identified physical barriers that persons with disabilities experienced when accessing community services including transportation and access to buildings and services.

Four stakeholders commented on the inaccessibility of buildings for some persons with disabilities, particularly shelters for abused women or homelessness.

*One extremely challenging [issue] is accessible services. It's either accessible for a walker, a wheelchair... Whether it's accessible in terms of that woman being able to get personal care in the home, we don't find that emergency shelters are always accommodating. CWES (Calgary Women's Emergency Shelter) and Sheriff King are more accessible. I think CWES has an accessible room on the main floor and a wheelchair shower. I think Brenda Stafford or Discovery House is not accessible. The homeless shelters... I think the Mustard Seed is not accessible at all. Resources that someone with a disability would use for long term care, they are accessible, and they need to be. (Disabilities Sector)*

*All the physical stuff, not just ramps but even, to come into a room, is it wide enough? People don't think about width or turns, like if you're turning one direction and then need to turn another, is there room for that turn? A lot of comfort things are pertinent to people with disabilities, maybe chairs that are a bit wider and for people with more body weight but also someone who's carrying oxygen. (Abuse Sector)*

*Individuals have a great deal of difficulty accessing services. Shelters are not geared for persons with disabilities, from a physical structure standpoint. Someone with mobility impairment oftentimes have physical difficulty accessing services. The services within a shelter, for instance, are geared for more mainstream clientele. So they have great difficulty accessing those services. (Community Stakeholder)*

*Women's shelters may not be accessible. That's a huge issue. (Community Stakeholder)*

Another key informant commented that persons with chronic illnesses also experience barriers to accessing services, especially shelters.

*The shelters don't have the resources, but it might also be a bit of fear. How do we deal with someone with this illness? Maybe some people have a chronic illness; that doesn't mean that they can't take care of themselves, some can better than others. The shelters may think that, if they've got that type of illness, we can't help them, when really they might be able to help. It would be great if the shelters could have a nurse on site. I don't know. It's a tough question. (Community Stakeholder)*

Two stakeholders from the abuse sector were concerned that persons with mental illness experience barriers to accessing shelters.

*Some people don't define disabilities the way I do. A lot of people with mental health issues can't get access to shelters because there's such a worry that their behaviour will pose a threat to other individuals in the shelter. There's got to be some way to work with that or, do we need to create a different system. (Abuse Sector)*

[Do individuals with mental health issues who've also experienced violence easily access the services in Calgary?] *I'm not sure. My best guess would be that they experience barriers in the same way that they experience barriers accessing the health system. They aren't good advocates for themselves, they don't know what to ask for, and they can be turned away by service providers who are afraid to deal with them. (Abuse Sector)*

Three stakeholders reported that persons with disabilities often encounter difficulty accessing transportation.

*Persons with disabilities should [have] the same choice to participate in their community. There should be equitable access. We talk so much about participation, inclusion, civic engagement so access to transportation will hopefully provide that support. But even the Handi-Bus is really hard to arrange -- they're late or they leave... Even for some scheduled trips, it's a challenge to make all the arrangements. So it would be really helpful for the service provider to make their service more user-friendly or accessible. (Abuse Sector)*

*They face very specific barriers related to the nature and severity of disability. It really varies. If you're a wheelchair user and reliant on Handi-bus or Access Calgary, being able to access transportation that works for you. If the building's not accessible then you have to find an alternative way of getting in. Often front room receptions are not accessible to people in wheelchairs because the counters are very high. In terms of the level of awareness, comfort, and training of people, that first response by the front line person may involve hesitation or uncertainty. That's just*

*one small example of someone who has a mobility disability... (Community Stakeholder)*

*The physical barriers are associated with the lack of barrier-free design in terms of physical space. It's the way that things are laid out, the lack of large print, inaccessible buildings, inaccessible transportation systems, being able to get from point A to point B. (Disability Sector)*

One respondent commented that the Kerby Centre shelter for abused older adults cannot accommodate individuals who are unable to care for themselves.

*The major barriers for shelter service are they have to be able to care for themselves, so that's a barrier for someone with higher needs, somebody who is maybe not able to bath themselves or get their own meal. Then they can't use (Kerby Centre) because (they) don't have the resources. So accessibility to this program is limited to those people who can look after their daily needs. (Abuse Sector)*

### Social Barriers to Accessing Services

Half (10) of the stakeholders identified social barriers experienced by persons with disabilities experience when accessing services. Three respondents reported that negative assumptions and beliefs impact accessibility of services for persons with disabilities.

*There are a lot of assumptions that all people with disabilities need a, b, c, d. I think they are unique depending sometimes on the disability. (Abuse Sector)*

*Persons with disability often encounter both physical barriers as well as attitudinal barriers. The attitudinal barrier is often the larger and more difficult to deconstruct. The negative values, beliefs, and assumptions regarding people with disabilities are often internalized and communicated through popular culture. Those beliefs are translated into inaccessible programs, inaccessible services, not having the appropriate supports that people need. (Disability Sector)*

*Public awareness is huge for everybody. People are different, diverse. Often people with disabilities are not treated as well. We need to change that; just because it looks different ... but that's how our society sees these things. (Abuse Sector)*

One stakeholder from the disability sector suggested that sexuality myths existed with respect to individuals with disabilities.

*People with disabilities are not seen as sexual and there are myths around abuse. There are many misperceptions about people with disabilities that work against them. So their needs are professionals and family members and staff who support them, understand those myths and constantly debunk them. (Disability Sector)*

One abuse sector stakeholder commented on social barriers that are experienced by persons with disabilities that prevent their participation in community services.

*Even though we're accessible through those different means, we're still not able to reach those people who are affected by disabilities who may be isolated like the senior population, who's very isolated. A lot of barriers make it difficult to access services like ours. Even though there may be multiple ways of accessing them, those societal barriers make it very difficult. (Abuse Sector Lissa Shivji)*

Another community stakeholder identified poverty as a barrier for persons with disabilities that impacts their ability to access services.

*Funding or poverty is another barrier that more than 50% of people with disabilities face. (Pat Winter)*

#### Language/Communication Barriers

A little more than one-third (7 or 35%) of the key stakeholders commented about the language and communication barriers that are often faced by persons with disabilities, particularly those with mental illnesses and those who are from immigrant populations. Cultural interpretation and supports for disabled individuals reportedly varied.

*Sometimes their language. Sometimes even knowing what's available to help them. It can be embarrassing, all the emotions, angry, or acceptance or denial; emotions that affect everybody. Persons with disabilities have the same and need a really good understanding of their rights and how to exercise those rights. Who do I talk to and how can I make them listen and how can I have somebody advocate for me and be my champion if I can't champion myself. (Disability Sector)*

*We have quite a few with a mental illness, diagnosed and undiagnosed. One of our biggest issues is language problems because a lot of our older people don't speak English. They're older immigrants or refugees. We'll have people, family members who say, "This person is a schizophrenic, has mental illness," When you observe this person you see no indications. You can't directly speak to them because they don't speak the language, so you have to find an interpreter. (Abuse Sector)*

*There's also how a culture deals with disability. How they comprehend this themselves and how the family will respond to it and get help because their language skills can interfere with how you support them. (Abuse Sector)*

*English is often a second language, so there are communication issues. It's a cultural difference and people are thinking they may be abused or might sound abusive when that certainly isn't the intent, but it's coming across that way. (Disability sector)*

*For those with developmental disabilities, some needs might be simply speaking in plain language at a level that they can understand. Explaining what abuse is, what their rights are, because, especially when a caregiver's been abusive, they might not know that that's abuse. (Abuse Sector)*

One abuse sector stakeholder suggested that shelters needed to ensure equipment that meets the needs of hearing impaired were functional.

*They need special communication devices, so TTY lines. I don't think a lot of counselling agencies have done anything to address the needs of persons with disabilities. The Alliance to End Violence does a resource directory every year, which we send out to service providers and we include the TTY numbers. When we call agencies to verify their TTY number is, they often say, "We're not sure what that number is, we're not sure if the equipment still works, if we even know how to use that equipment," and so what happens if they did get a call on their TTY line? Do they know how to respond? (Abuse Sector)*

## Barriers to Reporting Abuse

About two-thirds of the stakeholders (65% or 13) identified barriers to self-reporting, approaches to screening/investigating and reporting abuse of persons with disabilities. Three individuals mentioned a loss of support after disclosing as one barrier.

*We're probably seeing a very small portion of persons with disabilities who are affected by family and sexual violence. They may not be aware that we're able to accommodate their special needs. Depending on who their abuser is, they may not be able to access our services, even though we're available through a variety of means. (Abuse Sector)*

*A person with disabilities may be reliant on another person for their basic care needs be it formal or informal. Systems aren't structured and it limits the ability of the person to actually come forward to provide the support. So if you're pulling someone's primary caregiver, what are you going to put in its place? (Community Stakeholder)*

One stakeholder emphasized the difficult position that abused individuals are in when the abuser is the person who cares for them.

*Reporting's not the biggest thing; a lot of people don't report for many reasons. But people with disabilities, in particular, refuse to report for many, many reasons and it's so disheartening. The fear of loss, especially loss of services, loss of support, loss, loss, loss... How can we make sure that services can be there and the support can be real if that person who abuses them is the person who takes care of them? Is there a way that we can build something for them to say, "Okay, I can let go of this person because they're hurting me, they're killing me." (Abuse Sector)*

## Screening for Abuse

Four stakeholders commented on the need for screening for abuse when working with individuals with disabilities. Two stakeholders suggested the need for a screening tool at intake with all clients.

*One thing that would be handy is a screening tool around disability. A lot of agencies say, "How do we ask? Aren't they going to be upset or scared?" That is an issue, just to say, "Do you have a disability?" could be intimidating. However, if done in a screening tool, I have the right to not answer a question if I don't want to, the person can be given the choice of saying yes or no to the questions. (Abuse Sector)*

*Universal screening is a very good idea. At Canadian Mental Health, people are asked about previous experiences of abuse or current violence in their lives. The education piece for violence and abuse service providers regarding mental illness and for the mental health community around resources and services for people experiencing violence. People with a mental illness are more vulnerable to abuse so part of their service needs is educating them what they can expect in terms of respect. With education around bullying and harassment, service needs with regards to abuse would be the same as any individual who has experienced abuse. Individuals with mental illness may, in some cases, require a more specialized helper who's aware of the dynamics and the symptoms of mental illness in order to treat a person who also has mental illness. (Abuse Sector)*

Two stakeholders suggested that, along with screening, a clearer definition of abuse is needed.

*We'd like a tighter definition of abuse because the way our Act is right now, somebody looking at someone the wrong way could be considered abuse. And perhaps a screening mechanism. Right now if you [receive a report of abuse] you must report it. So tighter definitions of abuse and screening so that everything didn't have to be investigated; we could strengthen some investigations and put more efforts into education and prevention. (Disability Sector)*

*Things are just not set up in the most efficient process to address abuse against persons with disabilities. Across the board, the definition of abuse is not consistent: What constitutes abuse for some individuals is not abusive to others. You have to have one definition if it's going to be a standard across the province. (Abuse Sector)*

### Responding to the Abuse of Persons with Disabilities

Four stakeholders suggested that reporting the abuse of persons with disabilities should be mandated in a process similar to that of child welfare in cases of child abuse.

*There needs to be an independent agency akin to child welfare investigators. You would have a hotline and all alleged abuse and violence to a person with a disability would come in over this hotline. The hotline screener should be some type of officer whether it is a RCMP or a city police officer because they can tell whether there is a criminal element involved with the matters that coming through on that hotline. If a criminal offence hasn't occurred, then the ability to farm out those calls to appropriate agencies, whether it's individual agencies with individual investigators associated with specific disabilities or one group of investigators that's expected to work with any and all disabilities. (Abuse Sector)*

*There needs to be greater awareness of reporting abuse and neglect of persons with disabilities. The policy around that is something that government really needs to be looking at. (Abuse Sector)*

Two stakeholders recommended creating an investigative resource to investigate cases of abuse of persons with disabilities.

*One [issue] is the reporting structure for people who have disabilities. My understanding is they (Cultural Resources Unit) do have one constable in Calgary. However, that's just not sufficient to cover the calls that they probably get. I had called them and on one occasion it was fairly serious and we never did get a call back. (Community Stakeholder)*

*In conversations with the Domestic Conflict Unit, they've said they don't have the expertise to work with persons with disabilities and they really count on the liaison positions in the police. To me, that's a significant gap. The persons with disabilities position is a liaison position in the Cultural Resources Unit. That position was vacant for months. It's not an investigative position, so they have no investigative authority. There's a lot of confusion about: a) why the position is in the Cultural Resources Unit and not attached to some vulnerable victims unit and b) why it isn't investigative. I think they need is an investigator with special expertise in investigating crimes with persons who have disabilities. (Abuse Sector)*

One key informant from the abuse sector suggested that neglect needed to be criminalized as abuse against persons with disabilities.

*Legislation has to be changed, definitions of abuse have to be standardized and neglect has to be criminalized and added. To find somebody guilty of abuse against a person, you need to remove the word 'intent' from the current policies. If you have the responsibility to care for a person with a disability, you have to provide that care in the best interest of that individual so they don't get harmed. When you haven't, where say, a person with a disability who's non-verbal is becoming withdrawn and losing weight and perhaps more and more isolated; those are neglect issues and you'd have to compare to it to their base functioning. (Abuse Sector)*

This stakeholder further suggested supporting the prosecution of cases of abuse involving persons with disabilities.

*Physical injuries, sexual injuries, are more black and white but neglect really compromises an individual's daily living, I think there should be a statute for it to be criminalized if it reaches a certain level. In part, the whole system has to realize just because a person has a disability doesn't mean that they cannot get up on the stand or provide their voice by a sign language interpreter or a communication device or computer device. That doesn't make them a bad candidate for prosecuting the offender. (Abuse Sector)*

Two other abuse sector stakeholders suggested creating specialized response teams for responding to cases of abuse of persons with disabilities.

*In Boston, the response team has a police officer and social worker, so if it's not a police response that's required, you have an advocate to ensure that the person can access the services they need. There's a huge gap in service here. When we talk to the police service about the number of calls involving persons with disabilities; they don't track that. So we don't have a clue how many people that might involve. Persons with disabilities are the most marginalized within marginalized populations in being able to access services in Calgary. (Abuse Sector)*

*We don't have services that are really strong at saying, "Is there a specialized team in disabled abuse? No. But should there be?" Good question. My response (is) yes. (Abuse Sector)*

Three stakeholders were cautious about developing new specialized services and instead, emphasized the need to expand the existing resources.

*I think [what we need is] an expansion of Calgary Communities Against Sexual Abuse and other community resources so that you're not creating specialized services for people with disabilities. Why develop special, segregated services? Why not expand on the existing services because the information and knowledge is there, you just need to expand it. (Disability Sector)*

*I'm not sure there should be something separate. The ideal would be to have it included in the services already there for people who are abused. We have separate services for so many things and that seems to isolate and segregate people with disabilities, therefore, having a one-stop shop for everyone encourages inclusion. (Community Stakeholder)*

*The guiding principles, the heart and spirit of policies are universal. There are certain specifics, when you're looking at what access means for new Canadians for whom English is not a first language in comparison to someone with a visual impairment. But the end goal is to create inclusive organizations, where the supports and resources that people need are available, not separate. (Disability Sector)*

Two abuse sector stakeholders emphasized the need for a coordinated response using developed protocols to respond to cases of the abuse of persons with disabilities.

*As a community, more than 60 agencies participated in the protocol project. But I don't think there is a lens looking at the needs of persons with disabilities. Part of that would be developing the protocol for working with victims with disabilities. There's an accountability piece when you have a protocol. If the call isn't responded to in the way that you expected, you can go back to that agency and say, "This is what we expected." Protocol development would be important but there has to be some expectations of how that project links to other services in Calgary. We need to find out the gaps and develop some coordinating function, some way to screen and navigate, to make sure that these cases go where they need to. Part of that is developing the linking protocols between that process and the community agencies. (Abuse Sector)*

*The Protections for Persons in Care Act has been revised somewhat. Any policy or protocol where people are really looking at responding in ways where this is recognized are huge steps forward but sometimes with protocols, the client vanishes. It's so important to make sure that the individual rights are there, it's not just, "Okay, we've got to do this because it's in our protocol." (Abuse Sector)*

Several stakeholders commented that, if a person with a disability is in need of immediate crisis assistance, the police do not currently have the physical capacity to transport them.

*One significant gap is that there isn't an accessible police van. If you're a victim of violence, the police are not able to transport you. They apparently have a contract with an accessible taxi, so they have very specific mobility issues and other issues that really haven't been addressed in our community response. They've been totally neglected and in the 25 years we've worked towards a coordinated community response to address domestic and sexual violence in Calgary, the needs for persons with disabilities have just not been on the agenda. (Abuse Sector)*

*HomeFront's made some great strides in terms of domestic violence but in talking with [a representative] from CCASA, they still have barriers and that's just for the general population who don't have disabilities and then you add a disability... (Disability Sector)*

### **Increased Social Supports**

A little more than one third of the stakeholders (7 or 35%) suggested increasing basic and general supports such as the response to abuse, housing, staffing and funding were needed to meet the needs of persons with disabilities.

One abuse sector stakeholder suggested developing a navigator model within a family advocacy centre bringing all services under one roof to enable access for persons with disabilities.

*If people have mobility and other challenges, it makes perfect sense to bring them to a centre where they can access all the services in one spot. So if somebody's got mobility issues, might be in a wheelchair or has visual impairments or might be deaf, hard of hearing, it makes so much sense that you can walk in and there's a system navigator who would assess your needs and refer you to the services in the centre as well as to off-site partners to ensure your needs are met. (Abuse Sector)*

Two abuse sector stakeholders emphasized that the response to abuse of persons with disabilities should be the same as they are for able-bodied people.

*More funding equals more collaboration and maybe outreach services to people with disabilities so that they have an opportunity to say, "Yes, I am being abused" and an opportunity to be supported through the process of healing from that abuse. They'd have an opportunity to leave an abusive situation and to have a life of their choosing. (Abuse Sector)*

*They should be have a response model that is efficient and tight and provide them the safety and support that they need from personal care to emotional issues to financial issues, just like they do for able-bodied people. (Abuse Sector)*

In contrast, another abuse sector stakeholder recommended specialized therapy for persons with disabilities.

*It's always about having the right skill, having the therapist specialized in being able to support persons with developmental disabilities, to be engaged in therapy in a way that's going to help them, it's not easy. It would be wonderful if clients had the option to go to more than one agency for a refresher if they're having a hard time because it's an anniversary date of when the incident took place, for example, and they needed a support group for a period of time, that they could re-engage if they needed to. A lot our clients, it's hard for them to let go of or move on. Sometimes a year later or whatever they may have a struggle. (Abuse Sector)*

Two stakeholders recommended developing a public awareness campaign.

*We need a public awareness campaign that focuses on persons with disabilities and using some alternate media. Helping persons with disabilities understand what abuse is. (Abuse Sector)*

*There needs to be a social marketing campaign, to educate the public, in general, along with that you have a disability. (Disability Sector)*

One stakeholder suggested developing a Disability Council.

*If you had an Ability or Disability Council, you could have subcommittees. We're looking for a champion or an organization to step up and say, "We'll lead, we'll be the advocate, we'll get the funding from United Way and we'll pull together a council." I know there's the Premier's Council on Disabilities, but some sort of council or committee at an organizational level to help people. Organizations have told us that they're ready to do it, but they're tired and they have so much to do*

*already. If somebody leads it, they'll be there, they'll totally be there. (Community Stakeholder)*

Lastly, one stakeholder suggested the need for a Blind Persons Rights Act to uphold their rights of access to services.

*Looking again at policy generally, better legislation. I referenced the Protection for Persons in Care Act. Another thing that might help in terms of an act is a Blind Person's Rights Act in terms of providing equitable transportation and equitable access to facilities. If you've got a guide dog, for example, don't refuse the person. You have to provide equitable access. (Disability Sector)*

## Financial Supports

Forty per cent (8) of the key informants suggested that current funding levels for services for persons with disabilities whether or not they have experienced abuse, is insufficient.

*Funding is always an issue and it's very difficult to think that a person's physical wellbeing, emotional wellbeing can't be served because of funding. There are simple basic human rights that we all should be provided and persons with disabilities and seniors are low priorities. (Abuse Sector)*

*If there was more money from the government, then they would be able to purchase more buses and provide more services. There's this pie and more people are sharing the pie now and the funders will not be providing another pie. So, we are trying to collaborate but, that means we will be putting in more time because collaboration means time and is a big investment. (Abuse Sector)*

*Being able to access funding to address issues that arise during an audit of those services would be important. So if a specific shelter needs repair or modifications to make it more accessible, then funding should be available. (Community Stakeholder)*

*The numerous benefits of not-for-profits are common knowledge and the extremely low government funding they're doing it on. It's quite disproportionate to the money those agencies receive to do the work. (Abuse Sector)*

Three stakeholders highlighted that staffing resources are insufficient, including interpreters and agency staff.

*To increase the services, we need more resources, internal resources because we have a very small staff and a very small budget and external resources like interpreters, home-care, and assistance with people with higher needs. (Abuse Sector)*

*Anywhere, people would say that more staff would be helpful, but I don't have any statistical information on the ideal number of staff, what is currently there, where it can be improved. But in Alberta, but probably all across Canada, there is a staffing issue. (Disability Sector)*

*If Calgary starts to address the abuse of persons with disabilities, they don't have enough people power, staffing positions to handle it all. (Abuse Sector)*

Four stakeholders were concerned about lack of supportive living for persons with disabilities.

*We need more living options and supportive living for seniors; well any of the disabled ones have health issues. (Abuse Sector)*

*Housing for people with disabilities. There's not enough housing for anyone, certainly affordable, accessible housing is very limited. (Disability Sector)*

*More funding. I'm sure you've been told that by a hundred people, but there definitely needs to be more funding. The lack of funding is keeping people in situations where they're experiencing violence because they don't have the financial resources to leave. (Community Stakeholder)*

*If you've got an apartment building with no elevator, that's just not going to work. When you look at the current housing climate in Calgary, do you have the luxury of becoming homeless? There are a lot of options to weigh. (Abuse Sector)*

## Policy Supports

Almost half of the stakeholders (9 or 45%) suggested the need for more policy supports. Four stakeholders suggested that policies need to be audited, particularly using principles of universal design to ensure access for all persons with disabilities.

*A lot of times, an organization has policies internally recorded and followed but there's no external evaluation. There needs to be checks and balances if it's decided internally, or even externally sanctioned, but can there also be a more external, supervision or checks or balances. Those could be people that are very connected to disability issues. People with disabilities themselves could be consultants on these issues. (Abuse Sector)*

*The work is more encompassing than people realize. It's broader than violence and abuse. It's work that needs to occur across the human service delivery network. You're really looking at all the elements of organizational change that are grounded in universal design principles and elements that involve everything from organizational reviews of policies, procedures, practices, and systems to identifying what the training gaps are, what are the awareness gaps and training gaps that service providers hold. What are the interface points with transportation and police? To really advance things, a broader system's approach would look at the gaps, the good work that's happening, so working from a positive platform and the gap analysis from a system's perspective and then formulating strategy, an action plan that would look at the policy work that needs to happen more globally, the policy work that needs to happen at the organizational level. (Disability Sector)*

*Even within the city, regulations on buildings for a more practical day-to-day operations or challenges that people may have, like signage or even sidewalks, to legislate rather than, "Oh it would be nice to do that." Have that written in so you have to do it. That's something that the government or the politicians have a role to play. (Abuse Sector)*

One stakeholder suggested that universal design principles needed to be utilized to accommodate persons with disabilities, especially in domestic violence service agencies.

*There's the whole piece around the disability serving agencies but then more the mainstream serving agencies in the area of violence for people who experience violence and it would be great to ensure, to have some sort of competency or capacity. I would totally push the principles and philosophies of universal design. A first thing to do would be specific to the shelters or organizations doing work with people with disabilities, some sort of an audit pertaining to, do they subscribe to universal design principles and if a person with a physical or a developmental disability came, could they be there safely? (Community Stakeholder)*

Three key informants commented that they do not perceive the *Protection for Persons in Care* legislation as meeting the needs of persons with disabilities as well as anticipated.

*We've got Protection for Persons in Care but I don't think that's working as well as it could. So getting the laws that already exist to work properly not to necessarily create new ones. (Abuse Sector)*

*You might be familiar with the Protection for Persons in Care Act. If you took a look at that Act, it seems that everyone could be fined or, indeed, incarcerated with the exception of the perpetrator of the abuse. People in the province would say that's not a punitive act. But it is punitive to people with disabilities-- [they] can be fined or incarcerated if they file a false complaint. But, interestingly, there's nothing dealing with the perpetrator directly, other than educating them. I contend that there are mechanisms that society is trying to put in place, but we're not doing nearly enough. (Disability Sector)*

One stakeholder suggested that more protection-oriented policies are needed.

*Without being overly paternal, there could be policies that are more protection oriented. For example, individuals who had disabilities may have a guardian or a trustee who looks after their affairs. There could be policies that provide for greater protection of those individuals. (Community Stakeholder)*

One stakeholder suggested that organizational policies should support streamlined reporting of abuse of persons with disabilities.

*We have a policy that staff don't even have to go to their supervisor, they come directly to me or another manager and say, "This is what's happening." We're trying to eliminate the chain of command saying, "That's really not abuse." (Disability Sector)*

### **Training/Education and Awareness Supports**

Seventy per cent (14) of the stakeholders suggested the need for more training and education with service providers, counsellors and funders with respect to the abuse of persons with disabilities. First stakeholders suggested that service providers need further training and education on the abuse of persons with disabilities.

*It's education from both directions: educating service providers about accessible services, but also educating the potential client to consider what services they can tap into. Beyond someone who doesn't have a disability that's dealing with abuse, there has to be an understanding of how a disability affects a person's life. (Disability Sector)*

*It would be interesting to see some specific coursework for counselling folks who live with developmental disability. (Abuse Sector)*

*I don't think service providers have had a significant amount of training. The Independent Living Resource Centre has done some training with crisis service providers but there's been such a turnover that I don't think most service providers know how to begin to meet the needs of persons with disabilities. (Abuse Sector)*

*A combination of training needs to occur in agencies that work directly with abuse. They need to understand more about disabilities and accessibility; that probably also means that funders for the government need to, because they need the funding to make those facilities truly accessible. Other agencies, like AISH, that work with people with disabilities and low income, need to understand abuse. The same with homecare: (they) need to understand abuse as well as different types of disabilities. (Disability Sector)*

*Once you've got a policy and you offer training, it provides people an opportunity to acquire and/or enhance some skill sets. Then you're looking at how you integrate that training into performance reviews, how do you keep that alive beyond the document? But you've got to start with the document. (Disability Sector)*

*Another need is (that) the people who abuse them are paid staff. That's the biggest category and then family members and then the last category, which is really rare, is a stranger. So the need for education for staff. (Disability Sector)*

Two stakeholders suggested that additional training and education are needed with counselling professionals.

*When I was working in the community, the lack of education and awareness and training on the part of service professionals meant that often the individual seeking the service would be responsible for doing that educating, awareness, and training. Often professionals make assumptions about the issue that the individual is bringing forward, always relating it to the disability when, in fact, it had nothing to do with the disability. (Disability Sector)*

*Training, building capacity for practitioners to know that we have to walk in with an open mind but, on the other hand, have caution. Not to take anything at face value. (Abuse Sector)*

One disability sector stakeholder mentioned that persons with disabilities also need training on what resources and supports are available.

*Training for clients and training for staff: how do you respond and where you can go, which is different than responding under the protocols but giving them the tools and the supports and the resources to be able to move forward. (Disability Sector)*

Another disability sector stakeholder noted that their staff participated in mandatory abuse training.

*For our staff it's mandatory. It's called Recognizing Abuse and Taking Action and it looks at systemic issues, institutional abuse, all kinds of abuse and our role as staff and what we can do differently. We need to educate our staff so that there are staff that we haven't been able to screen out because, there's no screening for*

*perpetrators, that they come to an organization that believes strongly in empowering and enabling people and not tolerating any abuse. (Disability Sector)*

A stakeholder from the abuse sector suggested the need to increase knowledge between agencies that serve disabled clients.

*It's always about increased knowledge and education between agencies that serve and those other services that normally aren't in contact with people with disabilities. The more knowledge around the who and how our people are, the better services they're going to receive. (Abuse Sector)*

A stakeholder from the disability sector commented on the fact that reporting increases when training is provided.

*As soon as we do some training, we get more reports. Increased awareness makes them realize, "The way that person was treated wasn't proper and that could be abuse." So, with more training you'd see more reports of abuse but, over time, it does improve things. (Disability Sector)*

One abuse sector stakeholder noted that persons with mental illness are vulnerable to abuse and specialized mental health resources were needed, particularly in shelters.

*I would like to see mental health resources available to shelters, like a trainer and consultant to their staff or someone from mental health actually being on location. I have heard shelters asking for information and commenting on how many individuals appear to have serious mental illness that they feel ill-prepared to cope with. Also there needs to be education and support for the families of individuals with mental illness. Living with someone with mental illness can be extremely distressing and without alternate coping strategies, they may end up being abusive. (Abuse Sector)*

Four stakeholders suggested the need for more awareness around abuse of persons with disabilities.

*Educating people, similar to people who have disabilities, for example someone who has been in a wheelchair for years, having a chronic illness, In a sense it prevents them from living the way they used to live. But there aren't resources out there to educate people. We have to increase awareness of shelters or in the communities about people who have health care issues (who are) also experiencing domestic violence and how can we help them. (Community Stakeholder)*

*Awareness [that] abuse of anybody is not ok. I think the global context says abuse is not ok. (Abuse Sector)*

Three stakeholders emphasized that the professionals that are in a position to detect abuse, such as doctors and nurses in emergency departments and the police, needed more training.

*We need to do more training with professionals to detect abuse, doctors and nurses, emergency room staff, personal care attendants. That's a huge issue. There's a need to do much better training in the police communications around how to screen for and respond to abuse calls involving persons with disabilities and what some of their specific needs might be. (Abuse Sector)*

*I know from experience that people really don't understand or know how to deal with people with disabilities. So training in hospitals with doctors and nurses or if it's emergency workers, some policies where they need to understand not just the physical but the psychosocial, the awareness and training of front-line workers. Front-line workers typically these days don't always; They're taking them directly out of high school or with little or no training with people with disabilities. (Community Stakeholder)*

*You've got to have the leadership and the attitude. You can have a piece of legislation or policy in place but unless people are educated and understand why you have it, it's not going to go anywhere. (Disability Sector)*

One abuse sector key informant stated that further training was needed with respect to the changing needs of persons with disabilities as they age.

*As the disabled get older, we have to be more aware of the developmental needs of these groups of people; what different supports are we going to need from children to adulthood. (Abuse Sector)*

### **Community Wide Supports**

Almost two-thirds of the stakeholders (12 or 60%) agreed that additional collaboration and engaging with community stakeholders is needed. Two stakeholders suggested that the current services are fragmented.

*It could be improved. Services are very fragmented for this population, and there's a need for coordination. My guess would be the fragmentation is more complex than one solution. This community and population require multiple stakeholders and multiple solutions because everybody's disabilities are so different and violence can show up in so many ways. So I think it's going to take a variety of efforts. (Community Stakeholder)*

*With undiagnosed disabilities, it's difficult to provide for those specific needs. But that's where that collaboration piece with community services whose expertise is in this area comes into play. Consulting with them, we're more likely to meet the special needs of our clients. (Abuse Sector)*

Nine stakeholders strongly suggested that more collaboration is needed among community agencies.

*It's a long-term strategy: pulling together key stakeholders that are really: 1) decision-makers and, 2) champions to make a difference and then some resourcing. There needs to be a concerted effort to really acknowledge the issue and what action potentially could happen out of it. Getting the people to work together as a community to address this. This isn't a fragmented, oh it's the police's issue or it's a justice situation, it's not just the service provider's issue. It's a community issue and we need to have the community recognize that. (Disability Sector)*

*I don't think it's about reinventing the wheel. Calgary has a lot of resources. It's about how you draw upon these resources and shuffle them. (Abuse Sector)*

*In terms of policies needed to address the barriers and more of an agency level, that collaboration piece needs to be there and how do you go about doing that. (Abuse Sector)*

*The seeds are already there with this Collaborative Centre. That's a really good step forward. (Disability Sector)*

*A community-coordinated, multidisciplinary approach would enable us to meet the person's needs better. It's really multi-layered: the person may need more help in the home or to relieve the caregiver, they'll get some respite care and that will help because housing is the big issue, keeping the person in the home. Let's say we would provide the appropriate support to keep the person in the home, because change is always hard, especially for people at an older age and with a disability. You are compounding things, you are making it more complex and challenging. So a multidisciplinary approach is something we should at least look at. (Abuse Sector)*

Three stakeholders recommended that the domestic violence and disability sector need to work together.

*I don't know how the community does. I just know that when we are working with someone who needs to be in a shelter, we go in, whether by phone or actually they'll go in and do education. We do a lot more case management facilitation than we should. So it's not a streamlined system. I don't think it's working efficiently and ensuring that a woman with a disability who's in an abusive relationship is getting equal access to the services that she should. (Disability Sector)*

*It would be nice to see some partnerships between organizations, like ourselves working with organizations whose primary clients have disabilities to come up with a toolkit of how to best address their needs and better serve them, whether they're accessing those services for persons with disabilities or accessing services because they've experienced domestic or sexual violence. Those partnerships are going to be key in developing best practice programs or models. But we don't see enough of that. (Abuse Sector)*

*Connecting the family violence sector to services within the disability sector would be probably a shorter term solution to serving persons within the shelter. By coming together and mobilizing the two sectors, there might be some crossover, shared knowledge, as well as being able to access services within each sector to assist both. (Community Stakeholder)*

Six stakeholders recommended engaging community members in planning for services for persons with disabilities.

*The Elder Abuse Work Group was formed in spring of 2007. We started meeting to look at engaging community stakeholders in the developing a response model for Calgary. (Abuse Sector)*

*What could be done? Gathering and mobilizing individuals in the disability community, specifically service providers to address some of the gaps would be a good first step. (Community Stakeholder)*

*If you're trying to provide services to people with disabilities, who better to talk to than people with disabilities. That's probably some of the reason you're talking to me now. (Abuse Sector)*

*Community stakeholders and persons who work in those disability servicing agencies, they're going to have a better idea than myself in terms of how to get that out to people. (Abuse Sector)*

*The government is a stakeholder. How could they not be? They're funding these programs. At the same time, talking to organizations that are serving persons with disabilities as their primary client are probably the best people to find out how they address domestic and sexual violence and their policies in doing that. (Abuse Sector)*

## **Research Supports**

Five stakeholders suggested that additional research is needed, particularly qualitative research on abuse of persons with disabilities.

*I would go back to a system-wide approach that would have the required action at every level, from the private individual, through to the organizational, through to broader community, through to city, through to province because they're all connected. What hasn't been as successful is working in isolation. In order to truly move things forward, you want to be building critical mass. So you may, after doing a system's analysis, determine that for the next 5 years, the emphasis of the work would be on training and ensuring that shelters are accessible and that service providers have a level of training and awareness in terms of disability and that there's a way of measuring that in terms of performance. Or you may see that there's already a lot out there, that there's a few pockets that need to have more support and you want to focus on the policy work. That larger environmental scan would identify what more needs to happen. (Disability Sector)*

*Best practices. There's nothing in Calgary, I believe. That's the goal of the work is to look at what's out there. Qualitative research needs to happen. Maybe focus groups, finding out what has worked, talking to agencies. It's important to do a needs assessment. Are there agencies that actually meet with people with disabilities, do counselling? I don't think there's many. It's a lot of support-based but not really providing service that helps these people manage their feelings, deal with the abuse, the legal issues. There's very few. (Abuse Sector)*

*We have to look at violence as a complete overlay in society. Street violence, gang violence... People with disabilities are suffering those sorts of violence as well, so it's a complex mix. Complexity theory should be the base for disability studies. We compartmentalize things. We think by focusing on one violence realm and one disability that we can do inductive reasoning and provide services for all. It doesn't work that way. Life is much more complex. (Disability Sector)*

*It's a population that we don't hear from. It has to be done differently from traditional research. It can be a multi-barriered population... They (funders) like numbers, so we know that that will appeal to the government. But we also really need the qualitative piece, people's experiences and their challenges. Hopefully we can*

*build those relationships so they don't feel like they're being researched a lot. (Community Stakeholder)*

One disability sector stakeholder commented that research is political and tends not to reflect the needs of all individuals with disabilities.

*We've got half a billion dollars a year from the provincial government going into the Persons with Developmental Disabilities framework, whereas other disability groups receive maybe 2-5 million max. It's not just money; it's professionals glomming onto that money. You do the research where grants are available, so it reinforces one another. I don't mean to leave the impression that people with developmental disabilities are at any greater risk than other disability groups. Some professionals might disagree with that, but it's simply because more research is conducted in that realm. The Institute from Ontario has done cross-disability research in terms of crime/violence against people with disabilities generally. I believe they support the statement that we shouldn't concentrate on one disability over the other. (Disability Sector)*

## Chapter Six: Discussion and Recommendations

*At the end of the day, you want to eliminate the need for these services. If we create a society where there's zero tolerance for this behaviour, you eliminate the need for service. That's very long term, so what I would be measuring, is are fewer folks requiring services because we're doing a better job of prevention and identifying the variables that contribute to this. We're getting a bit more at the underlying root cause. (Disability Sector)*

In summary, the key stakeholders from the disability and abuse sectors in Calgary collectively 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 stakeholders were of the opinion that the Calgary community is not adequately addressing the complex needs of these individuals.

The majority of the stakeholders agreed that persons with disabilities experienced physical, attitudinal, language and communication barriers that are exacerbated by the increasing population in Calgary. Among the physical barriers identified were as 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. Lastly, poverty and isolation were also identified as barriers for persons with disabilities to participating in services and community activities.

Even though the key informants did not perceive the reported needs as being met, almost half acknowledged that attempts 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 agencies ability to staff appropriately to meet needs.

Language and communication barriers were also identified, particularly with immigrants and individuals living with mental illnesses. Individuals immigrating to Canada were identified as vulnerable due to inability to understand English and cultural variations in responding to disability and abuse. The key respondents suggested that equipment meant to enable communication with persons with hearing disabilities needs to be regularly checked for functionality.

Barriers to reporting, screening and responding to abuse were discussed by 65% of the stakeholders who also 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. 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.

Social, financial, educational, policy, training and education, community wide and research supports were identified by 35% of stakeholders as needed for persons with disabilities who have experienced abuse. Suggested social supports included the development of a navigator model within a family advocacy centre, specialized therapists, ongoing counselling supports, an awareness campaign, development of a Disability Council and a Blind Persons Act.

Financial supports in serving the needs of abuses persons with disabilities were noted as inadequate, which resulted in insufficient staffing resources. Limited affordable housing in the city was also noted as a barrier.

The key stakeholders suggested policy supports including enforcement of universal designs for access for various disabilities, particularly in shelters, higher wages for staff working with persons with disabilities and the re-examination of the *Protection for Persons in Care* legislation.

Training and education supports were recommended by 70% of stakeholders with 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.

Collaboration and engagement was identified by 60% of stakeholders and that together, service agencies could use their combined resources to better meet needs of persons with disabilities experiencing abuse. Increased knowledge and communication was also identified as needed between domestic violence agencies and those serving persons with disabilities.

Lastly, 25% of stakeholders suggested that research is needed; particularly using qualitative, non-traditional research methods. Research in the area of disabilities should be completed using complexity theories, which reflected the complexities of persons with disabilities lives' and also should not favour one disability over another.

## **Recommendations**

The following recommendations stem from the analysis of the key stakeholder interview with representatives from the disability and abuse sectors in Calgary in consideration of the environmental scan of promising practices. These suggestions are offered in light of the deep concerns expressed by 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 crafted 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.

**Recommendation 3:** 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 4:** Given the previously-noted lack of current research on the impact of abuse for individuals with disabilities, further research is needed. This includes updated research on the efficacy of programs developed to assist individuals with disabilities who have been abused.

An almost completed project in association with the environmental scan has been to conduct qualitative interviews with individuals who have disabilities and have been abused with respect to what services they received/needed. The voices of individuals from Calgary who have disabilities and have been abused have, thus far, been relatively absent in the current discourse. In partnership with RESOLVE Alberta, the Alliance to End Violence has secured funding from the Prairieaction Foundation to interview a small number of experiential individuals about their perspectives of the gaps, strengths and weakness of the local service response to their needs. The interviews are in progress.

**Recommendation 5:** 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 6:** 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 from 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 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 has 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 of the Alliance to End Violence 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 key community stakeholders provide support and additional direction to the team and its mission.

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## **Appendix I: Disabilities and Abuse Needs Assessment Interview Guide**

Script: The Alliance to End Violence Persons with Disabilities Task Team is a collaborative network of researchers, domestic and sexual violence service providers and disability service providers who came together out of a mutual concern for persons with disabilities who are experiencing abuse. The purpose of this needs assessment is to identify what could better assist persons with disabilities who are currently or who have experiencing abuse across the life-span.

1. Please describe your agency and your position.
2. How do you define the term “disabilities”?
3. With what types of disabilities do your clients primarily present? What ages are they?
4. From your perspective, do the persons with disabilities that have been abused (either currently or in the past) with whom you work, have specific needs? If yes, what are these? Are these needs being addressed in any manner?
5. How well does the current continuum of services in the Calgary community address these needs? What could be done to improve these services?
6. Do persons with disabilities easily access the available services or do they face barriers?
  - If yes, what are the barriers?
  - What policies are needed to address these barriers?
7. Do you know of any best practices models or programs that better address the needs of clients with disabilities that have endured domestic or sexual violence? If so, please tell me about them.
8. 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?
9. Is there anything else you’d like to add?
10. Who else should we speak to about this issue?

Thank you for your time

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<sup>i</sup> Descriptions from program websites