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The abuse of individuals with developmental disabilities

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The abuse of people with developmental disabilities has a long and horrific history, which extends from prehistoric to current times. Only in the past 20 or 30 years has society recognized that this abuse is a serious social problem and, with this recognition, research has been carried out on the topic. The limited research that has been done suggests differing causes for making this population so vulnerable to abuse. What is not under dispute is the fact that this abuse continues to this day, both in institutionalized care settings and in family care settings. This manuscript is an attempt to integrate the principal research findings.

Vulnerable people exist in our society. At some time in our lives, depending on circumstances, we all have been, or felt, vulnerable. One of the most vulnerable groups in our society—those with developmental disabilities—is sometimes viewed as belonging to the outskirts of society and is frequently shunned or ignored. This results in social isolation and often leads them to accept behaviour and treatment that they do not like or that causes them to be afraid (Furey, 1994).

Both the United Nations *Declaration on the Rights of Disabled Persons* (1975) and its subsequent *Convention of the Rights of the Child* (1989) were developed to protect the rights of individuals with disabilities. According to these *Rights*, member states have a responsibility to protect all children, with and without disabilities, as well as adults with disabilities, from discrimination and abuse in any form and to ensure that all persons are treated with dignity and respect. Yet, abuse of those with disabilities continues (Brown & Schormans, 2003; Carlson, 1997; Furey, Granfield, & Karan, 1994; Sobsey, 1994; Verdugo & Bermejo, 1997; Vig & Kaminer, 2002).

This abuse takes many forms, including physical, emotional, and sexual abuse, but also includes exploitation, neglect, and inappropriate use of

restrictive procedures. Examples of inappropriate use of restrictive procedures are deliberate overmedication or applying the brakes to wheelchairs for reasons other than safety (Persons with Developmental Disabilities Alberta Provincial Board, 2004).

Many studies have been conducted, especially over the past 30 years or so, in an attempt to explain the relationship between disability and abuse. However, several of these studies have produced conflicting results. Many were based largely on anecdotal evidence or case histories and lacked a sound scientific basis (Nettlebeck & Wilson, 2002). Crosse, Kaye, and Ratnofsky (1993) accessed a large national (United States) database of child abuse statistics (both children with disabilities and those without disabilities) and concluded that children with disabilities were 1.67 times more likely to be maltreated. Nevertheless, these researchers qualified their results; their sampling method might have missed most care settings, and many abused children might not have had their disabilities diagnosed yet.

Verdugo and Bermejo (1997) discovered difficulties in researching the abuse of children with disabilities. Previous studies had focused on one specific aspect of the differences between maltreated and nonmaltreated children, which gave only a generalized idea of risk but gave no indication of the factors that provoked maltreatment, supported maltreatment, or made a connection between those who were abused and those who abused. However, when the results of these small studies were collated, stronger evidence to support the link emerged. Sobsey (2002) suggested, "almost one third of [children with developmental disabilities] have substantiated histories of maltreatment while many more have probably experienced unreported or unsubstantiated maltreatment" (p. 29).

What is it that makes this population so vulnerable to victimization and abuse? The central thesis of this paper is that the abuse of individuals with developmental disabilities can be attributed to a combination of reasons related to the social and physical environment in which they live, and the characteristics of the person with the disability. Let us look at each of these factors in turn.

Environmental Factors

Societal Acceptance of a Climate of Abuse

Historically, societal attitudes toward those with developmental disabilities have been ambiguous, ranging between a positive response of caregiving to negative responses of rejection and death (Berkson, 2004). The attitude in the final decades of the 19th century was that the "poor, the unemployed, the mentally ill and the mentally retarded were somehow responsible for their own fate" (Kirkpatrick, 2003, p. 9). Therefore, just as in the Middle Ages, people with mental retardation were no longer seen as objects to be pitied or protected but were seen as menaces to society—a society that had to be protected from *them.*

The late 19th century attitude did not continue for long and, by the turn of the 20th century, those with disabilities, particularly developmental disabilities, were again seen as tragic figures in need of care and protection. Attitudes like this triggered the medicalization of developmental disability, even though, by and large, people with developmental disabilities are in no more need of medical care than any one else in their age group (Moss & Turner, 1995).

The latter half of the 20th century saw the move to deinstitutionalization, a policy that continues to this day. With the many changes in the structure and function of the family in postwar Europe and North America, many parents began to form groups to lobby for the needs of their children and, although many such groups were formed in the United States, very few were formed in Canada. The latter is not surprising, as Canadian parents were made to feel "embarrassed, ashamed, and guilty" about having children with disabilities (Kirkpatrick, 2003, p. 22). The U.S. parents' groups began to demand improved medical services for their children with disabilities. They also called for special recreation facilities, camps for people with disabilities, sheltered workshops, and segregated housing institutions—all demands that continued to mark people with disabilities as different, reinforced the public attitude of dependency and helplessness of people with disabilities, and introduced a different type of segregation (Enns, 2001).

The demands of these parents' groups inadvertently set up cultural stereotypes of people with developmental disabilities, portraying them as dangerous, dependent, sick, or useless (Sobsey & Doe, 1991). Today, the effects of this segregation and stereotyping can be seen in the teaching of work skills that are largely irrelevant for today's workforce requirements and in an associated system of remuneration that makes financial independence impossible.

The infantilization of adults with disabilities prevents them from being allowed to take risks in their lives and to experience what other people want to, or can, experience. Society believes that these actions are taken "for their own safety." One example of this way of thinking is the decision of parents to have their daughters sterilized to avoid the possibility of pregnancy (Brady, 2001). This paternalistic attitude gives people with developmental disabilities even less control over their lives, reinforces their dependency on others, encourages overcompliance, and increases their social vulnerability.

Researchers in this field are not unified in their views on whether developmental disability increases the risk of abuse. For example, Goldson (2001) has argued that society accepts abuse of people with developmental disabilities because they are perceived as being different. Westcott and Cross (1996), on the other hand, believe the risk for abuse in this population is decreased, because their abuse is too disgusting to consider. The daily life accounts of individuals with developmental disabilities suggest that the former is more likely. One young woman, who was sexually abused by her massage therapist, reported that he justified his actions by stating, "You will never have a boyfriend because you are different, use the opportunity you have now [his sexual abuse], you will never have another one" (Zavirsek, 2002, p. 279). The abuser was obviously implying that women with disabilities should be grateful for being sexually abused.

Living Environments

Residential (institutional) care. Although families were originally the primary caregivers for persons with developmental disabilities, history

has shown that their care settings frequently varied and included community care and institutional care. The first residential institution in North America specifically for people with mental retardation (the term used at the time) was the Perkins Institution, founded in 1848 by Samuel Gridley Howe, where, for more than a century, hundreds of thousands of children and adults with developmental disabilities were institutionalized, many for their entire lives (Caplan, 2003).

Before that time, individuals who were not cared for either by family members or in their communities were housed in asylums for the insane. The increased public fear that people with developmental disabilities contributed to societal degeneration was, among other things, responsible for the rapid spread of institutionalization and meant that institutions in the early part of the 20th century, far from being rehabilitative, were more custodial.

According to Sobsey (1994), there is a wide gap between public expectations of care and the realities of institutional life, as society still believes that institutions are safe places for people with disabilities. History shows a long-standing "tradition" of abusing people in institutional care. Institutional settings have unique features that promote abuse in ways that do not happen elsewhere (Paul & Cawson, 2002; Verdugo & Bermejo, 1997). Furey, Niesen, and Strauch (1994) suggested that the risk of abuse is increased in congregate situations and, according to their research, 82% of all cases of abuse and neglect of adults with developmental disabilities (over an unspecified 5-year period) were carried out in institutions or group homes. People who were unlikely or unable to report or resist the abuse were the most common victims. Sobsey (1994) attributed institutional abuse to an extreme imbalance of power between caregivers and residents. Verdugo and Bermejo (1997) added that the abuse of residents was likely also related to staff members being overworked and underpaid for monotonous and stressful work.

Personality traits of caregivers, such as low self-esteem and impulsiveness, have been shown to make a difference in the way individuals with developmental disabilities are treated by staff (Bromley

& Emerson, 1995; Hatton, Brown, Caine, & Emerson, 1995; Jenkins, Rose, & Lovell, 1997). Rose, David, and Jones (2003) found that the perception of stress among caregivers was related to their personality traits, that is, their normal coping skills. For some, the role of caregiving offered challenges and rewards, whereas others found these same experiences difficult and frustrating, particularly when they occurred within a context of other stressful life events.

Wardhaugh and Wilding (1993) made another suggestion in relation to institutional abuse — that it might be seen as "justified" through a dilution of ethical and moral standards, thus making a culture of abuse totally acceptable. Cambridge (1999) believed that all institutions create their own cultures of abuse, with isolation, staff intimidation, and poor or absent supervision being major components. This combination leads to a subculture whereby abuse is totally acceptable, indeed, encouraged — like a "rite of passage" for new staff.

The interactions between management and staff and the accompanying connection between staff stress levels and abusive behaviour was a factor suggested by Cambridge (1999). Competent management, supervision, and a culture of accountability, that is, "zero tolerance," have been reported to reduce vulnerability and risk of abuse. If management is seen to tolerate or ignore abusive behaviours, a culture of oppression and abuse may be cultivated. This sends a message to both staff and residents and discourages the reporting of abuse.

With a link between abuse by caregivers and stress verified, it would be expected that an increase in caregiver numbers would lighten the load of care and therefore decrease caregiver stress levels. However, earlier research by Rindfleish and Rabb (1984) and Sullivan, Vernon, and Scanlan (1987) showed this not to be the situation. According to these researchers, an increase in the number of caregivers only serves to increase the risk of abuse, particularly if the caregivers are incompetent. Currently there is no reason to believe that this situation has changed.

The attitude of caregivers towards those in their care is believed to be another predictor of abuse (Wardhaugh & Wilding, 1993). If people with

developmental disabilities are perceived as being less than human or unable to understand what is happening to them—a process known as dehumanization—then staff see nothing wrong in carrying out "forms of behaviour and treatment that would be unacceptable with those not stigmatized" (p. 27).

There is another form of institutional abuse that is subtler: policies and procedures that deny the right to privacy, to express sexuality, or to have someone available who will actually take the time to listen (Calderbank, 2000). Caregivers have free access to the bedrooms and the bodies of individuals who live in institutions. This access provides opportunities for abusive activities between caregivers and these individuals.

The move away from institutional care settings. In 1967, Niels Erk Bank-Mikkelsen from Denmark and Bengt Nirje from Sweden introduced the concept of normalization, a notion that "largely evolved as a human rights-based, critical reaction to large institutions, the service model that dominated services for people with…disabilities from the 19th century" (Cocks, 2001, p. 12). Between 1967 and 1975, Wolf Wolfensberger introduced this concept to North America and expanded on it, coupling it with advances in technology and changes in the attitudes of both health care providers and parents. This shift led to an increasing number of children with developmental disabilities being kept and cared for at home (Goldson, 1998).

Unfortunately, this change frequently meant that children, who were placed in homes and communities, were being cared for by even less experienced caregivers and the resources for their diverse medical, social, and educational needs were often not available. Thus, it is not surprising to note that the shift from living in institutions to living in the community was not associated with a decrease in abuse but might, in some cases, have actually resulted in increases in abuse (personal communication, Alberta Public Guardian Representative, November 14, 2005).

Parental/caregiver attributes. A great deal of research in the 1980s focussed on increased levels of parental stress, particularly in mothers who cared

for children with severe disabilities (Beckman, 1983; Burden, 1980, as cited in Redmond & Richardson, 2003). This research typically portrayed these mothers as tragedy stricken and their children as an encumbrance. The assumption, therefore, was that this combination would lead to negative parental behavioural reactions, maladaptation, and abuse. More recently, other investigators have demonstrated that, although some families are at risk for experiencing high levels of stress related to their child with a disability, many others actually do cope and adapt positively to this stress (Redmond & Richardson, 2003; Scorgie, Wilgosh, & McDonald, 1998).

Although these research results have been conflicting, there can be no doubt that caring for a child with a developmental disability (and, indeed, caring for any child) has profound effects on family life, both positive and negative. Not unlike early studies on abuse and persons with developmental disabilities, information on the positive aspects of family caregiving has primarily been the result of anecdotes and accounts provided by parents (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Hastings, Allen, McDermott, & Still, 2002). More current research appears to have focussed on the negative aspect of caregiving (Brown & Fudge Schormans, 2003; Hastings, 2002; Hastings & Taunt, 2002) which, of course, plays into the "blame the victim" mentality, although Hassal, Rose, and McDonald (2005) acknowledged that levels of stress varied among many parents, with many associated factors.

The negative factor focused on by Lukemeyer, Meyers, and Smeeding (2000) was that of finances. With the arrival of any child, both incoming and outgoing resources may be negatively affected. The primary caregiver, usually, but not always, the mother, might no longer be able to work outside the home and, as a result, family incomes are drastically reduced. In addition, the families of children who are disabled must also manage costs associated with special equipment, clothing, dietary needs, special transportation, and frequent trips to hospital.

The financial strain of having a child with a developmental disability is not the only factor that may have a negative impact on families. Hastings (2002) suggested that parents of children with developmental

disabilities, especially children with accompanying behavioural problems, experience greater stress levels than those parents of children who have behavioural problems but no developmental disabilities. Jones and Passey (2004) agreed by stating, the "unexpected and permanent nature of such an event generally increases a parent's vulnerability to stressors" (p. 31).

Although it should be remembered that there are numerous causes of abuse directed at individuals with developmental disabilities, many researchers have made the specific connection between parental stress and abuse. Others deny any such connection. Benedict, Wulff, and White (1992) sought to identify what differences, if any, existed between abusive parents in their perceptions of stress and fatigue caused by the care needed by children with a disability, and nonabusive parents with a child who has a disability. The results suggest that, "overall perceived stress and burden in these families…of multiple-disabled children…did not appear to differ significantly between families with an abuse or neglect history and those without such a history" (p. 160).

However, in common with Dyson (1993) and Tomison (1996), Verdugo, Bermejo, and Fuertes (1995) reported that high stress levels *are* common in families that are caring for a person with disabilities and that the stress levels had a direct correlation with the level of abuse. Kelley, Grace, and Elliot (1990) also found that abusive punishment was more prevalent and more acceptable in lower income households, particularly single-parent households. This was attributed to the additional responsibilities and stresses of single parenting, together with limited available support, and later research, conducted by Withers and Bennett (2003), demonstrated that marital discord often occurs following the birth of a child with developmental disabilities, thus increasing the numbers of single-parent families.

On the other hand, Redmond and Richardson (2003) found that, although their study was small (N = 17), two mothers had separated from their spouses since the birth of their child with a disability. However, the other 15 mothers still lived with a partner and more that 50% of the mothers in this study spoke of the positive aspects of caring

for their children – feeling they played a useful role and reporting an increase in their abilities to make decisions and cope with problems. Sobsey (2004), reviewing the literature on marital stability and children with disabilities, concluded that the findings in support of increased incidence of divorce among parents of children with disabilities are, at best, weak and inconsistent.

Hendy and Pascall (1998) expanded on another aspect of family caregivers and their stress levels. They believed that the societal attitude that people with developmental disabilities needed to "be taken care of" (remember when care*givers* were called care*takers?*), indicating that family caregivers needed help and support in their role, which again only added to the "blame the victim" mentality. Without doubt, caring for a person with a disability who may or may not be dependent requires support (e.g., respite care or financial aid), but placing the focus of care and support on the caregivers while ignoring the person being cared for can lead to loss of self-esteem, depression, and increased levels of vulnerability on the part of the latter. Morris (1993) stated, "the recognition of carers as an oppressed group has increased the oppression of individual disabled people and strengthened the social attitudes toward impaired people as burdensome people" (p. 49).

Characteristics of the Person with Developmental Disabilities

Gender

Sobsey (2001) stated that women with developmental disabilities are much more likely than women without disabilities to experience sexual abuse. The analysis by the University of Alberta Violence and Disability Project team, under the direction of Sobsey, analyzed a database of 100 women and adolescent girls with developmental disabilities who were sexually assaulted. Almost half (46.6%) had been assaulted more than 10 times. In their 1991 study, Stimpson and Best noted that 39 to 68% of girls and 16 to 30% of boys with developmental disabilities would be sexually abused before 18 years of age, and Wilson and Brewer (1992) observed that women with developmental disabilities were 10.7 times more likely to experience sexual assault compared to other women.

A number of factors might help to explain why abuse is higher among women. Women and girls are (generally) of smaller physical size and strength than men and boys, thus making them less able physically to reject abuse, especially by male perpetrators. In addition, their relative lack of economic power places women at greater risk than men. Gender might also have an influence on the type of abuse that occurs. According to research by the Roeher Institute (1995), men with disabilities are more susceptible than women to physical assault, and women with disabilities are more susceptible than men to sexual abuse.

Degree of Disability

Several studies have explored the link between severity of disability and risk of abuse. However, the results from these studies have been unclear, with only a few researchers finding an association between increased disability and increased risk of abuse. Among them were Zirpoli, Snell, and Loyd (1987) and Klopping (1984, as cited in Westcott & Jones, 1999). It should be noted, however, that these older studies reflected the research emphasis of the time. Currently, the focus is on the role of social factors in the abuse of people with disabilities rather than on individual traits.

Martin (1982, as cited in Zirpoli et al., 1987) was one of the first researchers to suggest that those individuals with more obvious "defects" or disabilities were less likely to be abused. This is consistent with the findings of Benedict, White, Wulff, and Hall (1990) and Verdugo, Bermejo, and Fuertes (1995), who found that children with a milder form of developmental disability were at a higher risk for abuse than those with an obvious congenital disability. The belief is that, if a child has an obvious disability, abnormal behaviour could be blamed on the disability, decreasing parental frustration and the risk of abuse; if the disability is not obvious, however, the child would be blamed for misbehaving, leading to increased parental frustration and the risk of abuse. Verdugo and Bermejo (1997) argued that the more severe the disability, the more parents are reconciled to the situation and thus do not expect a high level of functioning from their child. However, their

proposed reason for the increased risk for individuals with disabilities that are less apparent is that, although individuals with severe disabilities are more likely to have access to community resources, those with mild disabilities are more liable to "fall through the cracks" in the health care system.

An obvious exception to this reasoning is for individuals with hearing and language impairment. Verdugo et al. (1995) found that 75% of their research participants, who had been abused, had language problems (37% did not speak at all) and that the more severe the speech problem, the greater the prevalence of abuse. One possible explanation was that those with severe language difficulties are seen as "easy targets," because they are unable to report abuse. Visual impairment might make it difficult for a person to detect danger, to identify the abuser, or to escape from a dangerous situation (Roeher Institute, 1995).

Increased Dependence

Certain characteristics have been cited as predisposing factors for abuse of persons with developmental disabilities (Carlson, 1997). One is a high level of dependency on others. Dependency is particularly problematic, because it leads to a high number of caregivers in contact with a person with disabilities (Westcott & Jones, 1999). This dependency usually includes the need for constant intimate care, often given by strangers, which provides an opportunity for sexual abuse. The risk for abuse rises exponentially with the level of dependence.

Dependence on others might decrease assertiveness and foster the sense that one must comply with the wishes of the caregiver. Sobsey and Doe (1991) linked dependence and low self-esteem to "internalized devaluation." They stated that this perceived devaluation leads dependent individuals, such as those with developmental disabilities, to believe that they are somehow responsible for the abuse. The resulting feeling of helplessness increases the levels of vulnerability and the risk of being abused.

Behaviour

Challenging behaviour, although not limited to people with developmental disabilities, is more common in this population. Typically, the behaviour "puts the safety of the person, or others in some jeopardy or has a significant impact on the person's or other people's quality of life" (McGill, 2005, p. 1). These behaviours are cited as leading to increased stress levels in caregivers (and thus an "excuse" for being abusive.) The behaviours of importance here include bizarre styles of interaction or communication (Kirkpatrick, 2003), making inappropriate comments about people, touching people inappropriately, tantrums, making loud noises, or refusing to cooperate with caregivers (Ryan, 2005).

Conclusion

Throughout history, people with developmental disabilities have been particularly vulnerable to abusive practices. They have been called deviants, imbeciles, feeble-minded, morons, and retards—all negative terms that increase the dehumanization process and foster abuse.

The scarcity of Canadian research literature on the connection between disabilities and abuse suggests a lack of concern and community awareness about this important health problem. This, in turn, might lead to the perpetuation of a culture of abuse. Brown (1998) has suggested that societal attitudes and policies continue to make people with disabilities vulnerable to abuse: "If we all stopped treating people with disabilities like helpless vulnerable people, not only would they begin to feel differently about themselves, but others would as well" (p. 1). Over the past two or three decades, there has been an increased interest in people with disabilities and their risk of being abused. Society is beginning to recognize that abuse is a serious social problem. However, many myths, fallacies, assumptions, and stereotypical attitudes have surfaced, all of which can be seen to justify abusive behaviour without self-guilt or societal consequences. Many researchers have demonstrated a link between stereotyping people with disabilities and abuse.

A major disservice to people with developmental disabilities—which continues to this day—is that of segregation. One of the main factors in devaluing people with disabilities is the misconception that they are deviant or subhuman. Although many would argue that children with disabilities should be educated separately from other children, what better place than the classroom to teach children that everyone has different gifts and abilities? The more people with developmental disabilities are segregated, the less likely they are to learn social norms and the less likely others are to see that they are "just like anyone else" and see them as easy targets for abuse.

When vulnerable people are recognized as having gifts, talents, and something to contribute to their community, the risk of abuse diminishes (Persons with Developmental Disabilities Alberta Provincial Board, 2004).

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