Developmental disabilities: Abuse and neglect in children and adults

Vincent J Palusci, MD, MS*, Ellen Datner, PsyD, and Christine Wilkins, PhD, LCSW

New York University School of Medicine, New York, Frances L Loeb Child Protection and Development Center, Bellevue Hospital, New York, and New York University Langone Medical Center, New York, USA

Abstract

This paper reviews abuse and neglect among children and adults with disabilities and highlights the importance of identifying abuse and neglect in these individuals because of their increased vulnerability, difficulties in communication, and potential for ongoing victimization. Patterns of presentation of victimization are discussed and suggestions are given to aid in their recognition among several challenged populations. Developmental considerations in the evaluation of abuse are reviewed, as well as interviewing children with developmental disabilities and supporting parents with developmental disabilities. Adults with intellectual and developmental disabilities and abuse are also discussed, including issues with parenting and intervening with adults who have a disability. We conclude with recommendations to improve practice among adults and children with disabilities.

Keywords: Disability, developmental disability, child abuse, neglect, maltreatment, medical neglect, prevention

Introduction

Despite being extant since the beginning of human civilization, it is only relatively recently that we have come to understand the profound effects of abuse and neglect on persons with a disability. At the time of the classic description of the battered child by C Henry Kempe (1922-1984) in 1962, physical abuse and neglect were not strangers to children with disabilities (1). Later, people with intellectual and developmental disabilities (IDD) faced almost complete exclusion from schools, communities, and sometimes even homes. Families were regularly counseled to place children with IDD in state-run facilities and were assured that their children would be cared for and protected. Unfortunately, the facilities were often riddled with systemic neglect and abuse. It was within this context that the Federal Government began

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* *Correspondence:* Vincent J. Palusci, M.D., M.S., Professor of Pediatrics, New York University School of Medicine, Bellevue Hospital Center, 462 First Avenue, New York, NY 10016, United States. E-mail: Vincent.palusci @nyumc.org

providing funds to enhance institutions, and parents and others provided private special-education classes and sheltered workshops for children and adults who were living with their families (2). The United States Child Abuse Prevention and Treatment Act was passed in 1974 to establish a national center on child abuse and neglect and to further develop state-based child abuse reporting and response systems, including foster care and home-based services (3). As a result, a number of agencies have been put in place at different levels (e.g., local, state, federal) to improve our response to abuse and neglect.

Despite a variety of societal attitudes that resulted in these inhumane conditions in institutions, particularly for children and adults with IDD, these changes highlight how far we have come as a society while we still have far to go. Both then and now, children and adults present with any one of the variety of injuries associated with abuse, including fractures, bleeding, traumatic brain injuries, bruising, soft tissue and organ injuries, and death. Likewise, in addition to their higher rates of abuse and neglect, there is a disproportionately large percentage of children with IDD with maltreatment as a cause of their disabilities. Children and adults with disabilities are also victims of sexual abuse, the evaluation for which is made all the more difficult because of their disabilities, potential developmental delays, and difficulty with communication. Parents who have disabilities face heightened surveillance by a child welfare system seeking to reduce potential harm from the neglect to their children which may result from the limitations placed on them by their disabilities.

Child protective systems strive to protect all children but are especially challenged to help children with disabilities, those who are medically fragile, and those with parents coping with their own disabilities who also face their own increased risk for abuse and neglect as vulnerable adults. Unfortunately, these systems are ill-equipped to support parents with disabilities and their families, resulting in disproportionately high rates of continued involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights (4). Similarly, although domestic violence agencies are widespread and typically offer free quality professional services to adults and their children who experience violence,

they are not always best equipped to serve persons with developmental and intellectual disabilities. Likewise, adult protective services, with similar goals to protect vulnerable older adults and persons with IDD, are less institutionalized and much less funded, and are therefore less able to help when needed.

This review will emphasize these specialized areas of concern for children, adults and parents with disabilities in an effort to highlight important areas needing broader review by those caring for these vulnerable populations.

Definitions

Abuse and neglect have sometimes distinct definitions in different professional fields, for children and adults, and are codified under different federal and state statutes. Maltreatment, a more encompassing term which includes abuse, neglect and exploitation, is often used, and several types are discussed, such as physical abuse, sexual abuse, neglect, medical care neglect and emotional/psychological abuse and neglect. Physical abuse can be further subdivided into abusive head trauma, abusive fractures and other injuries, while sexual abuse is often categorized as penetrating or non-penetrating, contact or non-contact, or sexual exploitation. The broadest category, neglect, has been further classified as physical neglect (lack of appropriate food, clothing or shelter), medical care neglect (lack of appropriate medical attention, dental care or medications), and supervisional neglect (lack of developmentally appropriate surveillance and protection from environmental or other dangers).

For children, the World Health Organization (5) broadly defined these types of maltreatment for data collection and intervention.

- Physical abuse is the intentional use of force against a child that results in, or has a high likelihood of resulting in, harm to the child's health, survival, development or dignity. This includes hitting, beating, kicking, shaking, biting, strangling, scalding, burning, poisoning and suffocating.
- Sexual abuse is the involvement of a child in sexual activity that he or she does not fully comprehend, is unable to give informed

consent to, or for which he or she is not developmentally prepared, and/or that violates the laws or social taboos of society. This can be by adults or other children who, by virtue of their age or development, are in a position of responsibility, trust or power over the child.

- Psychological maltreatment is a pattern of failure over time on the part of the parent or caretaker to provide bonding and a developmentally appropriate and emotionally supportive environment. This includes restriction of movement, belittling, blaming, threatening, frightening, discriminating against, ridiculing, and other non-physical hostile treatment.

- Neglect is defined as isolated incidents and patterns of failure over time on the part of the parent or caretaker, when in a position to do so, to provide for the food, clothing, shelter, health, education, nutrition and safety of the child.

While similar definitions may be applied after the age of legal majority, there are important differences for competent adults able to give consent in sexual relationships and distinctions within couples and marital relationships. These are further modified when adults are disabled or deemed legally incompetent because of IDD, resulting in further blurring of definitions and distinctions between maltreated children and adults, those with special health care needs, and vulnerable populations. Domestic violence or intimate partner violence refers to violence and/or abuse towards persons in a marital, cohabiting or dating relationship, and it can take the form of physical, emotional and sexual abuse. In their landmark national survey, Straus, Gelles and Steinmetz (6) defined physical violence as "an act carried out with the intention, or perceived intention, of causing physical pain or injury to another person" (p.20). In addition to acts of physical aggression, intimate partner violence includes "psychological abuse, forced intercourse and other forms of sexual coercion, and various controlling behaviors such as isolating a person from family and friends and restricting access to information and assistance" (7). Threatened violence is also an integral part of

intimate abuse (8). It is not uncommon for different forms of violence to occur in tandem (7,9). The use of multiple types of violence particularly characterizes the phenomenon of men's violence against women (8). Violence against women with developmental and intellectual disabilities is seen as part of the broader issue of violence against persons with disabilities and includes violence by physical force, economic coercion, intimidation, psychological manipulation, deception, misinformation, legal compulsion, and the absence of free or informed consent (10).

The epidemiology of abuse

Intimate partner violence cuts across all populations, irrespective of social, economic, religious or cultural backgrounds (11). However, some studies suggest that younger women and those living below the poverty line are disproportionately represented in the available data (12). Similarly, women with disabilities are poorer than the general population, which places them at increased risk for abuse (13). Brownridge (14), who compared findings from three nationally representative surveys in Canada on women and partner violence, found that women with disabilities have lower educational levels and socioeconomic status are more dependent on their partners, are less powerful, and have higher risk for violent victimization by a partner.

Notwithstanding increased public awareness about intimate partner violence and the development of multilevel responses to it, violence against women by intimate male partners persists at alarming rates. In the U.S., nearly a quarter of all women are raped and/or physically assaulted by an intimate partner at some point in their lives (9, 15). In 2012, the New York City Domestic Violence hotline received an average of 290 calls daily (16). In previous years when the gender of callers was specified in the published statistics, 83 per cent of the calls made annually to the hotline were by women (17). At the close of the twentieth century, over a quarter of the women murdered nationwide were reportedly killed by their husband, former husband or boyfriend (18).

While men also experience abuse by intimates, data suggest women are much more likely to be victimized by their male partners. According to a

National Crime Victimization Survey, women accounted for approximately 85 percent of all victims of intimate abuse in 2001 (19). Similarly, according to the Bureau of Justice Statistics (20), trends in violent victimizations between 1973 and 2003 indicate that men were more likely to be violently victimized by a stranger, whereas women were more likely to be victimized by a friend, acquaintance or intimate. Men who batter women also have increased risk for abusing their children (21). It is clear that intimate partner violence is a serious and prevalent problem, and that women are most at risk of rape and physical assault by people they know and love (22). It is contended that: "[O]f course, individual cases of women's violence exist, but such cases do not alter the fact that the overall pattern of intimate violence is dominated by men as abusers and by women as the abused" (23, p.3).

Despite the limited data on intimate abuse of women with disabilities, it is suggested that they are at equal or increased risk for intimate partner violence when compared to women without disabilities (24,25). In particular, women with disabilities are more likely to experience sexual and physical violence, increased severity of violence, and longer duration of violence (26). In addition to enduring emotional, physical and sexual abuse, women with disabilities also experience disability-related abuse for longer periods of time, and by varying perpetrators (24). Women with disabilities tend to remain in violent relationships due to their dependence on their perpetrators and for fear of being alone.
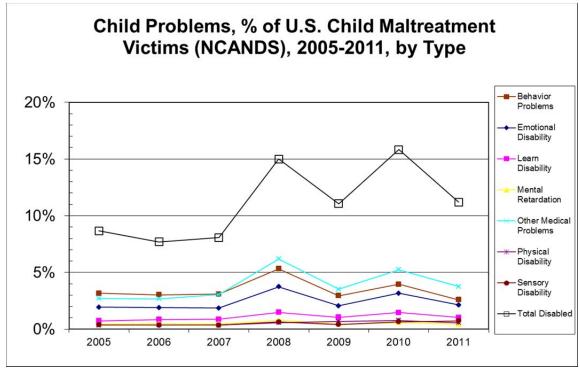
In a study that used data from the National Violence Against Women Survey conducted with a nationally representative sample of 8,000 women and 8,000 men, women with disabilities that severely limit activities of daily living were deemed to be at greater risk of sexual assault (27). When compared with women without disabilities, women who reported severe disability impairments were four times more likely to be sexually assaulted. In another study, although women with disabilities were not more likely to experience physical assault in the one year prior to the study, they were 4 times more likely to experience sexual assault when compared to women without disabilities (28). This study utilized data from the North Carolina Behavioral Risk Factor Surveillance System, an ongoing random-digit dial

household telephone survey. Likewise, in another study that employed a representative sample of 7,027 Canadian women living with a spouse or common-law partner, women with disabilities had a 40% greater likelihood of experiencing violence in the five years preceding the study (29). Further, these women appeared to be at risk for severe violence. Younger women tended to be most at risk for partner violence, similar to data from the general population that addresses partner violence (30).

Women with developmental and intellectual disabilities are seen as doubly vulnerable to partner violence because of their gender and disability. Indeed, as Curry and her colleagues emphasize: "Women with disabilities are at increased risk for emotional, physical, and sexual abuse. They are also at risk for experiencing disability-related abuse from multiple sources. This problem is compounded by the social context of disability, including pervasive discrimination and stereotyping by society" (31, p.60). In the same vein, it is argued that: "[v]iolence against women and girls with disabilities is not just a subset of gender-based violence: it is an intersectional category dealing with gender-based and disability-based violence. The confluence of these two factors results in an extremely high risk of violence against women with disabilities" (10, p.7).

Children with disabilities

Initial reports of child maltreatment in the special needs pediatric population were anecdotal rather than addressing the true population-based incidence. In the 1986 National Incidence Study for child abuse in the US, 35.5 per 1,000 children with disabilities were maltreated, compared to 21.3 per 1,000 children without disabilities, suggesting an epidemiologic connection (32). Physical abuse alone has been reported to be 3 times more likely among children with disabilities than among the general pediatric population (9% versus 31%). Spencer et. al. (33) found similar increases in the U.K. Another study found increasing proportions of children with physical and emotional disabilities associated with recurrence of abuse and neglect (34). However, a systematic review concluded that the evidence base for an association of disability with increased abuse and

neglect is weak (35), and another review found that physical disability did not increase the risk for any type of victimization once confounding factors and co-occurring disabilities were controlled (36).

In the US child welfare system, children who were reported to child protective services with any of the following risk factors were considered as having a disability in the U.S. National Child Abuse and Neglect Data System (NCANDS): mental retardation, emotional disturbance, visual or hearing impairment, learning disability, physical disability, behavioral problems or other medical problems (37). During 2005-2011, a progressively increasing proportion of children being reported have had an identified disability (Figure 1).

Source: US DHHS. (2007-2012). Child Maltreatment, 2005-2011.

Figure 1. Problems recorded among child maltreatment victims in NCANDS, 2005-2011.

Behavior problems and other medical problems had the greatest frequency, followed by emotional disability, and then mental retardation, sensory disability, and physical disability. Most recently, there were almost 800,000 substantiated cases of child abuse or neglect in 2011 in NCANDS. Approximately 3% of the children confirmed for abuse or neglect in NCANDS had one or more of these disabilities, although this is thought to be an undercount. When demographic factors are assessed, it is apparent that not all types of disability are equally related to child, family and community factors (Table 1). In 2011, sexual abuse was statistically significantly higher among children with confirmed maltreatment when mental retardation, sensory disability or physical disability was present. Similar relationships were not found for physical abuse and neglect. Some demographic factors were seen more frequently in some forms of disability, as were child and family problems with drugs, alcohol and other disabilities. Interestingly, children with disabilities were actually less likely to have other family violence present but were more likely to have services provided after child protective services investigation than were non-disabled children.

Table 1. Disability types associated with types of child maltreatment, child and family factors and services provided, among children with first confirmed maltreatment in NCANDS, 2011

Disability Type (% of total) (Total=398,841)	% of Victims	Mental Retardation (0.23%)		Sensory Disability (0.51%)		Physical Disability (0.41%)		Any Disability* (2.8%)	
		OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI
Physical Abuse	18.9%	NS[a]		0.79	0.70-0.90	1.48	1.32-1.66	1.46	1.40-1.53
Sexual Abuse	1.9%	2.86	2.13-3.84	2.16	1.72-2.71	3.88	3.19-4.72	3.97	3.67-4.30
Neglect	71.2%	NS		3.25	2.86-3.70	1.33	1.19-1.49	0.70	0.68-0.73
Medical Neglect	64.9%	NS		2.96	2.63-3.33	1.13[b]	1.01-1.25	0.67	0.65-0.70
Psychologic Maltreatment	5.2%	2.86	2.13-3.84	2.16	1.72-2.71	3.88	3.19-4.72	0.81	0.73-0.88
Child: Male	48.4%	1.57	1.36-1.81	NS		1.38	1.25-1.54	1.23	1.19-1.28
Live with Married Parents	9.8%	NS		NS		1.44	1.25-1.66	1.33	1.25-1.41
Native American	2.2%	2.78	1.93-4.01	3.03	2.39-3.85	NS		1.32	1.18-1.48
Asian	1.0%	NS		NS		NS		0.81[b]	0.65-0.99
Black	26.0%	1.19[b]	1.02-1.39	0.78	0.69-0.87	1.34	1.99-1.50	1.04	1.00-1.08
Native Hawaiian	0.3%	NS		2.69	1.58-4.58	NS		0.89	0.62-1.26
White	63.0%	1.23[c]	1.06-1.43	1.76	1.57-1.97	NS		1.40	1.35-1.46
Hispanic	18.5%	0.51	0.42-0.63	NS		0.27	0.22-0.33	0.53	0.55-0.59
Military	0.5%	NS		NS		0.12[b]	0.02-0.83	0.42	0.25-0.69
Housing Problems	19.9%	0.69	0.56-0.87	0.53	0.36-0.51	NS		0.88	0.83-0.93
Money Problems	24.6%	NS		0.55	0.47-0.63	1.89	1.68-2.13	1.62	1.54-1.70
Public Assistance	21.2%	2.37	1.96-2.87	2.41	1.96-2.96	4.54	4.05-5.09	1.18	1.12-1.23
Child Alcohol Exposure	0.3%	5.58	3.13-9.92	17.4	13.9-21.9	7.35	5.10-10.6	3.63	3.05-4.32
Child Drug Exposure	1.5%	2.48	1.78=3.45	4.43	3.73-5.27	3.11	2.48-3.89	2.51	2.29-2.75
Family Alcohol Problems	5.4%	1.49[c]	1.14-1.95	NS		0.41	0.30-0.58	1.13[c]	1.04-1.21
Family Drug Problems	12.1%	NS		NS		0.32	0.25-0.40	0.92[c]	0.86-0.97
Family Retardation	0.4%	26	19.8-34.1	2.63[c]	1.24-5.59	4.53	3.11-6.59	2.20	1.83-2.65
Family Emotional Problems	6.7%	3.05	2.43-3.83	NS		1.7	1.41-2.05	1.83	1.72-1.95
Family Physical Disability	0.8%	4.24	2.94-6.12	2.48	1.52-4.04	NS		2.08	1.80-2.39
Family Violence	22.4%	0.68	0.58-0.82	0.33	0.28-0.39	0.22	0.17-0.27	0.64	0.61-0.67
Post-Investigation Services	52.1%	2.16	1.84-2.53	5.15	4.52-5.87	7.66	6.46-9.07	1.96	1.88-2.05

*Includes one or more of child mental retardation, vision/hearing, physical disability, behavior, emotional, learning, or other medical problems.

p<0.001 unless noted: [a]NS: p>0.05; [b]p<0.05; [c]p<0.01.

The reasons for higher rates of child maltreatment in populations with disabilities are unclear. Premature infants may be at increased risk due to the lack of bonding created by their prolonged neonatal stay in hospital and the prolonged stress associated with this and with separation from their parents. Infants who may be seen for assessment and referral for early intervention services have histories which include being low birth weight or small for gestational age, being one of multiple births, having other structural anomalies such as spina bifida, chronic problems such as chronic lung or heart disease, chromosomal anomalies, including Trisomy 21, and visual and hearing impairments (38). Children with hearing and visual problems have increased risk for sexual abuse because of their inability to adequately report victimization. Children receiving bowel and bladder routines due to neurologic incontinence may be accustomed to having these performed by a variety of health care professionals and their index of suspicion may be lowered. They may also have reduced access to developmentally-appropriate sex education services. There are also issues regarding normal sexuality that pose additional risks for adolescents with disabilities (39). Subtle maltreatment can also occur in hospitalized children who are physically-challenged, as such children with cognitive limitations may not have procedures explained to them in a

developmentally appropriate manner by staff and/or may not have their privacy as well respected as do more vocal children who are able to complain.

Parents with disability

Current research reveals that there are 4.1 million parents with disabilities in the United States, reflecting 6.2 percent of all American parents with children under the age of 18 years (4). The rates are even higher for some subgroups of this population, with 13.9% of American Indian/Alaska Native parents and 8.8% of African American parents having a disability. Further, 6% of White, 5.5% of Latino/Hispanic, and 3.3% of Asian/Pacific Islander parents have a disability. Of the parents with disabilities, 2.8 percent have a mobility disability, 2.3 percent have a cognitive disability, 2.3 percent have a daily activity limitation, 1.4 percent have a hearing disability, and 1.2 percent have a vision disability. Many have more than one. Beyond the physical limitations placed on them by these disabilities, it is unclear if parents with disabilities have any difference in risk for maltreating their children.

There is a significant paucity in research and literature that addresses actual parenting differences by persons with developmental and intellectual disabilities. Historically, parents with disabilities have been regarded as facing obstacles to creating and maintaining families, but this perception results from the bias of varying entities involved with them and not necessarily based on the lived experiences of persons with disabilities (4). Studies report that parents with disabilities feel they are judged and viewed as incompetent parents (40). More recent studies have found that disability alone does not necessarily raise the risk level of parents. For example, in a UK study that used secondary data gathered from 101 parents with intellectual disabilities and 172 of their children, IQ levels of the primary parent and parents' perception of need were not seen as contributing factors that distinguish 'low-risk' from 'high-risk' parents (41). Rather, 'high-risk' parenting was linked to childhood trauma experiences (especially emotional abuse and physical neglect) of parents, parent's co-existing special needs, intellectual disabilities, or raising a child with special needs. This

is consistent with earlier research that also found that when children of mothers with intellectual disabilities were removed from the home, these mothers had problems in addition to her intellectual disability, failed to participate in the recommended programs, and/or lacked support (42).

As Tymchuk (43) points out, there are various positive factors associated with adequate parenting. These include: historical (a) environmental (e.g., living with own parents), (b) familial (e.g., having appropriate parent role models), (c) maternal (e.g., adequate physical and emotional health) as well as current (a) environmental (e.g., adequate resources and supports), (b) familial (e.g., supportive and healthy partner), (c) maternal (e.g., adequate education and skills), and (d) child factors (e.g., having only one healthy child). There is a need to more closely focus at these factors and on what predicts adequate parenting and to shift away from focusing on the prediction of inadequacy.

Similarly, legislation needs to emphasize what constitutes acceptable parenting and that persons with disabilities should not be discriminated against. In a study that utilized legal document analysis, the findings revealed that 37 states included disability-related grounds for termination of parental rights, while 14 states did not include disability language as grounds for parental rights termination (44). The authors recommend that the states remove "disability language from their statutes, as such language risks taking the emphasis away from the assessment based on parenting behavior" (p.927).

Abuse as a cause of disability

Frasier (45) reviewed the unquestionably negative effect of child abuse on the growth, emotional, social, and cognitive development of children. Psychological and emotional trauma, violence, abandonment, neglect, and failure to nurture can impact brain development at genetic, neuronal, functional, and neurodevelopmental levels. Abusive head trauma, as a form of direct physical trauma, can result in brain damage with global, pervasive developmental disabilities that affect a child and family for life. Conversely, patients with spinal cord injury, accidental drowning, suffocation, and burns who are

disabled may also have been abused. Spinal cord injuries in young children are rare, accounting for less than 5% of the total spinal cord injured population and are usually associated with high impact injuries such as motor vehicle accidents. However, in younger children, spinal cord injury may occur with or without associated head trauma and is often caused by abusive head trauma. These injuries may present clinically with neurological findings without radiographic abnormalities on spinal films, although MRI studies can be confirmatory of the lesions. Clinical lesions may be initially overlooked due to the severity of the head injuries even when upper cervical spine level injuries are sustained. With a concurrent central cord syndrome, lower extremity function may be preserved and upper extremity weakness may not be initially appreciated. More insidious lesions with hematomas of the cord may present with progressive gait difficulties, which may even make the examiner consider an initial diagnosis of a spinal tumor or Guillian Barré syndrome. Such presentations are neither associated with multiple fractures in various stages of healing nor with retinal hemorrhages, the injuries usually identified as concerning for child abuse.

One population-based study found the incidence of shaken baby syndrome to be 29.7 per 100,000 among infants and 3.8 per 100,000 in the second year of life (46).

The average age for occurrence of shaken baby syndrome is about 4-6 months, and these patients exhibit variable patterns of intracranial, retinal and preretinal hemorrhages, hematomas, edema, axonal injury and fractures. Younger children are more prone to tears of the tentorium and venous structures due to the weakness of their neck musculature that allows for their heads to be "snapped" back and forth. The prognosis may not always be apparent at presentation and may take up several months to evolve as interruption of brain growth may take this long to manifest. It may take 6 to 12 months for the lesions to evolve in the central nervous system pathways and up to 24 months for the onset of post-traumatic epilepsy. The full extent of the neuropsychological and behavioral sequelae may not evolve for 3-6 years and may make the retrospective diagnosis difficult (47). Even in the absence of structural abnormalities, verbal and performance IQ scores are often suppressed and

mandated intervention for special education services, cognitive remediation, and speech therapy are required.

In patients admitted to a pediatric rehabilitation unit, an overall incidence of 27% for abuse and neglect was reported over a 3-year period. About 20% of the patients had been directly abused de novo, and the remainder of patients suffered from secondary neglect in association with their pre-existing disabling condition.

In facilities where a greater number of patients with traumatic brain injuries were served, the percentage of admitted children who are directly abused approached 33%. Males were more likely to be affected. In Hagbergs' study of the changing panorama of cerebral palsy (48), child abuse is not mentioned as an etiology, but victims of inflicted traumatic brain injury have been noted to have motor deficits (60%), visual deficits (48%), epilepsy (20%), speech and language abnormalities (64%), and behavioral problems (52%).

Experiencing violence as a person with a developmental or intellectual disability

In addition to experiencing the same forms of violence as women without disabilities and their debilitating effects, women with developmental or intellectual disabilities contend with additional hardships. Women with disabilities who experience violence and abuse in their intimate relationships do not always recognize it as such. They often do not know how to report the abuse, and may be unable to reach out for help especially when their perpetrator intentionally seeks to isolate them or deprives them of needed assistance devices. They may be generally more vulnerable due to low self-esteem and social isolation and dependent on their perpetrator for their activities of daily living (31). Different from child protection, and as long as they have legal capacity, adults in many states have the right to not seek help for the abuse.

Margaret, aged 22, had been emotionally abused by her partner for a while before she disclosed this to her social worker. Margaret was wheelchair bound and

depended on her partner for her basic needs. Her family lived far, and she did not have many friends. She reported that her partner would move her wheelchair out of reach so that she would not be able to get to it. Without her chair she was immobile. He also would hide food in areas that she could not reach. He constantly called her names, told her she was 'stupid', 'crazy' and 'good for nothing.' She blamed herself, and believed there was nothing she could do to improve the situation. She was also very scared of telling anyone, because she feared being placed in a nursing home. She spent her childhood in a group home and was terrified at the thought of returning back to such a setting. She was also scared of ending up alone. When she disclosed the abuse to her social worker, the latter acknowledged the abuse, provided support and explored with Margaret what she wanted to do about the situation. Margaret worked with her social worker over many months before she decided to leave her partner. She filed for an order of protection through family court, and eventually also filed for divorce. Margaret continues to see her social worker for weekly therapy to help her cope with the trauma she sustained and to help her find meaning in her life without her partner.

Women with disabilities tend to endure more serious consequences as a result of violence. Notwithstanding their greater likelihood of experiencing violence in general, and severe violence in particular, women with disabilities are less eager to leave their partner because of their dependence and/or concerns about being alone (14). The distinct experiences of women with disabilities and the violence perpetrated against them are worth noting. In a qualitative study that sought to explore the abuse experiences of 25 women with disabilities (49), the women identified a myriad of stressors present on a daily basis. Financial problems, complex health-related difficulties and the ongoing stressors from a change of roles or difficulty fulfilling a role led to the women's uneasiness and strong dissatisfaction by the male partner. As the male partner's stressors increased, his capacity to cope decreased, and abuse escalated.

The partner's perception that the disability rendered these women 'less than' other women was another characteristic that emerged in this study (49). The women shared that their partners viewed them as 'damaged goods,' blamed them for their disability and for being unable to contribute to the family tasks as when they did not have a disability. Despite the experiences of some women without disabilities

whose partners show remorse after a violent episode, as Walker's (50) cycle of violence suggests, the women in this study expressed that their partners acted as if nothing had happened. This ongoing degradation and abuse cumulatively reinforced the women's sense of unworthiness, rejection, and dehumanization.

Sara, aged 32 was diagnosed with cerebral palsy as a child. Despite her disability, she led a very active and vibrant life. Shortly after she married her partner, her health started to decline and she became more dependent on her husband. Over time her husband became very verbally and physically abusive towards her. He refused to help her when she could not care for her own needs. He yelled at her, and reminded her constantly that she was 'good for nothing', 'useless', and the cause of their financial and relationship problems. He hit her regularly, broke things in the house, and tried choking her on various occasions. He forced himself sexually on her on an ongoing basis. He threatened that she would be placed at a facility if she called the police. Sara felt scared, isolated and fearful for her life. She did not want to report him because she depended on him. She was scared that if she disclosed the abuse to anyone the situation would worsen.

Sara suffered in silence for many months until she was admitted to hospital for spinal surgery. During her hospital stay while being away from her partner, she began to recognize how serious the abuse had become and plucked up courage to disclose this to her social worker. The social worker provided support, guidance and reached out to a domestic violence agency that specializes with working with persons with disabilities, to also provide support and assistance. Sara agreed to file a police report which led to her partner's arrest, and to the District Attorney's office being involved. She continues to receive counseling to help her cope with the past abuse she sustained.

There are many reasons why women with developmental and intellectual disabilities do not leave their abusive partner. Like all women, they fear retaliation and increased violence to themselves or significant others. The presence of children, limited financial resources, religious and cultural expectations, social isolation, and stress are other contexts within which intimate partner violence occurs (51-53). Dependence on a perpetrator for one's basic life needs also deters women from leaving their perpetrator (54, 55). Leaving a home that has been modified to accommodate their needs with often no

accessible place to go poses significant barriers to leaving abusive partners (31).

Gilson, Cramer and Depoy (56) likewise list reasons why it is so difficult for women with disabilities to leave. Unique forms of abuse that include sabotaging accessibility devices, withholding personal care, food, medication, neglecting to aid the individual transfer from wheelchair to bed or vice versa, refusing to communicate using sign language or communication device all adversely impact women with disabilities–emotionally and physically–and make it harder to leave. In a study that included a sample of 177 women with disabilities, financial dependence was seen a factor that keeps women with disabilities from leaving their perpetrators (57). Sadly, over time, abuse tends to escalate and relationships seldom end until the abuse becomes extreme. Even when women with disabilities contact a domestic violence agency or shelter, they are likely to be diverted to a disability service agency (58). As a result, a woman's disability and not the violence perpetrated against her becomes the focus, thereby hindering more appropriate interventions. In turn, this also deflects the attention from the violence as a social problem, and may communicate that their disability is what is most problematic.

Women with disabilities also tend not to report the abuse sustained. In a study with a sample of 305 women with diverse disabilities, that employed an anonymous audio computer-assisted, self-interview designed to increase awareness of abuse, almost half of the women who experienced abuse had not disclosed the abuse to a nurse, doctor, case manager or police officer (59). Self-blame, concern about being a burden to others, fear of retaliation, embarrassment, concern that they would not be believed, and to a lesser degree concern that shelter would lack the needed accommodations were among the reasons for not asking for help. Even if they report abuse, the fear of not being believed is even greater for women with disabilities. Additionally, common barriers to leaving an abusive partner include fear of losing independence, isolation from friends and family, being judged as unable to care for themselves and lack of accessible services (59, 60).

Children

Children and adults with IDD are a heterogeneous group of individuals who possess a variety of skills and experience a range of difficulties. The disability can affect, for example, a person's physical and cognitive abilities, language skills, memory, emotions, behavior, mobility and/or interpersonal interactions (61). Although there are commonalities among individuals diagnosed with a specific IDD, such as autism, each person demonstrates unique qualities. Early in life, IDD can affect a child's cognitive and adaptive functioning (62), and studies have demonstrated that children with IDD are at greater risk for abuse and maltreatment and report more severe forms of abuse than the general child population. In addition, the more profound the disability, the more severe the abuse (63). Despite their reported vulnerability to abuse, reports of child maltreatment among youth with IDD are less likely to occur and less likely to be believed (64).

Children with IDD often have contact with healthcare and other service providers whose role it is to support safety and well-being. However, the presentation of certain disabilities may disguise potential indicators of child abuse. Beliefs and attitudes can also affect how professionals view, assess and attend to children with intellectual and developmental disabilities. For example, beliefs such as that children with IDD cannot provide accurate information regarding their personal experiences; children with IDD are not affected by abuse and/or cannot benefit from interventions after a traumatic experience; and children with IDD are stressful or undesirable to work with, can negatively impact service providers and investigators interactions with this population and lead to unsupportive and less effective interventions (65).

As noted, children with IDD are sexually abused at higher rates than typically developing children (66). Several risk factors for sexual abuse in this population have been identified. These include characteristics of the child, the perpetrator of abuse and the child's environment and culture (67). For example, children with IDD may not feel they have the control or power to address or change a situation. Many undergo intrusive medical, educational and/or behavioral interventions that leave others in charge of their

functioning and blur their sense of personal space and boundaries (J. Manders, personal communication, July 30, 2012). They may not question or understand the inappropriate sexual behavior of others and may not know how to seek help. In addition, delays in cognitive, social and emotional skills can contribute to the difficulties of disclosing sexual abuse (66).

Children with IDD are often isolated in environments that place them at an increased risk for abuse. Some environments provide potential perpetrators easy access to this vulnerable population. In addition, staff turnover in institutions can decrease the likelihood of employed caregivers getting to know their child clients well, monitoring their safety and recognizing changes indicative of abuse. Society's lack of experience with youth and adults who have IDD can increase their isolation and promote misperceptions such as people with IDD are different, weak and vulnerable and/or lack the experiences of the community at large. It has been proposed that decreased isolation of individuals with IDDs may decrease their vulnerability to abuse (67).

Despite the multiple potential risks for child abuse in populations with IDD and the higher rates of reported abuse, few reported cases end up in the court system (68) or result in disciplinary action against the perpetrator of abuse (69). In addition, criminal cases have been dismissed because of uninformed interviewers who do not ask sound questions (66). Investigators of child abuse should take into account the individual abilities of each child before and during a forensic interview (68).

Assessing for abuse

The presence of a disability may not in and of itself change some of the basic findings of abuse on physical examination. Key concepts in assessing the potentially abusive nature of injuries in all age groups include the mobility and developmental abilities of the victim, the severity of the injury, the contribution of underlying medical conditions, and the ability of the victim to disclose what, if anything happened. As infants, patients are relatively immobile and passive in ways similar to frail adults. It is only with successful rehabilitation and mobilization that a child or adult may later become more vocal and more

demanding of care, prompting an alleged event of abuse or neglect. When there is an unclear or inconsistent mechanism of injury reported, the caretaker-patient dyad should be observed closely and a full psychosocial assessment by a multidisciplinary team should be obtained. In vulnerable adults, as with children, an asymmetric power in relationships can lead to the stresses triggering a variety of abusive and victimizing acts.

Children and adults who have pathological bruising or fractures may be suspected of having inflicted abuse (70, 71). Bruise patterns shaped like objects and located on specific target zones (face, ears, neck, torso) are particularly concerning. Unusually shaped lesions, such as cigarette burns, belt marks, or other objects, are grounds for report to protective services. Bruising may be confused with congenital hemangiomas alone or in association with a more generalized syndrome or with Mongolian spots. Unexplained generalized bruising requires evaluation with a blood count and coagulation studies regardless of the associated diagnoses to exclude the possibility of a hematologic abnormality and/or medication effect. Glutaryl-Co-A-dehydrogenase deficiencies, particularly glutaric aciduria type 1, are inherited metabolic disorders with encephalopathic findings in association with neurological degeneration. When there is potential for malabsorption or inadequate vitamin D supplementation, screening tests for serum calcium, phosphate and alkaline phosphatase should be obtained with mono- and dihydroxy-vitamin D levels, since serum chemistries alone may not reveal any abnormalities. Pathologic femur fractures may occur even in younger patients with spina bifida, as they may in patients with cerebral palsy, osteogenesis imperfecta, non-ossifying fibromas, osteoporosis, aneurysmal bone cyst, and fibrous dysplasia. In patients where the mechanism for accident or pathological fracture is clear, the clinician may need to advocate for the family and assist in dismissal of such allegations.

Skin breakdown is clearly a risk in patients who have loss of sensation even in the absence of inflicted injury. Children and adults with chronic skin ulcers below their sensory levels which are permitted to fester and get infected, with unreported and fetid drainage under casts and poor hygiene with secondary

infection, also pose a group of victims who should be admitted for skin care in addition to restorative services and should be reported. In such instances, if it is determined that the parent or guardian does not pose a direct threat to the patient, they should be directly supervised and involved with medical specialists and nursing to learn how to best provide care. If there are concerns that caregivers are directly harming the child, steps should be taken to restrict access pending investigation. Another example of potential medical neglect includes failure to keep appointments such as to have a medication pump refilled when there is prior knowledge that medication withdrawal is not only associated with rebound spasticity, but also with seizures, altered mental status, fever, and other serious morbidities.

The failure to comply with treatments and diagnostic testing is a marker of parental/caretaker noncompliance and potential neglect (72). Children in need of diagnostic testing, therapy for progressive limb contractures, or provision of orthotics and varied treatments, who are not provided with these services will not perform as well. These lapses may extend to the lack of provision of general medical care and failure to properly immunize, which would not only place them at jeopardy but also, in the absence of medical contraindications, limit the participation in center-based and rehabilitative programs. Intentionally not permitting a physically challenged adult or child to access their augmentative communication and other technological devices, or intentional breakage of such devices upon which they are dependent, is also a form of maltreatment. Parents and caretakers who have a history of substance use, childhood abuse or neglect, abuse or neglect of other family members, lack follow-through with their child's school, or who complain about the strain or burden of care, both financial and temporal, are at increased risk for victimizing those they care for. Their lack of acknowledgement of stressors and inability to request help may also be an additional risk factor.

Interviewing children

Maria is a 12 year old female with Down Syndrome who was referred for a forensic interview after disclosing to her mother that she was touched inappropriately at school. As reported and observed, Maria had difficulty with transitions, meeting new people and being in an unfamiliar setting. Facing these circumstances, she becomes isolative, non-communicative and/or cries. However, in familiar settings, she is verbal, interactive and has interests in dance and dolls. In order to address Maria's individual needs and functioning, two appointments were initially scheduled for the interview. During the first appointment with her mother, the goal was to introduce Maria to the surroundings and to the investigative team, address the mother's anxiety about Maria's disclosure and provide support for the family's needs. Maria was given a tour of the clinic and was able to explore play materials that gave her comfort and pleasure. Initially, she did not respond to the team's directives and made poor eye contact. Given choices and time to explore her new setting, Maria's comfort level appeared to increase. On her second visit, she easily joined the interviewer, was verbal and when needed found comfort in the play materials previously explored.

Given her cognitive and language difficulties, Maria was unable to provide a context for her disclosures or to assess the intent of her alleged perpetrator. Lack of information to support or refute abuse led to contact with involved agencies and further exploration of collateral information and a report to law enforcement. Special Victim's Detectives were informed of the abuse evaluation findings and visited the school to interview others involved. Maria's school also conducted an independent investigation through their department of education. Maria's safety was the focus and her mother was supported in navigating the educational system to request additional services for her daughter and to consider a transfer to a new school. Given her age, Maria was also referred to a special program that teaches youth with DDs about sexuality and body safety.

Few research studies address or attempt to understand the ability of children with IDD to provide reliable information (73) or report details of alleged abuse (74). Nonetheless, these youth are viewed as unreliable reporters and perpetrators are less fearful of the consequences for abusing this population (75). The legal system is hesitant to include children with IDD as witnesses (73) and therefore these children may not be given the opportunity to participate in a forensic interview and provide information (68) helpful to an investigation. Courts may not utilize experts to assess the reporting abilities of children with IDD and therefore not have an accurate assessment of their credibility. In addition, courts may use the same criteria to determine reliability in this population as children without IDD (74) potentially

yielding an inaccurate assessment of the child witness' abilities and perpetuating myths about the reliability of individuals with IDD.

The perception that all children with IDDs are unreliable witnesses and lack the ability to provide accurate information can lead investigators to discount their disclosures and/or behaviors and fail to conduct forensic interviews that consider children's individual capabilities and needs (76). As with any child, children with IDD should receive individualized treatment when being interviewed about child abuse. Investigators and courts should avoid making assumptions about their functioning (69), take into account the individual abilities of each child, and obtain information about a particular child before conducting an interview (68). Many children with IDD have the capacity to provide accurate accounts of their personal experiences (76, 77) but more research is needed on these abilities (68) in order to inform investigators and improve the effectiveness of child abuse evaluations.

Studies looking at children with non-specific IDDs have focused on children's free recall abilities, interviewers' open-ended questions to elicit narrative responses, directive or specific questions that require shorter responses from a child and suggestive or leading questions (69). Some research has shown that children with IDD may provide few details when asked to use free recall of events. However, the information they provide is generally accurate (73). This population has also been shown to respond with reliable information to open-ended and specific questions but appeared more suggestible to misleading 'yes/no' questions (73). In addition, children with mild to moderate intellectual disabilities have been shown to recall details important to a forensic interview (69). Many children with IDD have some form of communication difficulty but often know what happened to them and by whom (J. Manders, personal communication, July 30, 2012). This suggests that the assessment of a child's ability to provide reliable information should take into account the child's mental or developmental age not chronological age (69).

More research is needed on the accuracy of reports from children with IDD (68) as well as studies to increase investigators' understanding of how children with IDD function and provide reliable information in the context of a forensic interview for child abuse. Interviewers with little experience working with these children should seek consultation and resources to build their knowledge base and share ideas and impressions of the child they are interviewing. A multidisciplinary team approach or a group of knowledgeable consultants available to the interviewer are ideal in the evaluation of child abuse. There is no one approach to interviewing this diverse population. Each child will require flexibility on the interviewer's part and access to a variety of means to communicate the most accurate information possible (A. Grosvald-Hamilton, personal communication, July 30, 2012).

Preparation

The ultimate goal of conducting a child forensic interview is to protect a child's safety and/or prosecute a perpetrator by gathering reliable information to be used in civil or criminal court cases (78). In general, forensic interviews for child abuse have several components or phases, each influencing the next. Preparation before meeting the child is one of the first phases of the interview process and is extremely important to conducting a sound interview (66). Preparation for conducting a forensic interview regarding child abuse applies to all populations including youth with IDD. Given the modifications suggested for interviewing youth with IDD, it is important to prepare for the interview in order to increase the efficacy and accuracy of the interview (78), address children's and families' needs (64), help protect children and their family members from further harm and increase options for pursuing a criminal investigation (79). Using an ecological perspective to understand abuse and maltreatment in children with IDD can be helpful to understanding, preparing for and conducting forensic interviews and to developing interventions for children and their families (80). For example, obtaining information regarding the child's social context including his/her family, school, community and health care settings is vital to understanding the child (65).

Modifications before, during and after the interview can help support the needs and well-being of the child and his/her family during the

investigation process. They may include obtaining information prior to the interview regarding the child's developmental, cognitive and behavioral functioning, adjusting interview questions (e.g., shorter and more concrete), changing the pace of communication to maximize the child's and interviewer's understanding, focusing on the child's free recall abilities, avoiding repetition of questions, and providing appropriate referrals to address the specific needs of the family (69).

Parents and primary caregivers can provide a wealth of information to assist in the child abuse evaluation process. However, they are often very anxious and fearful during an investigation. They may not understand, minimize or exaggerate the extent of their child's abilities and/or disability and experience barriers to understanding and communicating with their child (76,77). Many parents are keenly aware of their children's vulnerability and often feel an inability to protect them. During an abuse investigation, they look to the investigative team to identify potential abuse, help protect their child from further harm and provide any necessary intervention. If child abuse allegations are made against a school or institution, gathering data from those institutions may not be feasible or appropriate (76). Helping parents navigate the reporting process against an institution and obtaining an advocate for the child's educational needs is often part of the interventions for the parents.

Information to be collected

When a child with IDD is referred for a forensic interview regarding allegations of child abuse, it is imperative that the interviewer and/or multidisciplinary team obtain as much background information about the child as possible to assess his/her unique abilities and needs. Preparation before the interview can decrease the amount of adjustments the interviewer and child need to make during their encounter and potentially decrease the amount of time, stress and confusion for both involved (76). Focus should be on obtaining factual information. Understanding the nature of the child's IDD, how he/she functions and adjusts to change and how these impact the interview process are part of the preparation (66). Children with IDD often have

complicated histories and are described by others in multiple ways. Demographic information including family composition, cultural practices, living conditions and information including the child's medical and school records, for example, should be obtained from those familiar with the child (79).

In addition to obtaining referral information and details concerning a child abuse allegation, it is important for investigators to obtain as much collateral information as possible. Children with IDD are often involved with multiple service providers and receive several evaluations to address their needs. A child's developmental history and current emotional, behavioral, and cognitive functioning can help inform an investigator's approach to the child. Individuals' capacities can change overtime. Therefore, current educational, psychological or psychiatric evaluations, for example, can provide information necessary to understand the child's functioning (76). Information regarding the child's primary IDD, when he/she was diagnosed with the disability, how he/she is affected by the disability and which interventions were provided is important to obtain. In addition, the child's history of behavioral functioning including baseline behaviors and behaviors identified as concerning or indicating abuse is important information to obtain before the interview (79; A. Grosvald-Hamilton, personal communication, July 30, 2012). Crucial to the interview process is the identification of the child's developmental age versus their chronological age to inform the interviewer's questions and interventions (76).

Information regarding the services the child receives in and out of school, medication regimens, the child's daily routines and special accommodations needed can help to schedule and structure the interview (76). An interviewer's preparation and how he/she conducts an interview may include making accommodations for a wheel chair or emptying an interview room of toys and objects that could be distracting or unsafe to the child, consulting a professional knowledgeable about IDD (66) or scheduling the interview for a time of day when the child is most alert and able to function at his/her best (76).

A child's attention span, distractibility and activity level can impact the interview process and require implementing modifications. Based on the

description of a child's behavior, interviewers may have to consider allowing a child with IDD to stand or pace during the interview, prepare for a child's need to be close or distant from the interviewer and consider the possibility of the child engaging in self-destructive or sexualized behaviors, repeated vocalizations or withdrawing from the interview (79; A. Grosvald-Hamilton, personal communication, July 30, 2012). Considering what would help a child focus including a structured setting or a setting where the child may be active can be helpful (76,77).

The child's level of independence or need for assistance during the interview should also be considered. Assistance may include the use of an interpreter or persons familiar with the child. Special care should be taken to assess the impact of having such a person in the interview room and how he/she may affect the child's disclosures and legal proceedings. It is suggested that if an assistant has to be present, he/she should not interact with the child during the interview and sit in a position that does not allow for direct eye contact with the child. Otherwise, the case can be viewed as invalid in the legal system. In addition, leaving an assistant or family member alone with the child to help him/her go to the bathroom, for example, could invalidate the interview (79).

Interview

Susan is a 10 year old female diagnosed with an Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder. She is social, verbal, and demonstrates several cognitive strengths. Susan made a concerning statement to her mother about a staff member in her residential school that made her mother concerned about sexual abuse. Building rapport with Susan was an easy task given her social and verbal skills. However, during the interview she became increasingly active and distractible. Play materials providing structure were made available to Susan. She was given permission to stand and for abuse-related questions she spontaneously chose to sing her answers. This approach appeared to help her focus and cope with the anxiety of discussing a difficult subject. Collateral information supported many of Susan's disclosures, led to a police investigation and allowed her mother the choice of pursuing a school transfer.

Forensic interviews are greatly impacted by the child's and interviewer's ability to understand each another. Attention should be given to identifying the most effective means of communicating and using different approaches to enhance communication (A. Grosvald-Hamilton, personal communication, July 30, 2012). Identifying how the child receives, understands and relays information and forming questions to maximize the child and interviewer's understanding (J. Kenniston, personal communication, July 30, 2012) can increase the chances of obtaining accurate information. It is important to consider if the child speaks more than one language or requires nonverbal materials to express him/herself.

Although a discussion of interview modifications related to specific IDDs is beyond the scope of this review, a few examples will be mentioned. When interviewing a child with a sensory disorder, investigators should consider the physical environment such as lighting and noise levels and the child's need to engage his/her tactile senses frequently. Language skills are often affected in children with cognitive delays. Asking short and concrete questions may be required as well as repeating questions before rephrasing or changing them. In addition, being patient and waiting for a child to give a response may be helpful and decrease confusion. However, several repetitions of a question are discouraged (69). Repetitions can be frustrating for children and give the impression they are not providing a "correct" answer. The interviewer telling a child he/she does not understand the child's response may provide an opportunity for the child to clarify information. Children with Autism may not have the capacity to understand sarcasm, jokes or innuendos and therefore the interviewer should be careful to avoid these while talking with the child. Children with Autism may be aversive to touch and engage in repetitive behaviors such as vocalizations or rocking movements that require the interviewer's patience and flexibility (A. Grosvald-Hamilton, personal communication, July 30, 2012).

The interview process can be anxiety provoking for any child and their family. For many children with IDD, this process as well as changes in their routine and adapting to a new setting may be daunting. They may need more time to prepare and adapt to the interview setting and investigation process or require

shorter sessions and follow-up appointments. If there is not an immediate safety concern, such accommodations may help the child feel comfortable and optimize his/her functioning (76).

Obstacles encountered when interviewing some youth with IDD can be similar to those encountered with young children (69). They may have difficulty providing a detailed narrative, require more directive and structured interviews or interview aids (e.g., drawings, dolls) to communicate information and may be more vulnerable to suggestibility. Some groups of youth with IDD may be more prone to acquiesce to interviewers' questions or provide incorrect responses to specific questions (81). In addition, children with physical disabilities may be used to and rewarded for compliance with adults and have difficulties talking about or to an adult without a disability (79).

Best practices

David is a 10 year old boy with profound Autism. He was referred for a child abuse evaluation after allegations were made against his foster mother for hitting him when he refused to eat his meal. His older brother who is developmentally age-appropriate overheard his brother arguing with the foster mother over the meal but did not directly witness the alleged hitting. David is nonverbal, has difficulties with social engagement and demonstrates repetitive body motions. He was describes as being "oppositional" at times making it difficult to direct him. He was accompanied by his school service providers who were trained in using a facilitated communication device with him. However, they complained that the device was outdated and did not give David the opportunity to express himself well. They were seeking funding for an updated device. Despite brief training on the device before the interview, the interviewer had difficulty assessing the reliability of David's responses. During a developmental assessment he appeared to provide both correct and incorrect answers. Physical abuse by the foster mother could not be determined. However, to ensure safety, Child Protective Services ultimately chose to remove the children from their foster home.

Best practices suggested for interviewing children with IDD about child abuse include following the best practice standards for interviewing all children and incorporating modifications that address the specific needs of the child with IDD (69). The structure of forensic interviews conducted with children for suspected child abuse generally include components of rapport building, developmental assessment, practice of decreasing suggestibility exercises, assessment of the child's ability to distinguish truth from lie, focused questions on the alleged abuse and closure (79).

Building rapport is essential to any forensic interview with a child. Studies have shown that children who built rapport with an interviewer had fewer recall errors than children who did not build rapport (82). Rapport can help increase a child's comfort level with the interviewer and the interview setting. For children with IDD, meeting a new person, visiting a new environment and being asked to engage in an unfamiliar task can be very stressful and make adapting to the situation difficult (79).

Children's social and communication difficulties may make building rapport more difficult and therefore more time dedicated to this phase of the evaluation may be needed. Asking general questions unrelated to abuse allegations such as questions about children's special interests and friends may help to engage them, build trust and openness, model and practice the type of questioning used throughout the interview and allow the interviewer to determine the child's preferred mode of communication and ability to communicate information about the abuse allegations (66). This phase of the interview can also help the interviewer to assess the child's adaptability and potential immediate needs (79).

When interviewing children with IDD, a variety of means should be used to allow the child several opportunities to report as much accurate information as possible. When possible, nonverbal aids should be used as a follow-up to verbal disclosures for further clarification (66). Several tools may be required to assist children with IDD to disclose information related to alleged abuse. Examples of nonverbal interview aids include anatomically correct dolls and drawings, toys and pictures (J. Kenniston, personal communication, July 30, 2012). Children with significant verbal deficits may especially need nonverbal aids to help them disclose information. Anatomically detailed dolls or drawings are examples of such aids and are often used with children who are suspected of being sexually abused (66). Although there has been controversy on the potential

suggestibility of interview aids, when used properly, and not alone, they can help children relay important information (83). "Facilitated communication involves the use of graphic mode communication systems (pictures, words, traditional orthography that are displayed on either electronic or non-electronic communication aids). Utterances are produced by having the user select symbols using a touching or pointing response. Touching or pointing may involve the whole hand or an isolated pointing finger" (84, p.495). In the field of child protection, there is controversy over the accuracy of facilitated communication including concerns about facilitators' influencing a child's responses. Studies have produced mixed results. Investigators have shown that some nonverbal autistic children may have cognitive abilities previously unrecognized. More research is needed on facilitated communication. Although difficult to prove in court, it is important to show in cases of child maltreatment that the child was not influenced by the facilitator (84).

Developmental assessment

A brief developmental assessment with a child can be conducted informally during rapport building (77) to avoid replicating a testing/evaluation situation and reduce potential anxiety. The assessment allows the interviewer to evaluate the child's language skills and to assess the child's understanding of concepts important to the disclosure of the reported abuse (66). It also considers the child's, social, emotional and behavioral functioning. The interviewer assesses for example, how the child receives, processes and expresses information, responds to seating arrangements, potential distractions, the interviewer's tone of voice and body language (A. Grosvald-Hamilton, personal communication, July 30, 2012).

A developmental assessment helps the interviewer adapt interventions and questions to the child's developmental age and provide a context for the abuse evaluation (69). Some interviewers may not be aware of the impact of the child's developmental skills on the process of the interview and on the child's ability to remember their experiences (66). Failure to conduct a developmental assessment can lead to inaccurate information or a lack of details

important to pursuing an abuse investigation further. Conducting an assessment of the child's vulnerability to suggestion and practicing skills to decrease suggestibility during the interview includes, but is not limited to, giving children permission to say "I don't know" and not guess their responses, correcting an interviewer's wrong statements and requesting permission to take a break during the interview. Assessment of credibility may include assessing the child's ability to distinguish truth from lie. "Historically, competency has been conceptualized as a capacity that is intrinsic or inherent to the individual" (85, p. 101). This definition does not take into account contextual factors that could influence competency. The perception that individuals with IDD are unreliable witnesses in court may stem from their vulnerability to authority figures and inconsistent responses in court. Ericson, et al., (85) suggest that it could be the authority figure's form of questioning and the impact of their questions on the responses of a person with IDD. Research has shown that cognitive difficulties are not related to the reliability of memory or to a child's ability to differentiate truth from lie (69).

Closure is the final stage of the interview. Families with children who have IDD face many stressors including fear of harm to their child. Providing closure to a child and their family after conducting the interview can provide an opportunity to assess their needs and reactions to the evaluation process, prepare them for the next steps of the investigation process and provide necessary support and referrals (66). This ending phase of a forensic interview with a child who has IDD is as important as the rest of the interview. This experience can be very stressful and leave a lasting impression on children. It is important to demonstrate respect and acceptance for the child, not only for his/her efforts but for him/her as a person. In addition, no matter how children function during the interview, what they disclosed or how their interview impacts the investigation, their efforts should be supported and appreciated and their reactions validated (66).

Reporting maltreatment

If a child discloses information or behaves in such a way that leads to a suspicion of abuse or neglect, a variety of professionals and agency staff members can be legally mandated (each state/country according to their laws) to make a report to the governmental entity designed to receive such reports. This entity determines if there is enough evidence to prompt an investigation and/or begins an investigation which includes assessing the safety of the home, interviewing family members and others known to the patient, and obtaining medical and other records. This investigation can involve law enforcement and child or adult protective services. Some jurisdictions have Child Advocacy Centers where child protective services and police are co-located and conduct forensic interviews and investigations. If abuse occurs in an institution or in foster care, the agencies involved may also conduct their own investigation. Given the variety of agencies that can become involved when a child or adult discloses abuse, collaboration and awareness of the needs of the patient and his/her family are essential. Efforts should be made to decrease the number of interviews conducted by different agencies. Lack of collaboration among agencies can negatively affect functioning and motivation during the interview and interviewers' ability to obtain reliable information. Multiple interviews also have the potential to create stress, confusion, and frustration for patients and families and lead victims to think they are not believed or are in trouble, to avoid disclosing information, accurate or not, to cope with the repetitive process. For victims with IDD, these potential negative effects can be exacerbated by their difficulties coping with and understanding the investigation process. Difficulties conducting a sound and informed interview can ultimately fail to protect a victim, halt an abuse investigation, and negatively impact subsequent civil and/or criminal legal proceedings.

Conclusion

The authors of a 2012 National Survey of Abuse on People with Disabilities found that "[T]oo many people are abused too much, with very little on the response side to help in the aftermath" (86, p.1). The need for a coordinated response is urgent. Such response however, is not complete until it also addresses the needs of persons with developmental and intellectual disabilities and their unique needs and struggles. Their plight has been so invisible that waiting for the attention they deserve is no longer an option.

Women with disabilities need to be embraced by domestic violence agencies as part of their constituency (87). There needs to be enhanced cross-collaboration between disability and domestic violence organizations to improve accessibility (55). We need services that intersect intimate partner violence and disability and that are accessible to persons with diverse disabilities, including IDD.

Given the interface between women with disabilities and health care settings, universal screening for abuse for every client in health care settings needs to be implemented (24,59). Education of staff on how to identify and intervene with persons who report maltreatment is also needed. Training on how to identify those most at risk will also help clinicians enhance preventive and intervention measures to ensure that those most in need receive the services they need (28). Likewise, training staff at all state disability offices on how to assess for intimate partner violence and child abuse is an important step (88).

In order to identify and prevent abuse and neglect, a high index of suspicion needs to be maintained. Clinicians and advocates need to be able to identify and report patterns of maltreatment while excluding mimics and other confounders. Children and adults with disabilities are seen by many subspecialists, and it is important that there is one individual or group of professionals who follow them on a consistent basis, preferably in a defined "medical home" integrated with community services. This can reduce the risk of abuse or neglect and permit proactive, preventative services to be put into place.

With mandated early intervention referrals for children with developmental delays, children are now more readily identified and services are initiated earlier. Formalized respite care also provides a hiatus from familial stressors. It is clinically believed that such interventions reduce the risk of abuse and

neglect because of the additional emotional support, which, in addition to direct benefits in enhancing child development, may be a secondary rationale for their existence.

While mandatory training for health care professionals in the identification of child abuse and neglect is required in many states, little or no training is available addressing the needs of disabled adults with disabilities. School personnel and other professionals, especially those dealing with special education populations, need additional training beyond baseline mandatory courses. In addition, there are several other services that need to be in place to prevent abuse and neglect among people with disabilities. Several studies have shown the potential positive effects of supportive social services, parent education, respite services, and counseling provided starting at birth (89,90,91). Programs for education and prevention need to be extended to parents and guardians in early intervention and preschool programs and for those who will be providing foster care services (92).

References

[1]   Kempe CH, Silverman FN, Steele BF, Droegemueller W, Silver HK. The battered-child syndrome. JAMA1962;181:17-24.

[2]   National Council on Disability. Rising Expectations: The Developmental Disabilities Act. Washington, DC: NCD, 2011;27-33. URL:http://www.ncd.gov/ publications/2011/Feb142011#toc1

[3]   Ten Bensel RW, Reinberger MM, Radbill SX. Children in a world of violence: The roots of maltreatment. In Helfer ME, Kempe RS, Krugman RD. The battered child, 5th edition. Chicago: University of Chicago Press 1997:3-28.

[4]   National Council on Disability. Rocking the cradle: Ensuring the rights of parents with disabilities and their children. Washington, DC: NCD. 2012. Accessed 2013 Nov 2. URL: http://www.ncd.gov/publications/2012 /Sep272012/

[5]   World Health Organization. Report of the Consultation on Child Abuse Prevention. Geneva, Switzerland: WHO Press. Document WHO/HSC/PVI/99.URL: http://whqlibdoc.who.int/hq/1999/WHO_HSC_PVI_99. 1.pdf

[6]   Straus MA, Gelles R, Steinmetz S. Behind closed doors: Violence in the American family. Garden City: Anchor Press, 1980.

[7]   World Health Organization. Violence against women (Fact sheet No. 239), 2002. URL: http://who.int/ mediacentre/factsheets/fs239/en/print.html

[8]   Hearn J. The violence of men. Thousand Oaks, CA: Sage Publications, 1998.

[9]   Tjaden P, Thoennes N. Prevalence and consequences of male-to-female and female-to-male intimate partner violence as measured by the National Violence Against Women Survey. Violence Against Women 2000;6(2):142-161.

[10]   International Network of Women with Disabilities. Document on violence against women with disabilities, 2010. URL: http://inwwd.wordpress.com/publications-of-the-inwwd/

[11]   National Center for Injury Prevention and Control. Intimate partner violence: Fact sheet, 2004. URL: http://www.cdc.gov.ncipc/factsheets/ipvfacts.htm

[12]   Heise L, Garcia-Moreno C. Violence by intimate partners. In: Krug E, Dahlberg LL, Mercy JA. World report on violence and health. Geneva: World Health Organization, 2002;87-121.

[13]   Hassouneh-Phillips D, McNeff E, Powers L, Curry MA. Invalidation: A central process underlying maltreatment of women with disabilities. Women Health 2005;41: 33-50.

[14]   Brownridge DA. Violence against women: Vulnerable populations. Florence, KY: Routledge, 2009.

[15]   Tjaden P, Thoennes N. Extent, nature and consequences of intimate partner violence: Findings from the National Violence Against Women Survey (NCJ-181867). Washington DC: National Institute of Justice and the Centers for Disease Control and Prevention, 2000.

[16]   Mayor's Office to Combat Domestic Violence. Domestic violence fact sheet 2012. New York City: Mayor's Office to Combat Domestic Violence. . URL: http://www.nyc.gov/html/ocdv/html/statistics_resources /fact_sheet.shtml

[17]   Mayor's Office to Combat Violence. Domestic violence fact sheet 2004. New York City: Mayor's Office to Combat Domestic Violence. URL: http://www.nyc.gov /html/ocdv/html/statistics_resources/fact_sheet.shtml

[18]   Rennison CM, Welchans S. Intimate partner violence (No.NCJ-178247). Washington, DC: Bureau of Statistics, US Department of Justice, 2000.

[19]   Rennison CM. Intimate partner violence, 1993-2001 (No.NCJ-197838). Washington, DC: Bureau of Statistics, US Department of Justice, 2003.

[20]   Bur Justice Stat. Crime characteristics, 2005. URL: http://www.ojp.usdoj.gov/cvict_c.html

[21]   Palusci VJ, Crum P, Bliss R, Bavolek SJ. Changes in parenting attitudes and knowledge among inmates and other at-risk populations after a family nurturing program. Children Youth Services Rev 2008;30:79-89.

[22]   Bachman R. A comparison of annual incidence rates and contextual characteristics of intimate partner violence against women from the National Crime

Victimization Survey (NCVS) and the National Violence Against Women Survey (NVAWS). Violence Against Women 2000;6(8):839-67.

[23] Dobash RP, Dobash RE, Cavanagh K, Lewis R. Changing violent men. Thousand Oaks, CA: Sage,1999.

[24] Hassouneh-Phillips D, Curry MA. Abuse of women with disabilities: State of the science. Rehab Couns Bull 2002;45(2):96-104.

[25] Plummer A, Findley PA. Women with disabilities' experience with physical and sexual abuse: A review of the literature and implications for the field. Trauma Violence Abuse 2012;13(1):15-29.

[26] Casteel C, Martin SL, Smith JB, Gurka KK, Kupper LL. National study of physical and sexual assault among women with disabilities. Inj Prev 2009;14:87-90.

[27] Powers LE, Hughes RB, Lund EM. Interpersonal violence and women with disabilities: A research update. Harrisburg, PA: VAWnet, a project of the National Resource Center on Domestic Violence/Pennsylvania Coalition Against Domestic Violence, 2009. URL: http://vawnet.org

[28] Martin SL, Ray N, Sotres-Alvarez D, Kupper LL, Moracco KE, Dickens PA, Scandlin D, Gizlice Z. Physical and sexual assault of women with disabilities. Violence Against Women 2006;12(9):823-37.

[29] Brownridge DA. Partner violence against women with disabilities: Prevalence, risk and explanations. Violence Against Women 2006;12(9):805-22.

[30] Rennison CM. Intimate partner violence and age of victim, 1993-99 (No.NCJ-187635). Washington, DC: Bureau of Statistics, U.S. Department of Justice, 2001.

[31] Curry MA, Hassouneh-Phillips D, Johnston-Silverberg A. Abuse of women with disabilities: An ecological model and review. Violence Against Women 2001;7(1):60-79.

[32] Sedlak AJ, Mettenburg J, Basena M, Petta I, McPherson K, Greene A, Li S. Fourth National Incidence Study of Child Abuse and Neglect (NIS–4): Report to Congress, Executive Summary. Washington, DC: US Department of Health and Human Services, Administration for Children and Families, 2010.

[33] Palusci VJ. Risk factors and services for child maltreatment among infants and young children. Children Youth Services Rev 2011;33:1374-82.

[34] Spencer N, Devereux E, Wallace A, Sundrum R, Shenoy M, Bacchus C, Logan S. Disabling conditions and registration for child abuse and neglect: A population-based study. Pediatrics 2005;116:609-13.

[35] Govindshenoy M, Spencer N. Abuse of the disabled child: A systematic review of population-based studies. Child Care Health Dev2007;33:552-8.

[36] Turner HA, Vanderminden J, Finkelhor D, Hamby S, Shattuck A. Disability and victimization in a national sample of children and youth. Child Maltr 2001;16:275-86.

[37] US Department of Health and Human Services, Administration on Children Youth and Families. Child Maltreatment 2005-2011. Washington, DC: US Government Printing Office, 2007-2012.

[38] Hibbard RA, Desch LW, Committee on Child Abuse and Neglect, Council on Children with Disabilities. Maltreatment of children with disabilities. Pediatrics 2007;119:1018-25.

[39] Greydanus DE, Omar HA. Sexuality issues and gynecologic care of adolescents with developmental disabilities. Pediatr Clin North Am 2008;55:1315-35.

[40] Olsen R, Clarke H. Parenting and disability: Disabled parents' experiences of raising children. UK: Policy Press, 2003.

[41] McGaw S, Scully T, Pritchard C. Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. Child Abuse Negl 2010;34:699-710.

[42] Tymchuk AJ, Andron L. Mothers with mental retardation who do or do not abuse or neglect their children. Child Abuse Negl 1990:14:313-23.

[43] Tymchuk AJ. Predicting adequacy of parenting by people with mental retardation. Child Abuse Negl 1992;16:165-7.

[44] Lightfoot E, Hill K, LaLiberte T. The inclusion of disability as a condition for termination of parental rights. Child Abuse Negl 2010;34:927-34.

[45] Frasier LD. Abusive head trauma in infants and young children: A unique contributor to developmental disabilities. Pediatr Clin North Am 2008;55:1269-85.

[46] Keenan HT, Runyan DK, Marshall SW, Nocera MA, Merten DF, Sinal SH. A Population-based study of inflicted traumatic brain injury in young children. JAMA 2003;290:621-6.

[47] Barlow KM, Thomson E, Johnson D, Minns RA. Late neurologic and cognitive sequelae of inflicted traumatic brain injury in infancy. Pediatrics 2005;116:e174-85.

[48] Hagberg B, Hagberg G. The changing panorama of cerebral palsy in Sweden: 5. The birth year period 1979-82. Acta Paediatr Scand 1989;78:283-90.

[49] Copel LC. Partner abuse in physically disabled women: A proposed model for understanding intimate partner violence. Perspect Psychiatr Care 2006;42(2):114-29.

[50] Walker LE. The battered woman. New York: Harper Colophon Books, 1979.

[51] Jenkins PJ, Parmer Davidson B. Stopping domestic violence: How a community can prevent spousal abuse. New York: Kluwer Academic/Plenum Publishers, 2001.

[52] Pence E, Paymar M. Education groups for men who batter. The Duluth Model. New York: Springer, 1993.

[53] Pence EL, Shepard MF. An introduction: Developing a coordinated community response. In: Shepard, Pence EL. Coordinating community responses to domestic violence: Lessons from Duluth and beyond. Thousand Oaks, CA: Sage, 1999:3-24.

[54] Center for Research on Women with Disabilities. Violence against women with physical disabilities: Final report submitted to the Centers for Disease Control and Prevention. Baylor College of Medicine, 2002.

[55] Lund EM. Community-based services and interventions for adults with disabilities who have experienced interpersonal violence: A review of the literature. Trauma Violence Abuse 2011;12(4):171-82.

[56] Gilson SF, Cramer EP, Depoy E. (Re)Defining abuse of women with disabilities: A paradox of limitation and expansion. Affilia 2001;16:220-35.

[57] Milberger S, Israel N, LeRoy B, Martin A, Potter L, Patchak-Schuster P. Brief report: Violence against women with disabilities. Violence Vict 2003;18(5):581-91.

[58] Ballan MS, Freyer MB. Self-defense among women with disabilities: An unexplored domain in domestic violence cases. Violence Against Women 2012;18(9):1083-1107.

[59] Curry MA, Renker P, Robinson-Whelan S, Hughes R, Swank PR, Oschwald M, Powers LE. Facilitators and barriers to disclosing abuse among women with disabilities. Violence Vict 2011;26(4):430-44.

[60] Curry MA, Renker P, Hughes R, Robinson-Whelan S, Oschwald M, Swank PR, Powers LE. Development of measures of abuse among women with disabilities and the characteristics of their perpetrators. Violence Against Women 2009;15(9):1001-25.

[61] Centers for Disease Control and Prevention (n.d.). Developmental Disabilities. URL: http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

[62] American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 5th ed. Washington, DC: APA, 2013.

[63] Hershokowitz D, Lamb ME, Horowitz D. Victimization of children with disabilities. Am J Orthopsychiatr 2013;77(4):629-35.

[64] Poole DA, Lamb ME. Investigative interviews of children: A guide for helping professionals. Washington, DC. American Psychological Association, 1998.

[65] Little L. Victimization of children with disabilities. In: Kendall-Tackett KA, ed. Health consequences of abuse in the family: A clinical guide for evidence-based practice. Washington, DC: American Psychological Association, 2004:95-108.

[66] Ballard MB, Austin S. Forensic interviewing: Special considerations for children and adolescents with mental retardation and developmental disabilities. Educ Train Ment Retard Dev Disabil 1999;34(4):521-5.

[67] Sobsey R. Violence and abuse in the lives of people with disabilities: The end of silent acceptance? Baltimore: Paul H Brooks Publishing, 1994.

[68] Cederborg A, Lamb ME. How does the legal system respond when children with learning difficulties are victimized? Child Abuse Negl 2006;30(5):537-47.

[69] Henry LA, Bettenay C, Carney DPJ. Children with intellectual disabilities and developmental disorders. In: Lamb ME, La Rooy DJ, Malloy LC, Katz C. Children's testimony. A handbook of psychological research and forensic practice, 2nd ed. Chicester: Wiley-Blackwell, 2011:251-83.

[70] Goldberg AP, Tobin J, Daigneau J, Griffith RT, Reinert SE, Jenny C. Bruising Frequency and patterns in children with physical disabilities. Pediatrics 2009;124:604-9.

[71] Leet A, Mesfin A, Pichard C, Launay F, Brintzenhofeszoc K, Levey EB, D Sponseller P. Fractures in children with cerebral palsy. J Pediatr Orthoped 2006;26:624-7.

[72] Jenny C, Committee on Child Abuse and Neglect. Recognizing and responding to medical neglect. Pediatrics 2007;120:1385-9.

[73] Henry LA, Gudjonsson, GH. Eyewitness memory, suggestibility and repeated recall sessions in children with mild and moderate intellectual disabilities. Law Human Behav 2003;27(5):481-505.

[74] Cederborg A, Hultman E, La Rooy D. The quality of details when children and youths with intellectual disabilities are interviewed about their abuse experiences. Scand J Disabil Res 2012;14(2):113-25.

[75] Perlman NB, Ericson KI, Esses VM, Isaacs BJ. The developmentally handicapped witness: Competency as a function of question format. Law Human Behav 1994;18:171-87.

[76] Anderson J, Heath R. Forensic interviews of children who have developmental disabilities, Part 1 of 2. National Center for the Prosecution of Child Abuse Update 2006;19(1).

[77] Anderson J, Heath R. Forensic interviews of children who have developmental disabilities, Part 2 of 2. National Center for the Prosecution of Child Abuse Update 2006;19(2).

[78] Toth P. Comparing the NICHD and RATAC Child Forensic Interview Approaches-Do the Differences Matter? APSAC Advisor 2011;24(3):15-20.

[79] Teachers College, Columbia University [producer]. Child Abuse and Children with Disabilities: A New York State Perspective: 2004 [CD-ROM]. Available from New York State Office of Children and Family Services.

[80] Llewellyn A, Hogan K. The use and abuse models of disability. Disabil Soc 2000;15:157-65.

[81] Finlay WM, Lyons E. Acquiescence in interviews with people who have mental retardation. Ment Retard 2002;40:14-29.

[82] Matthews E, Saywitz R. Child victim witness manual. Calif Center Judicial Educ Res J 1992;12:5-81.

[83] American Professional Society on the Abuse of Children. Guidelines for the use of anatomical dolls. Chicago, IL: Author: 1995.

[84] Heckler S. Facilitated communication: A response by child protection. Child Abuse Negl 1994;18(6):495-503.

[85] Ericson K, Perlman N, Isaacs B. Witness competency, communication issues and people with developmental disabilities. Devel Disabil Bull1994;22(2):101-9.

[86] Balderian NJ, Coleman TF, Stream J. Abuse of people with disabilities: Victims and their families speak out. A report on the 2012 National Survey on Abuse of People with Disabilities. Disability & Abuse Project, 2013.

[87] Balderian NJ. Domestic violence and individuals with disabilities: reflections on research and practice. J Aggress Maltreat Trauma 2009;18(2):153-61.

[88] Slayter E. Intimate partner violence against women with disabilities: Implications for disability service system case management practice. J Aggress Maltreat Trauma 2009;18(2):182-99.

[89] Ahn HY. The effect of a child abuse prevention program for parents with disabled children. Daehan Gango Haghoe 2004;34:663-72.

[90] Feldman MA. Parent education for parents with intellectual disabilities: A review of outcome studies. Res Dev Dis 1994;15:299-32.

[91] Zimmer MH, Panko LM. Developmental status and service use among children in the child welfare system. Arch Pediatr Adolesc Med 2006;160:183-8.

[92] Fallon MA, Eifler K, Niffenegger JP. Preventing and treating sexual abuse in children with disabilities: Use of a team model of intervention. J Pediatr Nurs 2002;17:363-7.