



Maltreatment of Children With Disabilities

Guidance for the Clinician in Rendering
Pediatric Care

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and Council on Children With Disabilities

ABSTRACT

Widespread efforts are being made to increase awareness and provide education to pediatricians regarding risk factors of child abuse and neglect. The purpose of this clinical report is to ensure that children with disabilities are recognized as a population that is also at risk of maltreatment. Some conditions related to a disability can be confused with maltreatment. The need for early recognition and intervention of child abuse and neglect in this population, as well as the ways that a medical home can facilitate the prevention and early detection of child maltreatment, are the subject of this report.

INTRODUCTION

The maltreatment of children, including those with disabilities, is a critical public health issue. For purposes of this report, the terms “disability” and “special health care needs” include the full spectrum of physical, mental, and emotional impairment. Current data on incidence and prevalence of maltreatment in children with disabilities are limited by varying definitions of disability and lack of uniform methods of classifying maltreatment. Nonetheless, children with disabilities and special health care needs are at increased risk of child maltreatment. This report is an update to the previous policy statement, “Assessment of Maltreatment of Children With Disabilities.”¹

The Children’s Bureau reported that an estimated 872 000 children were determined to be victims of abuse or neglect in 2004.² More than 60% of child victims experienced neglect, almost 20% were physically abused, and 10% were sexually abused. Of the 36 states that reported on disabilities, child victims who were reported with a disability accounted for 7.3% of all victims. Children with the following conditions were considered as having a disability: mental retardation, emotional disturbance, visual impairment, learning disability, physical disability, behavioral problems, or another medical problem. It was believed that these conditions were underrecognized and underreported, because not every child received a clinical diagnostic assessment when child maltreatment was suspected.

Child maltreatment may result in the development of disabilities, which in turn can precipitate further abuse.³ Studies have been unable to accurately document the extent or rate of abuse among children with disabilities or determine if disabilities were present before the abuse or were the direct result of maltreatment.⁴ It should be emphasized also that several case reports and epidemiologic data remind us that the natural history of some medical conditions can include conditions that mimic child maltreatment.^{5,6}

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Key Words

child neglect, child maltreatment, developmental disabilities, child abuse, physical abuse, child sexual abuse

Abbreviations

CPS—child protective services

AAP—American Academy of Pediatrics

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The numbers of children who survive disabling medical conditions as a result of technologic advances and children who are recognized and identified as having disabilities are increasing.⁷ The rates of child maltreatment have been found to be high in the child population in general and in children with blindness, deafness, chronic illness, developmental delays, behavioral or emotional disorders, and multiple disabilities.⁸ Minimal research on child abuse has focused specifically on children with disabilities; further study is indicated and has been encouraged.^{9,10}

The Child Abuse and Prevention, Adoption, and Family Services Act of 1988 (Pub L No. 100–294) included a mandate to study the incidence of child maltreatment among children with disabilities. This research was funded by the National Center on Child Abuse and Neglect and conducted by the Center for Abused Children With Disabilities at the Boys Town National Research Center.⁸ A study by Westat, Inc, determined the incidence of abuse among children with disabilities and the relationship between child abuse and disabilities.⁹ Data were collected from 35 child protective services (CPS) agencies across the country, and results indicated that 14.1% of children whose maltreatment was substantiated by CPS workers had 1 or more disabilities. A Nebraska study that used an electronic merger of hospital, central registry, foster care review board, and law enforcement records found disabilities to be twice as prevalent among maltreated children in hospitals as among hospital controls, which is consistent with the hypothesis that disabilities increase the risk of maltreatment. The data are also consistent with the hypothesis that maltreatment contributes to disabilities.¹¹

According to research performed by the Boys Town National Research Hospital, children with disabilities were found to be at greater risk of becoming victims of abuse and neglect than were children without disabilities. The study showed that children with disabilities are 1.8 times more likely to be neglected, 1.6 times more likely to be physically abused, and 2.2 times more likely to be sexually abused than are children without disabilities.⁸ Another study found the overall incidence of child maltreatment to be 39% in 150 children with multiple disabilities admitted to a psychiatric hospital. Of those children, 60% had been physically abused, 45% had been neglected, and 36% had been sexually abused.¹² In a 2000 study of more than 4500 maltreated children, Sullivan and Knutson¹³ observed children with disabilities to be 3.76 times more likely to be neglected, 3.79 times more likely to be physically abused, and 3.14 times more likely to be sexually abused when compared with children without disabilities.¹³ Children with behavioral disorders were found to be at the highest risk of all types of maltreatment, and neglect was the most common form of maltreatment across all disability types. A relative-risk matrix for all types of maltreatment among

children with specific disabilities was developed. In 1 recent study, caregivers reported that 18.5% of children with autism had been physically abused and 16.6% had been sexually abused.¹⁴ Spencer et al¹⁵ concluded that children with disabling conditions are at increased risk of child abuse and neglect, although the type of maltreatment varies with the specific disabling condition.

LIMITATIONS OF CURRENT RESEARCH

The prevalence of maltreatment of children with disabilities is difficult to calculate, because states do not use comparable definitions of child abuse and neglect. Another major problem with the published literature is the variable definition of “disabilities.”⁴ The Centers for Disease Control and Prevention describes developmental disabilities as a diverse group of severe chronic conditions that are attributable to mental and/or physical impairments and result in problems with major life activities such as language, mobility, learning, self-help, and independent living. The Americans With Disabilities Act¹⁶ defines “disability” as a physical or mental impairment that substantially limits 1 or more of the major life activities of an individual. This definition includes all types of disabilities, including physical disabilities, cognitive or learning disabilities, motor and sensory dysfunctions, mental illness, or any other kind of physical, mental, or emotional impairment.¹⁷ Perrin¹⁸ reported that most childhood chronic health conditions do not cause disability. The Maternal and Child Health Bureau has defined children with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”¹⁹ The term “children with special health care needs” is less limiting than some other terms.²⁰

Legal definitions do not always match clinical data. Child development evaluations do not always allow an immediate and precise diagnosis of extent or type of disability, and some studies rely on evaluations by untrained observers. Therefore, evaluation of research efforts is hindered by different definitions of terms (eg, disabilities and maltreatment), noncomparable methods, various study sample sizes, and lack of uniform data collection. Furthermore, changes in reporting laws and societal attitudes can occur during a study period.²¹

Another problem that has been cited in the literature is the lack of recognition and documentation of disabilities by CPS workers and their lack of training on evaluating children with disabilities.⁴ In the study by Westat,⁹ analyses were based on CPS workers’ opinions rather than data empirically derived from physicians or other professionals trained to diagnose disabilities. Bonner et al⁴ demonstrated that since 1982, correct and consistent use of a CPS-created system of collecting information regarding disabilities in maltreated children

had decreased, suggesting that disabilities were unlikely to be identified as children enter the CPS system. A survey of 51 state CPS agencies found that in 86% of states, CPS workers used a standardized form to record child-maltreatment cases, but in only 59% of those states did the workers record information regarding pre-existing disabilities on the form.²²

The Westat study was limited to intrafamilial cases.⁹ Because it is well known that individuals other than family members can commit harm to children, statistics limited to intrafamilial cases would be likely to underestimate the overall incidence of maltreatment among children with disabilities.

Along with the lack of well-designed research on maltreatment is the lack of research on how to respond to children with disabilities who have been maltreated. A needs assessment of parents, educators, and CPS investigators in 2000 revealed that knowledge and experience in child maltreatment were lacking.²³ Most respondents were interested in training, with recognition of maltreatment in the child with a disability as a top priority. In this same report, a collaborative team-approach response was recommended.

CAUSAL FACTORS

In general, the causes of abuse and neglect of children with disabilities are the same as those for all children; however, several elements may increase the risk of abuse for children with disabilities. Children with chronic illnesses or disabilities often place higher emotional, physical, economic, and social demands on their families.²¹ For example, a physical disability that causes difficulty in ambulation can place a child at risk of accidental falls. Therefore, much closer supervision will be needed, which itself can be stressful. Parents with limited social and community support may be at especially high risk of maltreating children with disabilities, because they may feel more overwhelmed and unable to cope with the care and supervision responsibilities that are required.¹⁷ Lack of respite or breaks in child care responsibilities can contribute to an increased risk of abuse and neglect. Finally, the added requirements of special health care and educational needs can result in failure of the child to receive needed medications, adequate medical care, and appropriate educational placements, resulting in child neglect.¹⁷

Numerous problems have been cited with the provision of care for foster children with disabilities. Foster parents sometimes are not told about a child's medical and emotional problems and are, therefore, not sufficiently educated or prepared to deal with the specific condition. Other problems for foster children with disabilities include lack of permanent placement, lack of a medical home, lack of financial support, and inappropriately prepared foster parents.³

Parents or caregivers may feel increased stress be-

cause children with disabilities may not respond to traditional means of reinforcement, and sometimes these children's behavioral characteristics (eg, aggressiveness, noncompliance, and communication problems) may become quite frustrating.⁸ Behavioral challenges in children who have disabilities may further increase the likelihood of physical abuse.¹⁷

Parents of children with communication problems may resort to physical discipline because of frustration over what they perceive as intentional failure to respond to verbal guidance. It has been noted paradoxically, however, that families who report higher stress levels may actually have greater insight into problems associated with caring for a disabled child, whereas parents with a history of neglect of a child may not experience the level of stress that a more involved parent may experience.²⁴

Although the use of aversive procedures and restraints for children who have disabilities has been fortunately diminishing, in part because of legislative changes (eg, modifications of the Individuals With Disabilities Education Act [Pub L No. 108-446 (2004)]), these practices are still used sometimes in homes, schools, programs, and institutions.²⁵ Aversive techniques are procedures that use painful or unpleasant stimuli to modify a behavior that has been found to be unacceptable or inappropriate. Restraints are physical measures (such as tie-downs or prolonged seclusion) used to prevent something physical from happening or for "punishment." This includes "therapeutic holding," which has been repudiated as being harmful.²⁶ During the past 20 years, much research has demonstrated the effectiveness of alternative measures, commonly called "positive behavioral supports," to change behavior.²⁵ Pediatricians and others who could use additional information about the problems that occur from the use of aversive procedures or restraints can easily get this guidance from the Web sites of organizations such as the Association for the Severely Handicapped (www.tash.org/IRR/resolutions/res02aversive.htm) and the Autism National Committee (www.Autcom.org/restraints.html). Information about positive behavioral support guidelines is available from a US Department of Education-funded program, the Technical Assistance Center on Positive Behavioral Interventions & Supports (www.Pbis.org), and other national and international programs. The American Academy of Child and Adolescent Psychiatry also provides guidance on this subject (www.aacap.org/page.www?section=Policy+Statements&name=Coercive+Interventions+for+Reactive+Attachment+Disorder).

The presence of multiple caregivers may heighten or reduce the risk of abuse of the child. Infrequent contact of a child with disabilities with other children and adults may make them uniquely vulnerable to molestation because there is decreased opportunity for the child to

develop a trusting relationship with an individual to whom he or she may disclose the abuse¹⁷ and decreased opportunity to learn to resist molestation. On the other hand, children with disabilities who require multiple caregivers or providers may have contact with numerous individuals, thereby increasing the opportunity for abuse, including sexual abuse. However, advantages to having a large number of caregivers are that there are more individuals who may detect the injuries or signs of abuse, and the additional assistance may actually lessen the amount of stress placed on the primary caregivers. Risk may be minimized by careful screening and selection of caregivers, sporadic and unscheduled monitoring of care, and an open mind to recognition that any child may become a victim.

Children with disabilities often have limited access to critical information pertaining to personal safety and sexual abuse prevention. Children who have increased dependency on caregivers for their physical needs may be accustomed to having their bodies touched by adults on a regular basis. Parents may object to their child being provided with education on human sexuality, because they may feel that their children will never be in sexually risky situations because of their special needs. However, children with disabilities may be unintentionally conditioned to comply with authority, which could result in them failing to recognize abusive behaviors as maltreatment.⁸ Children with disabilities are often perceived as easy targets, because their intellectual limitations may prevent them from being able to discern the experience as abuse and impaired communication abilities may prevent them from disclosing abuse. Because some forms of therapy may be painful (eg, injections or manipulation as part of physical therapy), the child may not be able to differentiate “appropriate” pain from “inappropriate” pain.

PEDIATRICIAN'S ROLE

Pediatricians should be aware that the presence of disabilities in a child is a risk factor for victimization and that disabilities can also be the result of child maltreatment. The pediatrician should work with families, other health care professionals, and other community resources to ensure the safety of all children, including those with disabilities. The following should be considered.

Identification and Reporting

Pediatricians always need be alert to signs or symptoms that are suggestive of abuse, no less in children with disabilities than in others. However, recognizing the signs and symptoms of maltreatment among children with disabilities may be difficult, because many children may not be able to verbalize that they were abused or they may not understand that what took place was wrong.¹⁷ Because it is common for the physical exami-

nation to be normal, especially in sexual abuse and emotional maltreatment, a high index of suspicion in selected cases is warranted.

Familiarity with the natural history of disorders that may mimic child abuse can prevent the misdiagnosis of child maltreatment.²⁷⁻²⁹ Children with motor and balance disabilities may experience increased injuries from accidents. Children with neurosensory disabilities may be predisposed to fractures, and in the absence of pain, there may be a delay in seeking medical attention. For example, children with spina bifida have a high risk of fracturing a paralyzed, desensitized limb.⁵ Children with severe nutritional deficiency and immobility or chronic steroid use may develop demineralized bones that fracture easily. Children with blood dyscrasias may have bruises of varying ages in unusual places. There are also reports of a variety of disabling conditions that mimic child maltreatment, including methylmalonic aciduria and glutaric aciduria, which can manifest as chronic subdural effusions and mild retinal hemorrhages, with other telltale findings including neurodevelopmental problems.^{6,30}

Awareness of injury patterns from inflicted versus noninflicted trauma is important for pediatricians and other professionals who work with children. Signs and symptoms of maltreatment in children with disabilities are commonly ignored, misinterpreted, or misunderstood. Furthermore, many schools, programs, and institutions may have a disincentive to recognize or report child maltreatment because of fear of negative publicity or loss of funding or licensure. Pediatricians may want to act proactively with these entities so that concerns and referrals are more forthcoming if questions or problems arise.

If abuse or neglect is suspected after a careful assessment, a report must be made to the appropriate CPS agency. Every child suspected of being abused or neglected needs a thorough evaluation by an experienced professional.³¹ The evaluation process should consist of a structured interview with the child, if possible, and a comprehensive physical examination including appropriate laboratory and radiologic studies as indicated. In many situations, a consultation with a developmental pediatrician, pediatric neurologist, child abuse pediatrician, or other expert in children with disabilities is also indicated.

Treatment

Appropriate medical treatment for injuries, infections, or other conditions should be provided. Each case of abuse or neglect that is clinically confirmed or strongly suspected needs a multidisciplinary treatment plan, which includes a mental health assessment and treatment component that is appropriate for the child's cognitive and developmental level and counseling for the family. This child and family treatment plan should be integrated

with other intervention plans that may already have been developed for the child. Federal legislation requires that each child identified as having a disability should have a written plan of service (an individualized family service plan for children from birth to 3 years of age or an individualized education plan for children 3 through 21 years of age).^{32,33} The pediatrician should also make appropriate medical recommendations and provide treatments that are preventive or prescriptive. The pediatrician may help the family explore available child care and respite services. A discussion of injury-prevention guidelines for children with disabilities is also helpful.³⁴ Although pediatricians can have input into the process, removal of the child from the home or therapeutic foster care placement is at the discretion of the CPS agency only after a thorough investigation.

Education

In-service training for CPS workers, law enforcement professionals, health care professionals, child care providers, early childhood educators, teachers, and judges is crucial, and protocols are necessary for the identification, reporting, and referral of all cases of suspected child maltreatment in all schools, programs, and institutional settings. Experts in child maltreatment and childhood disabilities would be the main group to assist with this educational endeavor. However, general pediatricians can have important roles, for example, with local school districts. In addition, education on risk factors for maltreatment of children with disabilities should be emphasized.

Pediatricians can also be important role models to parents, trainees, and others. In their own offices, clinics, or hospital settings, pediatricians and others who provide care for children with disabilities should not rush to use physical restraints during procedures for these children. Often, taking the time to explain procedures in terms appropriate to developmental level or in other ways to prepare such a child can make restraints unnecessary except in situations when children are dangerous to themselves or others. Even when some types of restraints are needed, such as to prevent a child from scratching at newly repaired lacerations, such restraints should be as comfortable and as minimal as possible and used for the shortest time feasible.

Pediatricians may also have roles to assist in the education about child abuse to their peers, residents, medical students, and other health care students. All health care professionals need adequate training to monitor children with disabilities for signs of abuse and neglect and to screen suspected victims of child maltreatment for disabilities.³⁵

Prevention

Support and assistance with parenting skills are often needed by families, especially families who have chil-

dren with special health care needs. Medical and non-medical needs of the child and family should be addressed at each health supervision visit. Child and family strengths should be recognized and fostered at each encounter. Family stressors should be identified and addressed, and referrals for appropriate support services should be made. Disability-specific injury-prevention guidelines can be presented to help the family minimize injury.³⁴ The availability of parent support groups, respite care, and home health services may be explored, and referrals may be made when appropriate. Pediatricians can help educate parents of children with disabilities about the various respite and medical waiver subsidies and programs specific to each state and how to qualify for such funds. Pediatricians can explain the need for getting placed on the inevitable waiting lists for these programs as early as possible. The American Academy of Pediatrics (AAP)-sponsored medical home Web site (www.medicalhomeinfo.org) is an important resource for the pediatrician to find out more information on these programs, including state-by-state resources.

All children with or without disabilities need a medical home that consists of a health care professional who is readily accessible to the family to answer questions, help coordinate care, and discuss concerns.³⁶ Medical home is an approach to providing comprehensive primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. Families should be encouraged and assisted by these health care professionals to work with a variety of agencies and disciplines and pursue resources and services that they need. Child abuse prevention, including indicators of abuse, should be discussed with parents and caregivers.^{23,24} Neurodevelopmental and developmental-behavioral pediatricians and child neurologists who are trained and experienced in the diagnosis and evaluation of children with disabilities can also serve as excellent resources to both the general pediatricians and the families.

Advocacy

The pediatrician, in providing the medical home and acting as his or her patient's and family's advocate, may review care that is provided by the various agencies and resources. Much of this advocacy effort can be performed by coordinating efforts and ensuring that recommendations are made and followed.³⁶ By providing this careful follow-up, if child maltreatment is suspected, the need for appropriate referrals can be identified immediately.

Pediatricians play an important advocacy role in their relationships with various governmental and nongovernmental agencies. State AAP chapters also have an important role in these arenas. State, educational, social, foster care, financial, and health care systems often function in isolation from each other, with very little coordination or communication.⁸ Community involvement

can also encourage the development of needed resources, including child care and respite services for families with a child with a special health care need. Foster children with disabilities and their foster parents often suffer from lack of adequate support systems.⁴ Communication with schools and other systems with which families interact is another avenue for heightening the awareness of the needs of children who have disabilities and/or special health care needs.

As child advocates, pediatricians are in an ideal position to influence public policy by sharing information and giving educational presentations on child maltreatment and the needs of children with disabilities. They should advocate for state practices or policies that mandate CPS agencies to gather disability information on child-maltreatment cases. Pediatricians should emphasize the devastating costs of child maltreatment to legislators, policy-makers, and the public.⁴ Pediatricians should also advocate for screening procedures for potential employees in educational, recreational, and residential settings to help ensure the safety of all children in their care.³⁷

One resource that is useful to the pediatrician is the report *A Call to Action: Ending Crimes of Violence Against Children and Adults With Disabilities*.³⁸ This is a report that includes recommendations on policy, surveillance systems and data collection, violence prevention, intervention, and research needs.³⁸ The Oregon Institute on Disability & Development has developed prevention resources that may be useful to the pediatrician (www.ohsu.edu/research/oidd/oakspublication.cfm).

GUIDANCE FOR THE PEDIATRICIAN

1. Be capable of recognizing signs and symptoms of child maltreatment in all children and adolescents, including those with disabilities.
2. Be familiar with disabling conditions that can mimic abuse or pose an increased risk of accidental injury that can be confused with abuse.
3. Because children with disabilities are at increased risk of maltreatment, remain vigilant not only in assessment for indications of abuse but also in offerings of emotional support and provision of equipment and resources to meet the needs of children and families.
4. Ensure that any child in whom maltreatment has been identified is evaluated thoroughly for disabilities.
5. Advocate for all children, especially those who have disabilities or special health care needs, to have a medical home.³⁶ If a child is hospitalized and does not have a medical home, the inpatient attending physician can help the family secure one before discharge, preferably as early as possible in the hospital course.³⁹

6. Be actively involved with treatment plans developed for children with disabilities and participate in collaborative team approaches.
7. Use health supervision visits as a time to assess a family's strengths and need for resources to counterbalance family stressors and parenting demands.
8. Advocate for changes in state and local policies in which system failures seem to occur regarding the identification, treatment, and prevention of maltreatment of children with disabilities.
9. Advocate for the implementation of positive behavioral supports and elimination of aversive techniques and unnecessary physical restraints in homes, schools, and other educational and therapeutic programs (both public and private), institutions, and settings for children who have disabilities.
10. Advocate for better health care coverage by both private insurers and governmental funding.

CONCLUSIONS

The AAP supports the belief that pediatricians play a significant role in the prevention, identification, and treatment of child abuse and neglect, especially in children with disabilities, who are at increased risk of maltreatment. Children suspected of being maltreated should be evaluated for developmental, physical, and mental health disabilities. In addition, CPS workers and others involved in the investigation of child maltreatment should work closely with pediatricians to identify disabilities in children.¹⁶ Every effort should be made to ensure the safety of children through collaboration with families, other health care professionals, schools, CPS agencies, and other appropriate resources.

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THE RISE OF IN-STORE CLINICS: THREAT OR OPPORTUNITY?

“The recent acquisition by the pharmacy chain CVS of MinuteClinic, a chain of in-store clinics founded in Minnesota, has put this model of primary care delivery back in the spotlight. Although still not widespread, the model is increasing in prevalence . . . and appeals to several stakeholders: payers note that primary care is less expensive when delivered at in-store clinics than when provided in a doctor’s office or emergency room, patients value the convenience and low price, entrepreneurs see a profitable business model, and proponents of consumer-driven health care see services that can be paid for out of health savings accounts. Physicians, however, express concern about the quality of care and the potential impact on their businesses. The typical in-store clinic is a kiosk—a small, thin-walled structure located inside a store—staffed by a nurse practitioner. The clinics differ from the old ‘doc-in-the-box’ model in that they are neither routinely staffed by a physician nor intended to provide all primary care services. Indeed, the range of services—posted as a ‘menu’ on the company’s Web site or on the kiosk—is strikingly small, including common adult vaccinations, screening tests, and treatment for simple conditions. . . . But for these circumscribed services, the clinics provide a compelling value proposition. Care is intended to be quick, inexpensive, and convenient; visits and waiting times are short, the charge is usually less than \$50, and extended hours are offered along with ample parking. It’s not surprising, then, that patients and investors have taken notice. . . . Some wonder whether this model is a ‘disruptive innovation’—that is, a service or technology that enters a market at the low end, initially not performing as well as higher-end incumbents, then improves until it captures the whole market.”

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Noted by JFL, MD

Maltreatment of Children With Disabilities

Roberta A. Hibbard, Larry W. Desch, and the Committee on Child Abuse and Neglect
and and Council on Children With Disabilities

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