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ABSTRACT

Literature indicating high rates of abuse in this population is reviewed, as is literature indicating high rates of developmental disabilities in child victims of abuse. Problems in data collecting practices are noted. Reasons for these children's greater risk for abuse are identified, including child attributes, stress, parent vulnerabilities, deteriorating interaction between adult and child, and a culture which fosters attitudes conducive to maltreatment. These findings are discussed in terms of problems of determining cause and effect and inadequacies in detection and reporting. The article also examines complex ethical issues raised by cases of possible child abuse or neglect, treatment considerations, and major schools of thought concerning effective prevention. Other brief articles in the newsletter describe a Seattle Rape Relief program, a Virginia respite resource project, the editor's ideas concerning child abuse and developmental disabilities, the Healthy Start Program, Project SpecialCare, Nurturing Programs, the PACER (Parent Advocacy Coalition for Education Rights) Center in Minnesota, the Center for Child Protection in San Diego, (California) and Boys Town (Nebraska). Additionally, 10 relevant organizations and 18 book and video resources are briefly described. An attached bibliography lists 38 references. (DB)

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Volume 37

Child Abuse and Developmental Disabilities

Don Bartlette, Ph.D., is an eloquent speaker. When he speaks, he talks of the pain. Born in 1939 of Indian parents, Bartlette knew the pain of poverty, malnutrition, and racial discrimination. But these were minor problems. Bartlette was born with half a nose, no upper lip, and a huge hole in the top of his mouth. In 1939 in rural North Dakota, no one offered anything to the Indian baby but a very crude repair job of the cleft palate. Bartlette could not talk.

When he was 9, the superintendent insisted that he attend school. Here he was laughed at, called names like "Donald Duck," and beaten. Other children hit him, kicked him, and spat on him. Once a group of children tied him and beat him bloody. When he arrived home, his father was incensed and attacked him also, as punishment for being a victim. Everyone told him he could not learn. Things stayed this way for many years. Bartlette became a "juvenile delinquent," in trouble with the law.

Things only changed because of the love and intervention of one person, "the white woman" who took Bartlette in, taught him to eat, taught him to talk, and arranged for an operation. Bartlette finished high school as the valedictorian, obtained a bachelor's degree, then a master's in social work, and a Ph.D. in counseling. His accomplishments and awards and service take pages to list.

More important, perhaps, than his personal achievements is what he symbolizes. Each child has a spirit. Each child has feelings. Each child needs friends, touch and caring. Every single child has a right to grow free of

physical abuse, neglect, emotional abuse or sexual victimization. For each child, regardless of abilities, feels pain and is harmed by disrespect.

Don
Bartlette,
Ph.D.

Developmental disabilities are physical or mental conditions that become apparent before age 22, continue throughout the individual's lifetime, and cause significant impairment in daily functioning. The term "developmental disability" encompasses a wide range of conditions, including but not limited to mental retardation, cerebral palsy, vision and/or hearing impairments, epilepsy, learning disabilities, communication problems, severe emotional disturbance, neurological impairments, and chronic illnesses.

Although figures differ with various definitions, people with disabilities comprise the largest minority group in the United States (Sullivan, et. al., 1991). In 1986, the U.S. Census Bureau estimated that there were 37 million people with disabilities over age 14 (compared to 29 million blacks and 17 million Hispanics). During the 1987-88 school year, 4.4 million U.S. children with disabilities were provided special education assistance (cited in Sullivan, et. al., 1991). Garbarino, et. al. (1987) estimate that 12 percent of all children and youth have developmental disabilities, with about 60 percent of the disabilities occurring after birth.

Child Abuse in Children with Disabilities

Children with developmental disabilities are generally regarded as at higher risk for maltreatment. In samples of children with disabilities, rates of abuse have varied between 20 and 83 percent (as cited in Sullivan, et. al., 1991). Typical of such studies is an investigation by Ammerman, et. al. (1989) of 150 consecutive admissions of multihandicapped children to a psychiatric hospital. Results indicated that 39 percent had a history of past or current maltreatment. Another study (Chamberlain, et. al., 1984, cited in Senn, 1988) found that 25 percent of a sample of 69 adolescent girls with developmental disabilities in contact with the Cincinnati Adolescent Clinic had experienced rape or attempted rape. Findings from surveys at residential schools for the deaf showed 11 percent in one study had

been sexually victimized. Two other studies found a 50 percent sexual abuse rate (Sullivan, et. al., 1987).

Such studies, although alarming, must be interpreted with caution. Some authors do not agree that disabilities constitute a risk factor (Starr, et. al., 1984). According to West, et. al., 1988 (cited in Warger, et. al., 1990), "Research does not conclusively place children with disabilities at higher risk for abuse..." (p. 9).

There are many technical problems with the studies including small sample size, biased samples, lack of control groups, retrospective data, and unsystematic data collection (Valentine, 1990). There is no standard definition of maltreatment. For example, one study included the following in its definition of sexual abuse: "isolated incidences of physical harassment which is experienced as sexual intent" (Cole, 1984/85, p. 71). The handicapping conditions of the subjects also vary, as do the validation procedures for determining developmental disability (Valentine, 1990; Sullivan, et. al., 1991; Warger, et. al., 1991). Selection bias is a problem. It is possible, for example, that the percentage of abused children without disabilities admitted to a given psychiatric hospital is equal to or greater than the percentage of abused children with disabilities admitted to the same facility. Studies of children with developmental disabilities who have lived in out-of-home placements may not be typical

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Virginians for Child Abuse Prevention Inc.



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The National Committee for Prevention of Child Abuse recently issued the results of their annual telephone survey of child welfare officials in all 50 states. Child fatalities due to abuse and neglect are up over 10 percent with 1383 children listed as victims in 1991. The total number of child abuse reports also

increased, climbing to almost 2.7 million or 42 reports for every 1,000 children in the United States. This figure is over 6 percent higher than the number reported in 1990.

"Every day in this country essentially four children die as a result of maltreatment and 7,300 are reported as suspected victims of abuse or neglect," said Dr. Anne Cohn Donnelly, NCPA Executive Director. "This level of violence toward children demands comprehensive and immediate action."

As in the past, the vast majority of child abuse fatalities involved young children: 78 percent of the victims were under 5 years of age, and 55 percent were 1 year old or younger. The factors most commonly cited by survey respondents as contributing to the increase in reports and fatalities were economic stress, including poverty and unemployment, substance abuse and increased public awareness of the problem and willingness to report suspected cases.

"We can no longer be content with increased child abuse fatalities and programs that can only serve 40 or even 100 families a year," noted Dr. Deborah Daro, NCPA Research Director and director of the study. "Reduction in child abuse reports and fatalities will only be achieved when all parents have access to the support they need."

In response to this need, NCPA in partnership with Ronald McDonald Children's Charities (RMCC) has launched a model national child abuse prevention program. The program, HEALTHY FAMILIES AMERICA, focuses on replicating a successful home visitor program operating in Hawaii, which provides voluntary home visitation by a paraprofessional to all new parents up to the child's fifth birthday.

RMCC has committed \$1 million over three years to help NCPA teach as many states as possible how to build a network of people and organizations who are willing to establish home visitor programs. Virginia will be participating in this effort to enhance support to parents. HEALTHY FAMILIES VIRGINIA is already off to a good start. In Fairfax County there is a Healthy Start program under way working with Hispanic mothers and their children and in Hampton, Va., there will be a pilot program starting this summer. Funding for the Hampton program will come from the General Assembly which appropriated \$300,000 over two years as a result of a budget amendment sponsored by Senator Joseph V. Gartland Jr. VCAP looks forward to following the progress of this essential prevention program.

Spotlight: Seattle Rape Relief

Seattle Rape Relief's Project Action provides assistance to victim/survivors with disabilities. Started in 1977, the project is one of the oldest efforts of its type. The project was funded by a federal grant until 1987.

One focus of the project in 1979 was to create a curriculum on sexual assault prevention. This was one of the first sexual abuse prevention efforts developed for children with disabilities. It was piloted and tested extensively in King County, then disseminated. The project also trained teachers in over 35 school districts across the country.

The project was discontinued for several years because of lack of funding. It was restarted in 1990. Carolyn Paige, M.Ed., who is the current project coordinator, discussed the focus of the project. "We have expanded to serve a wider range of people with disabilities, while focusing primarily on people with cognitive disabilities and people who do not communicate verbally. We have also shifted the focus of our written materials to reflect current best-teaching practices for children with cognitive disabilities. For example, in the early years of the project, there was nothing in our teaching materials that targeted generalization," she stated. "The children learned skills in an isolated,

specific context, but did not practice the skills in a variety of situations. Now we are focusing on teaching skills in a variety of natural environments. We have rewritten and revised the entire curriculum and have made significant changes."

The current project divides time between education and professional training and direct service. "This year, we are planning to train therapists who already work with children with disabilities. We will train them about how to address the issues of sexual assault and provide appropriate counseling," states Paige. She notes that this approach seems more effective than trying to train those who work with sexual assault survivors about

children with disabilities. Paige comments, "It is not appropriate to refer a child with a disability to a sexual assault therapist who has no experience working with children with disabilities. We have an existing pool of therapists who work with children with disabilities. They already know how a disability impacts a child's life and how to individualize their counseling methods. Therefore, training these professionals about healing from sexual abuse seems logical."

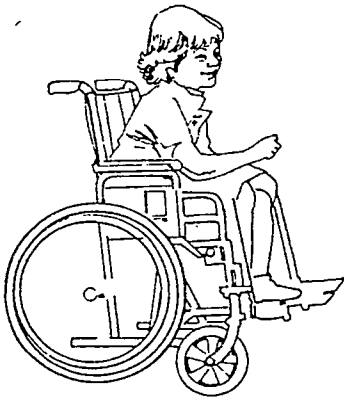
The project also provides direct service through case consultation, assisting with investigations, crisis and short-term counseling, and medical and legal advocacy. Seattle Rape Relief is not a clinical facility and does not perform assessments or offer long-term counseling. The majority of professional training has been of group home and congregate care facility staff as well as educational staff. They are hoping to train institutional staff. Paige notes that a governor-appointed task force is currently studying institutional abuse. The emphasis in Washington State is to accomplish deinstitutionalization.

For more information, contact Seattle Rape Relief, Project Action, 1905 South Jackson, Seattle, WA 98144, (206) 325-5531.

6th Annual Conference on Abuse of Persons with Developmental Disabilities November 1992

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of those who have remained in their own homes. Thus, accurate statistics describing the prevalence of maltreatment of children with developmental disabilities do not exist (Richardson, et. al., 1989; Tharinger, et. al., 1990; Zirpoli, 1986).

Disabilities in Abused Populations

Many studies of abused children report high rates of developmental disabilities in the child victims (Schilling, et. al., 1986; Sullivan, et. al., 1991). In 1971, Gil identified 29 percent of a group of 6,000 abused children as having developmental disabilities (Pacer Staff, 1985). Sandgrund, et. al. (1974) found 25 percent of their sample of 60 abused children to be functioning in the retarded range. Another early study (Johnson & Morse, 1968) found an incredible 70 percent of 101 Denver cases to have physical or developmental deviations. Kline (1977) reported that abused and neglected children were three times more likely to require special education and related services than children not identified as abused or neglected (cited in Valentine, 1990).

In contrast to studies on clinical populations, national statistics do not reflect higher than expected percentages of developmental disabilities. Analyzing reports submitted by all 50 states, the District of Columbia, Puerto Rico and the Virgin Islands, the National Center on Child Abuse and Neglect reported that 2.3 percent of abused children were mentally retarded, 1.9 percent had a physical handicap, and 1.8 percent were chronically ill (as cited in Schilling, et. al., 1986).

Why are percentages of children with disabilities so much lower in national data on founded abuse and neglect cases than in samples obtained for clinical research? One explanation for the low percentage of children with disabilities in national data is that they are not receiving the attention they need from child protective services (CPS) (Schilling, et. al., 1986). Children with special

needs would appear to need and deserve special attention from those responsible for protecting children. Yet, until recently, scant attention has been paid to the overlap between disabilities and abuse (Schilling, et. al., 1986; Sullivan et. al., 1991).

Camblin (1982) in a study of all 50 states and the District of Columbia found that nearly half of the states do not collect any information about "special characteristics" of child abuse victims. The remaining states varied in data collected and forms used for reporting, making it impossible to compare data from one state to another. Major studies by the American Humane Association, examining data from all states, have no reference to children with disabilities (Schilling, et. al., 1986).

Many states separate child welfare services and services to children with developmental disabilities by housing responsibilities in different agencies. As a result of bureaucratic separation, CPS workers may regard remediation of children with special needs as the responsibility of mental health agencies (Schilling, et. al., 1991).

Another roadblock to effective identification of abused or neglected children with disabilities is the education and training typically associated with CPS work. Few social workers, even those with graduate degrees, have taken formal coursework on developmental disabilities (Schilling, et. al., 1991).

Why are Children With Disabilities at Greater Risk for Abuse or Neglect?

Garbarino, et. al. (1987) have identified five broad categories of factors which increase risk of maltreatment. These are: 1) characteristics that render the child unacceptable or difficult to care for; 2) stress; 3) parent vulnerabilities or a lack of personal resources to function adequately; 4) a relationship between adult and child that includes a deteriorating pattern of interaction; and 5) a culture that fosters attitudes or actions conducive to maltreatment.

A number of authors agree that attributes of the child are important in predicting the likelihood of abuse (Friedrich & Boriskin, 1976; Frodi, 1981; Helfer, 1973; Sondgrund, et. al., 1974). There are several factors associated with developmental disabilities which serve to increase the risk of victimization. The disability may require increased physical contact to assist with toileting, dressing and bathing (Cole, 1984/85). Condoned physical interactions can escalate into abuse.

The child with a disability is physically less able to defend him/herself (Garbarino, et. al., 1987; PACER, 1985) and may not understand that the care provider is doing something wrong (Cole, 1984/85; PACER, 1985). Lack of knowledge is compounded in the case of sexual abuse, since children with disabilities often receive no or inadequate education about sexuality and are frequently excluded from programs designed to teach

abuse prevention skills (Sean, 1988; Sullivan, et. al., 1991; Tharinger, et. al., 1990).

Compliance is rewarded and considered necessary for the child with a developmental disability (Sean, 1988; Sullivan, et. al., 1991; Tharinger, et. al., 1990). Some are very compliant due to a need to be valued (Tharinger, et. al., 1990). Compliance can lead to a sense of social powerlessness (Cole, 1984/85; Sean, 1988). Life-long dependency can render a child more trusting and less likely to question (PACER, 1985; Sean, 1988; Tharinger, et. al., 1990).

The child with disabilities may have a restricted circle of friends and acquaintances. Some may not report abuse due to fears of losing the abuser or of retaliation (Musick, 1984; Sean, 1986; Tharinger, et. al., 1990).

Certain behaviors may elicit an abusive response from caregivers. For example, children with neurological dysfunction can be characterized by "high-pitched, disagreeable screaming" (Nichamin, 1973, as cited in Frodi, 1981). Excessive crying has been cited as a trigger for abuse in numerous studies (Murray, 1979; Weston, 1968 as cited in Frodi, 1981). Frodi and her colleagues (1981) have demonstrated empirically that cries of premature infants (who are more likely to have a developmental disability) are especially aversive.

Additionally, children with developmental disabilities may lack behaviors that normal children use to attract caretaking and attention (Embry, 1980, as cited in Valentine, 1990; Garbarino, et. al., 1987). Because of impaired levels of functioning, these children may not respond to ordinary expressions of affection (Lewark, 1983). One of the rewards of childrearing is to witness the child's growth through developmental stages. The child with disabilities, in contrast, may be "forever vulnerable" and never capable of self-care.

Caution is noted in interpreting these studies. "The hypothesis that the child's disability plays some process role in maltreatment has yet to be addressed empirically" (Sullivan, et. al., 1991). Additionally, Garbarino, et. al. (1987) note that some children with disabilities may be at *reduced* risk for maltreatment due to the disabilities eliciting greater nurturance, surveillance and resources.

The second risk factor is stress of dealing with the special needs. Most authors agree that the presence of a child with developmental problems is a family stressor. Parents are described as reacting with anger, guilt, ambivalence and sorrow to the birth of a child with a disability (Murphy, 1982). The special needs of this child are likely to require considerable expenditures of time and money with variable rates of progress. In short order, the family must learn about the child's disability and develop ways to cope. Services are not always available. Says Carol Burnham, a social worker who has adopted a child with disabilities, "We naively thought that a family's love and security could erase the trauma of the past." Burnham was "reduced

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to begging for services." In order to access services, she was asked to terminate parental rights. "This request came from a system that should be designed to protect a child's most important asset — a child's family," remarks Burnham. Lynne Davidson, a parent of two children with disabilities, eventually was forced to take the option of temporarily terminating rights to obtain services. Nancy Wheeler, who foster parents a child with profound mental retardation comments, "To penetrate the system takes divine intervention."

Even intact and supportive marriages can crumble under the strain. Susan Bassett, a former CPS worker, is currently involved in numerous parent advocate and support networks in Vermont. She also parents a daughter with significant developmental delays. She notes common reaction patterns. "Mothers can become consumed with the details of managing the child's service system. A father may feel a sense of failure, feel he has not protected his family, and feel like an outsider in the care of his child. He may avoid these issues by working long hours or escaping in other ways," explains Bassett. "Fathers can be the key to positive attitudes within the family. They need to be involved and supported by other fathers to help keep families intact."

Research supports Bassett's conclusions. In one study of children with spinal bifida, the parents' divorce rate was twice that of both a control group and the general population (cited in PACER, 1985).

Numerous studies cited in Murphy's (1982) review of the literature have chronicled the negative effects on parents and siblings caring for a child with a disability. In particular, the time demands involved in caregiving duties are a major factor which negatively impacts on parent and family functioning and can be associated with maltreatment (Garbarino, et. al., 1987).

Zirpoli (1986) hypothesizes that troublesome behaviors of younger children have a limited time period, whereas the stress associated with a child with a long-term or permanent problem continues. Thus, children with disabilities are not only at greater risk for maltreatment, but the risk exists for a longer time period than for the general population.

A third factor in abuse is parent vulnerabilities. Factors such as substance abuse (See VCPN, volume 33, "Substance

Exposed Babies"), poverty, very young parents or parents with mental illness or mental deficiency raise the risk for handicaps in children (Youngstrom, 1992).

One case in point is the parent with mental retardation raising a child who is mentally retarded. There does appear to be a higher incidence of children with mental retardation among parents with retardation (Valentine, 1990). Adequate child care does require a minimum level of competence. Certainly, parents with mental retardation are not a homogeneous group of equally skilled individuals. Still, as a group, parents with mental retardation appear to be at increased risk for maltreatment of their children, whether the children are disabled or not.

Polansky, et. al. (1972) reported that 9 of 11 mothers with IQ's below 71 provided below average care compared to other mothers in similar socioeconomic conditions (cited in Valentine, 1990). Schilling, et. al. (1982) reviewed 14 studies and found in all but one that persons with mental retardation were either unsatisfactory parents or over-reported in the abusing or neglecting samples. The authors feel that diminished intellectual capacity alone does not prove parental incompetence. Further, much of the research suffers from methodical flaws. However, they conclude, "If cognitive and social factors are important in child rearing, then mentally retarded parents, who by definition have fewer cognitive and social skills than parents not mentally retarded, will experience more difficulty providing adequate care" (p. 206). Since few communities have developed adequate support services for mentally retarded parents, this group appears at particular risk for inadequate parenting of a child with a disability (Crain, 1978).

Parents of children with disabilities often exhibit other characteristics that are common in those who abuse children. Unrealistic expectations play a role in child abuse in the general population. Failing to meet expectations can also play a role in the abuse of children with disabilities since denial of the disability is a common coping mechanism (PACER, 1985).

The fourth factor is the relationship between parent and child. Prolonged hospitalization and frequent early separations can lead to bonding problems (Ammerman, et. al.; 1989; Frodi, 1981; White, et. al., 1988). Bassett, a parent of a child with significant developmental delays and health problems, notes this problem. "The initial challenge," she says, "is simply to bond."

Problems do not end after bonding, however. Wikler (1981) has hypothesized 10 critical periods of stress for families of children with mental retardation. Five periods (walking, talking, beginning public school; onset of puberty and 21st birthday) are based on normal milestones. The other five are experienced only by families with a child with disabilities. These are diagnosis of retardation, younger siblings exceeding the accomplishments of the child with mental retardation, discussion of placement, exac-

erated health or behavioral problems and discussion of guardianship and extended care. It is not known if these stress periods correlate with abusive incidents.

The fifth factor is cultural attitudes that allow or even encourage maltreatment. Garbarino, et. al. (1987) suggest that our society has a lowered standard of care for "damaged" children. This sentiment is echoed by social worker Naomi Griffith. Griffith, executive director of Parents and Children Together in Decatur, Alabama, remarks, "We think if a child is mentally retarded, physical abuse does not hurt as much." Parents also are products of a culture. Their perceptions of their child play a crucial role (Friedrich & Boriskin, 1976; Frodi, 1981; Soeffing, 1975; White, et. al., 1988).

There is little agreement about the importance of the various factors involved in abuse of the developmentally disabled. Some researchers feel that the role of the child is minimal and that the disability is not directly related to the abuse (Lewark, 1983). Others say that dealing with the disability stretches the parents beyond their limits. Still others maintain that some parents with heightened risk to give birth to children with developmental problems are also at high risk for child abuse. An example is a substance abusing mother who gives birth to a premature child with health problems. The same substances that damaged the child also increase her risk for abusive behavior by lowering her inhibitions, impairing her judgment, and diverting family funds to maintain the addiction.

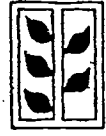
Most researchers conclude an examination of factors by stating that abuse is multiply determined and the product of a complex set of interactions (Friedrich & Boriskin, 1976; Frodi, 1981). This ecological model considers individual, family, community and cultural factors (Valentine, 1990). It can be summarized by remarks of James Garbarino, Ph.D., director of the Erickson Institute for Advanced Child Development, to Virginia's conference "Prevention: Promoting Healthy Lifestyles for Children and Families" last May. "Emerging research can be summarized by the phrase 'risk accumulates'", emphasizes Garbarino. Effects on the family of a child's developmental disability depend on factors such as degree of impairment, functioning level, type and amount of care needed, and family characteristics and resources (White, et. al., 1987).

Children with disabilities may also be at increased risk for abuse, neglect and sexual abuse because they comprise a considerable portion of institutionalized children. Abuse in residential or out-of-home care can come from staff, other children, or even from institutional practices.

Practices such as use of aversives (electric shock or other painful procedures) to halt self-destructive behaviors are still in use in many institutions, according to Adah Maurer, Ph.D., Executive Director of End Violence Against the Next Generation.



The Respite Resource Project



Virginia Institute for Developmental Disabilities

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The Virginia Institute for Developmental Disabilities (VIDD) is a federally-funded institute affiliated with Virginia Commonwealth University. VIDD works closely with state agencies, families, state organizations, advocates, community groups, and VCU faculty. With VIDD's support, these groups promote the independence, health, productivity and dignity of persons with developmental disabilities. VIDD's primary activities are interdisciplinary training, technical assistance to communities wanting to start programs, and innovative services such as the parent to parent network, respite care, infant screening, and an information hotline.

The Respite Resource Project was established in 1988 to foster the development of respite services to meet the needs of families with children with developmental disabilities and chronic illnesses. Project activities have included the development of model respite programs, resource development, dissemination, and technical assistance.

Two model programs were developed and successfully replicated from 1988 through 1991. The EveryBuddy Program, an integrated after-school experience incorporates after-school day care directly within regular community recreational programs. The PARTners (Parents as Respite Trainers) Project expands respite care options through parent designed and implemented training.

The Respite Resource Project has received a three year grant in 1991 from the U.S. Department of Health and Human Services which extends through September 1994. The

project is continuing to support the development of respite care services through competitive grants, technical support for respite programs, dissemination of information and resources, and state and local systems change.

Several local programs are currently receiving grant funds to address a range of respite needs. The Virginia Beach Community Services Board is developing respite services for families of medically fragile children. A respite voucher system is being piloted by the ARC/Northern Virginia. The Mount Rogers Community Services Board is developing a rural in-home respite support model.

Further information on the Respite Resource Project and an upcoming Request For Proposal are available from Monica Uhl, Respite Resource Project Coordinator at (804) 225-3876.

According to Maurer, "It is positive environmental change, not harsh punishments that is most successful in eliminating the self injury. Thus, not only are aversives inhumane, they are also ineffective" (Maurer, 1983, p. 277).

VCPN, volume 25, is devoted to examining abuse and neglect in out-of-home care.

Which Children with Disabilities are Abused?

Recently, researchers have sought to determine what characteristics in particular combine to trigger abuse or neglect toward a child with disabilities. The researchers seek to determine, within a group of children with similar diagnoses, what factors differentiate risk status.

Benedict, et. al. (1990) collected data from records of 500 children diagnosed as moderately to profoundly mentally retarded, with 82 percent also having cerebral palsy and 39 percent with a seizure disorder. Of the 500 children, almost 11 percent had substantiated maltreatment reports. Children whose parents were unmarried, had fewer years of formal education, or lacked stable employment were more likely to have substantiated abuse reports than were children of married, better educated, and employed parents. Marginally functioning children were at greater risk than more impaired children.

The finding that less impaired children are at greater risk for abuse and neglect is supported by other studies (Ammerman, et. al., 1989; Garfinkel & Gorka, 1988; Glaser & Bentovim, 1979; Martin & Beezley, 1974;

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Action for Prevention, Inc.

P.O. Box 11446
Richmond, VA 23230

Action for Prevention, Inc. is a voluntary non-profit organization with the purpose of promoting the prevention of developmental disabilities in Virginia. The major goal is to identify critical areas for prevention and to develop strategies to address these areas.

AFP was founded in 1983 following a statewide mental retardation/developmental disabilities prevention conference. That conference produced an Action Agenda of over 100 recommendations. AFP was established to ensure that these recommendations were carried out. The Action Agenda was updated in 1989. Membership dues are \$25/year. Members choose their degree of involvement.



Virginia Head Injury Foundation

3212 Cutshaw Avenue, Suite 315,
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Head injury can happen to anyone at any time. Head injury is the leading cause of death and disability in the United States for persons under the age of 34. Over two million head injuries occur each year. Of these, over 100,000 die. Another 70,000 to 90,000 people incur intellectual and physical impairments which preclude them

resuming a normal life. In Virginia there are over 14,000 new head injuries every year. Virginia Head Injury Foundation (VHIF) can help.

VHIF provides information and support. The organization advocates for rehabilitation programs and represents survivors in the state and federal legislative process. They sponsor "Project Head Coach" which matches families to trained volunteers. Family respite and adult survivor recreation is provided through Camp Bruce McCoy.



Department for Rights of Virginians with Disabilities

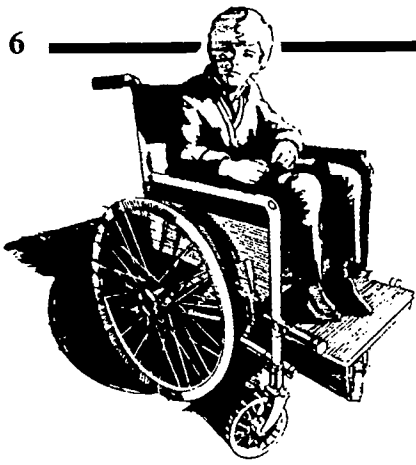
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This department protects and advocates for the rights of persons with disabilities, links them with available resources and seeks to improve public attitudes towards persons with disabilities. Services are provided at no charge.

First Steps

1-800-234-1448

A free service that answers questions about infant and toddler development. Provided by the Virginia Department for Rights of Virginians with Disabilities and the Virginia Department of Mental Health, Mental Retardation and Substance Abuse. A brochure with the phone number and a checklist of milestones birth to 36 months is also available. Every pediatrician's office and public health department should have these!



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Starr, et al., 1984). Various explanations for this finding have been offered. It may be that the seriously impaired child is identified at birth and services are offered immediately, lowering risk of abuse. Another explanation is that parental expectations for mildly impaired children may be high because no disability or reason for poor performance is apparent.

In contrast, a study of institutionalized children with mental retardation found a greater degree of impairment in victims of abuse. In comparison to non-abused residents, abused residents exhibited more aggressive and self-injurious behaviors, were younger, had lower social quotients, less verbal ability and had more ambulation ability (Rusch, Hall & Griffin, 1986).

In a similar study (Zirpoli, et. al., 1987), 182 abused and non-abused clients from five residential facilities were compared. Abused subjects were rated as "frequently violent" twice as often as non-abused subjects. The abused clients were also significantly more likely to be disruptive, rebellious, and hyperactive. Abused clients were most often in the "severe" range and were less likely to be profoundly, mildly, or moderately impaired. The researchers suggested that since abuse is an interaction, profoundly retarded may be at lesser risk due to decreased interaction. Those in the mild to moderate range may be in greater control of disruptive behaviors than those labelled "severe".

The Problem of Cause and Effect

"The maltreatment literature has generally not applied rigorous criteria to establish firmly whether abuse or neglect preceded or succeeded any identified disability" (White, et. al., 1987, p. 97). Garbarino and his colleagues (1987) note that 60 percent of handicaps occur after birth.

It is known that child abuse and neglect can cause a full range of disabilities (Baladerian, 1991; Dey, et. al., 1984; Nesbit & Karagianis, 1982; Souther, no date). Impairments due to abuse range from mild to severe. It is possible that the high percentage of abuse and neglect

in populations of developmentally disabled is because the maltreatment has caused the disabling condition. This point is of more than theoretical interest. The child who is damaged because of abuse needs a different intervention plan than a child born with disabilities who is abused due to parental stress.

Baladerian (1991), in a review of 18 studies, concluded that 25 percent of all disabilities were caused by physical abuse or neglect. The range in the studies was 3 percent to 50 percent.

An article not reviewed by Baladerian was written by Donna Zadnik, supervisor of children's services at Columbia Lighthouse for the Blind. She noted that two studies (Friendly, 1971 and Jenson, 1971) found eye disorders present in 40 percent of hospital samples of battered children. This, coupled with her clinical experience, led her to conclude "many children may be visually handicapped or blind because of child abuse, but this fact is almost totally unrecognized..."(242).

Baladerian (1991) estimates that 32,000 to 80,000 children per year become disabled due to abuse and/or neglect. This is a much more conservative estimate than that of Brandwein (1973) who estimated that 170,000 children become mentally retarded each year due to abuse or neglect.

Detection and Reporting

Maltreatment of the handicapped is thought to be significantly underreported

Barriers to Identification

- Children with disabilities are seen as unreliable reporters
- Child may not be able to communicate facts in detail
- Symptoms of disability may mask abuse
 - child may engage in self-abusive behaviors
 - child may be prone to accidental injury
 - child may act out sexually due to poor judgment or poor impulse control
- Touching may be required to assist the child, making accidental touching inevitable and exploitative touching difficult to identify
- Child may be more vulnerable to incentives due to cognitive impairments or emotional deprivation
- Child may be more socially isolated — may not know who to tell
- Child is less likely to receive sexuality education or prevention training — may be ignorant of the problem

compared to the general population (Sean, 1988; Seattle Rape Relief, no date; Sullivan, et. al., 1987; Tharinger, et. al., 1990).

There are many roadblocks to detection of abuse in the exceptional population. Perhaps the most obvious problem is communication difficulties (PACER, 1985; Sullivan, et. al., 1991). "Cases of abuse of people with limited verbal skills currently will only come to light if medical symptoms of sexual abuse (e.g., pregnancy, venereal disease) are present and diagnosed, if the abuse is witnessed (by another client or worker) and reported, or if the individual is somehow able to indicate that the abuse has occurred . . ." (Sean, 1988, p. 7). Indeed, some authors maintain that the best clues are found in medical reports (Zadnik, 1973).

A second problem is that one cannot rely upon behavioral indicators. Some symptoms of child abuse are similar to behaviors of non-victimized children with developmental disabilities (Davis, as cited in Sean, 1988; Sullivan, et. al., 1991). Children with disabilities may experience abrasions and contusions due to accidental falls or due to self-abuse (Ammerman, et. al., 1989). Medications may have side effects, changing mood so that emotional indicators may be absent. For example, an adolescent who is disabled may disclose abuse in graphic detail in front of a group of people while showing little emotion (Sean, 1988). Emotional reactions of those denied personal integrity by being institutionalized may be similar to reactions to sexual abuse (Cole, 1986, as cited in Sean, 1988).

Given the overlap between symptoms of child abuse and symptoms due to the disability, cases of abuse can easily be overlooked. Says Carolyn Paige, director for Seattle Rape Relief, "signs and symptoms are attributed to the disability rather than to abuse." Still, some researchers have documented changes in behavior occurring in those with disabilities following assault (Bernstein, 1985; PACER, 1986). "Look for sudden changes in behavior or a sudden onset of sexual acting out," states Nora Baladerian, Ph.D., of the Disability, Abuse and Personal Rights Project.

A third roadblock to detection is credibility problems (PACER, 1985). There is a bias against believing the disabled, even though there is no evidence that children with disabilities are any less reliable in disclosure than anyone else, although research is lacking (Sean, 1988).

Finally, some authors suggest that abused children with disabilities are reluctant to report abuse by caregivers due to fear of losing someone they depend upon for basic care (Cole, 1984/85; PACER, 1985). Others feel that the children fear retaliation or it may be simply that the child with disabilities has few people to confide in (Cole, 1984/85).

Assessment and Investigation

Even skilled professionals may feel overwhelmed when the victim is a child with a

Ideas from the Editor



Joann
Grayson

It has been an "eye-opening" experience to research this issue! I find myself asking again and again — What might help? I have some ideas to share. Most use existing resources and would not be overly costly to implement.

A toll-free hotline to connect CPS workers with specialists in developmental disabilities. It would be impractical to attempt to make CPS workers into specialists in all the various developmental disorders. Therefore, specialists who are knowledgeable about various developmental problems need to reach out and make consultation available to CPS. If there were at least one identified consultant for each handicapping condition, the consultant could advise the CPS worker about modifications needed in the investigation of a specific case.

Treatment teams of a specialist in developmental disability and a child abuse treatment expert. Psychotherapy has traditionally not been offered to those with developmental disabilities. Thus, most clinicians with experience in treating abused, neglected or sexually victimized children have not served this population. Combining the expertise of an experienced clinical therapist with that of a developmental disabilities expert could provide a treatment team that offered specialized treatment approaches.

Prevention programs should be offered to special education students as well as the general population. In Virginia this is accomplished through The Family Life Education Program. It is not known, however, how many schools have access to prevention programs designed for children with special needs.

An outside advocate should interview each institutionalized child several times a year to determine if that child is experiencing abuse or neglect or sexual abuse. Ideally, the advocate should be assigned the same children so she can get to know them over a period of time.

Child abuse detection training should be aimed at child prescription teams who do the special education evaluations. Since each special education student has a full evaluation every three years, part of that evaluation should be determining if the child is experiencing abuse, neglect, or sexual abuse. A checklist could be developed to assist the psychologist on the team in making a determination.

Special education teachers should be required to have training in the detection and reporting of child abuse prior to licensing.

Institutions that service only children with developmental disabilities should be required to hire or contract with a specialist in child abuse and neglect. This staff person or consultant could arrange for staff training, prevention training for the children, and offer specialized treatment services to those children already known to be victimized. Since high percentages of children in institutions for mentally retarded, deaf, or blind are known to be victims of abuse, neglect, or sexual abuse, this service should be considered as mandatory. Children suffering from effects of undetected and/or untreated victimization are unlikely to receive

maximal benefits from other remedial programs. Thus, treatment for victimization will likely be cost-effective by enhancing progress in other areas.

Organizations concerned with rights of the disabled need to address the right of children with disabilities to be free from abuse. Rights of disabled to access buildings, jobs, and education is certainly important. Many organizations contacted had accomplished much in advocating for these rights. The same advocacy skills are needed to address a child's right to be free of abuse.

Virginia is to be commended for what has been accomplished in starting to address the needs of developmentally disabled children who are also victims of abuse and neglect. First and foremost, our statistics suggest that we are identifying and protecting a significant number of children with disabilities, since over a third of children in a random sample of founded cases have a developmental disability. Secondly, the Virginia Institute on Developmental Disabilities has joined with the Department of Social Services to sponsor two conferences in the last two years to address issues facing CPS and service providers. Over 400 professionals attended each of the conferences. (Last year's targeted substance-exposed babies; this year's looked at child abuse and disabilities) Also, Virginia's Office of Prevention (housed in the Department of Mental Health, Mental Retardation, and Substance Abuse Services) has been active in fostering efforts to prevent both disabilities and poor parenting.

Still, linkages between those who focus on the needs of children with disabilities and those who work to treat or prevent child abuse, child neglect, and child sexual abuse are informal and under-developed. There is much still that can be done to better protect and help a group of very vulnerable children.

disability. Interviewing a child who is deaf or mentally retarded or who has a severe speech deficit can be intimidating.

Yet, the same components that make a good interview for any child are the essential elements of interviewing a child with disabilities. According to Robin Vanderlaan of the Center for Child Protection, the interview should occur in a comfortable place with sufficient time to establish rapport. The interviewer should avoid leading questions. Specificity is required. Says Vanderlaan, "It is not enough to know a child was touched. You need to know what the person was doing, and if there was a pattern. Was it day or night? The child needs to put the event into time and place."

Because a child may have limited vocabulary, it is important to know what a child calls each of his or her caregivers. "This can cause a great deal of confusion," notes Vanderlaan. "A child may have three or four

people that he calls 'daddy.'" Vanderlaan suggests that the interviewer get a description of the person from the child as well as additional details such as where the person lives.

Another source of confusion can be a child reporting accurately about the abuse, but due to fear of the perpetrator, naming someone else as the offender (Sean, 1988). It is also important to interview all caregivers. "The reporting party may see the child in only one context," says Vanderlaan. "The child may say something and the reporter does not realize how the child is using the language."

Nora Baladerian, Ph.D., a clinical psychologist who specializes in abuse issues of children and adults with developmental disabilities, discusses interviewing children who are impaired in communication. "The interview may rely more upon visual aids."

The selection of an interpreter is a choice

that must be made carefully. There are different levels of interpreters, and one that is recognized by the court is essential. "Make sure that the interpreter is comfortable asking questions about sexual activity," notes Vanderlaan, "and be certain that the interpreter can avoid leading questions." Baladerian stresses finding an impartial, certified interpreter. She says, "Never use a person who is well-known to the child to interpret, and especially avoid using a family member."

It is important to distinguish what information has come from the child and what concerns are being expressed by care providers. "A caregiver, especially a person who has been abused themselves, may be hypervigilant, ask leading questions, and then become convinced that the child has been abused," notes Vanderlaan.

While evaluations of children with developmental disabilities can require more time

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The Healthy Start Program

A great deal of enthusiasm has been generated for a child abuse prevention program which found its start in Hawaii in 1975. The program is the Healthy Start Program, and it has found its way to Virginia!

Healthy Start is a community based, multi-disciplinary program designed to prevent child abuse and neglect, enhance parent functioning and enhance child development in a multi-ethnic/cultural environment. The program includes the following components:

- Early identification of families at risk, made possible by the review of hospital records by using a list of risk indicators. Those families meeting specific criteria are assessed using the Family Stress Checklist created by the E. Henry Kempe Center. Families determined to be at risk are encouraged to accept visiting support services on a voluntary basis. Only five percent of Hawaii families identified as "at risk" refuse services.
- Home based intervention services are offered where family support workers provide emotional support to parents and model effective skills in coping with everyday problems. Workers use the Nursing Child Assessment Satellite Training Scales to identify problem areas needing improvement. The frequency of home visits is based on the family's needs.
- Linkage to medical facility for well-baby visits. Developmental screening using the revised Denver Prescreening Developmental Questionnaire is conducted as necessary.
- Referral and coordination with other community agencies is an integral part of this program.

According to project organizers and researchers, the model in its entirety is what produces the desired outcome. Anything less will not get the results, and the results are impressive! The project goal of no abuse or neglect for 95 percent of targeted children after one year of service has been exceeded in every year. An evaluation of 1,204 high-risk families served during FY 1987-1989 revealed only one case of abuse (a 99.99 percent non-abuse rate) and six cases of neglect (a 99.95 percent non-neglect rate).

One of Virginia's Healthy Start programs is implemented by Northern Virginia Family Services and serves families in Fairfax County. It is funded by a five year child abuse prevention grant awarded to the Fairfax County Department of Human Development from the National Center for Child Abuse and Neglect.

Modeled very closely after the Hawaii project, Healthy Start of Fairfax County accepted its first referral in February of 1992. Its primary referral source is the Maternity Clinic of Fairfax Hospital which refers



families from designated high risk areas to project staff consisting of Linda Dunphy, Project Coordinator and four trained paraprofessionals who are bilingual and bicultural. "Our project differs slightly from the Hawaii model in that our first year specifically targets indigent families and we begin services prenatally," Dunphy explains. "Otherwise, we have followed the model very closely."

Once a family is referred, the Early Identification Specialist administers the Family Stress Checklist. Any family found to meet the at-risk criteria established by this instrument is offered services. "Of those families offered services, 95 percent have accepted," Dunphy states. "This is higher than our expected goal of 90 percent. We are pleased that so many families desire services."

Regular home-based visits focus upon fostering positive parent-child interaction, ensuring safety of the child and informal teaching of child rearing skills. Periodic developmental screenings help detect delays. Dunphy hopes to use the HOME Inventory to assess changes in parent-child interaction, as is done in Hawaii.

A unique feature of the Hawaii model is its level system. Home visits are conducted weekly for a minimum of two months. Upon review of specific criteria, the families may at this point move to level 2 which includes semi-monthly visits. Eventually, they progress to level 3 with monthly visits, and finally, level 4 which involves quarterly visits. According to Dunphy, the level system allows a family to receive services according to their needs and fosters a sense of progress, deters worker burn-out, and allows more families to enter the program. Each worker is expected to serve no more than 25 families at one time.

This project is being evaluated by an independent evaluator and there are very specific project outcomes to meet including: 80-95 percent of served children will not experience abuse or neglect, have no developmental delays, and will be up-to-date on immunizations. Gains are also expected in parenting skills and parent-child bonding. Dunphy feels certain these goals will be met.

There is another Healthy Start program which is located in Hampton. It is one of three programs offered by the newly formed Hampton Family Resource Project.

"We are excited about having the opportunity to replicate the Hawaii model," explains Debbie Russell, Resource Development Supervisor for the Hampton Department of Social Services. "The highly acclaimed Hawaii program was selected because it has demonstrated through repeated evaluations that it is effective in reducing the incidence of child abuse and neglect."

Two other aspects of the program appealed to Russell and the Citizens Services Task Force, who spent months researching several different prevention strategies. "First, it provides individualized, comprehensive home-based family support services. Second, the program focuses on the needs of the entire family for as long as the family needs the support. Many home visiting programs work with the family for six months to two years. Healthy Start provides services until the child enters school at age five."

Healthy Start of Hampton recently hired its first team of workers: five family support workers, one early identification worker, one clerk and a supervisor, all of whom began Aug. 3, 1992. The second team will be hired in January.

A second component of the Hampton Family Resource Project is "Healthy Family." "Healthy Family" provides several parent effectiveness services including nurturing programs, parent support groups, play groups, an informative newsletter timed to be sent to all parents of children ages 1,



3, 6, 9, 12, and 18 months, and 2, 3, and 5 years. In addition, there is a Young Family Center in all four branches of the Hampton Public Library with tapes, videos, books, and other materials.

The "Healthy Family" component also supports a family life education program for all eighth grade boys and girls in the Hampton public schools. The goal is to reduce teenage pregnancy. Pre- and post-tests measure the amount of information youth have regarding the realities of single parenting, living on welfare, and support services. School and social services personnel are heartened by the changes they see as a result of the classes. The schools have asked that this program be expanded to include all youth in sixth through tenth grades. Russell has submitted a grant to Health and

Human Services which will allow for the expansion and evaluation of the program.

Funds for the Hampton Family Resource Project come from a variety of sources. Grants have been awarded by the Virginia General Assembly, the City of Hampton and the Virginia Family Violence Prevention Program. Some activities, such as the family life education program, are totally supported by the efforts of the Department of Social Services staff and community volunteers.

"We are excited about the possibilities these services offer the families in Hampton," Russell exclaims. "The cost and severity of today's problems require a new strategy, one that is based on prevention. The services offered by the center seek to reinforce and support, rather than replace, the family."



For more information about these program, contact Linda Dunphy, NOVA Family Service, 100 N. Washington St., Suite 400, Falls Church, VA 22046, (703) 533-2566 or Debbie Russell, Hampton DSS, P.O. Box 9347, Hampton, VA 23670, (804) 727-1943.



PROJECT SPECIALCARE

SpecialCare is a program of Child Development Resources (CDR). CDR is a 25 year old private, nonprofit agency providing services for young children and their families and training for the professionals who serve them. SpecialCare is designed to expand child care options for families of young children with disabilities. The project provides training, technical assistance, and continued staff development for caregivers in Tidewater Virginia, including the Eastern Shore. Training from the project builds on caregivers' existing skills and helps them enhance their skill and comfort in caring for children with disabilities.

SpecialCare is a three year model demonstration project funded by the U.S. Department of Education, Early Education Program for Children with Disabilities. The project is in its third year. They have completed five trainings and have trained over 60 providers. The project keeps a list of providers who have completed the training. Parents wishing to hire a child care provider can consult the list. Barbara Kniest, coordinator, did not know how many parents of developmentally disabled had used the service.

For more information contact Barbara Kniest or Sheri Osborne, Co-Coordination, CDR SpecialCare, 1490 Government Road, Williamsburg, VA, 23185, (804) 898-0171.

Nurturing Programs

Another exciting prevention program has recently found its way to Virginia. Nurturing Programs is an outgrowth of a 1980 award by the National Institute of Mental Health to Family Development Resources, Inc. in Eau Claire, Wis. This project measured the impact of dysfunctional parenting practices on children. Project staff began to develop an effective prevention program in order to meet the concerns that were raised, resulting in the first of the Nurturing Program: The Nurturing Program for Parents and Children 4-12 Years. Since that time several more programs have been developed: Parents and Children Birth to 5 Years; Parents and Adolescents 12 to 18 Years; Teenage Parents and Their Children Birth to Five Years; Foster and Adoptive Families and Their Children; Parents With Special Learning Needs and Their Children. A tool to measure high-risk parenting attitudes — the Adult-Adolescent Parenting Inventory (see review, VCPN, volume 30) — was developed as well. Two of the programs — Nurturing Programs for Parents and Children Birth to 5 Years, and 4 to 12 years — are available in Spanish.

The programs are designed to promote the development of the building blocks of effective parenting. These component parts include:

- bonding with the child in the earliest stage possible, hopefully within 24 hours after birth;
- empathy for the needs of the child and an ability to act on the child's behalf;
- parental awareness of one's own needs, as it is difficult to meet the needs of children if parents cannot identify, understand and take care of their own needs;
- gentle, calm, nurturing touch;
- setting limits by establishing boundaries, creating rules, and providing appropriate consequences, all of which help children develop self-control and positive character;
- providing unconditional love, being

honest in communications, and treating children with respect and dignity; and

- acquiring adequate knowledge of childhood development.

Each program comes with a multitude of material — curricula, children's books, workbooks, posters, assessment tools, and audiovisual materials — to meet the goals. Implementation can be in groups or in the home. However, the program should include all members of the family.

Funds from the Virginia Family Violence Prevention Program and from the federal challenge grant monies awarded to the Virginia Department of Social Services have made it possible for Virginians for Child Abuse Prevention to hire a project coordinator and buy 30 sets of the six adaptations of the Nurturing Program. "So far we have been able to train staff in 22 agencies statewide," explains Sherry Herbert, Project Coordinator.

In order to adopt the program, an agency must be willing to 1) have volunteers and staff complete a two day training program; 2) adhere to policies and procedures developed for effective program implementation; and 3) provide statistics about the families being served. If an agency is willing to comply, it can borrow one of the six adaptations to begin a program. Once they have used it and decide they want to continue the program, the agency raises local funds to buy the materials and return the one borrowed. "One agency borrowed our program for children ages 4-12 years," Herbert remarks. "It was so successful, they found the funds to buy their own materials, returned ours, and borrowed the 0-5 adaptation so they could expand their services! That is the kind of use we hope to continue to see."

For more information readers can contact Herbert's successor, Karen Schrader, at Virginians for Child Abuse Prevention, 224 E. Broad Street, Suite 302, Richmond, VA 23219, (804) 775-1777.



Child Abuse and Disabilities

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and initiative than the usual referral, it is important to realize that many cases can be handled routinely.

In order to document, Vanderlaan stresses the need to videotape or at least audiotape, the interviews. Documentation allows the clinician to establish what the child can produce in terms of credible history.

The medical exam is a crucial component for children with developmental disabilities. Vanderlaan noted that a review of records of 20 cases in 1985 indicated that half of the children with disabilities showed significant medical indicators. "The expense of a medical evaluation is always worthwhile with this population," explains Vanderlaan. "A medical evaluation can rule out injury, pregnancy, and STD's. Children worry that their bodies are damaged in some way. A medical exam can reassure them that they are 'ok' physically. Physical findings that indicate an injury or infection in children who have not been able to give complete histories on interview would remain unknown and untreated without a medical evaluation."

Conflicts with No Easy Answers

Even if a case of possible abuse or neglect is identified, referred, and properly investigated, some unique problems remain in interpreting and labeling the results.

Is it neglect if a family fails to follow prescribed treatments suggested by professionals? If a family lacks the time or inclination to carry out a treatment program, the CPS worker may be caught in a dilemma. Support groups and parent advocates may encourage a parent to define their limitations. Writes one father, "The problem with Laura having multiple disabilities is that the attention she needs can be overwhelming ... We are constantly getting advice from teachers, doctors, therapists... We are gradually running out of steam and realizing we can't realistically address everything ... we need to strike a balance in our lives or we'll have deep-seated frustrations forever" (National Father's Network Newsletter, Winter, 1992, p. 4).

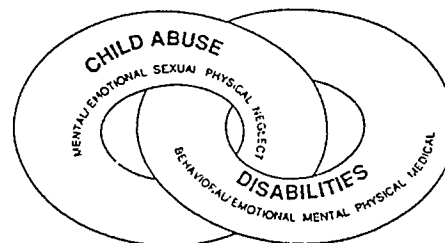
If we allow parents to ignore treatment directives, has our society then adopted a "lower standard of care" for the disabled? Can the state force a parent and family into extraordinary sacrifice of time and finances because they happen to have given birth to a child with disabilities? Can we define the parent as neglectful if they fail to meet the

challenge? Since foster homes are increasingly scarce, since few foster parents have had disability training, and since the incidence of abuse of disabled in residential care is so high, can the state who removes a child for neglect or abuse or sexual abuse offer the child an abuse-free environment? If the problem is lack of respite or services and if these are not available, does labeling the problem "abuse" or "neglect" help?

Interpreting cases of possible sexual abuse may contain some dilemmas. Emphasis on sexual exploitation may, in some cases, be directly opposed to efforts to allow disabled individuals the right to sexual activity (Tharinger, et. al., 1990).

Sean (1988) writes about "sexual neglect" where persons with developmental disability are deprived of their sexual rights. In the next paragraph Sean decries sexual abuse of residents by other residents. How is one to determine the difference in all cases? When can persons with mental retardation consent to sexual activity? Many non-handicapped teens have chosen to become intimate sexually, then later decided that the activity or the relationship was not in their best interest. If the disabled teen or young adult engages in sexual activity and later is disappointed or decides that they regret the activity, is their partner automatically a sexual abuser? Laws in some places forbid sexual activity with mentally retarded or mentally ill persons, and would, thus, define the partner as abusive regardless of consent (Tharinger, et. al., 1990). How much freedom are we willing to give teenagers and young adults with disabilities to make the same choices (and, perhaps the same mistakes) as their non-handicapped peers?

Questions about sexual behavior and birth control are not easily addressed or answered, nor is there consensus among professionals (West, 1987). What is asked of the legal system is both protection of a legal right to engage in sexual relationships while at the same time providing protection from exploitation due to a disability (Tharinger, et. al., 1990).



Treatment Considerations

There are few published reports of the effects of abuse on children with developmental disabilities (Sean, 1988). Indeed, little attention has been paid to the general emotional, psychological and personality development of children with disabilities (Tharinger, et. al., 1990). Persons with developmental disabilities, especially those with mental retardation, have typically been regarded as unsuitable candidates for psychotherapy, thus, little attention has been

paid to therapy needs for emotional difficulties in this population. The authors who address this question of effects of abuse on the child with disabilities feel that the effects are likely to be more severe (Tharinger, et. al., 1990; Varley, 1984 as cited in Sean) than for a non-handicapped population.

There is some suggestion that care providers such as schools and medical personnel tend to withdraw services and support following a referral to CPS (Zadnik, 1973). This can occur if teachers or medical personnel are uncomfortable with dealing with abuse or if they perceive CPS as now "in control" of the case. Zadnik notes that this response can make parents feel deserted by those providers who know them best. The need is for an increase in service, or at least keeping services already in place at a consistent level.

Effective therapeutic interventions for facilitating recovery from abuse in children with disabilities have not been researched (Tharinger, et. al., 1990). Therefore, any conclusions should be considered preliminary.

The therapeutic needs of the child with disabilities are not thought to differ from those of non-handicapped children. The choice of treatment will depend upon the child's age, cognitive and social development, gender, diagnosis, family and living situation, and the materials available to assist the therapist.

Prevention

Prevention ideas are numerous and there is little agreement about how to spend limited prevention dollars.

Some authors stress the importance of *preventing disabilities*. Efforts on this front include adequate prenatal care and prevention of teenage pregnancy.

Others stress *preventing abuse which can cause disabilities*. Baladarian remarks, "At least 25 percent of all disabilities are caused by abuse, with each disabled child costing taxpayers over \$20,000 per year per life. The dollars become significant when you realize that 32,000 to 80,000 children each year are disabled due to abuse. Prevention of disability caused by abuse should be a national priority."

Those who agree with Baladarian are enthusiastic about programs that identify parents at high risk for abuse and offer them intensive assistance prior to abuse occurring (Starr, et. al., 1984). Typically, the at-risk parents are identified by one of three approaches. Some programs target groups such as teen parents, those who give birth to a low birth weight baby, first time parents or mothers who abuse substances. While not all parents in the group are high-risk, the group in general is over-represented among those who abuse. A second approach is to select participants by virtue of a checklist of characteristics which are typical of families who abuse (For a discussion on predicting

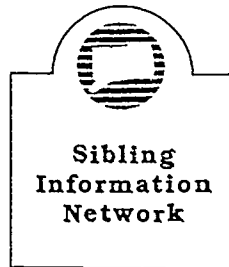
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Organizations

National Resource Institute on Children and Youth with Handicaps

University of Washington WJ-10
Seattle, WA 98195
(206) 543-2213

NRICH works to provide training and consultation to agencies so they may work together to protect vulnerable children. They also publish Special Issues, which are four page information capsules on issues such as children with disabilities within the child welfare system.



Sibling Information Network

The A. J. Pappeniou Center
991 Main Street
East Hartford, CT 06108
(203) 282-7050

The Sibling Information Network, founded in 1981, was established to assist individuals interested in the unique needs of families of persons with disabilities. The Network has information about audiovisual materials, resources for sibling programs, sibling group information and bibliographies. The quarterly newsletter is a major project and contains SIBPAGE, an insert for children 5 to 15. Sample copies are available upon request.

Membership dues are the Network's sole support. An individual membership is \$7, organizations or institution dues are \$15.



NFN NATIONAL
FATHERS'
NETWORK

National Father's Network The Merrywood School

16120 N.E. Eighth Street
Bellevue, Washington 98008
(206) 747-4004

Too often, dads are the neglected parent in the family and in service delivery to children with special needs. The National Fathers' Network was created to promote and advocate for the needs and concerns of men, to enhance their abilities to be competent, caring fathers.

Over the past six years, the Network has developed more than 43 support programs for fathers in 32 states and Canada. A quarterly newsletter is available free of charge. Several monographs and videos are available for sale. The Network does a limited number of outreach trainings each year.

National Coalition on Abuse and Disabilities

American Foundation for the Blind
15 W. 16th Street,
New York, NY 10011
(212) 620-2043 2067 (TDD)

Contact: Christine E. Pawelski, Ed.D., Chair

The National Coalition is an informal group of individuals who first joined together in November 1990. Their purpose is to increase the impact of their work related to abuse and disability issues. The Coalition meets at various national conferences and communicates through periodic newsletters and computer bulletin boards. There are no membership fees.

Funds for this publication are provided by the Virginia Department of Social Services, Child Protective Services Unit with a grant from the National Center on Child Abuse and Neglect Administration for Children, Youth and Families, Department of Health and Human Services.

Spectrum Institute Disability, Abuse and Personal Rights Project

P.O. Box "T"
Culver City, CA 90230-0090
(310) 391-2420 EXT 333

Interested readers can obtain a list of publications from the "Disability, Abuse and Personal Rights Project." Included is one on interviewing skills for those investigating abuse of disabled adults. Also available are over 50 publications by Nora J. Baladerian, Ph.D. Included is a survivor's manual for people with developmental disabilities who have limited reading skills, articles on prevention, tapes of conference presentations, articles for prosecutors, materials for parents of disabled children, and bibliographies.



The Council for Exceptional Children 1920 Association Drive

Reston, VA 22091
(703) 620-3650
FAX: (703) 264-9494

From modest beginnings in 1922, the CEC has grown to an organization of 52,500 members with 975 local chapters, 3 state or provincial branches, 54 federations, and 17 divisions. The principal purpose of the organization is the advancement of the education of exceptional children and youth — both those who are gifted and those with disabilities. They publish two journals, *Exceptional Children* and *Teaching of Exceptional Children*. They also host the ERIC Clearinghouse on Handicapped and Gifted Children.

The ERIC Clearinghouse acquires literature and unpublished literature which is abstracted and indexed into a database. They respond to inquiries and network with agencies that share similar interests. They analyze and synthesize literature into research reviews and similar documents.

ERIC offers free reference and referral services to the general public. For more information about the ERIC system, call (1-800) USE-ERIC. For specific information about disabilities, call (703) 264-9474.



Children of Alcoholics Foundation, Inc.

P.O. Box 4185
Grand Central Station
New York, NY 10163-4185
(212) 754-0656
(1-800) 359-COAF

Contact: Ms. Luvon Roberson
Director of Public Information

The Children of Alcoholics Foundation, Inc., a non-profit voluntary organization, develops programs in child advocacy, public policy, and public education to reach, help, and offer hope to the nation's 28 million children of alcoholics (7 million under the age of 18).

The Foundation's primary goals:

- to educate the public and professionals about children of alcoholics.
- to promote research and new data, and
- to develop programs and materials for prevention of future alcohol-related problems.

The Foundation's report "Children of Alcoholics in the Medical System: Hidden Problems, Hidden Costs," is the country's first large-scale study to document health care patterns and use rates of children of alcoholics. Among its many findings, the study reports that health care costs for children with FAS (Fetal Alcohol Syndrome) is estimated at \$321 million.

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James Madison University
Harrisonburg, VA 22807
(703) 568-6482
FAX: (703) 568-3322



Child Abuse and Disabilities

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risk, see VCPN volume 10). A third approach is more informal, identifying at risk parents by referral from practitioners. To avoid the stigma of labeling, some programs offer intensive intervention to all new parents regardless of risk.

An example of a program that targets risk groups is the Hand-to-Hand program in Harrisonburg, Virginia. This program matches trained volunteer mentors with pregnant teenagers.

Murphy (1982) describes a program that uses a psychosocial risk inventory to determine risk. Several other instruments are also available (see VCPN, volumes 10 and 30). The Healthy Start Program (see Spotlight, this issue) is an example of this approach being tried in two Virginia locations.

A program relying on the more informal referral method with no fixed criteria for defining "at risk" is the Nurturing Program (see Spotlight, this issue and VCPN, volume 30).

A third group of prevention ideas are based on *reducing stress for families of children with disabilities and assisting families in anticipating problems*. These approaches attempt to lower stress through the use of support groups, respite care, parent training and support (Davis & May, 1991; West, et. al., 1988). Several such programs are described elsewhere in this issue.

A fourth set of prevention strategies recommends *teaching abuse prevention skills and/or human sexuality education for chil-*

dren with disabilities (Cole, 1984/86; Paige, et. al., 1991; Schor, 1987; Sean, 1988; Sullivan, et. al., 1987; Zantal-Wiener, 1987). Only a few curricula specific to developmentally disabled are available. Those that could be located are reviewed in the resource reviews.

Prevention efforts do appear promising. Hard (1986, as reported in Sean, 1988) has convincingly demonstrated the utility of a prevention education approach for those with developmental disabilities. All of the disabled women without sex education interviewed had been sexually victimized while only 12 percent of those with prevention education had been.

A fifth initiative seeks to *institute reform in institutions, residential centers and schools*. Most substantial reforms (such as not allowing staff to be alone with a child or not allowing a child to be transported or accompanied by only one staff person) would be expensive. Until funding and staff ratios are considerably improved, opportunity to be alone with a child will continue in most settings.

Another institutional reform is to improve hiring practices by using criminal records checks and more thorough background searches (Sean, 1987; Zirpoli, et. al., 1987). Hiring practices will continue to be hampered, however, by a low level of pay, thus attracting less qualified applicants. Better quality of staff can facilitate another reform, that of eliminating dangerous practices such as use of aversives like shock rods (Mauer, 1973). In order to manage difficult behaviors without overuse of aversives or isolation requires skilled staff and good staff/child ratios.

Staff training has also been suggested (Sullivan, et. al., 1987; Zirpoli, et. al., 1987). Although a sensible idea, there appears to be no research to determine the effectiveness

of staff training in preventing abuse (Musick, 1984). One negative effect noted is that after training, some staff may become wary of touching children at all and try to adhere to a "no touch" policy (Sean, 1988). Carolyn Paige of Seattle Rape Relief comments, "One fear service providers commonly express is that they will become guarded and reticent to show affection for a child. We need to keep in mind that staff are service providers, not friends. If we want to keep children safe, it is in our best interests to set clear guidelines with the way we show affection while encouraging positive relationships within a child's peer group."

The choice does not appear to be a simple one, however. Bartlette, in his autobiographical talk, speaks over and over about how important it was for "the white women" to touch him. Affectionate touch may even be essential to survival for very young babies. Service providers may be the only "friends" an abused child with disabilities has. If foster parents or residential staff do not offer affection as well as physical necessities, the child may be further damaged.

A sixth prevention strategy is *trying to detect abuse early*. With this goal in mind, various authors have suggested educating doctors in abuse detection (Elvik, et. al., 1990), training special education teachers to spot abuse (Tharinger, et. al., 1990; Zantal-Wiener, 1987; Zirpoli, 1986), encouraging evaluators and case managers to request and carefully examine medical data on all new referrals (Zadnik, 1973), asking children frequently if they are being abused (Sean, 1988; Sullivan, et. al., 1987), and designating at least two non-family adults for a child to contact if they are abused (Paige, et. al., 1991).

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Spotlight on Minnesota: The PACER Center



PACER (Parent Advocacy Coalition for Educational Rights) is a coalition of 19 Minnesota disability organizations. It is staffed primarily by people who are parents of children and adults with disabilities or people who have disabilities themselves. PACER offers information about laws, procedures, rights and responsibilities. Its programs help parents become informed and effective representatives for their children and young adults in educational, vocational and other service decision making.

"PACER was founded on the concept of 'parents helping parents,'" explains Deb Jones, of PACER's Let's Prevent Abuse Project. "A major way we do this is through education." PACER programs are numerous. There are parent training workshops, ranging from general information about special education to communication with schools to special topics such as siblings, sexuality or the role of grandparents. There are workshops to train trainers. There is

individual assistance and support, and services designed for African-Americans, for parents of Hispanic backgrounds, those who are American Indian, Southeast Asian or other cultural groups.

PACER workshops also target the child's needs developmentally. There is an early childhood family training, transition activities for parents of secondary students, transition planning in health care, and programs in supported employment.

PACER also sponsors activities for students and schools. "Our disability awareness project, COUNT ME IN, reaches over 14,000 school children each year. We have 30 volunteer puppeteers who take the life-sized puppets to schools." The performance is designed to promote understanding of children with disabilities and help children feel at ease with disabled classmates. The puppets and scripts are available for purchase by groups wishing to conduct disability awareness programs.

PACER puppets are also used in programs to teach children about child abuse. Scripts have also been developed for children with mental retardation.

The computer resource center allows parents, teachers, children, and adults with special needs to acquire hands-on experience with personal computers, adaptive devices and educational software. A software lending library is available to families.

PACER publishes four different newsletters and offers an extensive collection of resource materials and videotapes. A 12 page catalogue lists booklets, newsletters, information handouts, workshop materials, books, videotapes, and other items.

A copy of the publications catalogue and/or further information about the PACER model is available from: PACER Center Inc., 4826 Chicago Ave., S., Minneapolis, MN 55417-1098, (612) 827-2966 VOICE/TDD; FAX (612) 827-3065.

Spotlight on San Diego: The Center for Child Protection

When Robin Vanderlaan, L.C.S.W., joined the staff at Children's Hospital and Health Center in 1986, she noticed that there were few referrals of sexually abused youth with developmental disabilities. Vanderlaan and Marilyn Kaufhold, M.D., who had a background in work with mental retardation, began asking why. Their inquiry culminated in the addition of forensic assessment of developmentally disabled victims of sexual assault to the Center's forensic service.

The Center for Child Protection is a specialized service that offers assessment and treatment to child victims of sexual assault. Over 95 percent of their referrals are from law enforcement. "We have a very good relationship with law enforcement," explains Vanderlaan. "We do a videotaped interview and afterwards the child receives a complete medical examination."

The Center also offers a four week course for children who are scheduled to testify in court. The course was developed in cooperation with the state office of Criminal Justice Planning and the Family Protection Unit of the District Attorney's office. The "Kids in Court" class meets for four evenings and is taught by a judge, an attorney, and a social worker. "We avoid any reference to the specific facts of a child's case," notes Vanderlaan, "because that could be construed as 'coaching'. Instead, we instruct the children about court procedures, and we role play a trial so they can understand what job each person does." While the children attend their course, sessions for family are also offered.

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A final prevention effort targets early identification of disabilities by CPS (Schilling, et. al., 1986). This strategy suggests that if a disability is spotted and treated, then risk of abuse or neglect will be lowered. West Virginia University is pilot testing this approach. To date, over 130 CPS and social workers have been trained in typical versus atypical development and how to refer for further evaluation (For a description of work book materials, see Resource Reviews, this issue). The project has concentrated upon birth to six years, since older children will likely be identified by the school system.

Virginia's Picture

Virginia's CPS data is quite different from the national statistics cited earlier. Virginia does collect data on child characteristics, although this data has been collected only on a random sample of cases.

A recent sample of 4240 cases shows that 19 percent were "founded" for abuse or neglect. Fifty-five percent of children in founded cases were listed as having no developmental problems. In another 13

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In addition to support for the legal system, the center offers counseling and treatment. Approximately 1200 children are served each year.

The Center has maintained an excellent relationship with law enforcement and the staff have extensive experience with sexual abuse investigation and treatment. Even so, getting referrals of developmentally disabled victims was difficult. "In the beginning," says Vanderlaan, "there was a real lack of experience with this population on the part of law enforcement and the bias was that a case with a mentally retarded victim couldn't be prosecuted. Consequently, the investigation of a case with a mentally retarded victim wasn't as vigorous."

Vanderlaan notes that investigation has two focuses, prosecution and protection of the child. "Even when prosecution is not possible, a vigorous investigation by law enforcement helps child protective services to protect the child," she notes.

If there is a specialized unit, then staff begin to gain confidence in their ability to work with difficult cases. In 1986, the Center for Child Protection made a video (see review, this issue on "Evaluating Developmentally Disabled Victims of Sexual Abuse"). In San Diego, there are seven prosecutors who work full time on child abuse cases. The chief of this unit arranged for the child abuse detectives from law enforcement to attend a workshop and view the film. He encouraged police officers to refer the cases for screening so they could be evaluated by these prosecutors. The results have been promising.

Vanderlaan explains, "Over the last five years we have gone from no cases with developmentally disabled victims to having cases referred routinely."

At first, Vanderlaan did all the interviewing for developmentally delayed clients. She later decided that all clinicians should learn the assessment skills. Now handicapped clients are seen by the entire staff.

There is a community-based bimonthly case review for mentally retarded children and adults. It is staffed by the regional center case manager, law enforcement, CPS, and the center clinicians. The case review serves as a forum where emerging concerns can be brought and the team can arrive at a consensus about how to proceed with the case. The team can also advocate for services for the child victim.

One test of need is whether or not a service is utilized. The literature suggests that children with disabilities are at increased risk for all forms of child abuse. The Center for Child Protection has used a "fool-proof" formula — offer the service and see what happens. If there is a need, people will come forward. Did it work? Says Vanderlaan, "When we became visible as a place where mentally retarded victims could get help, we got lots of referrals."

The Center for Child Protection offers a variety of on site and off site training programs and sponsors an annual conference. For more information, contact Center for Child Protection, Children's Hospital, 8001 Frost Street, San Diego, CA 92123. (619) 576-5814; FAX (619) 278-2365.

Spotlight: Boy's Town

The Boys Town National Institute for Communication Disorders in Children has a Center for Abused Handicapped Children. The Center provides evaluation and treatment for 250 to 500 abused children with communication disorders each year. The short-term residential program specifically for hearing-impaired abused children is the only program of its kind in the United States.

The Center uses a model titled TEACH (Therapeutic Education of Abused Children Handicapped). Three families at a time can enroll in the six week program which entails the entire family living in a unit that adjoins the hospital.

"Virtually all of the children have behavioral management problems," explains Executive Director Patricia Sullivan, Ph.D. "We use a social learning theory model. We work with the entire family because the family is the basic unit of our society."

The Center's programs employ staff with disabilities who are good role models for the

parents. There is also a 20 week outpatient program for those close enough to commute.

The Center has several other projects. They are developing protocols for police and CPS to assist them in investigations. The Center is one of five sites selected by the National Center for Child Abuse and Neglect to conduct outcome research. Two studies are currently underway. One is a screening of 1000 CPS cases to determine if any of the children have disabilities. The second study is merging a data base of police data on extra-family abuse and CPS data on intra-family abuse with a data base of 50,000 children with disabilities.

More information is available from Patricia Sullivan, Ph.D., Clinical Director of the Center for Abused Handicapped Children, Boys Town National Institute for Communication Disorders in Children, 555 N. 30th St., Omaha, NE 68131, (402) 449-6600 (Voice or TDD).



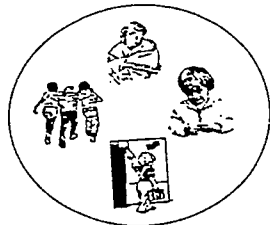
Book and Video Reviews

Evaluating Developmentally Disabled Victims of Sexual Abuse, 1987. videotape. color, 1/2" VHS, \$150 purchase. \$50 rental.

Available from: Children's Hospital and Health Center

Center for Child Protection
8001 Frost Street
San Diego, CA 92123
(619) 576-5803
TDD 576-5831

This excellent video shows excerpts from forensic social work interviews of three developmentally disabled victims of sexual abuse. The video explains the use of a structured interviewing protocol and focuses on how to conduct the difficult inquiry about the sexual activity. The video is a confidence-builder for those who feel overwhelmed by interviewing mentally retarded or victims with disabilities. It is clear from the video that some of these clients are very credible reporters when properly interviewed. The video contains many practical suggestions for how to word questions and elicit information.



A Guide to Typical and Atypical Child Development. No author, no date. 40 pages

Available from: West Virginia University
University Affiliated Center for
Developmental Disabilities
College of Human Resources
and Education
Morgantown, WV 26506-6122
(304) 293-4692 6220-3350

This guidebook is presented with a video in a 4 hour workshop. The purpose is to give child protective service workers a better understanding of typical versus atypical development. The first 10 pages detail expected development through age 4 and give warning signs for each stage that may indicate need for evaluation and referral. Communication skills, cognition, gross and fine motor skills, and social and emotional growth are covered.

There are also sections on child nutrition, age-appropriate discipline, and difficult phases of development. The last 20 pages list West Virginia's referral sources, including comprehensive community behavioral health programs, developmental disability programs, residential programs, and specialized adolescent services.

States or regional offices would do well to examine this resource with an eye toward producing a similar booklet for their locality. This approach could assist CPS workers in identifying preschool children with developmental delay. Children of any age might be better served if all referral sources are identified in a single publication. West Virginia has trained 130 CPS and social workers to date.

Training Tape on West Virginia's Child Protection Services (CPS) Policy on Baby Doe (1/2" VHS), 1991. 10 minutes

Available from: University Affiliated Center for Developmental Disabilities (UA CDD)
West Virginia University
Health Sciences Center
918 Chestnut Ridge Road,
Suite 2
Chestnut Ridge
Professional Bldg
Morgantown, WV 26506
(304) 293-4692

In recent years, controversies have arisen over how disabled infants with life-threatening conditions should be treated. The Child Abuse Amendments of 1984 requires CPS to investigate suspected cases of medical neglect. Medical neglect is defined in part as withholding of medically indicated treatment for disabled infants with life-threatening conditions. The law does not allow withholding of nutrition (food), hydration (water), or medication. This video assists CPS workers in learning the medical terms, definitions, and procedures applicable to "Baby Doe" cases. A Self-Instructional Manual accompanies the video.

Interviewing Skills to Use with Abuse Victims Who Have Developmental Disabilities by Nora J. Baladerian, Ph.D., 1992. 39 pages. \$4

Available from: National Aging Resource Center on Elder Abuse
810 First Street, Suite 500
Washington, D.C. 20002-4205
(202) 682-2470

This manual defines developmental disability and covers myths and stereotypes that could negatively influence an interview. In particular, the manual covers communication difficulties, use of nonverbal techniques, and how to "cross check" for response sets. The manual offers specific suggestions for structuring the interview.

The manual appears to be written for interviews with adults, although much of the information would apply to older teens as well. Those working with children will find the resource helpful in thinking about issues involved in investigation.

Abuse Causes Disability: A Report from Spectrum Institute, by Nora J. Baladerian, Ph.D., 1991. 30 pages. \$15.

Available from: Spectrum Institute
Disability, Abuse and Personal Rights Project
Disability Issues Division
P.O. Box "T"
Cuver City, CA 90230
(310) 391-2420 ext 333
FAX (310) 390-6994

This paper contains a report of a national survey on legislation addressing the issue of abuse and disability. Eleven states, including Virginia, have legislation addressing both issues. Suggestions for state legislation are included. The paper also contains abstracted information from studies showing abuse to cause disabilities.

The information is well organized and very readable. Fiscal costs are discussed. The final section details the need for a national program.

Special Children Special Risks: The Maltreatment of Children with Disabilities, by James Garbarino, Patrick E. Brookhouser, Karen J. Authier and Associates, 1987. 320 pages. \$44.95 cloth. \$27.95 paper

Available from: Aldine de Gruyter
Division of Walter deGruyter, Inc.
200 Saw Mill River Road
Hawthorne, NY 10532

This book brings together a diverse group of experts to address most major topics concerning abuse of children with disabilities. The topic is examined in both the broad context (response of society and federal government) and more narrowly (the role of siblings and peers in abuse, identifying special risks for children with disabilities). Both residential and intrafamilial abuse are discussed. Models for therapy are offered, as well as suggestions for restructuring medical care. A variety of legal issues is considered. Promoting change through use of mass media and community systems is explored.

This book covers most issues, except for investigation of complaints and operation of the child protective service system. The work provides an excellent overview of child abuse in children with disabilities.

Let's Prevent ABUSE

Let's Prevent Abuse: A Prevention Handbook for Early Childhood Professionals and Families with Young Children with Special Emphasis on the Needs of Children with Disabilities, by PACER Center, 1990. 107 pages. \$10.

Available from: PACER Center, Inc.
4826 Chicago Ave. South
Minneapolis, MN 55417-1098
(612) 827-2966

This handbook covers very basic material. It offers an overview of the types of child maltreatment and indicators at each developmental stage. The book reviews how to report child abuse or neglect and discusses reporting laws. It also covers prevention of maltreatment, including checklists for programs to use in lowering risk of abuse or neglect.

Application of the information to children with disabilities is accomplished in several ways. The Education of the Handicapped Act Amendments of 1986 (PL 99-457) is reviewed. For each developmental stage, a section discusses children with disabilities. Finally, a special report on drugs and babies is included.

This handbook will assist those training day care staff, teachers of children with developmental disabilities, or parent advocate groups about the existence of child abuse and neglect among those who have disabilities.

The Project Action Curriculum: Sexual Assault Awareness for People With Disabilities, by Carolyn S. Paige, Sarah Wright, and Melanie Schaefer, 1991. 130 pages. \$125
Available from: Seattle Rape Relief
1905 South Jackson
Seattle, WA 98144
(206) 325-5531 (VITTD)
FAX: (206) 325-5536

The first sections of the manual are devoted to general information about sexual assault. The curriculum covers concepts about people's sexuality, sexual assault and disclosure. Role plays and a care provider packet are included. A School Environment Inventory and a Home Environment Inventory are included to assist in assessment of inappropriate touching. Learning to engage in meaningful interactions is seen as a complementary method of teaching sexual assault awareness. A nine page guide for parents is available for \$3. Some information in this pamphlet is specific to Washington State.



A Resource Manual on Child Abuse by PACER Staff, 1988. 115 pages. \$15
Available from: PACER Center, Inc.
4826 Chicago Ave S
Minneapolis MN 55417-1055
(612) 827-2966
(Voice & TDD)

This resource manual provides a comprehensive set of information about child abuse and disabilities. It offers an overview of child abuse, then discusses child abuse of those with disabilities. It discusses institutional abuse and how abuse in institutions differs from family abuse. Sections are devoted to explaining the child protection system and to an overview of prevention programs. Fifteen pages of specialized biographies cover topics such as sexual abuse of children with disabilities. Twenty-five pages are devoted to short descriptions of books, videos, printed resources, and curricula. Seventeen pages describe Minnesota programs and agencies and six pages describe national resources. Some addresses and telephone numbers are outdated. An appendix includes the Child Abuse Prevention and Treatment Act.

Early Intervention Programs for Infants, edited by Howard A. Moss, Robert Hess, and Carolyn Swift, 1982. 122 pages
Available from: The Haworth Press
28 East 22 Street
New York, NY 10010

This book provides an interesting collection of articles about intervention for high-risk infants and their parents. A paper by Tiffany Field offers a set of interventions (interaction coaching) which improves parent-infant interaction. Another paper details differences in high-risk versus low-risk mothers. Bell and Pearl in a third paper, propose a system of developmental review for high-risk children.

A fourth paper reviews 18 exemplary primary prevention programs that were designed to prevent developmental retardation. A fifth paper examines the idea of aiming prevention efforts towards the social milieu rather than the child. The book ends with an article on defective infant formula and one on conducting research on prevention.

A Manual on the Primary Prevention of Developmental Disabilities, by Elizabeth B. Whitley, Ph.D., and Laura Lopater Skiles, M.S., 1992. 209 pages, no charge while supplies last
Available from: Virginia Institute for Developmental Disabilities
301 W. Franklin St.
Box 3020
Richmond, VA 23284
(804) 225-3876
FAX: (804) 371-0042

This manual is packed with information! It identifies the major causes of developmental disabilities, discusses prevention strategies, describes resources, and lists reference material. It offers information about disabilities caused by or associated with genetic disorders, infectious diseases, maternal conditions, nutrition, substance abuse, environmental exposures, maternal age, preteen labor, unintentional injuries, and child abuse or neglect.

The manual also discusses how to do needs assessment, program development, and evaluation. Virginia data and projects are described. Those working in prevention should obtain a copy of this manual and refer to it frequently.



Exceptional Parent: Parenting Your Child With a Disability, \$18 (one year) or \$42 (3 years). 9 issues per year.

Available from: Exceptional Parent
P.O. Box 3000
Dept. EP
Denville, NJ 07834
(800) 247-8080

This magazine is winner of the 1992 Distinguished Service Award presented by the National Parent Network on Disabilities. Since 1986, Exceptional Parent has also won three media awards.

A recent issue dealt with topics as diverse as "laws and disability" to "accessible theme parks." There are pages devoted to parents writing to network with other parents. There are guides for products, software and media selections. One feature article dealt with support groups for fathers, another with "Challenger Little League."

Abuse and Neglect of Exceptional Children, by Cynthia L. Warger with Stephanna Tewey and Majorie Megivern, 1991. 44 pages
Available from: The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589

This booklet is part of a series of 12 publications on the topic "Exceptional Children at Risk." It reviews incidence data, types of child abuse, physical and behavioral indicators, and research on child abuse and disabilities. The manual instructs readers about reporting procedures and strategies for supporting child abuse victims. Prevention programs applicable to schools are discussed. A reference list is included, as well as a listing of organizations.

Early Intervention News, Free of charge
Published four times a year
Available from: Virginia Department of Mental Health
Mental Retardation and Substance Abuse
P.O. Box 1797
Richmond, VA 23214
(804) 786-3710
Attention of Jeanne McCann

Publications from NCPCA



Available from: NCPCA Fulfillment Center
200 State Road
South Deerfield, MA 01373
(800) 835-2671

Getting New Parents Off To a Good Start, 2nd Edition, by Ann L. Wilson, 1988. 33 pages

This booklet provides an overview to support needed during the crucial prenatal, birth and perinatal periods. For each stage the manual details the information, support and relationships that will help ensure successful parenting. Communities interested in the primary prevention of child abuse can use this booklet as a guide to identify service gaps and to assist in programs that are comprehensive.

Parent-Child Bonding: The Developmental Intimacy by Stanley I. Greenspan, second edition, 1992. 11 pages.

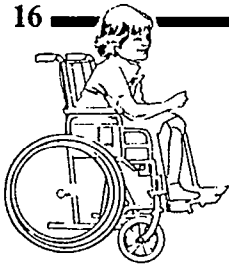
This pamphlet explains parent-child bonding and how to know if there are bonding problems. Ideas to enhance bonding and obtain assistance with bonding are included. The question-and-answer format is very readable.

Growth and Development Through Parenting by Elizabeth Elmer, revised edition, 1992. 27 pages

This booklet offers an overview of what parents should know about their children. It covers parenting techniques for each stage of development, general components of the parent-child relationship, parenting as a developmental process, and signs suggesting a need for professional consultation.

The Disabled Child and Child Abuse by Donald F. Kline and Anne C. Kline, 1987. 15 pages.

This booklet is a revised version of the 1982 publication by the same name. In "question and answer" style, the pamphlet covers some of the major considerations about abuse of the disabled child. The booklet defines handicapping conditions, discusses why developmentally disabled are at heightened risk, looks at the causes of capabilities and abuse, and discusses how parents can react to having a baby with disabilities. Potential solutions and resources are given. This pamphlet is a good resource for the lay public.



Child Abuse and Disabilities

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percent, problems of the child were unknown. The remaining 32 percent had developmental delays or chronic medical problems. Over 2 percent had a physical disability, 1.6 percent were mentally retarded, almost 9 percent had medical problems, over 9 percent had learning disabilities, nearly 12 percent were emotionally disturbed and 15 percent had behavioral problems. Figures for the "at-risk" category were similar. The "unfounded" cases were more likely to be children with no known problems (66 percent).

Thus, it appears that Virginia's CPS workers are more likely to make a finding of abuse and neglect if a child has a handicapping condition than if he or she does not. This is in contrast to most authors in the literature who stress repeatedly that children with disabilities have a credibility problem and thus are not taken seriously by CPS.

In Virginia, CPS workers are not routinely trained in child development or atypical development. The Virginia Department of Social Services is concerned, however, about

the overlap between child abuse and disabilities. One major effort has been coordination with the Virginia Institute for Developmental Disabilities and with the Office of Prevention in the Department of Mental Health, Mental Retardation and Substance Abuse Services. Over the last two years, several conferences, attended by 400 or more, have provided a training forum for those interested in child abuse and its prevention in children with disabilities.

Several state agencies that serve children with developmental disabilities were contacted. Although many services and programs are available to children with developmental problems, apparently none have focused on the identification of abuse, neglect and sexual abuse as a primary goal. Therapeutic services are available to children with developmental disabilities, but no service appears to have specialized therapy for the effects of abuse, neglect, or sexual abuse.

For example, the Department of Mental Health, Mental Retardation and Substance Abuse Services has funded five positions for counselors to work with deaf clients. Sonya Stagnoli, LPC, is the Regional Deaf Services Coordinator with the Fairfax/Falls Church Community Services Board. She has served as a liaison to CPS and has helped to start an innovative parenting skills program for deaf parents with hearing children. However, most of her counseling caseload are adults. Stagnoli did not know how many deaf children were in her catchment area and

noted that confidentiality guidelines often prevent her from directly identifying the children who might need her services.

VCPN is interested in locating service providers in Virginia who have developed special programs for treatment of abused, neglected, or sexually abused children with disabilities. We would also like to locate educators who are using abuse prevention programs especially designed for children with disabilities. Write and tell us about yourself!

Summary

A sizeable percentage of abused, neglected, or sexually abused children fit a definition of "developmentally disabled." As awareness of the overlap between abuse and disabilities increases, CPS and service providers can begin to develop more sophisticated methods for detection, investigation, and intervention for these children who are felt to be at higher risk for maltreatment.

In order to move forward, specialists in developmental problems need to develop positive relationships with those who are expert in child abuse, child neglect, and child sexual abuse. Children suffering from the effects of trauma will not be able to achieve their potential. Meeting the needs of exceptional children is likely to require persistence and innovation. Our most vulnerable children deserve this additional effort!

References Available Upon Request

JMU

James Madison University
Department of Psychology
Harrisonburg, VA 22807

Attention: J. Grayson

Address Correction Requested

Non-Profit Organization
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Harrisonburg VA 22801
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COMPILED BY JOANN GRAYSON, PH.D.

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