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FOSTER CARE AND ADOPTION OF HANDICAPPED CHILDREN

Recently there has been a great deal of concern for the handicapped child who is in need of temporary or permanent placement. This concern has led to an adoption assistance program funded by state and federal funds. The four children featured in this issue are examples of handicapped children needing placement. This article examines the problems and potential solutions surrounding placement of handicapped children.

FOSTER CARE

Handicapped children are entering foster care every day. In fact, in Virginia at the end of June 1985, 1,287 or 21 percent of the 6,101 children in foster care were handicapped.

Children enter foster care for a variety of reasons. This is also true for handicapped children. While some enter because of abuse and neglect, others enter because they need special services, or because their parents request that the state assume custody. However, there are a growing number of children entering foster care in a category unique to the handicapped. "We are seeing an alarming number of infants who have been in neonatal intensive care with a multitude of serious medical needs," says Kitti Kestner, Director of Northern Virginia Special Foster Care Program. "As a matter of fact, our last twelve referrals fell into this category. These are children who may have a tracheotomy, a cholestomy, a shunt for hydrocephalus, suffer from sleep apnea, or may need tube feedings, just to name a few of the problems! Their parents are overwhelmed and unable to care for the child, or the parents are so young that they cannot possibly manage the kind of responsibility these children entail. These children need very specialized care even after release. Some may even need 24-hour skilled nursing care."

"About 25 percent of these children will outgrow the problems, although their development will not be normal," Kestner continues. "Approximately half of these children will have serious developmental delays. The remaining 25 percent will have severe and limiting physical and mental handicaps. We find ourselves looking for foster parents with

very specialized skills to take care of such children."

Everyone agrees that it takes a special person to be a foster parent. To foster parent a handicapped child takes an exceptional person. Handicapped children require a tremendous amount of time and energy. There can be continued medical needs, or extra caretaking needs because, for example, a child is so unable to control muscle activity that he or she has to be fed. Along with its many rewards, foster parenting a handicapped child takes an emotional and physical toll.

Since it is preferable from a financial as well as emotional standpoint to place children in homes rather than institutions, it appears that social workers are challenged when placing handicapped children. In order to best meet the challenge of finding exceptional foster parents, social workers need to consider three things: recruitment, training and remuneration.

Recruitment

Finding qualified foster homes for *any* foster child is becoming more and more difficult. First, the complexion of the American family has changed. In her testimony before the State Board of Social Services and again in an interview with VCPN, Nancy Abell, Foster Home Finder for the Loudoun County Department of Social Services, voiced her concern.

"The traditional foster family is fast disappearing in Virginia just as the traditional family itself is disappearing," she laments. "As more families are coping with divorce, working mothers and tightened budgets, there are fewer and fewer families who are willing or able to extend themselves to troubled children. In fact, only 15 percent of U.S. households now describe themselves as a two-parent household with the father working and the mother at home. If this traditional family

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Chandra is a ten-year-old girl who has large, brown, expressive eyes and a bright smile. Chandra responds to attention and affection. She is multi-handicapped and has a visual impairment. This does not stop Chandra from smiling and responding with short sentences. She is able to feed herself and has other self help skills. Chandra is dependent on others for most of her needs and has a bright smile to return.

Foster Care and Adoption of Handicapped Children

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is the one most likely to choose foster parenting, we have a frighteningly small spectrum of households from which to choose."

"Nationally, only six percent of the families who inquire about foster parenting actually follow through to the point of getting a child," Abell adds. "Even the most successful regional recruitment drive in Virginia, using a public service announcement featuring Governor Robb, had only a 15 percent success rate."

Secondly, the complexion of the foster child has changed. "I have been with social services on and off since the 60s," says Sonja Bible, Director of Harrisonburg's Department of Social Services. "Therefore, I can compare foster children then and foster children now. There were many more foster children in placement in the 60s than now. However, the children in care now have much more severe problems." Abell reiterates this point. "All the children seem to have special needs right now, there is merely a variation in the amount."

While most agencies do their own foster parent recruitment for a majority of the children needing placement, many purchase recruitment services from private agencies for placing children with special needs. One of these agencies in Virginia is the Northern Virginia Special Foster Care Program.

"We recruit homes for five counties and several incorporated cities in Northern Virginia," Kestner explains. "We not only recruit foster homes but also respite care homes for foster families. We believe that foster families must have at least one weekend a month when they are free from the responsibilities of their handicapped foster child."

This agency, like others, uses traditional means for recruitment: public service announcements in newspapers and on television and radio; brochures and pamphlets left in strategic places. "Our richest source for recruitment, however, is the foster families themselves. Word of mouth seems to be an important recruitment tool," says Kestner.

What kind of person wants to foster parent a handicapped child? "Well," says Abell, "sometimes it is a person who has had a family member with a handicapping condition. However, frequently it is a person just like you or me who just has something to give, and sees the rewards and challenges in caring for a handicapped child."

Training

Once potential foster families are found, one might assume that the state would train them for this difficult task. Families need to have a realistic picture of the amount of time and energy they will be expending, and must have a realistic idea of what it is like to have a handicapped child in the home.

The assumption, however, may not be valid.

In 1985 the General Assembly requested that a task force be established to look at the



Karen is a six year old white child who, according to her foster mother, is a joy to parent. Karen is blind but sees shadows and objects. She is dependent on her foster family for many things but can do some things on her own. She can feed herself with assistance and can take off various pieces of clothing. Karen is multi-handicapped and is learning new skills to help her be more independent. Karen has only partial hearing. Karen loves music and gets around the house by touch. Karen needs a family who can give her a lot of affection and attention. She needs a family who can help her reach her potential.

area of foster care in Virginia. The panel randomly chose several workers and looked at the homes they served. The task force, headed by Linda Booth, Functional Analysis Manager involved in various special projects for the Division of Service Programs, Virginia Department of Social Services, investigated several issues and wrote a report for the General Assembly. One of the issues concerned training for foster parents. A survey showed that only 31 percent of the agencies required preservice training and only 18 percent offered inservice training. Abell, a task force member comments, "Recruitment without training is an inefficient and tragic waste of human resources. We can no longer afford it."

In the report to the General Assembly, there is a recommendation for training for both local agencies and foster parents. There is also a monetary request for \$350,000/year for three years to train local agency staff and \$620,000/year for local staff to train foster parents.

In Kestner's agency, training is required for anyone considering foster care of the handicapped as well as anyone who would like to be a respite care provider. The training program has six structured sessions consisting of the following training topics:

- 1) An overview of the program, including a realistic definition of foster care and an explanation of the need for preservice preparation;
- 2) A discussion of foster care for children with special needs, explaining the roles of all the professionals involved with these children, the biological family, the role of the respite care provider and the goals of the program;
- 3) A discussion of the impact of placement on the child, covering the feelings of the child about rejection, separation and loss, the grief process in general, as well as behaviors which may occur;
- 4) A candid discussion of the impact of a foster child on the family, especially the other children, with dialogue about family rules, and how these rules are communicated to new members, as well as how family members express emotions;
- 5) An overview of the expectations of a foster

parent in regard to handling the foster children including a discussion about discipline, child abuse and neglect and how families can serve as an advocate for the child especially in relation to the school system; and 6) A meeting in the home of a foster parent with a handicapped child, which is primarily a question and answer period aimed at making a contribution to a realistic view of having a handicapped child in the home.

In addition to the above training sessions, there is one meeting within the six-week period that is held at a local public school which serves multiply handicapped children. This gives families a view of the range of disabilities and the developmental levels one can expect. And, of course, if foster parents complete the required training without being screened out, they must be trained in the specific needs of the handicapped child which has been assigned to the family through mutual agreement.

Remuneration

In Virginia, all foster parents receive a minimum allowance to reimburse the family for the costs of care. Foster parents receive no payment for their time. This monthly rate is mandated by the state, and is as follows: for age 0-4—\$147; age 5-12—\$186; age 13 and above—\$235.

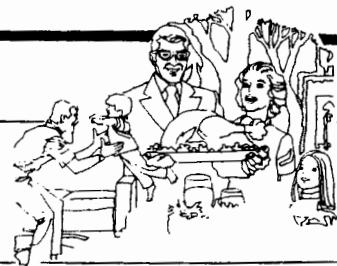
Clearly, handicapped children require a great deal of time and energy. In many cases, these children require a standard of skilled care, such as skilled nursing care, that other foster children do not. In Virginia there is a mechanism for making special needs payments through the use of Title XX funds but not all agencies choose to use it. Why? "We aren't exactly sure," says Beverly Buran, Supervisor in the Bureau for Child Welfare Services overseeing foster care and adoption services.

One of the recommendations of the Foster Care Task Force investigating foster care issues concerned special needs payments to people foster parenting handicapped children. Abell was a member of the task force and makes the following comments: "Our committee recommended that the state establish

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Child Abuse and Handicaps



There are millions of handicapped children all over the nation. In the public schools at the close of the 1983-1984 school year the population of handicapped children in Virginia alone was 116,034 (statistics provided by the State Department of Education).

Frequently we read or hear the assertion that children with handicapping conditions are at higher risk of child abuse and neglect than "normal" children. In fact, there are studies that suggest this is true. A 1970 study by Gil who reviewed 6,000 confirmed cases of child abuse revealed that 29 percent of the abused children had some form of developmental disability prior to the abuse. In a national survey cited by Chotiner and Lehr (1976), it was reported that 58 percent of the abused children of members of Parents Anonymous had developmental disabilities before they were abused.

Mark Souther, Abuse/Neglect Project Coordinator at the University Affiliated Center for Developmental Disabilities at West Virginia University, discussed his own data regarding the role of disabilities in abuse. "If you look at the population of handicapped children in the United States, which is about 6 percent of all children, and compare this figure to the percentage of abused handicapped children, you would expect to see the same 6 percent if handicapped children were at an equal risk for abuse with normal children. However, in localized geographical areas, the incidence of abuse among the handicapped population can be as high as 70 percent."

While the Central Registry shows only 2.5 percent of the founded cases of child abuse and neglect in Virginia to be physically handicapped or mentally retarded, the statistics, unfortunately, are not very reliable. There are questions on the abuse investigation form regarding the presence of handicapping conditions in children reported for abuse. However, they are contained in a section of the form which the investigator is not required to complete. In a discussion with Sonja Bible, Director of the Harrisonburg Department of Social Services, about the investigation form she commented, "Our workers make every attempt to complete the entire form. However, situations such as time constraints and lack of adequate staff can interfere with our doing it. Therefore sections that are not mandatory may not be completed."

Another reason workers may not identify developmental disabilities is because they may not know how to do so. "Presently, CPS workers are not getting special training in the identification of handicaps," says Miriam Justa, Program Specialist with Virginia's Department of Social Services.

Factors in Abuse and Neglect of Handicapped Children

There are several factors which may contribute to a handicapped child's increased risk for abuse and neglect. These factors include the added stress on family members; the grief, frustration and isolation felt by parents of handicapped children; the vulnerability of the child; and parental lack of knowledge about how to handle the handicap. Each of these issues will be explored.

Increased Stress

While dealing with all of the stresses that are normal to parenting, parents of handicapped children face additional stresses that are unique to their situation. There are medical problems such as cleaning and changing tracheotomy tubes in infants whose survival depends on this, or contending with a cerebral shunt in a hydrocephalic child. There are management problems such as seeing for a visually impaired child, managing hyperactivity in a nonverbal child, or lifting a spastic teenager from a wheelchair. (Wickler, 1981). Or, there can be communication problems such as those experienced by parents with a hearing impaired child, or one who is autistic.

Beth Edwards, parent of a handicapped child, addresses the stress she and her family have felt. "There is a tremendous amount of stress on the family as far as being accepted in society, really anyplace. When I take Matthew to the hospital they treat him like a UFO."

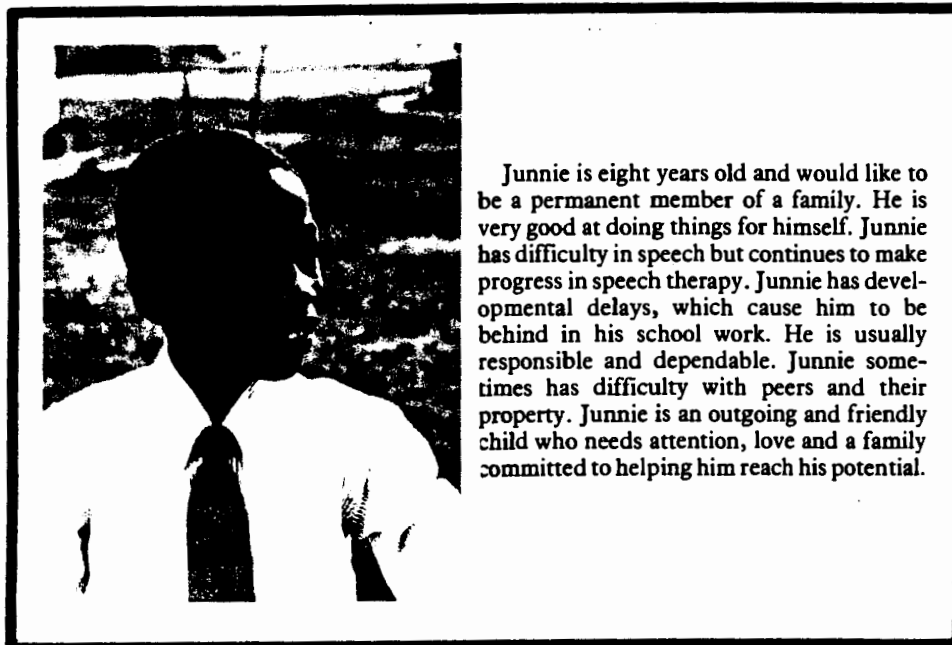
Both Edwards and Pat Lynn, also a parent of a handicapped child, speak of the stress of the added financial burden a handicapped child poses. Lynn explains that the cost of services adds up fast. "Pam has been in about every service we could find to help her develop physically and emotionally. We have good insurance coverage. But, there are financial burdens involved; all the programs are costly."

Wickler (1981), in her review of the literature, states that professionals are often of little help to the parents. "Even when the parents go to specialists for advice and information they may find that the general principles presented are inadequate for handling the daily practical tasks of child rearing. Moreover professional texts and behavior management programs tend to focus on the early years of development rather than on management issues that arise over time" (p. 282).

George Shanks, adoptive parent of three handicapped children, agrees. "We don't need platitudes and generalities. We don't need to be told how noble we are. We need answers: What angle do you use for a wheelchair ramp? How do you convert a van on a limited budget? How do you change a catheter in a shopping mall?"

Grief, Frustration and Isolation

With a pregnancy is the expectation for the fulfillment of every parent's desire: the perfect, healthy, bright and beautiful child.



Junnie is eight years old and would like to be a permanent member of a family. He is very good at doing things for himself. Junnie has difficulty in speech but continues to make progress in speech therapy. Junnie has developmental delays, which cause him to be behind in his school work. He is usually responsible and dependable. Junnie sometimes has difficulty with peers and their property. Junnie is an outgoing and friendly child who needs attention, love and a family committed to helping him reach his potential.



Barbara Rawn, Executive Director of SCAN (Stop Child Abuse Now), has had experience working as a therapist for the deaf. She comments on this point. "All parents have a dream: Their child will be the ideal baby. The child born with a handicap is less than perfect and does not fulfill the dream. In order for things to go well the dream must die. However, this does not happen immediately. There are numerous strong emotional reactions which accompany the news that a baby has a handicap. The same is true if a child is handicapped later than infancy. Parents go through the same experience as in dealing with death—shock, denial, anger, despair, sadness and, hopefully, acceptance. Some parents actually wish their child would die because they are handicapped. They feel guilt: They ask what they have done to deserve this. Many parents withdraw and become isolated. Often friends can't deal with the situation and disappear. Parents often lose their basic support group." Some parents can overcome this trauma in time with minimal damage to them and their child; others do not.

Psychological and adjustment factors on the part of parents play a role in risk for abuse and neglect. Blumberg, author of "Character Disorders in Traumatized and Handicapped Children" (1979), remarks, "Some parents react with overprotection, overindulgence, and self-sacrifice beyond that which is necessary for the child. Others react with rejection often to the point of neglect or abuse of the child whom they blame for their own social restrictions and frustrations."

Another issue regarding emotional reactions to the handicap is that of the parents' perceptions. It is possible that even if parents accept that a child is handicapped, they may not accept the child. Paul Marchand, Director of the Governmental Affairs Office of the Association for Retarded Citizens, suggests that, in some cases "parents are unwilling to accept the child as a member of the family." The child is perceived as different or abnormal and is thus more likely to be abused (U.S. Dept. of Health and Human Services, 1979, p. 3).

Physical Characteristics

The actual physical or mental characteristics a handicapped child possesses can contribute to the risk of abuse or neglect. Marchand explains: "Handicapped children's disabilities may contribute to abuse and neglect by virtue of their vulnerability and inability to defend themselves. They are immobile, or weak. They are available, an easy target for scapegoating."

Physical characteristics may also contrib-

ute to abuse because the child may not be able to exhibit expected, or appropriate responses. Cathy Allport, Infant Program Coordinator for Child Development Resources in Lightfoot, Va., comments, "The handicapped child is less able to interact with the parent and the parent is less able to 'read' the child. Therefore, one has a frustrated parent and a frustrated child. The full communication that a normal parent and a normal child would have does not exist. There is a lack of facial expressions, laughter and other forms of

"We don't need platitudes and generalities. We don't need to be told how noble we are. We need answers..."

feedback." The child's lack of responses may be so severe as to prevent a normal bonding between the parent and the child.

In addition, characteristics such as temper tantrums, hyperactivity, and other emotional or behavioral problems often accompany disabilities. Allport explains that "a child can be irritable, not because he or she is bad, but because of neurological problems. For example, a baby may cry a great deal regardless of parental response because he is uncomfortable. No matter what the parents try to do, the crying is not assuaged. This adds to parental frustration and a child's vulnerability."

Lack of Knowledge

Related to the issue of vulnerability due to physical or emotional manifestations of the handicapping condition is the issue of parental lack of knowledge. Frequently parents simply do not understand the ramifications of the disability or do not know their child is disabled and, therefore, are confused by the child's behavior. Parents rely on children's responses to let them know if their needs are being met. If, because of a disability, this two-way communication is blocked and the child does not exhibit an expected response, the parents feel a tremendous amount of frustration. Extremely frustrated parents may mistreat the child.

"In some cases of child abuse with the handicapped, the parents aren't even aware that their child is handicapped," explains Souther. "After they realize a handicap exists, the parents treat the child differently and are more understanding and tolerant of the child's behavior. Of course, this situation occurs most frequently in the young child, before the handicap is easily detected."

Abuse and Neglect of Other Children within the Household

The issue of child abuse in a family becomes more complex when a child has normal siblings. In a family that abuses a handicapped child, will normal siblings be abused, too? Of the studies that address this issue, the results are mixed.

Lewark (1983) studied 95 abused children with developmental disabilities on a variety of dimensions. Seventy of these children had siblings. When reporting on the incidence of abuse amongst the siblings of the disabled children, Lewark found that 95.7 percent of the siblings were also abused. However, the results also indicated that 89.6 percent of these siblings were developmentally delayed. One could conclude from the study that the handicap was a significant factor in abuse.

However, Lewark draws a different conclusion, stating that the abuse and neglect was a function of general family disorganization and stress. In fact, the majority of the families in this study were living at poverty level and faced a multitude of problems, such as alcoholism, spousal abuse, marital distress and criminal acts. The relationship between the abuse and the children's handicaps is unclear except to conclude that the handicaps were one more cause of stress.

Other studies have been clearer in their conclusions about the relationship between abuse of handicapped children and the potential for abuse of their normal siblings. These studies indicate that in multi-child families, only the handicapped child is abused. According to Frederick and Boriskin (1976), the reason is because the handicapped child is perceived by the parent as "different."

Many of the professionals interviewed by VCPN had never considered the question of whether or not it is likely that a sibling of an abused handicapped child would also be abused. While Souther did not know whether other children are likely to be abused or not, he believes that "the abuse affects everyone. Everyone has an emotional tie into abuse at minimum. If there are three or four children in the family and one is handicapped, there are numerous stresses on the parents. The parents' stress is felt by all of the children."

In fact, the literature suggests that he is correct. In a review of the literature, Murphy (1982) cited one study that found a large amount of deviant behavior among the siblings of 104 Down's children and that "the poorer and larger the family size, the greater the susceptibility to stress" (p. 76). Another study showed that siblings of children with spina bifida "were more than four times as likely to show signs of maladjustment in schools than were siblings of healthy control

SPOTLIGHT: Bill and Cindy Howard



In 1969 Bill and Cindy Howard, parents of seven children, accepted their first foster child. Initially they had only planned to have one foster child, but they have cared for over 160 foster care children, for periods ranging from a few days to several years. Many of these children have had handicaps, ranging from mild to severe, and covering the entire spectrum of handicapping conditions, including deaf, severe and profoundly retarded, emotionally disturbed, fetal alcohol syndrome, Down's syndrome, orthopedic problems and chronic illness. Currently the Howards have with them two severely handicapped children who require a great deal of care and supervision.

Why have they taken on such tremendous responsibilities? The Howards, devout Mennonites, explain that it was a natural outgrowth of their religious beliefs and philosophy of life. Cindy was staying at home caring for her own children, and felt that she should be doing something more. After the first foster child, they "got hooked." Both parents, and all of the Howard children, have been very much involved in the care of the foster care children. They have delighted in teaching them, playing with them, watching them grow, and in some cases proving the experts wrong, especially when they were able to help a child develop beyond the experts' expectations. Cindy explains further that "All the work and worry are forgotten when you see a child blossom."

The work and worry of being foster parents of handicapped children, however, are considerable. Cindy says, "We have battled with teachers who sometimes undid our hard work, or who were too quick to label a child. We have fought with doctors who wanted to put these kids in institutions, when what they needed was a normal family life and lots of loving attention. We have taken care of children who had been in institutions before they came to us. One of them was considered to be mentally retarded when in fact she was deaf. Fortunately someone finally recognized this and she was removed from the institution and placed with us, but it was too late to make up for all those years when she was surrounded by retarded children and not given normal experiences." Observing institutional neglect, and parental neglect, have been among the major frustrations for Bill and Cindy. "It just breaks your heart when you see a child treated like that," Bill says.

The Howards have also had frustrations with social services and the legal system.

When they were living in Kentucky, they had a foster son who was deaf and retarded as a result of spinal meningitis. He was with them for many years and then placed elsewhere for adoption; returned to them when that placement did not work out; then institutionalized but sent back to them for weekends; and finally, "Rather suddenly, they put him somewhere else." Tearfully, Cindy continues: "We never saw him again." The Howards say that the most difficult aspect of being a foster parent is "your powerlessness when it comes to placement decisions. And it really tears you up when you see them returned to the very home that created the handicap."

Despite such demands on their time and energy as teaching basic social skills, diapering and dressing a child well beyond the toddler years, and managing hyperactivity and behavior problems, the Howards do not view the practical, day-to-day care of their handicapped foster children as having been a major problem area. Cindy explains, "We've always been a close family and working together to help these children has made us even closer. Everybody just pitches in and somehow all the work gets done. I've always had a positive attitude and I just take it one day at a time." Although five of the Howards' children are now grown, they live close by and continue to assist with the care of the foster children.

Bill and Cindy realize the difficulty social services has in finding enough good foster care homes. They say, "Some of our own people (Mennonites) won't take foster children because they're afraid the natural family's problems will rub off on their own children. That hasn't happened with us. Instead, our family has been challenged, strengthened, and immensely rewarded."

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There are plans to recruit through an educational approach, too. "We want to educate people across the state about developmental disabilities, what they are and what needs developmentally disabled children have," Richardson explains.

Once prospective adoptive homes have been identified, they may begin the home study process. "The home study will be a group process with six meetings. It will be educational in nature, explaining what developmental disabilities are, discussing specific children, doing some values clarification activities, and discussing available services. This is designed as a screening tool as well as a training tool," Richardson summarizes. "At the end, we will conduct home visits with those people who are still interested."

The major recruitment began in November in conjunction with the recruitment for families to adopt black children. Richardson hopes to have the first informational session in January, 1986, with a second group beginning in the spring.

The second activity, the resource directory, is well under way. "It is designed to be a 'hands on' booklet," Richardson explains. "It will contain both state and national resources, with information that will be stable over time. It should serve as a valuable tool."

Training

In addition to the recruitment component which has been contracted to United Methodist Family Services, there is a training component. Kerr explains, "Georgetown University's Child Development Center has also received federal discretionary funds from the U.S. Department of Health and Human Services. Their funds have been earmarked for training for professionals serving adoptive and potentially adoptive families of special needs children. The service will provide specialty training in developmental disabilities and handicapping conditions to enable professionals to enhance their knowledge and skills in the area of facilitating placement services. An important objective of this training

is to develop a collaborative model between child welfare agencies and other service delivery systems to extend the scope and range of supportive services to families adopting special needs children."

Two staff members at Georgetown's Child Development Center are responsible for this project: Nancy Striffler, Director of Training, and Virginia Lapham, Director of Social Work. "Our project is funded for 17 months, from July, 1985, through November, 1986," Striffler states.

"The primary objective of the program is to train professionals—social work, school, and public as well as private mental health agency personnel—in a variety of topics that will enable them to provide needed support services to adoptive families of special needs children," Lapham adds.

Training is organized around a core of concepts that provide the framework for assessing the needs of children and families, understanding the impact of handicapping conditions upon family functioning and designing

Interested?

... in more information about adoption of handicapped children? If so, call your local Department of Social Services, or call the State Adoption Exchange at 1-804-281-9149. Pictures and descriptions of children in this issue were provided by Sharon Richardson of United Methodist Family Services, Inc.

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and implementing services to promote healthy coping strategies. Specific topics include:

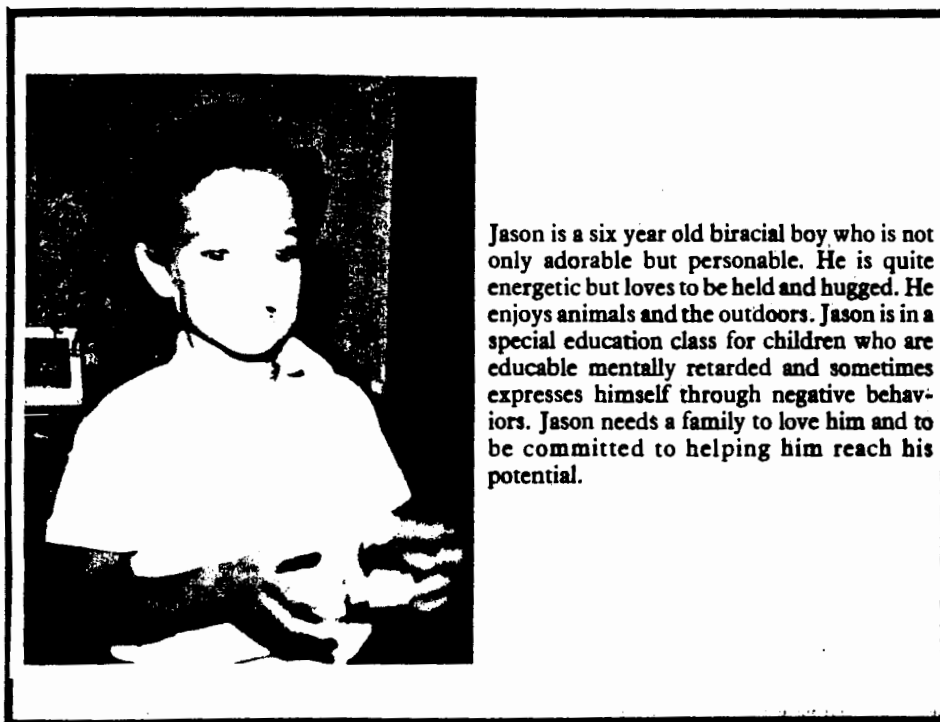
- Overview of Developmental Disabilities
- Family Issues in Parenting the Handicapped Child
- Developing the Child's Profile
- Mental Retardation
- Down's Syndrome
- Fetal Alcohol Syndrome
- Spina Bifida
- Cerebral Palsy
- Learning Disabilities
- Attention Deficit Disorders
- Autism
- Genetic Counseling
- Psychosocial Development
- Accessing Resources
- Agency Collaboration

The training program consists of 36 training hours. The initial phase consisting of 24 training hours, is offered over an eight-week period. Each of these sessions includes didactic material, case presentations and clinical application. This formalized training will be followed by four, three-hour consultative conferences with the training participants and the training staff. "The purpose of these collaborative conferences is to enable the trainees to integrate theoretical knowledge into their clinical casework," Striffler explains.

How will personnel be recruited? Striffler answers, "We are primarily recruiting through the directors of agencies. The primary focus is towards public agencies, with plans to fill in spaces with private agency staff."

All of the services offered under this adoption assistance program—recruitment of adoptive homes, development of a resource directory, and training for professionals—are relatively new. Therefore, it is too soon to report on their effectiveness in meeting their goals. However, the focus of the program is essential to the well being of a special population of children in the state. VCPN congratulates everyone involved whether it be professionals or adoptive parents. We will follow the progress and report again at a later date.

REFERENCES FURNISHED
UPON REQUEST.



Jason is a six year old biracial boy who is not only adorable but personable. He is quite energetic but loves to be held and hugged. He enjoys animals and the outdoors. Jason is in a special education class for children who are educable mentally retarded and sometimes expresses himself through negative behaviors. Jason needs a family to love him and to be committed to helping him reach his potential.

Child Abuse and Handicaps

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subjects...The siblings of children with slight handicaps were the most disturbed group followed by those with severe and then moderate handicaps" (p. 76).

"However," Souther notes, "the handicapped child can become the target of the stress if the parents feel that he or she is the cause of most of the family's problems. Or because the parents may wish to deny the disabled child, he or she may be neglected while the other children are lavished with attention and praise.

Annette Pipia, a member of the staff with Parents Anonymous of Virginia, suggests a different possibility. "Sometimes siblings of handicapped children are neglected because the parents spend so much time with the special child," she says. A number of parents of handicapped children reinforced this idea by stating that they are required to spend more time with the handicapped child giving them special help with homework, feeding them, dressing them, and meeting their incredible medical needs.

Risk in Relation to Age

What is the relationship between the risk of abuse and age of the child? The answer could not be found in the literature so we turned to professionals in the field. While there were a variety of responses, two ideas emerged. One idea is that there are age clusterings when a child is at greater risk, and the second idea is that risk of a specific kind of abuse—sexual abuse—increases with age.

In terms of age clusterings, Dr. Bruce Cushna, a physician at Children's Hospital in Boston, pinpoints increased risk around the age of two and again at adolescence. "These

are the periods when, during the normal developmental process, children are more likely to act in an irritating manner just as a function of their age. Add that to the behavioral or emotional manifestations of a handicapping condition, or to the already overstressed family, and there is a real possibility that abuse will occur."

Allport discusses the potential for sexual abuse as a child grows older. "Handicapped children are more at risk than normal children for sexual abuse as they mature. They need greater assistance in dressing and undressing, or other special care which may make them more vulnerable to sexual assault." Sandy McGhee, who is with the advocacy department of the Virginia Department of Mental Health and Mental Retardation, expands this possibility to those outside the home. "As a handicapped person gets older the risk of sexual abuse generalizes to outside the family, to other people in the community as the handicapped child receives more public exposure."

A second issue related to age is whether a handicap occurs later in a child's life rather than at birth. Many handicapping conditions are not present at birth. In fact, Kline states that less than half of handicapping conditions occur at birth. (National Committee for the Prevention of Child Abuse, 1982.)

The literature does not address risk factors as a function of the age at which the handicap appears. However, Mary Ann Bevilacqua, a member of the staff at the Parent Education and Monitoring Program at Virginia Commonwealth University, believes there is lower risk if the handicap occurs later. "The parent has had time to develop a normal relationship

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SPOTLIGHT: Beth Edwards



Parenting a handicapped child is always difficult. But parenting a child with Chronodysplasia Punctata, rhizomelic form—a very rare syndrome of which there are only about 45 cases in the world—adds numerous complications to an already difficult task. Beth Edwards, mother of Matthew, three, and Micah, six, in Hampton, faces this task every day.

Matthew's handicap is a genetic syndrome caused by recessive genes. The syndrome left Matthew severely retarded, with short limbs and calcium deposits in his abnormally large joints. He wears glasses to correct a cataract problem, has a colostomy, will always wear diapers, and is very small, weighing only 18 pounds.

There are problems with hospital separation, sitter care, and stress on the marriage. Often there is social isolation. Beth says this was especially true the first year. "I had no car. I had to borrow cars from relatives." When Matthew got pneumonia she was homebound continuously. Since then, someone in the community gave the family a car and other items have been donated.

Beth continues, "With us it was a big mess financially. When Matthew was born my husband, a cabinet maker, was not working. We had low option insurance which didn't cover Matthew at all. When we finally got benefits, from state and local agencies, we still had bills. We finally declared bankruptcy. Now if we make above a certain level, they'll take away Medicaid. And we can't afford that. For example, two weeks in the hospital cost \$15,000."

One reason for the financial difficulties is that Matthew is uninsurable. Children with his type of syndrome rarely are expected to live past two years old. However, Matthew is three and is now attending a multi-handicapped center. Since Matthew is in school, Beth is able to work part-time.

Although eventually Beth was able to locate, and utilize, many excellent services, she wishes there had been more information available to her from the beginning and better coordination among the agencies, particularly between social services and the hospital. She learned about some of the available services through the informal parents' grapevine, and through persistence.

Matthew has been seen by at least 100 agencies and professionals. The time commitment has obviously been enormous. "Now Matthew mostly goes to the pediatrician and the eye doctor. But at first we were going to Richmond three times a week," Beth comments. "I do not keep in touch with the genetic doctors much. They never really have anything good to say. I don't want to hear how retarded he is."

All of these factors combined can result in unbearable pressure. Beth admits, "I contemplated hopping a train and never coming back. Also I had anxiety attacks and I had to have valium for my nerves when Matthew was hospitalized. The first two years were hard, but now I feel I've climbed over a huge mountain."

"Handicapped children are not as hard to raise as people think. They are a delight and can bring you as much happiness as normal children."

Friends' and family support have been mixed. Beth says, "My mother had a real hard time. She didn't want to accept the fact that she had a handicapped grandchild. My mother-in-law, who is no longer living, was very helpful. A lot of friends really helped. But some said they didn't call because they didn't know what to say or how to react."

Beth describes an especially touching moment for her. "I gave Micah a penny to throw in a wishing well in the park. And I asked him what his wish was. He said, 'I wished that Matthew would get well and never die.' Sometimes he'll say 'When Matthew gets older I'll let him ride my bike.' He doesn't realize that Matthew will never be able to do that."

"I hate for someone to feel sorry for him," Beth emphasizes. "He's a happy little boy, except when he's sick. And he's just adorable..." Beth pauses. "I don't think about the future anymore. I just take one day at a time and hope for him to be well."

"From the moment he was born I loved him. I never had the feeling I didn't want him. I would like to adopt another child in the future, maybe a Down's syndrome child. Handicapped children are not as hard to raise as people think. They are a delight and can bring you as much happiness as normal children."

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with the child, probably a healthy relationship. However, it all depends on the parents' ability to cope and how they handle the handicap at the time it occurs."

Handicaps as a Result of Abuse

While it has been noted that handicapped children are at higher risk of abuse and neglect, there is another very serious issue. That is, many children are "permanently handicapped, either emotionally, physically or mentally" as a result of abuse (Soeffing, 1975, p. 126).

Often it is difficult to determine which occurred first, the abuse or the handicap. Solomon (1979) suggests that the abused child is in a constant state of double jeopardy. "A disability in a child may provoke abuse by others, while the abusive act itself may be sufficient to cause a specific handicapping condition in the child. So related is the abuse and the disability that it would be extremely difficult to determine which was first to occur" (as cited in Camblin, 1982, p. 466).

Elizabeth Horn, Executive Director of the Virginia Head Injury Foundation, is very aware of the relationship between abuse and handicapping conditions. "There is limited data as to the exact number of head injuries that are a direct result of child abuse," she says, "but in a study conducted by the Virginia Head Injury Foundation, 15 percent of all head injuries were a result of interpersonal assaults. Child batterings were a portion of these."

She explains that "many believe that head injuries are sustained as a result of a direct blow to the head. That is not always true. There are incidences of closed head injury where the head is shaken so fiercely as to cause it to hit against the sides of the skull, causing the brain to be bruised or bleed resulting in a subdural hematoma. Or, the result can be brain lesions which is the tearing of cells. All of these cause damage which results in learning disabilities or other handicapping conditions. This is the kind of brain injury that is common in children who are abused."

The problems for these children are exacerbated by the fact that frequently it is not known that they have brain damage. They develop learning disorders and professionals do not relate the disorders to brain injury. "Even so, teachers are not trained in the problems associated with brain damage, and as a result don't provide appropriate teaching techniques," Horn asserts. "These children may have difficulty with short term memory and have trouble learning; they may have difficulty with sequencing; there may be emotional deficits such as agitation, frustration, outbursts, disinhibition and inappropriate crying or laughing, all of which may lead to behavior problems; or, the child may just appear lazy whereas we know that in head injured children there is a lack of motivation

due to the injury. If we don't diagnose these conditions professionals and parents may continue to cause more problems for the child."

Prevention

Whatever the risk of child abuse and neglect in the handicapped population, it happens. It, like all abuse, can be prevented. It takes intervention on behalf of the child, as well as education and support for the parents.

In many cases early detection of handicaps might lower the potential for abuse. It is possible that abuse occurs because the parent does not know a child is handicapped. Instead a parent believes a child is merely being stubborn or aloof while in fact he or she can't hear, can't understand or cannot process the information for reasons out of the child's control. Souther gives an example of such a situation. "A child that has an auditory learning disability is asked to do something. He doesn't do the task because he never processed the information. After a few tries, Dad gets real frustrated. So Dad tries punishment. This, of course, accomplishes nothing in terms of the problem, and Dad's level of frustration may increase as does his level of punishment. Thus, potential for abuse."

Friends and professionals must intervene if something unusual is noticed by them that is not noticed by the parent. Doctors must explore parents concerns rather than consider them the exaggeration of an overreacting parent; neighbors need to suggest seeking medical assistance if a parent complains that a

young child never responds or never smiles, or relates other unusual occurrences.

In many cases, however, the handicap is obvious. In this situation, parents need to be educated and supported. For instance, many communities have early intervention programs. In Harrisonburg, the infant program is called PACE for Parent and Child Education.

PACE, like other infant programs, is designed to serve infants between 0-2 years of age who are developmentally delayed, physically handicapped, or at risk with special needs. The 'at risk' category includes children with a variety of special needs, such as children who may not be handicapped but are abused or neglected, and therefore are at risk of suffering a handicap in the future. "One hour ago a child was referred because of abuse," says Ann Stokes, Program Coordinator for PACE. "We will work with that family in an effort to try to prevent future occurrences."

PACE is based on the principle that early intervention can help children with special needs reach their greatest potential. "This intervention is in the form of education," Stokes explains. "We help parents understand the nature of the problem, the behaviors they can expect, and how to assist the child in his or her development."

PACE has three staff members—a physical therapist, a speech therapist (Stokes) and an infant educator. After receiving a referral, a screening is completed to determine if the

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SPOTLIGHT: Richard and Sandy Pennington

Richard and Sandy Pennington are parents of a handicapped child. They adopted Melinda, who is severely visually impaired, when she was four and a half years old. Melinda, now 16, has a visual acuity of 20/2000 in one eye, approximately 1-5 percent of normal vision, and light perception in the other.

Sandy says that one stress factor in rearing a handicapped child is the time input and effort, "what I may have to do that other parents don't." For example, Sandy does daily lesson preparations, in order to continue mainstreaming her daughter. "We tried to take advantage of the free taping services available for the blind but many of the readers read too fast." Although Melinda can get some content visually, she would be totally behind if she had to keep up visually in every subject.

Extensive travel and financial burdens are additional stress factors. "We put as much as 10,000 miles a year on our car for medical, special-ed types of programs and extras needed as a result of her handicap," Sandy continues. "Extra equipment is required, some of which can be borrowed, but the borrowed equipment is not always satisfactory.

We wound up buying a closed-circuit TV to enlarge her materials. You spend \$100 here, \$300 there and \$1,200 somewhere else."

The Pennington's have had relatively few problems in obtaining services. "We have had absolutely super response from the Virginia Department for the Visually Handicapped and our county school system!" they comment.

However, one problem has been that Melinda's peers are not always open-minded and understanding. Sandy explains, "There isn't a lack of acceptance, but behaviors of handicapped children are sometimes not up to age level and this kind of scares people. People are less tolerant and therefore isolation occurs. Handicapped children do tend to be cut off more."

The Penningtons have been fortunate to have very encouraging family and friends' support. "My mom and dad loved Melinda like she was theirs from the day they met her. It was love at first sight. They just flipped over her," Sandy exclaims. "Our friends have offered the same support and have delighted in her progress over the years."

"It is important that parents of the handicapped get involved in advocacy, which is also time-consuming. I have made many trips to Richmond lobbying for services for our visually impaired children. I found that our representatives do listen and respond if you have your facts accurate."

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child is in need of services. If so, the child is assessed by the team. This assessment includes evaluation in the development of language, cognition, gross and fine motor skills, socialization and self-help skills. A staffing is held where the team meets with the parent to review the various test results, and a decision is made regarding the child's need for services. If services are needed, a plan is developed and staff are assigned to the case.

"An essential aspect of PACE is training the parents to teach their own children. To accomplish this the staff goes directly into the home weekly to provide training and programming. In addition, parents are always actively involved in developing plans and carrying out activities with their own infants. Infants are reassessed every four months to evaluate progress and review goals, ensuring that we are meeting each child's individual needs. Again, the parents are an integral part of this process," asserts Stokes.

In a study conducted by Moran (1985), the effect of early intervention programs on such variables as parent-child interaction, family stress, social networks and social support were assessed. The types of programs compared were home-based, center-based and parent-oriented programs. In order to qualify for the study, a child had to be involved in the program for a minimum of four months. The summary of findings indicated that no one program was superior in all ways. However, whether early intervention services for devel-

opmentally disabled infants were offered in the client's home or in the center did make a difference for the family. "Mothers participating in the home-based programs had more positive attitudes toward their special needs children and sought child care advice from a relatively large number of sources. In addition, trends in the data suggested that "mothers in home-based programs...may develop stronger, possibly more dependent relationships with service providers and are more apt to follow through with their children on program suggestions" (Aware, 1983, p. 19). However it is important to note that women in center-based projects reported larger social networks and decreased homemaking stress.

A second prevention thrust is respite care. Parents of handicapped children need support and relief from continuous child care. Some parents have family members who can or will take on this function. Unfortunately, however, many do not. "We need to be providing respite care for parents of handicapped children," says Rita Katzman, Supervisor of the CPS Unit in the Virginia Department of Social Services. "Mothers need a morning out; families need a weekend away. Enough of these programs simply do not exist."

Aware (1982) reports another type of support service that was developed in Georgia. Called Parent-to-Parent, this program matches trained volunteers with parents who have just received the news of a child's disability. Their role is to bring comfort, under-

standing and support. "The volunteers are trained to develop skills in dealing with stress. A key point is that supporting parents are not there to advise, but rather to provide support and guidance to new parents during a difficult time" (p. 9).

The parents of handicapped children need love and help from friends, neighbors and families. And, they need a professional community which provides services adequate to assist them in their parenting and personal needs. We have a start, but we have a long way to go.

REFERENCES FURNISHED UPON REQUEST

Curriculum for Adolescents with Disabilities

Preventing Sexual Abuse of Persons with Disabilities: A Curriculum for Hearing Impaired, Physically Disabled, Blind and Mentally Retarded Students by Bonnie O'Day, 1983, 173 pp., spiral bound, \$19.95. Available from: Network Publications, ETR Associates, 1700 Mission St., Dept. P., P.O. Box 8506, Santa Cruz, CA 95061-8506.

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