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 permanene 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 hospital intensive care with a multitude of serious medical needs," says Krisi 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 chloistomy, 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 at this point, and children need care for the child, or the parents are so young that they cannot possibly manage the kind of responsibility these children need. 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 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: training, recruitment, and remuneration.

**Recruitment**

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

"The traditional foster family is fast disintegrating in Virginia just as the traditional family itself is disappearing," she lamented. "As more families are coping with divorce, working mothers and tighter budgets, there are fewer and fewer families who are willing or able to extend the mantle of foster care 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 continues to decline, then we as social workers and case managers must be prepared to serve the children differently."

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 eating and responding to 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.
Karen is a six year old white child who, according to her foster parents, is a joy to have in the family. She is blind but has many skills and objects. She is independent in her foster family and is learning many new skills to help her be more independent. Karen has only partial hearing, and can see limited colors with her eyes. She can read Braille and is learning many new skills to help her reach her full potential.

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 not considered a living wage. 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 Burns, 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 for foster parenting handicapped children. Abell was a member of the task force and makes the following comments: "Our committee recommended that the state establish a separate fund for these children, which would be administered by the Department of Social Services. This would provide a more stable source of funding for these children and allow for greater flexibility in meeting their needs. In addition, it would provide a way to ensure that the children receive the necessary support and services they need to thrive. 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 not considered a living wage. 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 Burns, Supervisor in the Bureau for Child Welfare Services overseeing foster care and adoption services.

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Factors in Abuse and Neglect of Handicapped Children

There are several factors which may contribute to the abuse of handicapped children. Some of these factors include the stress of caring for a handicapped child, the lack of understanding and support from family members, and the financial burden placed on the family.

Increased Stress

Stress can be caused by a variety of factors, such as the need to manage the medical needs of a handicapped child, the financial burden of caring for a child with special needs, and the emotional toll of dealing with the challenges of caring for a child with special needs.

Grief, Frustration and Isolation

The isolation and frustration that families may feel can lead to feelings of grief and Helplessness. This can be especially true for families who are dealing with a child with a severe disability.

Both Edwards and Pat Lynn also point out that many children with special needs are isolated, as they may not be able to participate in typical activities with their peers. Additionally, parents may feel isolated because they may not have access to support from other parents who are also dealing with similar challenges.

Jumie is eight years old and would like to be a part of normal activities. However, she has difficulty reading and writing, which makes it difficult for her to participate in school activities. She also has difficulty socializing, which can be challenging for her. However, Jumie's parents are committed to helping her reach her full potential.
Barbara Kowen, Executive Director of SCAN (South Carolina Abuse and Neglect) at a therapy session for the deaf. She comments on the importance of the deaf child's health and development.

**Physical Characteristics**

The actual physical or mental characteristics of a handicapped child are consistent with the image of a child who is developmentally delayed. However, the handicap may be a symptom of a more underlying problem. The child's health and well-being are critical.

**Abuse and Neglect of Other Children within the Household**

The issue of child abuse in a family becomes more complex when a child has a special need. The abuse can be physical, emotional, or sexual. The effects of abuse on the child's development are profound and long-lasting.

**Lack of Knowledge**

Related to the issue of abuse and neglect is the lack of knowledge and understanding of the effects of handicapping conditions. Knowledge is power, and the lack of knowledge makes the child more vulnerable.

**Feedback**

The child's lack of response may be due to a variety of factors, including the child's environment, the parent-child relationship, and the child's physical or mental abilities.

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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 6 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, fatal alcohol syndrome, Down’s syndrome, and chronic illnesses. Currently the Howards have with them two severely handicapped children who require a great deal of care and supervision.

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 teaching 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.

Why have they taken on such tremendous responsibilities? For the Howards, devout Mennonites, explain that it was a natural outgrowth of their religious belief 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 "As the work and worry are forgotten when you’re a child, the work and worry and forgetting of child care, is all that you’re left with." The Howards have taken care of foster parents of their own children, who are, however, considerable. Cindy says, "We have battled with teachers who sometimes found 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 who 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, by too late to make up for all those years when she was surrounded by retarded children and never given normal experiences."

"We have had our share of neglect, and parental neglect, have been among the most frustrating aspects of being a Foster Care Parent. It just breaks your heart when you see a kid 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 dead and treated as a result of spinal meningitis. He was with them for many years and then placed elsewhere for adoption, returned to them when the placement did not work out, then institutionalized for some time back up to the death, and finally, "Rather suddenly, they put him somewhere else."

"Fearfully, 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 those demands on their time and energy, in teaching basic social skills, disper- sing and caring a child well beyond the coping special needs children.

Training

In addition to the recruitment component which they have been contracted by United Methodist Family Services, there is a training component. Kent 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 targeted for training for professionals serving adoptive and temporarily adopted families of special needs children. The service will provide special training in developmental disabilities and handicapping conditions to enable professionals to enhance their knowledge and skills in services of facilitating successful homes. An important objective of this training is to develop a collaborative model between child welfare agencies and other service delivery systems to expand the range and type of support services to adoptive and foster families of special needs children."

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

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, another notes, "the handicapped child can become the target of the stresses 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 Vipis, a member of the staff with Parent 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 reinforce this idea by stating that they 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 on the field. While there were a variety of responses, two ideas emerged. One idea is that there are age clusters when a child is at greater risk, and the second idea is that risk is specific to kind of abuse—sexual abuse—increases with age.

In terms of age clusters, Dr. Bruce Camba, a physician at Children's Hospital Boston, points out that the risk increases 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 impulsive manner just as a function of their age. Add to this the behavioral or emotional manifestations of a handicapping condition, or to the already over-stressed family, and there is a real possibility that abuse will occur."

Altport discusses the potential for sexual abuse in a child's growth cycle. "Handicapped children are at more risk than normal children for sexual abuse as they stature. They need greater assistance in dressing and undressing, or other special care which may make them more vulnerable to sexual assault," Sandy McGee, who is with the advocacy department of the Virginia Department of Mental Health and Mental Retardation expands this possibility so that outside the home. "As a handicapped person gets older the risk of sexual abuse generations to outside the family, to other people in the community is 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. (Continued in part 10)
Spotlight: Beth Edwards

Parenting a handicapped child is always difficult. But parenting a child with Chromosome Punctata, a rare genetic condition—'
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 Michael, 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 nearsighted problem, has a colostomy, will always wear diapers, and is very small, weighing only 18 pounds.

There are problems with hospital separations, 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 housebound 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 no health insurance which didn't cover Matthew at all. When we finally got benefits from state and local agencies, we still had bills. We finally declined 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 $1,000.

One reason for the financial difficulties is that Matthew is uninsured. Children with this type of syndrome rarely are expected to live past two years old. However, Matthew is three and is 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 use community 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 rarely have anything good to say. I don't want to hear how bad it is."

All of these factors combined can result in unbearable pressure. Beth admits, "I contemplated hanging a train and never coming back. Also I had anxiety attacks and I had to havevaluums 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 that they are. There is a saying that says, "What a handi- capped child 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 we had a handicapped grandchild. My mother-in-law, who is no longer living, was very upset. She didn't get to know him. 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 Michael a penny to throw in a wishing well in the park. And I asked him what his wish was. He said, 'I wish that Matthew would get well and never be sick.' 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 have for someone to feel sorry for him," Beth emphasizes. "He's a happy little boy, except when he's sick. And he's just ador- able..." 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 pleasure and can bring you as much happiness in normal chil-
dren."

Child Abuse and Handicaps

While it has been noted that handicapped children have a higher risk of abuse as a result of neglect, there is another very serious issue. That is, many children are "permanently handi-
capped, either emotionally, physically or mentally" as a result of abuse (Soeffing, 1975, p. 466).

Often it is difficult to determine which occurred first, the abuse of the handicap. Someone (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 Cambin, 1982, p. 466).

Elizabeth Brown, 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 a study conducted by the Virginia Head Injury Foundation, 15 percent of all head injuries were the result of interpersonal abuse. 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 lacerated, 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 exac-
erbated by the fact that it is frequently not known that they have suffered a brain injury. They develop learning disorders and professionals do not relate the disorders to brain injury. "Even so, teachers are not trained in the prob-
lem associated with brain damage, and as a result don't provide appropriate teaching techniques," Hearn asserts. "These children may have difficulty with short term memory and have trouble learning; they may have difficulty with sequencing; there may be emotional problems, such as depression, frustration, outbursts, and inappropriate crying or laughing, all of which may lead to behavior problems or, the child may just appear to be 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 professionally and父母 may continue to cause more problems for the child.

Prevention

Whatever the risk of child abuse and neglect in the handicapped population, it happens. If, 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, the Penningtons of handicapped may lower the potential for abuse. It is possible that abuse occurs because the parent does not know how to handle the child. Instead, a parent believes a child is merely being stubborn or out of control. In fact, he or she is just, can't understand or cannot process the information for reasons out of the child's control.

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 20/200 and a visual field of only 20 degrees. She is 50 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 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 tutoring services available for the blind but many of the readers read too fast."

Although Melinda can read with some content visually, she would be totally helpless if she had to keep up visually in every subject.

Excessive travel and financial burdens are additional stress factors. "We put as much as 10,000 miles a year on our car so medical, special-purpose types of programs and extras needed as a result of her handicap," Sandy says.

"Extra equipment is required, some of which can be borrowed, but the borrowed equipment is not always satisfactory, 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 Harrisburg, 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 eligible on the basis of physical handicap, 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 at increased risk due to their risk of suffering a handicap in the future. "One hour ago a child was referred because of," says Ann Stoker, 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," Stoker 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, occupational therapist, and an infant educator. After receiving a referral, a screening is completed to determine if the

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

"The Penningtons have had relatively few problems in obtaining services. "We have absolutely super response from the Virginia Department for the Visually Handicapped and our county school system."

However, one problem that has been Melinda's eyes are not really the same size at 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 friend's 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 explains. "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. By making many trips to Richmond for 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 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 FACE 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 need. Again, the parents are an integral part of this process,” asserts Scales.

In a study conducted by Mote (1985), the effect of early intervention programs on such variables as parent-child interaction, family stress, social networks and social support were assessed. The type of programs compared were home-based, center-based and parent-trained programs. In order to qualify for the study, the child had to be involved in the program for a minimum of four months. The majority of findings indicated that no one program was superior in all ways. However, whether early intervention services for developmentally 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’” (Mote, 1985, p. 9).

However it is important to note that women in center-based programs 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 Risa 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.” While non-Adapted Parenting program met the needs of some children and families, others proved unsatisfactory for the following reasons. The program was not designed to meet the needs of families with more severe disabilities.

The costs of services for handicapped children are high. In order to be reimbursable, the program must be designed to meet the needs of the child and family. The program must provide a continuity of care and support services. The program must be designed to meet the needs of the child and family.

The program must be designed to meet the needs of the child and family.