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In summarizing recent research, we try to give you new ideas for refining your practice. However, this publication is not intended to replace regular supervision and peer consultation—only to enhance them.

Let us hear from you!

If you would like to comment about something that appears in this or any other issue of Children's Services Practice Notes, please do so! Address your comments to:

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BEHIND THE GROWING NUMBER OF SPECIAL NEEDS CHILDREN

We call them "special needs" children. Some are HIV positive, others have full-blown AIDS. Some are born prematurely, some are born addicted to drugs. Others have physical handicaps or are developmentally delayed. All of them have one or more medical conditions that seriously affect their bodies, their behavior, and the lives of those who care for them.

In recent years, departments of social services have seen a dramatic rise in the number of children with special needs. Many social workers, even those with years of experience, may be daunted by the tasks of learning about these children, assessing their safety, and arranging for foster and adoptive placements that meet their complex needs.

In this article we will address the following questions: Why have the numbers of these challenging children increased so sharply? What should social workers know about the risks faced by special needs children? Most importantly, what can social workers do to support these children and the families who care for them?

INCREASING NUMBERS

Across the country, more and more children are coming into foster care with serious medical problems. In 1986, estimates indicated that between 29 and 41 percent of the young

children coming into care in the U.S. had serious medical problems. That percentage shot up to 62 percent in 1991, and this figure is thought to be a conservative one (MacLafferty, 1994). North Carolina is just beginning to collect data on special needs children involved with social services (Fulton, 1997).

In her 1994 article in the journal *Community Alternatives*, Ann Helton Stromberg explores this rise in the numbers of special needs children coming into the child welfare system. In her discussion, she names the factors she believes have contributed to this increase:

- 1) Since 1985, the incidence of substance abuse during pregnancy has tripled. Consequently, there has been an increase in the number of infants born drug-exposed or drug-addicted;
- 2) The number of infants and children who are HIV-positive or have AIDS is on the rise;
- 3) As a result of improved medical care and technology, the survival rates for seriously-impaired neonates and children



What are the risks faced by special needs children in DSS care?

BEHIND THE GROWING NUMBER OF SPECIAL NEEDS CHILDREN

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with serious pediatric disorders has increased. The range of traditional social services has not been able to meet the growing demand for support from families who care for these children;

- 4) Changes in medical insurance coverage and the cost-effectiveness of home health care, have limited the amount of time a seriously-ill child can remain in hospitals or other institutional settings;
- 5) Nationwide, there has been a concerted effort (often driven by deinstitutionalization legislation), to care for seriously-ill children in a family-like environment. This effort is motivated by our growing understanding of the negative impact long-term institutional care has on children's development and well-being (Stromberg, 1994).

INCREASED RISKS

We know that record numbers of children with special needs are entering the child welfare system, and we have some idea as to why, but what do we know of the risks they face?

Children with physical disabilities are at greater risk for maltreatment than other children (Glaser & Bentovim, 1979; Jaudes & Diamond, 1985). The demands they place on any caregiver are exceptional; when combined with financial, marital, or other stresses, some families find them unbearable.

Research suggests that this is especially true in the case of families with low socioeconomic status. According to Roger White and colleagues (1987), "the most consistently reported demographic factor associated with reported child abuse or neglect is low socioeconomic status." It is reasonable to assume, they say, that the strain of caring for a physically handicapped child only adds to existing financial and social stresses, sometimes pushing a family's ability to cope to the breaking point.

Studies also suggest that children with physical disabilities are at greater risk for certain types of maltreatment. In their paper *Abuse and Risk to Handicapped and Chronically Ill Children*, Danya Glaser and Arnon Bentovim (1979) found that parents of handicapped children were



Support the child's caregivers to the extent you expect them to support the child.

much more likely to neglect than abuse them. These researchers do not speculate as to why this is the case.

Studies have also shown that handicapped children are at greater risk of maltreatment after the disability becomes apparent to the parent or caretaker (Benjamin & Uchytol, 1982). Most parents experience pain and trauma when their child is born or diagnosed with a physical or mental disability. Some parents will feel inadequate and view the child's disability as a threat to their self-esteem. Given this fact, social

workers should be especially attentive to parents during this time, supporting them through empathic listening.

In addition, children with serious medical needs are at an increased risk of experiencing developmental delay, above and beyond the trauma of parental abuse or neglect (Jaudes, 1985). For example, a chronically ill child who spends a substantial amount of time in the hospital may fail to bond to a primary caregiver. Furthermore, these children have often experienced hurtful medical interventions and may have permanent physical impairments. These experiences can lead to body image problems and low self-esteem, which can in turn be manifested in family, peer, and school problems (Telfair, 1994).

Children with chronic conditions often run into difficulty at school. Some of these difficulties take the form of academic troubles caused by absences and inability to participate due to their health (Morgan & Jackson, 1986). Physically handicapped children can also be vulnerable to problems of fitting in with and being accepted by their peers, especially at school (Van Hook, 1992). Teachers and school counselors can be great resources to assist the child in managing his or her life at school.

There are also medical risks for children with special needs when they move into foster care. These children often cannot continue to see the doctors familiar with their conditions. Sometimes this is due to the placement itself—the child's foster home may be in a new neighborhood far from the child's current medical care provider. Other times the quality of medical care is compromised by insufficient information—when a child is removed from

her home, parental anger or other factors sometimes prevent a social worker from obtaining complete information about the child's medical condition and care (Benjamin & Uchytol, 1982).

SUPPORT NEEDS

There are several steps social workers can take to support the children with special needs in their caseload.

A good place to start is education: learn about the child's disability and how it could affect his or her development. If he or she has a medical condition with which you are unfamiliar, it may be necessary to consult a physician or specialist. In North Carolina, another place you can turn is the Family Support Network, a nonprofit service that provides information to social workers and families caring for children with special needs. They have a database with information on over 900 medical conditions. They can be reached by calling (800) 852-0042.

It is also important to learn about the laws that govern the rights of disabled children. For information about education laws, call the Exceptional Children's Assistance Center (800/962-6817). For other disability-related legal information, call the N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (919/733-3654).

The best way to support the special needs child, however, is to support the family taking care of the child. Work with the family (birth, foster, or adoptive) to develop a diverse network of support resources to help them manage the demands of caring for the child. This network may include devices (such as a cellular phone or special walkers) as well as people. Equally crucial to the success of a special needs foster placement is respite care. Our practice experi-

ence tells us that special needs children do best in foster care if we can support foster parents to the degree that we desire and expect them to support the child. ♦

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STEPS YOU CAN TAKE

- Learn about the resources for families of children with disabilities available in your community and at the state level. The CARELINE (800/662-7030) is a good place to start.
- Help the parents work through the grief reactions that occur when the diagnosis is first made. This may help prevent maltreatment of the child.
- Educate yourself. Understanding the symptoms and long-term prognosis is crucial to your ability to serve this child and his or her family.
- Learn about the laws that govern the rights of disabled children, and encourage the family to learn about them.
- Begin a candid, ongoing conversation with the family regarding their financial situation and stress levels. Explain to them that these discussions will help you assess their need for respite care and other support in caring for this child.
- Plan for respite care well ahead of time. Regular respite care is critical for families of special needs children.
- Work with the family to develop a diverse network of support resources to help them manage the demands of caring for the child. This network may include devices (such as a cellular phone or special walkers) as well as people.
- Help the family keep the child's life as "normal" as possible. Encourage the child to participate in sports and clubs, if that is at all possible.

SHOULD MEDICATION BE USED TO TREAT AD(H)D?

The number of children diagnosed as having attention deficit or attention deficit/hyperactivity disorder [AD(H)D] continues to hold steady at three to five percent of the school age population in the United States (Parker, 1992). At the same time, coverage in the media has sparked a controversy surrounding use of the drug Ritalin. In this context, parents, teachers, and social workers find themselves asking: Do children with AD(H)D benefit from prescription medications? What part should drugs play in the overall treatment of this medical condition?

When it comes to treating AD(H)D, there are three broad classes of treatment: behavior therapy, special parenting techniques, and medication. Although most experts agree that interventions should be directed at various levels of a child's functioning, by far and away, medication is the most frequently used intervention. And not

without reason—medication has been shown to be effective in alleviating the problems associated with AD(H)D in up to 75 percent of children (McGough, 1995).

Doctors James McGough and Dennis Cantwell are quick to point out that medication is not an appropriate treatment for all children, however, but should only be considered in severe cases of AD(H)D. Most doctors, they say, will not even prescribe medication for children under four.

Those children who are on medication should receive ongoing supervision and monitoring by a physician. As they grow and their body weight increases, stimulant medication dosages may need to be increased to adjust for this change. Approximately one percent of children treated with Ritalin or other stimulants develop tics.

While some people are concerned about the risk of addiction to stimu-

lants, studies do not bear this out. Rather it has been determined that 30 percent of AD(H)D children who are **not** treated become substance abusers (McGough, 1995).

The key to effective medication intervention with AD(H)D is getting the right type of medication, in the right dose, at the right time. This can only be done in collaboration with a physician or other trained medical staff.

Experts agree that medication alone is not the most effective intervention. It should be complemented with behavioral and psychosocial interventions for long-lasting effectiveness. ♦

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MEDICATIONS COMMONLY PRESCRIBED FOR AD(H)D

Drug	Side Effects	Duration	Pros	Precautions
Ritalin Ritalin-SR	insomnia, decreased appetite, weight loss, headache, irritability, stomachache	3–4 hours (Ritalin-SR lasts 7 hours)	works in 30–60 minutes; good safety & effectiveness record; Ritalin-SR useful for teens	not recommended for children with marked anxiety, motor tics or with a family history of Tourette syndrome
Dexedrine	insomnia, decreased appetite, weight loss, headache, irritability, stomach ache	3–4 hours (spanule lasts 8–10 hours)	works in 30–60 minutes; good safety record; may avoid noon dose in spanule form	not recommended for children with marked anxiety, motor tics or with a family history of Tourette syndrome
Cylert	insomnia, agitation, headaches, stomachache	12–24 hours	given only once a day	may take 2–4 weeks for clinical response; regular blood tests needed to check liver function
Tofranil	dry mouth, decreased appetite, stomachache, dizziness, constipation	12–24 hours	useful for depressed & anxious AD(H)D children; lasts through the day	may take 2–4 weeks for clinical response; baseline ECG recommended for children suspected of having a preexisting heart condition; discontinue gradually
Norpramin	dry mouth, decreased appetite, stomachache, dizziness, constipation	12–24 hours	useful for depressed & anxious AD(H)D children; lasts through the day	may take 2–4 weeks for response; baseline ECG recommended for children with a preexisting heart condition; discontinue gradually
Clonidine	sleepiness, hypotension, headache, dizziness, stomachache, nausea, dry mouth, localized skin reactions with patch	3–6 hours (oral) 5 days (patch)	useful for AD(H)D children who have a tic disorder or severe hyperactivity and/or aggression	sudden discontinuation could result in rebound hypertension; start medication at bedtime & increase slowly to avoid daytime tiredness

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FOSTER PARENTS WHO SUCCEED WITH CHILDREN WITH MEDICAL NEEDS

TIM AND THE WILSONS

The following is based on a family profiled in Home Is Where the Care Is, produced by the Oregon Children Services Division's Foster Parent Education Program. Although Tim and the Wilsons are real people, their names have been changed to protect their confidentiality.

Tim was born with two strikes against him. He was born with grossly-enlarged lymph nodes, and his mother abandoned him shortly after his birth. The doctors could not correct the problem until Tim got older and stopped growing. In the meantime, his lymph nodes got so large that Tim needed a tracheotomy to breathe. His lymph nodes so altered his facial features that several potential foster parents said that they were physically unable to hold Tim and care for him.

But Tim was lucky. The Wilsons discovered his plight and decided to bring him into their foster home. Tim is one of three medically-needy foster children in the Wilsons' home.

Mrs. Wilson says that it was scary at first, and very demanding. She says that it takes more than love, that "a family must have a commitment to really help children who are physically handicapped." And the Wilsons could not have done it without medical and other community support services. But Mrs. Wilson also believes that the rewards by far outweigh the costs. The payoff comes when she sees the child's condition and behaviors improve.

What is the Wilsons' formula for success? The Wilsons foster as a family. Every family member participates in the care of the foster children. Mrs. Wilson sets small and realistic goals, ones the child can easily achieve. Every time a goal is met, a new one is set. The Wilsons describe themselves as flexible and patient. Mrs. Wilson says, "you have to believe you have something to offer physically handicapped children." Respite care is important, but hard to come by. The Wilsons count on support groups and ongoing training opportunities to keep them energized and knowledgeable about how to care for their foster children.

Successful fostering of special needs children takes highly-skilled families with a special interest and feeling for handicapped children. Their skill and interest is what enables children to develop positive, hopeful attitudes about themselves.

Source: Benjamin, T. & Uchytol, E. (1982). *Home is where the care is*. Oregon: Children Services Division, Foster Parent Education Program.

Foster parents are at the center of things when it comes to taking care of children in foster care. Caring for a child with special medical needs is a complex, demanding task. In most cases, the child is not likely to be cured. Progress, when it comes, is slow, hard to achieve, and hard to recognize.



In addition to their roles as caregivers, these foster parents must be case managers and advocates for their children. It also falls to these parents to counsel their foster children, to help them cope with the fall-out of their physical conditions—body image problems and low self-esteem—which can be manifested in family, peer, and school problems.

Recently, we talked with several North Carolina foster parents who care for children with significant medical needs. We asked them what they found to be essential to success with their children, and what they would like to change. Their replies have implications for best practice not only with those who foster children with medical needs, but for practice with all foster parents.

The individuals we talked to felt that to truly succeed with children with medical needs, foster parents need to have a higher level of participation than they do as members of a review team. "As team members, our input needs to be considered with the same weight as social workers' input," one said. They felt this was especially important when it came to getting medical information. "After we talk to a doctor we need to be able to talk directly to the team so that we avoid multiple translations of critical details," one parent said.

The biggest mistake one parent felt she made was not advocating more strongly with her county DSS for regular respite care. Without it, she feels she can't do her work as a foster parent properly. "When I'm tired, nothing helps," she says. ♦

GRANDMOTHERS WHO CARE FOR DRUG-EXPOSED CHILDREN

Nationally and in North Carolina, “grandcare” is on the rise. Between 1990 and 1996 the number of children under 18 being raised by grandparents grew 44 percent. In 1990, 111,000 children in North Carolina lived in households headed by grandparents; about 30 percent of these (33,624) lived in households where the grandparents were the sole caregivers (Stanley, 1997).

There are many reasons for this increase. Child abuse and neglect, teen pregnancy, and parental incarceration are common reasons. The major factor cited in many studies, however, is substance abuse (Minkler & Roe, 1993). As most social workers know, drugs and alcohol interfere with parents’ abilities to care for their children. In cases where mothers abuse drugs while pregnant, the consequences for children—and those who care for them—can be severe.

While raising the average child can be difficult, children born crack-exposed or addicted require a level of care far beyond that of a healthy infant. Some of the outcomes typically associated with prenatal exposure to crack include pre-term delivery, low birth weight, growth retardation, irritability and lethargy, poor sucking ability and muscle tone, irregular sleep patterns, and attachment difficulties (NCFCRP, 1996). Older children may also have ongoing health problems as the result of prenatal exposure to drugs (Minkler & Roe, p. 159).

In their 1993 book *Grandmothers as Caregivers*, Meredith Minkler and Kathleen Roe looked at the challenges faced by 71 African American grandmothers who were the primary caregivers for their crack-exposed children. The interviews were conducted over a 15-month period beginning in 1990; the grandmothers ranged in age from 41 to 79, with a median age of 53.

In addition to the burden of physical care of these infants, grandmothers interviewed by Minkler and Roe iden-

tified several factors that contributed to the high levels of stress they experienced. These included:

- **Problems with government assistance.** On the whole, grandmothers participating in this study felt unsupported by the government when it came to meeting the needs of their grandchildren. When they did qualify for financial assistance, it usually came in the form of AFDC rather than the more substantial support provided to non-relative foster parents. As recipients of welfare, they felt stigmatized in a way that foster parents are not. A 58-year-old grandmother said, “They make you fill out forms, save receipts, justify everything you do. They tell you what you can and cannot buy and even question my judgement . . . it’s insulting!” (p. 94).
- **Trouble with an adult child still using drugs.** Balancing their concern for their adult children with their need to keep their grandchildren safe was a difficult task for all of the grandmothers in this study. Some tried hard to keep the maternal-child bond strong; one grandmother constantly reminds the children not to call her ‘Mama,’ that they have a real Mama. Others, afraid of the risk of violence and the disruption they cause in the lives of the grandchildren, cut ties with their adult drug-involved children (p. 169).
- **Worries about elderly parents.** For several of the women interviewed by Minkler and Roe, caregiving for grandchildren was complicated by their responsibilities as primary caregiver for a frail or disabled parent or relative. The women reported that the combination of parent-care and child-care left them with the feeling that “everyone is depending on me” (p. 147). One woman remarked, “I had planned to kick back and relax at this stage” (p. 148).
- **High cost of caregiving.** Most of the women in the study experienced a serious drain on their finances after taking grandchildren into their home. One woman stated, “Before we were fine, we finally had plenty. Now, we can just barely make the basics, and it’s getting worse” (p. 83). The emotional and physical cost can be a tremendous shock. For one respondent, the extra responsibility resulted in a separation from her spouse. Interestingly, women without a confidante were far more likely to report that their emotional health had improved since caregiving began (p. 77). **cont. page 8**

GRANDCARE IN NORTH CAROLINA

These statistics pertain to grandparents of all racial groups who are the sole caregivers for their grandchildren (Source: Stanley, 1997).

- Most are in their mid-50’s.
- Over 40% are below poverty level; another 15% are near-poor.
- About 44% are working for pay as well as raising grandchildren.
- About 58% are African American, 40% are White.
- About 77% are raising one grandchild; almost a quarter of these are under 2 years old, though children of all ages are represented.

N.C.'S FAMILIES FOR KIDS COUNTIES: LOOKING AT DIVERSITY

Since this initiative began two years ago, people in the department of social services in the eight *Families for Kids* counties have been taking stock of what they do to see if there are better ways to work with families and each other.

It was in this spirit that Cleveland County DSS began looking at how their agency handles issues of difference and cultural diversity.

NOT JUST A BUZZWORD

Why look at cultural diversity? What does diversity have to do with a county's ability to achieve the Families for Kids goals?

To Bob Hensley, Cleveland County's DSS Administrator, the relationship is clear: "What I know about how I respond to different types of people affects my practice. If I don't understand a family's values or customs, I may run into trouble helping them."

Convinced of the impact culture has on their work, Cleveland DSS set out to determine where things stood in their agency and how they could improve. Hensley called Robert Leibson Hawkins, a cultural di-

versity expert at the UNC School of Social Work, and asked for his help in putting together a plan. Instead of simply scheduling training, the two decided it would be more helpful—and cost effective—if the agency developed its own resources in this area.

As Hawkins explains, "If workers attend a workshop they may return to their agency with a new way of looking at their clients, their work, themselves. But if the prevailing views in their work environment haven't changed, then a few days or weeks later they may find that they have slipped back into their old, less effective way of working and thinking." Cleveland County wanted something more sustainable and comprehensive.

THE PROCESS

After talking with Hensley, Hawkins and Mary Anne Salmon, a researcher at UNC, designed a survey to help Cleveland DSS determine how its employees thought the agency was doing in terms of cultural competency. Then they made the survey available on the world wide web; everyone in the agency was given access to a computer with an Internet connection, and a password, so that it would be completely confidential. Out of 180 people in the agency, 125 completed the questionnaire—a very high completion rate.

After the survey was completed, Hawkins conducted a series of cultural competency discussion groups, attended by most agency staff, where he presented preliminary results of the survey and provided basic instruction in cultural competency.

Next the agency created a Diversity Team composed of volunteers from the different specialized areas within the agency. Members of this team will identify training needs and make recommendations to the director, Lorene Rogers. Bob Hensley explains their role: "For example, we are seeing more and more Spanish-speaking individuals, and more Vietnamese individuals. This group would try to

determine what we need to support our work with these families."

Hawkins and others at UNC will also conduct telephone interviews of 300 clients of Cleveland County DSS so the agency can get specific feedback about how it handles diversity. Interviewers will ask clients about their perception of the attitude within the agency and whether they feel there are barriers due to their age, race, gender, religion, or socioeconomic status.

This information will help Cleveland County build its growing expertise in diversity so that it can continually improve outcomes for families and children. ♦

Editor's Note: If you have questions about cultural diversity or the process Cleveland County has begun, contact Robert Hawkins at 919/962-4363.



"The more you know about different people and your reactions to these differences, the more successful you will be in recruiting foster and adoptive families and, hopefully, in preventing placement in the first place."

—Robert Leibson Hawkins

Families for Kids Goals

1. Accessible support for all families.
2. A single, coordinated assessment process for each family.
3. One case manager or case management team for each family.
4. One stable foster care placement for every child.
5. A permanent home for every child within one year.

GRANDMOTHERS from page 6

How can the child welfare system help ease the burden for caregiving grandmothers of drug-exposed children? *Grandmothers as Caregivers* concludes with a summary of a number of interventions being implemented around the country. Over 250 grandparent caregiver support groups have been formed in recent years. These support groups provide a place to share feelings and frustrations and to get information on services and resources. Occasionally these groups become a vehicle to lobby for more effective laws, both for grandchildren and the grandparents who care for them.

In California, a telephone "warm" line has been established for caregiving grandparents to call for emotional support and information. The service is staffed by volunteer grandparent caregivers who serve as peer telephone counselors. In the first six months of operation, the service received over 1,000 calls. In Deerfield Beach, Florida, a local senior citizen center operates a respite/intergenerational child care program. There are several training centers that provide special training to caregiving grandparents, in an attempt to meet the special needs of this population.

In the political arena, coalitions are forming to help concerned individuals, community groups, and agencies as they pursue the common goal of supporting and assisting grandparent caregivers. These efforts are occurring at the local, state, and national levels. In fact, in 1991 the first "Washington Summit" on grandparent caregiving took place. Ten leaders of the grandparent caregiver movement traveled to Washington, D.C. to meet with policy makers and key groups and organizations about the needs of relative caregivers raising children in what are being labeled "skipped generation" families. ♦

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