

CLINICAL REPORT

Guidance for the Clinician in Rendering Pediatric Care

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Committee/Section on Children With Disabilities

Helping Families Raise Children With Special Health Care
Needs at Home

ABSTRACT. One goal of *Healthy People 2010* is to reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles, to 0 by 2010 for persons aged 21 years and under (objective 6–7). Congregate care, in this regard, is defined as any setting in which 4 or more persons with disabilities reside, regardless of whether the residence is located in the community, such as a school, group home, nursing facility, or institution. Although this particular public health objective may reflect an unfamiliar concept for some pediatricians, the American Academy of Pediatrics supports the goals and objectives of *Healthy People 2010* as well as the medical home and the provision of community-based, culturally effective, coordinated, and comprehensive care for children with special health care needs and their families. To advise families caring for children with special health care needs effectively, the pediatrician should be familiar with the principles of permanency planning and well informed of local family-support services. The pediatrician should also work with the family to identify the range of long-term supports and services available for their child. These supports may include respite for biological families as well as various additional parenting models such as shared parenting, foster care, alternate parents, and adoption. Although family-based supports are preferable, families may consider other out-of-home placements including group homes, placement in a nursing facility, or other forms of institutional care when sufficient family-based services are not available. Once all the options are understood, issues regarding quality of care can be individualized and judged by the parent or guardian, in close collaboration with the pediatrician and other professionals with expertise in permanency planning and long-term supports and services.

The purpose of this clinical report is to educate physicians on the philosophy of providing a permanent family environment (permanency planning) for all children, including those with special health care needs, and the importance of adequate and accessible community services to support and maintain the well-being of all family members. *Pediatrics* 2005;115:507–511, *children with special health care needs, family support, permanency planning, special-needs adoption, deinstitutional-*

ization, medical home, foster care, Healthy People 2010, transition, self-determination.

STATEMENT OF THE PROBLEM

Most parents desire to raise their children* with special health care needs at home. However, sometimes individual circumstances and societal factors strain the family’s ability to provide for their child’s special needs. Advanced medical care and sophisticated technology have made it possible for more children with special health care needs to survive into adulthood, often with chronic illness and disability. Family structure and patterns of family life have changed dramatically in the last 2 decades. More and more children (including those with special health care needs) are living in single-parent households. More mothers are in the workforce, and at the same time there has been a decline in the purchasing power of the family income.¹ A growing number of children are living in poverty. Social isolation secondary to the additional caregiving demands imposed by the child’s condition coupled with an increase in residential mobility often separates families from their extended families and natural support systems.

A family’s requirement for community supports depends not only on the characteristics of the child (ie, the degree of supervision, habilitation, and health care needed) but also on structural (eg, single-parent household), functional (eg, coping strategies), and external (eg, income and work schedules) characteristics of the family.² Resources available to families can be conceptualized along 4 levels of support (as shown in Fig. 1).³ The family is the child’s best resource. The second ring represents the family’s natural supports and includes extended family members, neighbors, and friends. The third ring represents informal supports, which include social networking with other families through various support groups, community organizations, specialty clinics, and, most recently, the Internet. The outer ring represents formal supports (financial, legal, and health insurance benefits, respite waiver vouchers, and early intervention and special educational programs)

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

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* In accordance with the policies of the American Academy of Pediatrics, references to “child” and “children” in this document include infants, children, adolescents, and young adults up to 21 years of age.

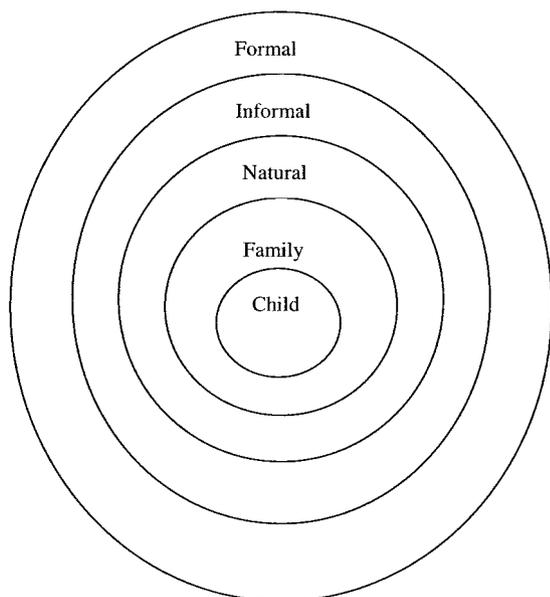


Fig 1. Levels of support for families of children with special health care needs (modified from *J Dev Behav Pediatr.* 1994;15:117-119).

to which families of children with special health care needs are entitled.

THE PHILOSOPHY OF PROVIDING A PERMANENT FAMILY ENVIRONMENT (PERMANENCY PLANNING)

Permanency planning is the philosophy and practice of securing for children with special health care needs permanent family placements and ongoing relationships with caring adults.^{4,5} Permanency planning emphasizes the use of supports necessary to enable a child to be raised in a home, focuses on promoting a sense of belonging, and is evaluated according to the ability of the setting to promote ongoing, secure relationships. Permanency planning philosophy can be contrasted against “placement strategies,” which emphasize delivery of services, focus on location, and are evaluated according to competence of care providers.⁶

Central to permanency planning is the belief that all children, regardless of the presence of a disability, belong in families. Permanency planning may entail supporting the birth family, recruiting a temporary family placement during a crisis, recruiting an alternative family when adequate supports for the birth family are rejected by the family or are not available, and, ultimately, helping the family and child transition to an adult community-based independent-living environment. When an alternative family is necessary, it could be a foster family, an adoptive family, or a shared-parenting family. A shared-parenting family operates similarly to shared parenting by divorced parents with blended families and may include 1 of the following 3 arrangements: (1) the birth family plus an extended family share parenting responsibilities; (2) the birth family plus an unrelated family share parenting responsibilities; or (3) 2 unrelated families share parenting responsibilities.

Also, adoptive families are available for children with a range of severe disabilities.^{6,7} A limited num-

ber of studies on the topic have revealed generally positive perceptions and experiences of adoptive family members in the short term.^{8,9} For example, in a study of 56 adoptions completed by families, Glidden⁸ concluded that all but 5 were successful as measured by a variety of outcomes. However, the children had only been living with these families for an average of 25 months when data were collected.

There is only 1 long-term study of outcomes for children with disabilities who were adopted. Glidden and Johnson¹⁰ conducted a follow-up study of 42 adoptive families of children with special needs. Twenty-one families (50% of the original sample) were lost to follow-up. Of the remaining 21, 16 of the adoptees were still living at home. “The remaining 5 had left home, as older teens and young adults, and moved to residential schools or training centers or independent group residences. Because these moves were made to age-appropriate settings, these cases were not considered to be adoption disruptions. Only one child left home before age 17 and one after age 21; the others left at an average age of 20. The four individuals living away from home were still considered to be part of their families at the current follow-up.”¹⁰

Glidden and Johnson also looked at changes in family function over time. They found that families frequently identified the benefits of adoption as giving and receiving love, positive child characteristics, pride in child’s achievements, and happiness. Families less frequently reported problems including negative child characteristics, worry, anxiety or guilt, developmental delay, family disharmony, and lack of emotional bonding. Over time, there was a statistically significant worsening of family stress, particularly items related to family or parent problems and pessimism.¹⁰

The findings of this study may reflect the stress that accompanies the challenge of caring for a child with special health care needs and may validate the need to make sufficient family-support services available. The long-term follow-up demonstrated that family stress can increase over time when caring for a child with disabilities. On the other hand, the fact that 5 adoptees moved into residential settings outside the home may be a reflection of the individuals’ exercising their right to self-determination and transitioning to adult independent-living settings. This situation would not necessarily be inconsistent with *Healthy People 2010* objective 6-7 (reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles, to 0 by 2010 for persons aged 21 years and under).¹¹ More studies of long-term outcomes are needed.

For additional information regarding the importance of establishing a child’s attachment to caregivers in general, see the American Academy of Pediatrics policy statement “Developmental Issues for Young Children in Foster Care.”¹⁵

THE IMPORTANCE OF FAMILY SUPPORT

Permanency planning is not synonymous with family support. Permanency planning focuses on the

developmental needs of the child, whereas family support focuses on the needs of the entire family to provide an environment conducive to the child's need for permanency. In so doing, family supports attempt to strengthen the family unit in the community while preventing alienation and family dysfunction.¹ Family supports may include providing cash stipends, delivering services (child care, respite, transportation, home modifications, durable medical equipment, behavior-management training, crisis intervention, faith-based services, assistance with transition to adult group homes, etc), and other supports that promote family well-being. In the context of permanency planning, family support may be seen as a means to achieve a permanent placement for the child and facilitate the philosophy of permanency planning.

Indeed, there have been major shifts in services for children with special health care needs over the past 50 years.⁴ A strong parent movement that initiated the move toward deinstitutionalization and free public education for children with special health care needs was started in the 1950s. Whereas the early efforts focused on the person with the disability, later momentum was focused on supporting the family. Several laws and funding streams were created to increase community supports for families raising their child with special health care needs at home. In 1974, the Supplemental Security Income (SSI) program became the cornerstone of national commitment to support youth with disabilities by providing financial aid to their families. In 1975, federal education laws (Education for All Handicapped Children Act [Pub L No. 94-142]) ensured that all children regardless of their disabilities or special needs were entitled to a free and appropriate public education. These laws were amended in the 1980s and 1990s to be more inclusive by extending services to children from the time of birth or diagnosis.

The Adoption Assistance and Child Welfare Act (Pub L No. 96-272 [1980]) expressed as legislation the set of permanency-planning principles that emerged in the 1970s for children removed from their homes because of abuse and/or neglect. Additionally, it established a new Title IV-E of the Social Security Act to provide federal matching funds for adoption subsidies for "special needs children" in out-of-home placements.¹² However, this law is problematic in that it applies only to public welfare systems and not to agencies serving individuals with mental retardation and developmental disabilities. Because only approximately 20% of children with mental retardation and developmental disabilities are placed in foster care through the child welfare system, most children with mental retardation and developmental disabilities were not included under the protections of this law.¹²

In 1981, the Tax Equity and Fiscal Responsibility Act of 1982 (Pub L No. 97-248), also known as the Katie Beckett Act, provided a variety of supports, including monetary assistance, to parents so that they could hire trained care providers to receive periods of rest (respite). Respite is regarded by many parents as one of the most important supports nec-

essary to continue to care for a child with special health care needs at home. The Support for Families of Children With Disabilities Act of 1994 (Pub L No. 103-322, Part 1) provided additional means to reunite families of children with disabilities who had been placed out-of-home.¹³ Finally, pending legislation such as the Family Opportunity Act of 2003 and the Lifespan Respite Care Act of 2003 may further expand options and services for children with special health care needs. Although this report targets family supports, the willingness and/or ability of the local school system to respond adequately to the child's education, rehabilitation, nursing, and behavioral needs certainly influences the experience of families of children with special health care needs. These issues can be addressed when schools have access to technical assistance, consultation, and support, but this may not be the case in some communities. When these systems fail, families may feel pressured to look outside their community, even to residential settings, to find other resources (although they are not necessarily failing to provide the needed home supports).

Although all states now have family-support programs, few states have allocated adequate funds, and long waiting lists exist. Furthermore, depending on the state, supports may be withdrawn or decreased when the child transitions to adulthood. Despite tremendous relative advances, spending for family support still constitutes only a small portion of most state budgets for mental retardation and developmental disabilities services. Overall, the United States spends \$2.4 billion annually on family support, which accounts for only 2.8% of total developmental disability funding. In fact, only 5 states have allocated more than 5% of their total mental retardation and developmental disabilities budgets for family supports.¹⁴

For additional information regarding family supports in general, see the American Academy of Pediatrics policy statement "The Pediatrician's Role in Family Support Programs."¹¹ For information regarding additional challenges encountered as the child transitions through adolescence and adulthood, see the *Pediatrics* supplement "Improving Transition for Adolescents With Special Health Care Needs From Pediatric to Adult-Centered Health Care."¹⁵

SUMMARY

To support and achieve *Healthy People 2010* objective 6-7 (reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles, to 0 by 2010),¹¹ pediatricians should work closely with biological families to identify local resources that can assist them in caring for their child with special health care needs to prevent out-of-home placement. If, however, the family considers out-of-home placement, the pediatrician should be knowledgeable of and be able to recommend other alternatives and supports and convey this information to the family to reinforce the principles of permanency planning and achieve and sustain an optimal nurturing environment for the child.

CONSIDERATIONS FOR PEDIATRICIANS

1. The goal of the medical home is consistent with *Healthy People 2010* objectives and includes the provision of community-based, culturally effective, coordinated, and comprehensive care for children with special health care needs and their families.¹⁶
2. The ongoing assessment of children with special health care needs ideally is family-centered, focusing on the child's quality-of-life goals as envisioned by the family. Ultimately, assessments will focus on the child as he or she matures into adolescence and adulthood and prepares for transition to adult living settings.
3. Throughout the ongoing care of the child, the pediatrician is encouraged to support the tenets of permanency planning. Permanency planning is the philosophy and practice of securing for children with special health care needs permanent family placement and ongoing relationships with caring adults. Permanency planning emphasizes the use of supports necessary to enable a child to be raised in a home, focuses on promoting a sense of belonging, and is evaluated according to the ability of the setting to promote ongoing secure relationships.
4. The pediatrician is encouraged to address the child's need for and the availability of an appropriate education, including later transition services. If the child is not being served appropriately by the local school system, physician advocacy may be necessary to both obtain the needed services and decrease the burden on parents in their own efforts to secure them.
5. The pediatrician is encouraged to address the parents' need for and ability to access and obtain family-support services, including faith-based services. If parents are in need of family-support services but have not been successful in accessing them, the pediatrician may advocate on behalf of the family through referral to social service agencies, which are usually housed in state agencies (ie, state departments of health, human services, mental retardation and/or disability, or education).
6. Pediatricians are encouraged to advocate for the most reasonable and appropriate supports and services. The measure of what is reasonable and appropriate should always be in the best interest of the child. If, after careful consideration, the family determines that congregate care is the only available option, it should be considered a temporary placement followed by reunification or an in-home alternative-care option whenever possible. Pediatricians also are encouraged to help adolescents prepare for transition to adulthood and advocate for self-determination as some adults may choose to pool resources and share attendant care in group home settings.
7. Pediatricians, especially those in states that have not yet accessed waiver services through the Tax Equity and Fiscal Responsibility Act (Katie Beckett Act), can be effective advocates for increased

funding for family supports by working collaboratively with legislators to access and match federal resources. The public policy link on the Family Voices Web site (www.familyvoices.org/Policy/home.htm) is helpful in providing the clinician with information about important proposals to Congress that relate to permanency planning and family supports.

8. Pediatricians can be helpful in identifying possible alternative families. Good prospects are families already caring for a child with special health care needs, foster parents of typically developing children, and parents who work in the health care fields. Pediatricians can also be helpful in educating and training care providers.

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