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Out-of-Home Placement for Children and Adolescents With Disabilities—Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity

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abstract

Children and adolescents with significant intellectual and developmental disabilities and complex medical problems require safe and comprehensive care to meet their medical and psychosocial needs. Ideally, such children and youth should be cared for by their families in their home environments. When this type of arrangement is not possible, there should be exploration of appropriate, alternative noncongregate community-based settings, especially alternative family homes. Government funding sources exist to support care in the community, although there is variability among states with regard to the availability of community programs and resources. It is important that families are supported in learning about options of care. Pediatricians can serve as advocates for their patients and their families to access community-based services and to increase the availability of resources to ensure that the option to live in a family home is available to all children with complex medical needs.

INTRODUCTION

The clinical report "Out-of-Home Placement for Children and Adolescents With Disabilities,"[1] published by the American Academy of Pediatrics (AAP) Council on Children with Disabilities in October 2014, provides information about the option of pediatric congregate care settings for children with complex medical conditions and severe developmental disabilities whose families cannot or choose not to care for them in their own family home. The children and youth (referring to "adolescents") discussed in the article are those who have significant medical complexity and medical fragility, often requiring 24-hour skilled care for medical stability or survival. Although the Council on Children With

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Disabilities believes that all children, including those with complex medical conditions and technology dependencies, ideally are cared for in their own homes and with their families whenever possible, for some children and their families, this may not be a safe or sustainable option. The clinical report, written in response to the expressed needs for information by AAP members, was not intended to endorse out-of-home placement for children with severe disabilities and complex medical conditions but rather describes the one option of out-of-home congregate care when children cannot live with their families. This addendum responds to reader requests for additional information about noncongregate, family-based out-of-home options, supplementing but not repeating or replacing the content of the original publication.

AAP POLICIES/CLINICAL REPORTS IN SUPPORT OF CHILDREN LIVING WITH FAMILIES

The AAP has been, and continues to be, a strong advocate for providing all children and youth with environments that foster optimal physical and psychosocial development. The psychosocial and cognitive benefits of living with a family in a nurturing home environment have long been established.[2] As such, children with disabilities, like all other children, develop better in the context of a loving and supportive environment. The AAP promotes comprehensive and coordinated supports and services for children and youth with special health care needs within the context of the medical home and medical community.[3] The basic tenets of the medical home are in line with the Developmental Disabilities Assistance and Bill of Rights Act of 2000[4] and the Americans With Disabilities Act,[5] which are laws that support all people with disabilities to live in their homes and communities as fully integrated members of society. The AAP endorses permanent family and community environments for all children, with adequate and accessible community services to support children with all types of needs and their families.[6] The AAP values partnerships among parents, primary care providers, and the community to improve outcomes of children with disabilities.[7] The AAP provides resources for providers to support the care of children with complex heath care needs in the home, including those who are dependent on technology.[8] For example, the AAP *Guidelines for Pediatric Home Care* offers information to support children with special health care needs in the home setting, including information about respite, in-home nursing care, and medical day treatment programs for children with complex medical conditions.[9]

IMPORTANCE OF NURTURING FAMILY SETTINGS

Children with significant disabilities and complex medical conditions, like all children, need stable homes with loving families and caregivers who provide the essential physical and emotional resources to promote well-being. There is a consensus among the disability community, consistent with federal disability laws like the Americans with Disabilities Act,[5] that all children should reside with families – their own, whenever possible, or another family when that is not an option. Much has been written about the significance of an enriched, interactive environment on child development and attachment. Pediatric skilled nursing facilities are a type of congregate, institutional setting that may provide care to children and youth with severe disabilities and significant medical complexity who require 24-hour skilled nursing care. Children in skilled nursing facilities do not have the advantage of being in a small setting with a family that provides consistent care. It has also been noted that children cared for by different providers working in shifts, such as in pediatric skilled nursing facilities, develop less strong emotional connections with caregivers compared with children being cared for in family homes.[10]

Research has documented the deleterious effects on development and attachment for children without disabilities who reside in settings that lack adequate stimuli for learning and bonding with caregivers. Findings from neurobiology have deepened our understanding of the vital role of the parent-child relationship in early development. Custodial care in large institutions has been characterized historically as “warehousing” individuals and denying opportunities for social interaction, engagement in stimulating activities, and individualized processes of care. Studies in Romanian orphanages have shown the importance of a nurturing and enriched environment on children’s developmental outcomes. Although these studies were not focused specifically on children with significant disabilities and associated medical conditions,[11–14] they underscore the importance of stable and loving environments in which all children can develop a close bond with their caregiver(s).

Well-established factors that contribute to healthy development that are embedded in most families are missing in even the best congregate care setting.[15] Factors inherent in congregate care that distinguish it from a family and render it potentially harmful to children include (1) large ratio of children to caregivers; (2) absence of a primary caregiver for each child; (3) turnover of caregivers; (4) inferior cognitive, linguistic, and socioemotional stimulation; (5) regimented schedules and lack of spontaneity in child-adult interactions; and (6) limited peer-to-peer interaction.[15]

Problems with attachment can occur when young children are raised in socially deprived environments.[16] Conversely, resilience in children has been strongly associated with stable and supportive relationships with attuned and responsive adults, particularly with parents.[17,] The relationships and experiences of early childhood influence the long-term well-being of individuals.[18] Strong family functioning mediates against adverse neighborhood and environmental conditions,[19] and a strong community with reduced potential stressors also ensures better health outcomes in children.[20]

More recently, national attention has been directed to the effects of toxic stress on children residing in environments that do not provide adequate supports to promote optimal development, early literacy, and better academic outcomes. Exposure to adverse environments can have lifelong negative effects on a child's development.[2] Similarly, we know that children who are abused and neglected, whether in familial or congregate settings, are at risk for long-lasting negative effects on developmental and psychosocial well-being. There is convincing evidence about the importance of early identification and intervention of children who are abused and neglected.[21] Some children exposed to traumatic experiences in the home do require removal to a safe, nurturing environment, such as foster care. Evidence shows, however, that young children can recover after placement in a nurturing home with an attuned and responsive parent.

Some studies have found that children with disabilities, in general, are at increased risk of abuse, both in congregate settings and in their own family homes,[22–25] although in a systematic review of population-based studies, a weak association was found between disability and abuse and neglect.[26] It is imperative that all children, including those with developmental disabilities and medical complexity, are provided with safe and secure environments that meet their physical and psychosocial needs.

FAMILY AND PARENT FACTORS FOR CHOOSING HOME VERSUS OUT-OF-HOME CARE

Most families want to care for their children in their home, have expertise about their children's needs, and make decisions that support their children's best interests.[27] In a review of technology-dependent children and their families, Wei Wang and Barnard[28] noted that it is more cost-effective to discharge children to home care, which also normalizes their care. Berry et al[29] conducted a retrospective analysis of more than 2 million acute care hospital discharges in the United States in 2012 for patients from 0 to 21 years of age, evaluating discharge to home health care and postacute care facilities. Analysis of discharge data revealed that 5.5% of these patients were discharged to home health care, and 1.1% were discharged to postacute care facilities. Children and youth who accessed these services had longer hospitalizations and greater medical complexity (eg, use of technology and multiple chronic medical problems). However, most children and youth with these complex medical issues do not use these resources and also use them significantly less than adults. Significant variability of use also was found on the basis of geographic location, race, and ethnicity.[29]

Parents who care for their children at home have been noted to do best when supported by professionals who value their input and work together with them toward common goals.[30] To support families, programs have been developed to train them to care for their child with medical complexity in the home setting.[31] Although some families caring for a child with complex medical needs may experience less time for other activities and work loss to care for their child with special health care needs,[32,33] there is evidence that raising a child with chronic medical conditions has positive effects on family cohesion and appreciation for life.[34] However, home care is demanding and can affect the quality of life of these children and their families. Currently, the demand for in-home nursing is greater than the supply, and there are many geographic areas where it is especially difficult to find adequate nursing support. In a recent comparison of parent and child physical and mental health outcomes when children with complex conditions and technology dependencies are cared for at home, in long-term care settings, and in medical day-care settings, Caicedo found no differences in parent/guardian perception of child health outcomes, but the highest levels of parent physical health and vigor were experienced by the parents of children in long-term care settings.[35] The dynamic interplay of the function of parents and their children (in this case, with cerebral palsy) also was described by Murphy et al,[36] who found significant correlations between parent and child physical health, mental health, psychosocial function, and health-related quality of life. When considering placement options, the needs of both the child and the family warrant consideration.

Children with special health care needs who have disabilities experience more severe health conditions and unmet routine and specialty care needs compared with those without significant disabilities.[37–39] This disparity is most notable for adolescents with significant limitations, those living below or near poverty, those residing in the South and West, and those of Hispanic or non-Hispanic “other” (not white or black) ethnicity.[40] These children have greater medical complexity and technology dependence, placing increasing demands on caregivers.[41] Unmet care requirements may lead some families to explore different care options, such as in-home nursing, personal care and home health and therapies, and other care options such as host homes and medical foster care.[42–44]

Bruns[45] noted that the decision to place a child in a setting outside the family home is complex and involves multiple factors, including need for additional assistance, significant medical care needs, and financial concerns. Rosenau et al[46] evaluated reasons for placement of children with developmental disabilities (not limited to children with complex medical needs) in congregate care settings in Texas and found that this decision usually is influenced by stress-related situations that were worsened by lack of resources and/or alternative options of care. The study found that another factor influencing parental decisions regarding placement in congregate settings was the availability or absence of a trusted, knowledgeable facilitator with the time and energy necessary to assist them to explore family-based alternatives.

CARE OPTIONS OTHER THAN THE FAMILY HOME AND CONGREGATE SETTINGS

Medical, surgical, and technological advances over the years have resulted in more children surviving with disabilities and/or complex medical conditions. Most children with disabilities or complex medical conditions are cared for in their homes, where they receive supports, services, and medical care.[47,48] The 2012–2013 National Core Indicators Survey, in collaboration with the National Association of Directors of Developmental Disabilities Services and the Human Services Research Institute, captured data on more than 13 000 adults with intellectual and developmental disability who received services from state developmental disabilities agencies in 26 states. Those surveyed included a small subset of individuals between ages 18 and 22 years identified as having severe to profound developmental disabilities. Ticha et al[49] found that the vast majority of these youth are living with families; 69% lived with their own family, and 4.5% lived with host families. The majority of the remaining individuals lived in small community settings (21.9%, of which 2.6% were living on their own; 5.8% were living in provider-run settings of 1 to 3 people; and 9% were living in provider-run settings of 4 to 6 people). Only 1.3% lived in large provider-run settings with 7 to 15 people, and 3.8% lived in institutional settings.

When families believe they cannot care for their child in their home, other noncongregate family-based options may be possible. These may include host families, shared care arrangements, and voluntary foster care. One type of family-based alternative is placement in the home of a relative who is able to provide care. Support may be available for care by relatives through Medicaid Home and Community Based Waivers (discussed later). Although higher placement stability has been found in kinship settings for children removed because of neglect or maltreatment, problems such as higher rates of poverty and living in disadvantaged neighborhoods have been associated with kinship placements, particularly when the biological family faces those same disadvantages. Overall, kinship placements are considered to be more positive, with greater family and cultural connections,[50] although some studies indicate that more data are needed to better understand their true benefits compared with other placements.[51,52]

Children with complex medical needs also can be placed with another family who can care for them through medical foster care or host home arrangements. Medical foster care is an option of care for children with special health care needs and disabilities to live with families who are specially trained to provide needed supports and services. This option is available in some but not all states.[53,54] Approaches have been developed to recruit, train, and support alternative families to be able to care for children with medical complexity in their homes as an alternative to congregate placement.[41–43] Many states offer family-based alternatives that include the use of host families, shared care, shared parenting, life sharing, and voluntary foster care. In these alternative care arrangements, the child’s parents retain legal authority yet delegate the child’s care to families who are trained and supported to care for children with special health care needs.[35] Forty-eight states report use of host family options.[55] An Internet search found that more than half of states offer out-of-home family-based alternatives to congregate care to children in their Medicaid waiver programs (discussed later). Texas, for example, offers host family homes funded by Medicaid Home and Community-Based Services waivers that parents of children living in nursing facilities can choose as a voluntary placement option, enabling family life for their child with their continued involvement or shared parenting arrangements. Availability of these host family options in Texas has contributed to the significant reduction of nursing facility use by children younger than 22 years since 2002.[56]

CURRENT STATE/POLICY IMPLICATIONS

The availability, flexibility, and capacity to develop robust plans rapidly to support children with complex medical needs in a family home vary by state and local community. The availability and type of services and supports are affected by decisions made at the state level on which services and supports to offer, how to fund programs, and eligibility for services. An additional complication is the coverage, or lack thereof, provided by private insurance companies.

Medicaid Home and Community-Based Services (HCBS, also commonly referred to as "waivers") funding exists in all states, although states vary in terms of the specific services they offer. HCBS is one of the most flexible types of funding to pay for services and can be used to access different community supports.[57] HCBS can be used to provide both in-home and out-of-home support. In-home supports can include respite, personal assistance, homemaker, and other specialist care. In some states, parents can become personal care assistants and be paid for the care they provide to their children.[58] HCBS also can be used for out-of-home supports such as respite, medical day-care programs, and living arrangements such as medical foster care and host homes.

Children with complex medical needs and developmental disabilities are often eligible for Medicaid, which must cover all necessary medical services for eligible children. For families with income levels too high for Medicaid, some states provide additional funding.[59] The Tax Equity and Fiscal Responsibility Act of 1982 State Plan Option allows states to provide Medicaid coverage to children and youth with severe disabilities who require care at a level provided in congregate care facilities but who receive care at home.[60] Most states also have a Medicaid Buy-In program, whereby families may be eligible to pay relatively low premiums to obtain Medicaid coverage that can be used for services they otherwise would be unable to afford.[60] Despite these payment options, there continues to be a lack of adequate financial and staffing support for families of children with disabilities and medical complexity.

Families, providers, and their allies need to know the options that exist in their communities. Several resources are available in each state that can assist medical providers and families in obtaining information on care options, including Governors' Councils on Developmental Disabilities, state protection and advocacy organizations, and University Centers on Excellence in Developmental Disabilities. All states also have advocacy organizations, such as the Arc and Family Voices.

CONCLUSIONS

Family life with caring and loving caregivers should be the goal for every child with disabilities and medical complexity. Additional funding and resources are needed for community supports, and families require more care options for their children. Waitlists for services need to be shorter, with larger pools of home-based providers and more respite services for family caregivers. It should be a priority of the nation and states to improve policies and financing that promote services and supports for children and youth with disabilities and medical complexity to live in their own family homes or alternative family homes when that is not possible. Advocacy is needed to ensure that the option to live in a family home is available to all children with complex medical needs across this country. Community pediatricians should consider advocating for system changes that would lead to more comprehensive community resources that promote home care for children and youth with severe intellectual and developmental disabilities and complex medical problems. For those children who are in more restrictive environments, there should be ongoing assessment of their needs and exploration of appropriate home-based services that may lead to discharge. Most important, all children and youth with significant disabilities and medical complexity should be cared for in safe environments that provide comprehensive supports to meet their medical and psychosocial needs.

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ABBREVIATIONS

AAP: American Academy of Pediatrics

HCBS: Home and Community-Based Services

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