

## For Optimal Outcomes, Children Belong in Homes

In the Clinical Report “Out-of-Home Placement for Children and Adolescents With Disabilities,” Friedman and colleagues<sup>1</sup> review options for placing children with disabilities in congregate care settings. However, the report omits discussion of the best interests of the child in selecting out-of-home options and fails to review and prioritize noninstitutional models of care. When families of origin are unable to provide adequate care, children with disabilities retain their right to receive care in the least restrictive setting. Like all children, children with complex disabilities benefit from family and community life. Therefore, it is a national priority to reduce the number of children and youth with disabilities aged 21 years and under living in congregate care residencies.<sup>2</sup> It is also a national priority to increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree they wish.<sup>3</sup> This clinical report undermines these important priorities by lowering the bar to institutionalizing children. The report does not address the negative impact of institutional care on growth and development of children with disabilities beyond a few narrow medical outcome measures.

As reviewed in the Clinical Report “Parent–Provider–Community Partnerships: Optimizing Outcomes for Children With Disabilities,” with proper support most children with disabilities thrive at home.<sup>4</sup> Families who lack the resources to care for their children with medical and behavioral needs can be referred to their state protection and advocacy organization for assistance with exercising their right to community services and supports. These rights were established through the Supreme Court’s decision in *Olmstead v. L.C.* Families struggling with social stigma, guilt, isolation, or feelings of inadequacy can be referred

to their local parent information center or for individual counseling. When out-of-home placement is the best option for a family, homelike settings such as host family, voluntary foster care, and small group homes should be explored before long-term care settings with 4 or more residents are considered.

Pediatricians have an important role in advancing and implementing public policy to ensure that all children enjoy the benefits of full inclusion and access to community life, regardless of their medical, behavioral, or support needs.

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### Conflict of Interest:

None declared.

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## Response to Out-of-Home Placement Clinical Report

The American Academy of Pediatrics (AAP) article fails to emphasize the developmental imperative for all children to grow up in loving, nurturing families, whether their family of origin or another family, and that need is just as great or greater for children with complex support needs.

The article lays out details for pediatricians only about institutional care when children with complex support needs are no longer able to continue to live with their families.

Some families may be seeking additional supports for their child at home, and for those families additional supports may be critical. But the AAP article leaves the impression that there are only 2 options: living at home with supports or in one of a variety of congregate care settings described in the AAP article. There is another option that honors the child’s developmental needs to grow up in a loving, nurturing family. A number of states have developed the capability for a child’s family to choose an alternative family who welcomes the child into their home and raises the child with the input of the child’s family. Alternate families are not part of the child welfare system. No judgment of neglect is made when parents are no longer able to care for their child, whether because they have a chronic health condition, their child’s episodic health care crises put their jobs at risk, or they face some other barrier. We recommend first exploring additional supports for the family and child to make it possible for them both to thrive. But sometimes that is not enough. And when that happens, the child should not be forced to forgo the developmental benefits of a nurturing family and have some form of institutional care as the only option. Settings with only shift staffing patterns deny the child an attachment to a single adult.

In some states these arrangements are funded and supported under the name of life sharing, host homes, resource families, or shared living. Because there is variation between states in how to access this alternate family service, we strongly recommend that each state AAP chapter establish a mechanism to identify the agencies in their state that offer life sharing and provide pediatricians with an outline of the process that includes specific contact information and how they can assist in making those arrangements, such as

making a referral or providing documentation of medical needs.

We appreciate that there will be instances when a child is not able to remain at home with his or her family. When this occurs we firmly believe that the AAP could play a helpful, perhaps critical role in encouraging states to make family-based alternatives more readily available to children with complex health care needs. It is critical that pediatricians have information about alternate families as the next best choice rather than directing families to institutional care as the only referral option because they lack knowledge of how to make referrals to agencies that can assist with arrangements for alternate families.

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#### **Conflict of Interest:**

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## **Author's Response**

We thank those who took the time to provide feedback on the recently published clinical report from the American Academy of Pediatrics (AAP) about out-of-home placement for children and adolescents with disabilities and for their interest, comments, and care of children and adults with disabilities. We recognize and support the national goals for decreasing the number of children not living in home settings.

We absolutely agree that almost all children receive the best care in family settings with appropriate access to all community services and experiences, including school, recreation, travel, and relationships with others inside and outside the family. Our clinical report indicates this belief, and it is codified in an earlier AAP statement.<sup>1</sup> For children with extraordinary medical, nursing,

and personal care needs, the supports that they and their families need for life maintenance and safety, let alone development and socialization, may be extensive and may not be available or accessible to the family in their home and community. As the report notes, at times the family may be unable to provide needed and safe care for their child for a variety of reasons, and no other home-based options, such as an appropriate medical foster home, exist.

This clinical report arose in response to questions from pediatricians to members of the AAP Council on Children with Disabilities on the care options available for children with complex and highly technical medical and nursing care needs. The clinical report focuses on a very small group of children and youth who need 24-hour skilled nursing care. It does not focus on children with intellectual and developmental disabilities without severe medical needs. The report provides information for pediatricians who may see children with these complex needs only very rarely. The AAP sought review and input from multiple sources before publication, including a leading family advocacy organization.

The clinical report strongly recommends referring parents for information, support, and community services to maximize their abilities to care for their children in their own home. However, we noted that resources, geography, waiting lists, and other requirements can severely limit access to home-based services and that many communities lack medical group homes and other types of care settings.

Parents and physicians should work closely together to understand the medical needs of the child and the sources of support and care, in the home and elsewhere. Together they should discuss how to balance the needs of all family members with the resources available. Parents have broad authority to decide on the goals, types, and intensity of treatment for

their children. Parents make judgments and set priorities that the physician may disagree with and vice versa. Parents may decide that the best or safest place for a child with extreme special care needs is an out-of-home placement, a matter of parental choice that must be respected, as are other treatment decisions. Such a decision is not in itself neglect. When the parents' lack of care endangers a child, or when the care in a facility, group home, skilled nursing home, or foster home places a child in danger, physicians can consider referral to protective services. However, responsible, loving parents can decide that within their family's available resources their child's best option is placement in residential care.

We join you in advocating for improvements and innovations in services for all people with chronic illness and disability. Improvements should lead to fewer families finding pediatric skilled nursing facilities as the best option for the multiple challenges faced by their child and family. We also advocate for the best care possible for this small, specialized, and vulnerable group of children and families in pediatric skilled nursing facilities when that option is chosen.

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#### **Conflict of Interest:**

None declared.

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1. Murphy NA, Carbone PS; Council on Children With Disabilities; ; American Academy of Pediatrics. Parent-provider-community partnerships: optimizing outcomes for children with disabilities. *Pediatrics*. 2011; 128(4):795-802

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## Response to Out-of-Home Placement Clinical Report

Elisabeth T. Healey

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