

For Optimal Outcomes, Children Belong in Homes

In the Clinical Report “Out-of-Home Placement for Children and Adolescents With Disabilities,” Friedman and colleagues¹ 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.² 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.³ 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.⁴ 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.

Clarissa C. Kripke

Director of Developmental Primary Care,
University of California, San Francisco

E-mail: kripkec@fcm.ucsf.edu

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

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