

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:

Elisabeth T. Healey is the executive director of the Parent Education & Advocacy Leadership Center.

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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.¹ 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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