

Placing children with special needs in congregate care vs. home care

Editor's note: The following viewpoints are written in response to the AAP clinical report *Helping Families Raise Children with Special Health Care Needs at Home* (Pediatrics. 2005;115:507-511) and subsequent AAP News article "Permanency planning preferred for children with special needs" (AAP News. 2005;26:18).

Congregate care settings

by Caroline Eggerding, M.D., FAAP, Richard Grossberg, M.D., FAAP, and Sister Katherine Smith, Ph.D., R.N.

We disagree with the goal to remove all children from congregate care settings by 2010 as stated in the AAP News article "Permanency planning preferred for children with special needs," which addressed key points in the AAP clinical report *Helping Families Raise Children with Special Health Care Needs at Home*.

We agree that supports are necessary to allow families the option of having their children at home. We are advocates for all families, including those unable to care for their children at home, and we believe these families are entitled to equal respect and support. While home is the best place for most children, it is not the best place for every child.

We are professionals who belong to Building Bridges, a network of more than 100 pediatric long-term care facilities in the United States and Canada, representing approximately 4,500 medically fragile children. We care for a small but growing population of children with complex health needs, often beyond the skill of most parents.

In our experience, parents' decisions to seek facility placement are enormously painful. The marriage is often in trouble; siblings suffer from inattention; work life is threatened due to sleepless nights, frequent hospitalizations, and caregivers in short supply. For many parents, turning over their child's 24-hour care to the professional staff allows them to resume their roles as parents, delighting in their child rather than providing medical care.

Limiting choice only to in-home services fails to represent the needs of all families. It ignores practical considerations such as the limited availability of nurses to support in-home care, lack of physicians trained in the care of medically fragile children, poor reimbursement rates for community providers, and lack of access to sophisticated medical centers.

Offering families a menu of options represents a more balanced approach to serving children with disabilities. These include care in a pediatric nursing facility with readily available medical, nursing and allied therapy services. The availability of these skilled services results in fewer hospitalizations and improved quality of life.

Educational resources for pediatricians learning to care for medically fragile children are limited. Even medical directors of the facilities within our network felt inadequately prepared to care for these complex children. The growing numbers of "children of technology" imply that pediatricians will encounter them with increasing frequency in their practices.

We suggest that the Academy take a more reasonable and balanced approach to *Healthy People 2010* and 1) recognize individual preferences among families; 2) promote the availability of a range of care options for families with children needing long-term nursing care; and 3) establish pediatrician education requirements for care of medically fragile children; these should include knowledge about pediatric long-term care facilities.

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Family-based alternatives

by Ted A. Kastner, M.D., FAAP, Chris Plauché Johnson, M.D., M.Ed., FAAP, Adrian D. Sandler, M.D., FAAP, and Paul H. Lipkin, M.D., FAAP

We appreciate the authors' thoughtful response to our clinical report, *Helping Families Raise Children with Special Health Care Needs (CSHCN) at Home*. The authors, representing Building Bridges, raise many important points that illustrate a need for a broader array of community supports for families as advocated in our report.

The report was written to address the public health goal of eliminating congregate care for children by 2010 as stated in *Healthy People 2010*. As members of a committee devoted to the health of CSHCN, our report was intended to introduce our fellow pediatricians to the principle of permanency planning and family-based alternatives. In addition, the report is intended to support, not undermine, the primacy given to parents and guardians in asserting their rights to exercise control over the health care decisions that affect their children. This includes making choices that may sometimes result in out-of-home placement. Our hope is that pediatricians will work with families to identify services and supports that will enable families to raise their CSHCN at home.

Our comments should not be construed as a lack of support for a full continuum of care and service delivery options for CSHCN. On the contrary, our goal was to introduce a wider array of innovative in-home options that would support parents so that out-of-home considerations do not become necessary. When out-of-home options are needed, we suggest that families learn of and consider family-based options.

We believe that all service delivery components are important and should continue to be a part of the broader service delivery system so that they may be accessed when in the best interest for both the family and the child. Although community-based supports have increased over the past two decades, the authors are correct in their concern over inadequate home and community-based services and supports available to children and families. If such supports are not available locally, then our role as providers is to advocate for access in every way possible.

While the Academy has endorsed the general public health goals of *Healthy People 2010*, it has not otherwise endorsed the specific goal of eliminating all congregate care for children by 2010.

We believe that it would be useful for the Academy to develop a policy regarding the role of out-of-home placements in the future service delivery system for CSHCN. It is our expectation that the Academy will continue to support the provision of those services that are in the best interests of children and their families, and which may include access to a full array of service delivery options including family-based alternatives to congregate care.

We hope that this debate will inform the work of the Academy as it participates in the process of drafting public health goals for *Healthy People 2020*.

Drs. Kastner, Plauché Johnson, Sandler and Lipkin are members of the AAP Council on Children with Disabilities.

View the AAP News article on permanency planning online at <http://aapnews.aapublications.org/cgi/content/full/26/2/18>.

The clinical report can be accessed at <http://aappolicy.aapublications.org/cgi/content/full/pediatrics;115/2/507>.