

BUILDING BRIDGES

A Network of Specialized Pediatric Healthcare Settings

Serving Children who are Medically Fragile, their Families, and the Facilities Caring for Them

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TO THE EDITOR:

We agree with some points in the recent *Pediatrics* article (Johnson & Kastner, "Helping Families Raise Children with Special Health Care Needs at Home," *Pediatrics*, February, 2005) particularly that it is ideal for children to be raised in their own homes. However, other opinions in this article cause significant concern.

We represent Building Bridges, a network of more than 100 pediatric long-term skilled nursing facilities in the United States and Canada. In our facilities, we provide family-centered residential nursing care to approximately 4500 children who require the most intense levels of care following acute care: children who are medically fragile and technology-dependent with complex disabilities. These children are unlike the other 24,300 reported to be in congregate care facilities. They are a small but growing segment of the population of children with special health care needs; their care can be extremely sophisticated and is beyond the skill level of most parents. Despite their fragile conditions and contrary to opinions in some popular press, these children do have cognitive awareness and responsiveness. As care providers for this special group of children, we offer the following comments.

First, families differ in their available resources. This article holds up the concept of "family" as the highest good for the child. Yet, failure to recognize diversity of family models and ranges of need is an injustice. Limiting choices is not a fair practice, particularly for families who have restricted options at the start. Limiting choice to only in-home services fails to represent the needs of all families and ignores practical considerations such as the limited availability of nurses to support in-home care, limited community-based physicians trained in the care of medically fragile children, and inadequate reimbursement rates which leave community providers unable to cover the costs of devoting the time these complex children require.

Offering families a menu of options represents a more balanced and reasonable approach to serving children with disabilities and recognizes a range of severity of children's health conditions. These can include in-home care with support services; medical foster care; group home care; or care in a pediatric nursing facility with readily available in-house medical, nursing, and allied therapy services. In many instances, even though children are cared for in a pediatric nursing facility, they can still go on family outings, celebrate holidays at home, or visit home for a day or a weekend.

Secondly, the concepts of permanency placement as outlined in this article imply that parents who lack the physical, emotional, social, and/or financial resources to provide round-the-clock nursing care to their severely impaired child single-handedly, day after month after year, somehow have failed. The recommended solution of seeking other untrained, non-medical families to provide care which the parents could not, disregards parents' crushing guilt and grief for what they already perceive as failure. In our experience, parents' decisions to seek nursing facility placement are enormously painful and are made as a last resort after physical, emotional, and financial exhaustion from raising a medically fragile child at home. The guilt that has pushed them into being super-parents is soon overtaken by the reality of their shattered lives. The marriage is often over or in trouble; siblings suffer from inattention; work life is threatened due to sleepless nights, frequent hospitalizations, or caregivers in short supply who may not show up for their shifts. Many have not taken a vacation since the child's birth. Having a facility-based alternative, even for the most intact of families, is often the only viable option for families to have the opportunity to thrive. Yet, the pain of these parents' decisions often never heals despite the realization that they were made in the best interest of their families. How gut-wrenching to require

parents who are unable to provide care themselves to allow their child to be adopted by another family, as suggested in your AAP article!

Quality pediatric long-term nursing facilities develop partnerships with parents in which both parents and staff share decision-making regarding the medically fragile child's care. Parents are supported in their recognition of their limitations and the needs of other family members as they seek out-of-home care. Both the family and the facility staff recognize that the child continues to be an integral part of the family of origin, even when residing in a pediatric nursing facility. 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 life supporting medical care and/or therapy.

Lastly, educational resources for pediatricians learning to care for medically fragile children are limited. Even medical directors of the pediatric facilities within our network felt inadequately prepared by their own education to care for these complex children, and became experts through "trial by fire." When children are admitted to the facility for care, it is apparent that their community-based pediatricians are often floundering to achieve the proper use of effective medications to treat seizures, spasticity, reflux, constipation and behavior problems. This is especially true for children who live in rural areas without manageable access to sophisticated medical centers or hospitals with specialty clinics.

We suggest that the American Academy of Pediatrics would better serve its constituency by establishing requirements for education during residency and for continuing education for the care of medically fragile, technology-dependent children with long-term complex health conditions, rather than supporting the limitation of options for families seeking assistance with their children's care. The growing numbers of these "children of technology" imply that pediatricians will encounter them with increasing frequency in their practices. Part of that education process should include learning more about pediatric long-term nursing facilities and their care of children and families.

In summary, we encourage AAP to 1) recognize individual differences among families and promote the availability of a range of care options; 2) recognize parents' perspectives related to ongoing care of medically fragile, technology-dependent children and the role of facility-based care in assisting them; and 3) institute course requirements for pediatric residency and for continuing education on care of this population of children. We in the Building Bridges Network stand ready to assist in any way we can.

Sincerely,

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