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Medically Fragile Children Challenge Medical Home Concept

The Medical Home concept has been an active concern of the American Academy of Pediatrics (AAP) for more than a decade. Certainly, for a disabled child a home environment is preferable to an institutional setting. However, when the degree of chronic illness exceeds the capacity of families, care givers and physicians, alternatives are necessary. Otherwise disabled children will be condemned to death. In the winter of 2004, I first learned that the AAP had made a definitive decree that all institutional settings for disabled children should be closed. I immediately wrote to all the members of AMDA's Pediatric Long-Term Care Section and requested that this issue be the primary discussion topic during the annual meeting in March, 2005. As part of the outcome of these discussions, Ms. Frampton wrote this article.

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*Experts question whether in-home care
is the only right choice.*

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Medically fragile children often require significant ongoing technological support and intervention, including ventilation, oxygen, enteral feeding, tracheostomy care, complex medication regimens, and intravenous therapy. The most recent epidemiological profile estimates that 5%-6% of children can be characterized as medically fragile. And this proportion has likely grown with improved technology and new advances in neonatal and pediatric intensive care, cardiology, trauma care, microsurgery, and oncology.

The American Academy of Pediatrics (AAP) has stated unequivocally that all children, regardless of the presence of a disability, belong in families. The Department of Health and Human Services has echoed this position, and one goal of Healthy People 2010 is to reduce to zero the number of people with disabilities, 21 years of age and younger, in congregate-care facilities. The AAP embraces a philosophy and practice called "permanency placement," whereby children with special care needs require permanent and ongoing relationships with caring adults in a home. This may include respite for biological parents as well as additional parenting models, such as

shared parenting, foster care, alternative parents, and adoption. Pediatricians are urged to consider out-of-home placements, such as group homes, nursing facilities, and other forms of institutional care, only when family-based services are unavailable.

But experts are beginning to question whether in-home care is the *only* right choice for these children and their parents as well as the health care team. Each family has unique strengths and weaknesses. Communities might lack enough nurses and adequately trained physicians. It makes sense to offer families a menu of options to care for children with disabilities and those with a variety of complex conditions. These can include in-home care with sufficient support services such as medical day care and respite care, as well as medical foster care, group home care, or care within a pediatric nursing facility with in-house medical, nursing, and therapy services.

The Concept of a Medical Home

In 2002, the AAP published a policy statement reinforcing the importance of medical homes for children with special health care needs and calling on *all* primary care physicians to establish medical homes within their practices. Medical homes should provide six components: preventive care, assurance of ambulatory and inpatient care 24 hours a day, continuity of care from infancy through adolescence, appropriate use of specialty consultation, interaction with school and community agencies, and a central record and database that contains all pertinent medical information.

Whenever feasible, most parents want to raise their children with special health care needs at home. Therefore, expert home health nursing care and a coordinating pediatric practice must be firmly in place and capable of meeting the child's extraordinary needs outside of an institutional setting. According to Dr. Sonia Imiazumi, of the AAP Section on Home Care, "The Academy is just beginning to conduct research on this population, establish relevant clinical guidelines, and educate pediatricians in the home care of this specific population of children."

Katherine Smith, Ph.D., R.N., executive director of the Building Bridges Network of Portland, Ore., said the medical directors in her network of more than 100 pediatric and long-term care facilities recognize that educational resources are limited for pediatricians learning to care for medically fragile children. "Even the medical directors in

pediatric facilities within our network felt their education inadequately prepared them to care for children with complex needs." When children are admitted for long-term or respite care, community-based pediatricians often flounder to treat "seizures, constipation, spasticity, reflux, and behavior problems. This is especially true in rural areas that lack access to sophisticated medical centers and hospitals with specialty clinics."

Indeed, primary care physicians attempting to create medical homes for these children are often unfamiliar with medical and community resources, are unable to allot the

time to provide comprehensive care, and are challenged to coordinate the many specialty consultations required. The practices best able to meet these challenges are close to a tertiary medical center, have established liaisons with specialists, and employ a pediatric nurse practitioner to provide expert case management and family advocacy.

Impact on Families

The home undoubtedly provides a developmentally appropriate care environment that is emotionally nurturing and socially stimulating. Yet, children who have disabilities or need life-saving technical support bring many challenges to families. The primary caregiver is typically the child's mother, whose health may be threatened by the stress of the vigilance required to provide the constant and sophisticated care. The risks are especially high in unemployed mothers in single-parent homes. Mothers who lack social support are at risk for depression and are more likely to compromise the care of their child.

The siblings of a technology-dependent child can become jealous and resentful. Unevenly divided home duties, physical and emotional burnout, loss of privacy, intense social isolation, and tremendous financial burden can result in marital discord. Although a 1987 study by the Office of Technology Assessment asserted that home-based care is less costly to society and insurers, it focused on hospital-incurred expenses and gave less consideration to the social and financial costs to families, including lost income, ancillary expenses, and caregiving.

Home vs. LTC Facility

Home care can only be a consideration when the child's medical condition is physiologically stable. "If a child is still being seen by a physician every day or even every other day, he or she is certainly not a candidate to be placed out of an institutional setting," said Dr. Eddie Simpser, executive vice president and chief medical officer of St. Mary's Health System in Bayside, N.Y.

The level of support and intervention the child requires should be able to be safely and practically provided in the home *before* the child is considered a candidate for home care. The family must be educable, motivated, and willing to learn the skills necessary for the child's care. Fam-



ily members must also demonstrate proficiency in providing all aspects of the child's care since they will have the primary responsibility for treatment. If the family cannot provide all care, prepared home health care staff must be in place *before* the child goes home.

Dr. Simpser also said "financial support must be available to fund equipment, supplies, and personnel in the home, and a reliable company must be engaged to provide the necessary equipment and supplies. The home must also

be clean and structurally appropriate for the around-the-clock care." And finally, it is desirable that community resources for emotional support and respite care be available.

Not every child can be cared for at home, however. According to Dr. Smith, "There is a small but growing segment of the population of children with special health care needs whose care can be extremely sophisticated and beyond the skill level of most parents. In these cases it makes sense for the child to be in a quality pediatric long-term nursing facility where the environment is homelike and

the staff respects parental insights into the care of their child. Here we have three shifts of staff and therapists available to render the care and take the tremendous burden from the mother. I am able to encourage her to be a mama again and delight in her child—be a parent."

The most critically ill are those who have cerebral palsy of the quadriplegic type. Dr. Audrius Plioplys, C.M.D., of Little Angels in Elgin, Ill., and of Marklund Children's Home in Bloomingdale, Ill., and former chair of AMDA's Pediatric Section, says that for these children "the existence of a 'medical home' in today's pediatrician offices is a fraudulent concept. ... Recognizing and supervising these chil-

dren's acute episodes of pneumonia, managing their difficult seizure disorders, severe spasticity, and complex nutritional issues [are] not something pediatric practices are equipped to do. These children require so many ongoing specialty consultations ... to think that this can be handled in an expeditious and organized manner by a busy pediatric office is absurd."

Dr. Simpser has seen these types of children treated in the home on very rare occasions, "where all factors were perfectly in place, highly skilled and dedicated parents, suitable home, excellent insurance reimbursement, sophisticated pediatric back-up, and dedicated catastrophic case management by a nurse available 24/7. However, this scenario is certainly not the norm, he said, adding that unless "we totally change our entitlement system, train enormous numbers of nurses and pediatricians ... [at-home care for these children] cannot work." 

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