Medical Foster Care for Seriously Medically Ill Children: A Growing Need

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ABSTRACT: This article identifies and lists the problems of children with complex medical conditions and/or complex home health care needs. Five categories of seriously chronically ill children are identified and programs to meet their needs discussed. The authors believe many of these children could benefit from foster home placements; they discuss one project in which there is collaboration between a pediatric medical center and a social service agency.

The Problem

Throughout the country there is a growing number of children residing in hospitals who are seriously chronically ill with complex medical conditions and/or complex home health care needs. Many of these children could benefit from the systematic development of specialized foster home placements. The medically complex child is defined as a child requiring prolonged dependence upon medical care and high levels of technologic and/or nursing support. Because few programs currently exist for developing and maintaining the foster homes and community resources required by these children to live outside of institutions they often remain hospitalized for years. Chronic illness affects 10-15% of the population under 18 years of age (Pless and Perrin, 1985). Of children with chronic illnesses about 10% (or 1% of the total childhood population) has severe disabilities such that they

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interfere with the child's ability to carry out tasks appropriate for his or her age.

Among children with chronic illnesses, there is a small but growing number who are inappropriately hospitalized in acute care hospitals. These children receive a higher level of medical and nursing care than they require at unnecessarily high cost. They may also experience the detrimental effects of long-term care in acute hospital settings unable to support their developmental needs or the psychosocial needs of their families. Additionally, the unnecessary hospitalization of these children adds significantly to inflating the “need” for acute care beds and to the cost of care that ultimately must be supported by the public (Merkens, 1983). The cost of caring for these children in acute care hospitals is great and is generally supported by public funding agencies such as Medicaid, state departments of Public Aid or Services for Crippled Children. The cost to these children in terms of compromised development, lost educational opportunities and arrested emotional growth as a result of growing up in a hospital environment is incalculable.

Limited information suggests that the number of medically complex children requiring long-term care is increasing (Newacheck, Budetti, and McManus, 1984; U.S. Department of Health and Human Services, 1982). In 1980, approximately 70,000 children younger than 17 years of age with chronic disorders were residents of health care-related institutions (National Center for Health Statistics, 1967-1981). The overwhelming majority of these children lived in institutions for the mentally ill or mentally retarded. The number of chronically impaired children residing in acute hospitals on an on-going basis is unknown. However, a review in 1979 of children hospitalized in Minneapolis-St. Paul revealed that 624 patients, representing 31,500 days of inpatient care in one year, fit into the above criteria. This study estimated that there would be a continuing need for 45 pediatric transitional care beds in the Minneapolis-St. Paul metropolitan area.

A variety of factors have conspired to place a greater emphasis on home care for the seriously chronically ill children. These factors include: the increasing numbers of children with a variety of chronic diseases (Gortmaker, 1985); the increasing survival rate of seriously impaired neonates due to improved medical care and technology (Kohrman, 1985); changes in public policy such as Public Law 94-142 (U.S. Congress, 1975) emphasizing the care of children in the “least restrictive environment,” and the Education for all Handicapped Children’s Act (Division of Educational Services, 1981), as well as other