

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

Diane M. Yost, M.S.W. and Neil J. Hochstadt, Ph.D.

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

Ms. Yost is Director, Foster Care /Adoption Services Children's Home and Aid Society of Illinois. Dr. Hochstadt is Director, Behavioral Science Department, La Rabida Children's Hospital and Research Center; Assistant Clinical Professor, Department of Pediatrics, Pritzker School of Medicine, Univ. of Chicago. Address correspondence and requests for reprints to Ms. Yost, Children's Home and Aid Society of Illinois, 1122 North Dearborn St., Chicago, IL 60610.

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

legislation for developmentally and physically disabled individuals; and the change in medical economics which is reflected in such developments as diagnosis related groups (DRGs). These regulations have been established by Medicare to provide for prospective payment of medical services hence establishing limits on fees.

The Population

Five groups of seriously chronically ill children can be identified (Merkens, 1983). The first group is composed of seriously chronically ill children requiring 24 hour skilled nursing care. These are children who, while generally medically stable, have high technological care needs i.e., therapies, treatments, equipment, continuous observation and monitoring. Their technical care needs have been traditionally interpreted as necessitating hospitalization within an intensive care unit or in an acute care hospital. However, recent experience demonstrates that once stabilization has occurred such children can often be managed successfully in different environments. Examples of children in this category are those with long-term tracheostomies, feeding gastrostomies, on intermittent or continuous ventilator support, and a variety of children with congenital anomalies on whom surgical approaches are only partially or temporarily satisfactory. This group includes children with "short bowel syndrome" who may require total parenteral nutrition (intravenous feeding for several months and then carefully monitored enteral nutrition (venous feeding through subcutaneous material into the intestine).

The second group includes those chronically ill children who need a change in medical management or counseling for adaptation. An example is the adolescent diabetic with psychological dysfunction, hospitalized for "fine tuning" of diabetes and simultaneous supportive counseling for the child and/or the family.

The third group includes children recuperating from complicated surgery or accidents whose illness involves a prolonged recovery during which skilled nursing and medical care is required. Children "in transition" from tertiary centers to home care represent a fourth category. These children are generally medically stable but their parents or care givers need a setting in which to learn the technical and developmental aspects of their care and management. Finally, there are children who are medically stable but for whom there is no satisfactory home setting. They may not have parents; there may only be one par-

ent, while two parents are required for medical management; or their parent(s) cannot cope with the home care of the child, either permanently or transiently.

Existing Programs

To meet the needs of this growing population of children several unique demonstration programs have evolved. Project Impact (Boston, Massachusetts, 1984) is a private, non-profit, specialized adoption and foster care agency. In 1983 Project Impact developed a partnership with the Developmental Evaluation Clinic at Children's Hospital (Boston) to work more closely with developmentally disordered and special needs adoption children to improve permanency planning. The goals of this project were to increase the number of adoptions of developmentally disordered children, to increase the level of training and support for adoptive families of developmentally disordered children, to broaden community awareness of the needs of these children, and to develop curricula and improve understanding of the dynamics of successful adoption of children with disabilities.

The Medical Foster Care Family Project (Davis, Foster, & Whitworth, 1984) established in Florida by the Children's Medical Service Program developed a unique program of using a registered nurse as the principal foster parent caretaker in each home. Each family is restricted to the placement of a single child with medical problems and is provided with a wide range of support services including case manager, continuing medical support, training and coordinated treatment planning. Preliminary results of this program show not only significant cost effectiveness but also extensive medical and therapeutic assistance to the child and to the biological family. Another program, the Baby House (United Cerebral Palsy Association, 1986) also located in Miami, Florida provides small cottage living with trained staff for medically involved and developmentally disabled children.

The La Rabida-Children's Home and Aid Society Project

A program model developed by the La Rabida Children's Hospital and Children's Home and Aid Society of Illinois (HHS, 1986) is a unique collaboration between a pediatric medical center and a social service agency. This differs from those identified above in two important

ways. Unlike the Project Impact Program this program can provide care for seriously chronically ill children as well as developmentally delayed children. Unlike the Florida Project, which relies on professional nurses, or the Miami Project, which relies on residential care, the program trains motivated foster parents to care for seriously chronically ill children in their homes. La Rabida Children's Hospital and Research Center has been concerned in recent years, about the growing population of medically complex children who are medically ready for discharge but are remaining hospitalized for extended periods of time. When the biological parents of these children have been unable or unwilling to have the children return to the home environment, La Rabida's commitment to their home care has continued. As a result, foster care is being viewed as a highly desirable alternative to continued hospitalization. In July 1986, the United States Department of Health and Human Services awarded a grant to Children's Home and Aid Society of Illinois and La Rabida Children's Hospital and Research Center to support a collaborative effort to develop and train foster families for this population of medically complex children.

Children's Home and Aid Society is a state-wide, non-profit, private child welfare agency providing foster care, adoption, day care, residential treatment, child and family counseling and research and professional training. La Rabida is a chronic disease hospital of the University of Chicago, Department of Pediatrics. The hospital and its outpatient programs care for children with a wide range of chronic diseases and handicapping conditions. In its initial stages it is providing leadership in the development of home transitional care for this population of children.

The main goal of this project is to provide a comprehensive medical foster care program to sixteen children requiring high levels of nursing and technologic support within a seventeen month time frame. A hospital and child welfare agency collaboration has become necessary in order to provide services to this population of children who require highly trained foster families and intensive supportive services. La Rabida's knowledge and skill in the in-home medical management of seriously chronically ill children combined with Children's Home and Aid Society's requisite expertise in the recruitment, development and support of specialized foster parents is critical to the success of these placements.

The target population for this project includes seriously medically ill children who are currently under the custody or guardianship of the

State through the Illinois Department of Children and Family Services. La Rabida has been instrumental in creating a functional schema for this population of children which details diagnosis and syndrome identification, levels of care and service required, specialized agencies involved and anticipated problems linked to home health care (Hochstadt & Freeman, 1984).

Children with the following conditions are likely to be included in this program: brocho-pulmonary displasia (requiring tracheostomy care, oxygen or frequent respirator treatments), ventilator dependent children, cystic fibrosis, cardio pulmonary diseases, neuromuscular diseases, severe brain injury, children requiring total parenteral nutrition programs (i.e. feeding through machines) and children with colostomies. Levels of care required range from acute chronic (intensive care and machine dependent) to high intensity chronic (machine dependent) usually provided through the assistance and involvement of as many as five agencies.

Under the best circumstances home management problems can be anticipated. Parent training and support present unique challenges for hospital and social services staff. Families must grapple with complex conceptual problems, compliance with on-going care, access to equipment, home modification, coordination of services and other major intrusions into their routines.

In general, La Rabida's role is to provide specialized training in regard to the complex management needs of this population to project personnel, biological families, foster families and other community resources. Children's Home and Aid Society's role is to recruit and develop foster families for the identified population, supervise the foster care placement and facilitate reunifications with biological families when possible.

Clinical Issues

As the developers of this project, we have identified some important clinical issues which we anticipate will present themselves as services are delivered. Counseling will be provided to biological parents, foster parents and children, all of whom will be experiencing difficulties with the event of placement in their lives. The population of children is unique and presents complex planning challenges to social service and medical personnel. Unquestionably, the professional community finds itself challenged to provide services which are made necessary by rapid

technological advances. Observation of a relatively small number of medically complex children maintained in in-home services provides some preliminary knowledge and impressions about the services and support required for such an undertaking. It is becoming more clear what issues substitute foster care will present to the child welfare community and society as more children survive and require family living arrangements.

Since the medical needs of these children are tremendous, their management and survival become the focal point of service delivery. Thus, they differ markedly from children requiring other types of child welfare services. Medical foster care reflects a different conceptual orientation from standard foster care in a variety of ways. Unlike regular foster care, medical foster care deals with children unlikely to be cured. Foster parents more often find themselves in the dual role of advocate/coordinator and care giver (Diamond, 1984). While pre-existing child welfare skills are necessary, new skills and concepts must be added in this evolving arena. It is anticipated that this will be a slow and sometimes painful process raising many ethical considerations for staff service providers and agency administrators.

The most pressing clinical issue in regard to the hospitalized children is the concern about compromised development. Specifically, hospitalization itself is viewed as a crisis which has a major negative impact on child development (Foster, Davis, Whitworth, & Skinner 1982). "Hospitalism" was a phrase coined to describe the undesirable psychological and developmental effects of long term institutional care of infants (Spitz, 1945). Additionally, the actual body damage, anomalies and physical assaults including sometimes hurtful medical interventions, lead to negative body image and damaged self-esteem. All of these aspects are reinforced by peer relationships within the hospital setting with others who are also damaged.

Ten year old Maria, ventilator dependent and suffering from leg paralysis since birth, resided in a chronic care hospital until the age of eight. When she was returned to her parents home she was shocked to live in a community and attend school with children who could walk and breathe independently. She was embarrassed by her appearance and ill equipped to make relationships with "normal children."

The hospitalization itself represents an interruption in bonding between parent and child, so critical to healthy ego development. Health care professionals have long been concerned about bonding failure with infants confined to neonatal nurseries who are not able to be held

by their parents. The reciprocal smiling response which exists between parent and infant as a primary bonding technique (Cline, 1979) breaks down during prolonged hospitalization when the biological parents are absent and the caretakers rotate.

When Terry was born prematurely his parents were overwhelmed to discover that they could not hold or feed him as they had their first child. The sight of Terry in the intensive care nursery, dependent on machines and assaulted by the lights and noise was painful for them to see. They could hardly stand the disappointment of leaving him in the hospital. As he got older, they were able to hold him but felt intimidated and frightened by his tracheostomy. His lack of response to their facial and verbal overtures forced them to withdraw emotionally making the situation worse.

Home placement for these children may begin to address some of issues. However, when foster care rather than biological home placement becomes necessary a new set of dilemmas is created. Katz (1987) cited Erikson, Bowlby and Litner as commenting that intensive anxiety, anger and developmental delay are the natural by-products of separation and loss in early childhood caused by broken bonds or disrupted caretaking arrangements which necessitate foster care. Consequently, coupled with the other issues these children grapple with, psychic energy must be invested in real or fantasied reunion with the biological parents and conflict over affectional ties.

Four year old Sarah was placed from the hospital into foster care in the hopes that her single mother could learn her tracheostomy care and take her home. However, when her mother visited she showed extreme confusion and anxiety which usually erupted into major tantrums. She was unable to settle down for days. When her foster mother attempted to comfort her she asked for "other mommy."

System Issues

The provision of services to this population of children demands that social service personnel highlight certain skills more dramatically and add others to their repertoire. Overall, staff become "system intervenors" in a role which stresses resource acquisition.

A critical variable tied to in-home placement becomes funding which, for these children, is a complex process. In Illinois, obtaining funding involves a medicaid waiver process as well as application through the Division of Services for Crippled Children and the Illinois

Department of Public Aid. This funding is generally linked to equipment acquisition and modification of the home environment. This can include installation of equipment as well as selection of nursing personnel to be present to be in the home.

Josua's foster family was selected three months before he actually went home. While everyone was eager for this to occur, funding and equipment had to be secured first. This process required that the Division of Services for Crippled Children submit a proposal to the Department of Public Aid for equipment which included a suction machine, apnea monitor, tubing, tracheostomy ties, saline solution, collars, filters, a hospital bed and selection of nursing staff. Josua's foster family also receives specialized boarding care through the Illinois Department of Children and Family Services which defrays medical and transportation costs not covered through the other sources.

Dealing with the school system to obtain adequate educational services for this population is also a formidable task. Often confusion exists on the part of parents and social service personnel as to what is adequate, appropriate and optimum (Dane, 1985).

Susan's foster mother became distressed when she got conflicting recommendations from the speech pathologist, the learning specialist and the psychologist at a school staffing. It was clear that her child's education and social development would be compromised without an adequate and agreeable plan. She was told repeatedly that there was no ideal plan for Susan and that compromises must be made.

Emotional and medical support services are a must for foster families who can be overwhelmed by the needs of the children and the demands of their role.

Families with a severely handicapped child are viewed as families at risk. The high divorce rate of families with a handicapped member (Featherston, 1980) and the negative reaction of siblings (Dane, 1985) demands that these supports be provided and monitored carefully. At the present time there are no recognized therapy programs for families with a medically complex member. Therapists may not be aware of the special needs these families really have, and exactly what stresses they are coping with (Murphy, 1987).

The intrusion of equipment in the home and the presence of nursing staff for extended periods of time is an additional major stressor. Social Service personnel must be sensitive to the need for intensive family support and intervention.

The J. family reported the disruption they experienced with twenty-four hour nursing services. No longer were the family members able to be so casual about dress or mannerisms. The nurse was a constant presence who began to discipline the other children in the home.

The medical training foster families receive will need to be intensive and suited to the individual needs of the child. It is anticipated that training may include up to twenty sessions of general medical training related to a specific child's problems and needs.

Josua's foster family received medical training at the Children's Hospital over a two month period of time which assisted them in understanding tracheostomy care and cleaning, all necessary for his survival. Suctioning the trach and placing him on an apnea monitor during sleeping hours were only two of several major requirements of the twenty-four hour care he required.

Ultimately support staff need to help the family develop skills to access the support they require and to interface effectively with all parts of the service delivery system which will be required to support the child in foster care. Therefore, a healthy working relationship between support staff and family is critical so that teaching and training can occur. The adequate development of these skills will make the work of social service staff and medical staff remarkably easier and enable the successful foster placement of this population of children.

Summary

The La Rabida—Children's Home and Aid Society of Illinois Project is the first undertaking of its kind in the nation. A unique medical and social service partnership of this magnitude is essential to provide in-home foster care services to this complex population of children requiring much therapeutic and medical assistance. Clearly there will be many challenges and risks to be faced on the part of all those affected by this project. As human service and medical professionals we have much to learn from the biological and foster families who parent these children and certainly from the children themselves. The impressions and knowledge yielded from this experience will have great impact on the development of a model of service delivery to be replicated in other communities throughout the nation.

References

- Cline, F. W. (1979). *Understanding and treating the severely disturbed child* Evergreen, CO: Evergreen Consultants in Human Behavior.
- Dane, E. (1985). Profession and lay advocacy in the education of handicapped children *Social Work* Nov./Dec.
- Davis, Foster Whitworth (1984).
- Department of Health and Human Services, (1985). Office of Human Development Services, Administration for Children Youth and Families Washington D.C., Grant No. 90-CW-0790.
- Diamond L., Turner A. (1984). *Placement of children with medically complex conditions in foster care: A preliminary discussion of state agency policies*. Children Home Health Network.
- Division of Educational Services, (1981). Special education programs to assure the free appropriate public education of all handicapped children, Third Annual Report to Congress on the Implementation of Public Law 94-142: The Education for all Handicapped Children Act. Washington D.C.: Department of Education.
- Featherstone, H.F. (1981). *A difference in the family* New York: Basic Books)
- Foster, P., Davis, A.B., Whitworth, J.M., & Skinner, R.G. (1982). Medical foster care: An alternative nursing practice. *MCN*, 7 245-248.
- Gortmaker, S. Demography of chronic childhood diseases (1985). In N. Hobbs, M. Perrin Eds. *Issues in the care of children with chronic illness* (pp. 135-154): San Francisco Josey Bass.
- Hachstadt, & Freeman, (1984).
- Katz, L. (1987). An overview of Current Clinical Knowledge about Separation and Placement. *Child and Adolescent Social Work*, 3 & 4.
- Kohrman, A.F. (1985). Home Health Care for Chronically Ill Children. Invited testimony to the U.S. Senate Committee on Labor and Human Relations. Washington, D.C.
- Merkens, M. (1983). Transitional Care for Chronically Ill Children. La Rabida Children's Hospital Chicago, Illinois.
- Murphy, K. (1987). Conversations with K. Murphy, Social Work Specialist Children's Home Health/Network of Illinois.
- National Center for Health Statistics, 1967-1981.
- Newacheck, P.W., Budetti, P.T., & McManus, P. (1984). U.S. Department of Health and Human Services.
- U.S. Congress (1985, November 29) P.L. 94-142 5. 6., 94th Congress.
- Pless, I.D., & Perrin, J.M. (1985) Issues Common to a Variety of Illnesses. *Issues in the Care of Children with Chronic Illnesses*, pp. 41-60.
- Project Impact Inc. (1984) (Member of Family Builders) Boston, Massachusetts.
- Spitz, R.A. (1945) Hospitalism. *In the Psychoanalytic Study of the Child*, Vol. 1 (pp. 53-74). New York: International Universities Press.
- United Cerebral Palsy Association. (1986). *The Baby House*. Miami, Florida.