BEACH CENTER RESEARCH BRIEF

Inclusion of Students Supported by Ventilators

who: 77 families in 27 states
what: Two surveys (one for families, the other for educators) relating to the barriers faced by families whose children are supported by technology
when: 1990-1991 school year
where: Beach Center on Families and Disability at the University of Kansas
why: To collect data on factors affecting parents and local education agencies when making educational placement decisions for children supported by ventilators
How: Mail surveys (plus 25 parents and 20 educators who supplemented survey findings)
BOTTOM LINE: Parents and educators face a lot of problems to get appropriate educational services for children who are ventilator assisted. Major barriers cited to a free appropriate public education in the least restrictive environment possible were: policies, personnel shortages, conflicts over service funding, and educators' stereotypes about students. Many solutions were given, including open communication and flexibility on the part of all involved.

Background: Until 1970, most children supported by mechanical ventilation lived in hospitals or long-term facilities. Cost containment, equipment portability, and increased home nursing support have resulted with many of these children living now in their home and using community-based care. This change impacts schools unused to providing services for this student population.
Methodology: With assistance from state and local agencies, Beach Center researchers launched an extensive search across 45 states to locate families with K-12 students using ventilators. One hundred and seven families returned consent cards and were sent survey materials. From that number, 77 families from 27 states returned usable surveys.
Principle findings: The study confirmed that parents and educators must overcome a significant number of structural and attitudinal barriers. A significant roadblock was that no one agency or service system was responsible for providing transitional service from hospital to home. This deficiency frequently resulted in uninformed parents left to use trial and error devices to establish educational services for their child. After initiating their service search, parents found no clear policy concerning funding for health care and related services during school hours. Additionally, despite growing awareness of students with disabilities, negative attitudes still presented barriers. Schools feared liability lawsuits and the use of complex medical technology in the classroom. Findings did show, that once initial fears were addressed through written emergency plans and familiarization with ventilator technology, the majority of educators readily accepted students. Data indicated that establishing appropriate services took a variety of approaches ranging from passivity to aggressive litigation. A clear majority (87%) were satisfied with their children's current educational placement; dissatisfied parents typically raised concerns about school ability to provide therapy for children and/or expressed concern regarding increased opportunities for integration. Regarding planning, 92% of parents reported they had an Individualized Education Plan (IEP) or other written education plan, and that planning was seldom completed during a single IEP meeting. Typically, planning occurred informally through the year with notes, short conferences, and telephone

calls. In nearly every case, parents or other family were involved in planning process with 78% reported satisfaction with their level of responsibility in planning. Members of the non-school medical team, particularly physicians, were reported to play a critical role in dispute resolutions over related service.

Suggested strategies: Because planning is labor intensive and frequently involves persons from diverse, professional backgrounds, participants must be open to new problem solving approaches. Open communication using good listening skills, respect for differing opinions, and good faith negotiation should lead to positive relations.

Related publications:

Clatterbuck, C. C, & Tumbull, H. R. (1995). The role of education and community services in supporting families of children with complex health care needs. In G. H. Singer, L. E. Powers, & A. L. Olson (Eds.), Redefining family support: Innovations in public-private partnerships (pp. 389-412). Baltimore: Brookes.

Jones, D. E., (1993). The Disney connection. In P. J. McWilliams & D. B. Bailey, Jr. (Eds.) Working Together WIth Children and Families: Case Studies in Early Intervention, (pp. 121 -136). Baltimore: Brookes.

See also the "How To" fact sheets developed by the Beach Center from this research: *Improve the School Day of Your Student Supported by Medical Assistance* (for teachers), *Get Educational Services for Your Child Supported by Medical Assistance,* and *Obtain Quality, In-Home Nursing for Your Child Supported by Medical Assistance.* Fact sheets are available for $.50 each (price includes shipping).

This research was conducted by the Beach Center on Families and Disability . Funded by the National Institute on Disability Rehabilitation and Research and private endowments, the Beach Center concentrates on research, training, and dissemination activities to aid family empowerment. For more information, contact The Be ach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045, 785-864-7600 (Voice/TDD), e-mail: Beach@Dole.Lsi.Ukans.Edu