

MINNESOTA Health care News



From hospital to home

A team approach to care for children with special needs

By Judy Giel, RRT, CRTT

There is no day more special than the day a child comes home from the hospital. That day is even more important when the child has spent months, perhaps even years, in the hospital. For the parent or caregiver, bringing home a child who relies on technology and therapy for survival is much easier when there is a team approach to taking care of the child. Such an approach involves the hospital, the home care provider, and the family caregivers. In recent years, advances in medical technology have made it possible for more and more children to be cared for at home rather than in hospitals. At the same time, because of the high cost of inpatient hospital care, the home care industry has seen an increase in technology-dependent patients being discharged to the home environment.

In addition, both families and medical professionals often feel that children who require life-sustaining equipment and services will do better at home than in a hospital. The American Academy of Pediatrics' Committee on Children with Disabilities has stated that home care for technology-depend-

ent children "may offer the advantages of supporting the child's growth and development in a more nurturing family environment without compromising comprehensive health care delivered in a cost-effective manner."

With all of this support for getting children home, it is more important than ever to coordinate care for children who are discharged to the home with supportive technology, whether it involves feeding tubes, catheters, mechanical ventilators, monitors, or other devices. Some conditions may require the use of rather simple technology for only a short time, while others require lifelong support on more than one complex device.

Helping technology-dependent children—and their families—make the transition from hospital to home presents coordination, communication, and education challenges. Providing the necessary tools and education to coordinate the care for the technology-dependent child, as well as access to a team

of professionals to help answer questions, helps reduce families' and medical professionals' frustration and anxiety and, most importantly, contributes to positive outcomes for the child.

St. Paul-based Pediatric Home Service (PHS) has developed such an approach over the past 17 years in greater Minnesota. The pediatric health-care community, payers, schools, and families have partnered with the PHS staff of respiratory therapists, nurses, pharmacists, dietitians, social workers, and educators to create individualized plans of care for thousands of children with special needs.

The move home from the hospital requires a coordinated effort by physicians, home care providers, and the family. The physician must be consulted regarding necessary changes to the child's care plan and must receive reliable and timely information to ensure the child has access to urgent treatment. The home care providers need to be trained effectively and demonstrate the proper skills to care for the medically dependent child. The family relies heavily on both the physician and the home care providers. In addition to advocating for the health of their child, the family caregivers also manage the child's care. PHS works with other health care professionals, payers, and family caregivers to ensure that the care team effort is well coordinated.

Beginnings

In the early 1990s, Logan, a ventilator-dependent child, could have faced growing up in an institution rather than in his home. For his family, physician, and hospital clinicians, such a future for Logan was unthinkable. The hospital team contacted PHS to help coordinate



with the physician, hospital staff, home-care nursing agency, and family to bring Logan home.

Bringing Logan home required more than exceptional health care. Many obstacles had to be overcome before he could be discharged. PHS focused on Logan's individual needs by working closely with the hospital care team to develop a plan of care.

Because of the highly specialized medical life-support equipment and technology required, the plan of care was designed to cover customized, hands-on training for the home-care nurses and family caregivers. A simulated home care set-up was created in the hospital so that caregivers could learn and practice while under the supervision of the pediatric pulmonologist, critical care nurses, and respiratory therapists. Key elements of the plan of care include ensuring the ability to respond immediately to an emergency and providing technical support, customized written educational materials, and 24-hour on-call clinicians.

While clinical professionals prepared the "medical home" environment, employees at the Minnesota Department of Health and the Department of Human Services worked with the federal government on payment and services. They helped obtain a waiver that allowed adequate payment for in-home nursing, medical equipment, supplies, and services that were paid for in the hospital setting but not to the extent required in this home-based model.

In the end, the team effort was a success. Logan lived with his family and progressed to living in a group home. He will always be ventilator-dependent because of his neuromuscular trauma, but he has participated in community life as normally as is possible with his disability.

Key components of care

The relationships built in this model of family-centered home care are the foundation for taking care of children with special medical needs. This type of care requires a dedicated team that embraces the value of thinking about the possibilities in caring for these unique children, rather than dwelling on the difficulties. In addition to this "care from the heart," the following factors are essential for successful outcomes.

Safety. A care plan focused on safe medical care provides the framework

for achieving positive outcomes. The team approach to developing a coordinated care plan begins with the family and involves the hospital and health care providers, payers, and family members, as well as the patient. The plan incorporates needed services, such as pediatric and neonatal respiratory care, infusion therapy with on-staff registered nurses and pharmacists, medical equipment and supplies, nutrition care provided by dietitians, and asthma management supervised by respiratory care practitioners.

Planning for care begins when a PHS clinician reviews the child's medical history and current status and assesses the needs of the child and the family during a hospital visit. Once the equipment, supply, and service requirements have been identified, PHS clinicians visit the home to assess the environment and ensure safe operation of medical equipment; safe storage of medications, supplies, and formula; and emergency back-up plans for extended power failures, severe weather, and potential community catastrophes. This information is given to the treating physician. When the safety issues have been addressed and resolved to the physician's satisfaction, discharge planning can proceed.

Comfort. While assessing the home for safety concerns, PHS clinicians also evaluate how to make the child most comfortable at home. A natural instinct is to set up the child in his or her bedroom. While this may sound logical, it's not always the most practical solution. Because the goal is to fully integrate the child into family life, it's often best to set up the child in the family room or "close to the action," especially if mobility is an issue.

Primary care. Assigning a PHS primary care clinician (e.g., a respiratory therapist, nurse, dietitian, or social worker) to each child's case facilitates communication, coordination and continuity of care, and advocacy for the child. The clinicians work closely with the family, earning their trust and confidence as a consistent and reliable member of the care team. Physicians work in tandem with the clinicians.

Insurers' care managers have access to the medical rationale and individual requirements to authorize payment for care outside the hospital setting. In addition, they have access to PHS reimbursement specialists to consult regarding

payment issues and a knowledgeable clinician to consult on medical issues.

Education and training. As soon as the home caregivers are identified, PHS provides clinical education and hands-on training on sophisticated medical equipment, supplies, medications, and delivery devices. Educational materials are written for the family and other caregivers based on clinicians' first-hand experience, matching the appropriate technology to the prescribed plan. Emergency response procedures and equipment troubleshooting are practiced in controlled settings before the child is discharged from the hospital.

Technological support. PHS employees are trained to evaluate sophisticated medical equipment performance on a regular basis. Those involved in caring for special needs children have immediate, around-the-clock access to employees who can answer questions and address concerns about the technology.

Electronic medical records (EMRs). EMRs enable physicians to access privacy-protected patient information. Because caregivers provide patient-specific details only once, they don't have to repeat them to each care team member. The physician has easy access to this up-to-date information in the PHS database.

Social services. As part of the coordinated care plan, PHS social workers connect families with community resources and help families manage crises.

Special needs, special teams

Caring for children with special and often complex medical needs requires treatment plans specifically designed for them. The child's family serves as the best advocate for health care necessary to achieve positive outcomes. PHS respiratory therapists, nurses, pharmacists, dietitians, social workers, and educators work with the family, physicians, and other caregivers to plan the needed care and acquire the necessary equipment. Positive outcomes for these children are the result of meticulous planning, coordination, communication, and education—and care that comes from the heart.

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