Meeting the Unique Needs of the Pediatric Home Care Patient—Lessons from a Full-Service Provider

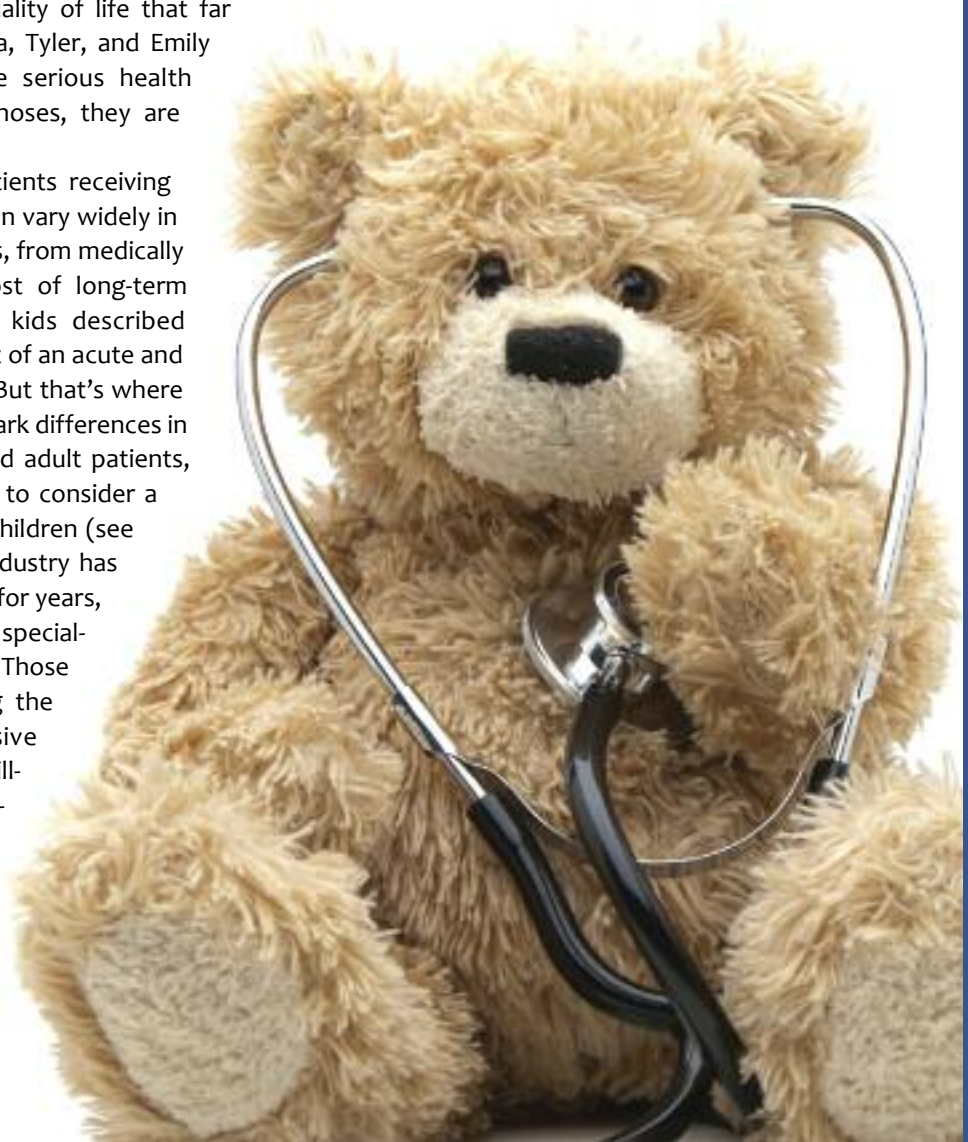
By Susan Wingert

Tana was diagnosed at birth with spina bifida, along with a brain malformation, breathing disorder, and Methicillin-resistant Staphylococcus aureus (MRSA). Ira was born with Pompe disease, a rare neuromuscular disorder, and spent most of the first year and a half of his life in the hospital. Tyler required two surgeries within 16 hours of birth that left him with an extremely short bowel and little chance of survival. Born with multiple congenital problems, Emily struggled with basic functions most kids do without thinking: moving, eating, and breathing.

For these kids with multiple, often life-threatening health problems, survival means reliance on thousands of dollars of high-tech medical equipment, complex therapies, and a host of caregivers to manage them. In the last 20 years, the gradual shift in care of these children at home rather than in a hospital or long-term care facility has resulted in better outcomes as well as cost savings. Today, thanks to medical advances, more sophisticated equipment available for the home, and the help of a team of dedicated health care providers, including organizations that provide alternate-site infusion therapy, they not only survive, but also thrive. They are able to be at home with their families, take part in daily activities, and enjoy a quality of life that far exceeds expectations. Tana, Ira, Tyler, and Emily are shining examples. Despite serious health problems and early dire prognoses, they are each living life to the fullest.

As with adults, pediatric patients receiving infusion therapy in the home can vary widely in terms of their health care needs, from medically complex cases requiring a host of long-term home care services (like the kids described above), to the simple treatment of an acute and time-limited episode of illness. But that's where the similarities end--there are stark differences in the clinical care of pediatric and adult patients, requiring health care providers to consider a host of factors when treating children (see box, page 22 for more). Our industry has been treating younger patients for years, but only a handful of providers specialize in this patient population. Those that are dedicated to meeting the unique, ongoing, and extensive needs of children with chronic illnesses are even more uncommon.

This article shares some of the core essentials—from both the clinical and business model perspectives—based on my experience founding and building an organization that specializes in treating medically complex pediatric patients in their homes. From day one, our mission has been to do everything possible to help these children live life to the fullest despite medical challenges most people can't even imagine. At times fulfilling this mission has meant balancing two seemingly opposing forces: passion and profitability. We are driven to provide intense, high-quality care to high-acuity patients. Yet, to continue doing that, we must remain profitable. Fortunately, we've been able to do both—all while filling a meaningful niche and growing a successful business.



Factors to Consider When Treating Pediatric Patients

- **Metabolism.** Children metabolize drugs differently than adults—their hydration needs are even different, based on their evolving physiology. Pharmaceutical dosing must be performed based on weight with more frequent follow-up and increased scrutiny as that weight changes. For patients with multiple medical conditions, drug interactions must be closely monitored.
- **Growth.** Children are constantly growing, so nutritional and drug regimens also require constant monitoring and adaptation to meet changing needs. The fact that growth typically occurs in spurts makes it less predictable. In addition to physical growth, children pass through many stages of cognitive development and emotional awareness as they mature. Providers who are working closely with pediatric patients need to be able to understand and adapt to a child's current physical and emotional construct.
- **Body Size.** Smaller body size means different needs in terms of venous access, ambulatory infusion pumps, ventilators, and so on. In addition, depending on their development and mobility, catheter securement and site care can be a challenge to maintain.
- **Developmental Considerations.** Depending on their age and maturity level, children aren't always able to understand their condition, or even that the medical team is trying to help them. It takes a special touch to calm a nervous or fearful child, gain their trust, and execute a care plan that could include painful procedures, such as lab draws or injections.
- **Family.** While the child is the patient, the entire family is involved in the treatment. Family members act as caregivers—and often as coordinators of care for medically complex patients—who need education, training, and support. Families with chronically ill children are typically subjected to emotional and financial stressors, and need additional resources to navigate the complex health care environment.
- **Coordinating Care.** Providing care as part of a team requires good collaboration, but this is especially true for providers working with pediatric patients. Growth and other factors call for more frequent assessments, checking in with parents for observations, and a never-ending feedback loop. Medically complex children add more members to the team, requiring more deliberate communication.

Tana

Tana, 13, goes to school, swims, skis, tubes, and takes family vacations despite the fact that she is in a wheelchair, doesn't speak, and receives enteral therapy. She was born with spina bifida, brain malformation, and a breathing disorder.

Recognizing a Need, Filling a Niche

Twenty years ago there were few in-home services available to support the complex needs of medically fragile children like Tana, Ira, Tyler, and Emily. While the roots of home care stretch back more than a century, in the 1960s when Medicare made home care services available to the elderly and, later, to some disabled younger Americans, the industry took off. But medical equipment and supplies were mostly designed for adults, and finding medical equipment for pediatric patients was a challenge. [*Editor's Note: Medicare currently has no comprehensive home infusion benefit, offering only limited coverage under related benefits in Medicare Parts B and D, with better coverage for those enrolled in many of the Medicare Advantage plans. NHIA is strongly advocating that the U.S. Congress and federal administration fix this Medicare coverage gap with a consolidated, comprehensive Medicare home infusion benefit. Visit* ***www.nhia.org*** *to learn more about how you can lend your voice to this critically important industry-wide legislative effort.*]

In 1987, I met a group of pediatric pulmonologists in the Twin Cities who believed kids with multiple health problems could do better at home—with their families

and the proper support—rather than in a hospital or long-term care facility. These physicians, who often treated young patients with multiple medical conditions and severe underlying conditions, were strongly convinced that children who live at home have better outcomes than children who are institutionalized. Their belief coalesced with advances in medical technology, making it possible to provide ventilator support and respiratory care for pediatric patients at home.

With a clear need for home care services for children, the support of the community, and the advent of the technology to make it possible, Pediatric Home Respiratory Service (now Pediatric Home Service, or PHS) was formed. Our organization was supported by many in the pediatric medical community, including the pulmonologists mentioned earlier. In fact, one of those physicians, Roy Maynard, M.D., began working with PHS in 1993 as the Medical Advisor and this January joined the company as its on-site Medical Director.

PHS was founded in 1990 with six employees operating out of a basement in St. Paul, Minnesota. The company grew and moved to accommodate expanding services and staff. Based on the underpinning that we were—and still are—part of a larger team effort, an infusion department and on-site pharmacy were added in 1996. Today, PHS provides a wide range of increasingly complex pediatric infusion therapies, including new therapies such as enzyme replacement and cardiotonics. Over the years, we also added nutrition, social work, and education services. The name was changed in 1997 to reflect the full range of care offered. Covering such a wide range of care requires comprehensive services including specialized clinical care, integrated nutrition and pharmacy support, equipment and supplies, education, training, help with reimbursement, and family support.

Ira

Ira, 4, was born with Pompe disease and spent most of the first 18 months of his life in the hospital. At three years of age, he received alglucosidase alfa (Myozyme® Genzyme) in the home. His progress has stunned many health care professionals.

Kids Need to Be Treated Like Kids

Children are not small adults and no two pediatric patients are the same. They are growing, and have distinct developmental stages and milestones—as babies, children, and adolescents. They need care, treatment, and equipment geared to their little bodies and changing needs. And often, they can't tell you how they feel or what they need.

A variety of clinical and support factors need to be considered when pediatric patients begin service. Our team is keenly aware of these, and over the years has modeled our organization on responding to them. Following are some examples of the most common considerations with pediatric patients and strategies to address them.

- ***High-tech equipment for little bodies.*** Twenty years ago, bringing a ventilator-dependent child home meant adapting a clunky piece of equipment, originally designed for hospital use, to fit into the home environment. Fortunately, finding medical equipment that works for pediatric patients isn't as challenging today as it once was. For example, many medical suppliers now offer lines of catheters and tubing in smaller sizes. In addition, pump manufacturers have developed small-volume pumps for delivering enteral therapy. Elastomeric pumps also offer advantages for pediatric medication delivery because they support smaller tubing without creating additional pressure, they're easy to use, and they require no programming in the home. For smaller and more active children, backpacks that hold the IV solution and pump promote activity that is so essential to growth and development. Our nursing staff do a great deal of patient and family education on a variety of topics, but one area of critical importance to pediatric patients includes special training on care and maintenance of IVs and ports, including securement and protection for active patients.
- ***Customized clinical care plan.*** The work to transfer a child from hospital to home begins before discharge. A multidisciplinary care team is needed, including the

physician, family, and all providers who will be involved in the care at home, in order to create a safe care plan customized for the child. An environmental assessment of the home is essential to ensure the necessary medical equipment can be safely operated, and to establish an emergency back-up plan in case of power outages. Infusion supplies such as compounded medications can often be stored in a family refrigerator, but for parenteral nutrition, which can be supplied in large-volume bags, a separate refrigerator may be necessary.

- ***Caregiver education.*** A critical element of the care plan involves training the family members and other caregivers to use the equipment, administer infusion medications, and troubleshoot. PHS's education department develops materials and teaching tools that are used for training and left in the home for reference. Parents are also encouraged to call—any time--with questions. Depending on the acuity of the therapy ordered by the physician, multiple home visits may be needed to ensure the family will be able to comfortably deliver safe care in the home. Nurses and pharmacists perform ongoing clinical monitoring, assessing the efficacy of the prescribed therapy through physical assessments and lab result monitoring.
- ***Pharmacy service designed for kids.*** In order to compound highly individualized sterile preparations, plan and monitor drug regimens, make recommendations on the selection, dosage, interactions, and effects of drugs, and work with a multidisciplinary team to coordinate care of young patients, pharmacists must attain a level of clinical expertise with pediatric care. Knowledge must include an understanding of weight-based pediatric dosing, as well as the differences in drug metabolism between pediatric and adult patients. Careful attention is needed in order to detect adverse effects and possible interactions—keeping in mind that smaller children may not be able to verbally report symptoms of these negative events so parents must be taught what to look for. Finding the maximum therapeutic effectiveness is also part of the care plan. PHS pharmacists perform frequent pharmokinetic monitoring, and confer with the physician on adjustments.
- ***Additional family support.*** Caring for medically fragile children at home can take an emotional, physical, and financial toll on the family. PHS provides resources and training for family members and offers medical social work services that range from help with transportation and housing to emotional support and counseling. Health insurance coverage and reimbursement are more complicated for parents whose kids require expensive, high-tech equipment and complex infusion or respiratory therapies. PHS billing and insurance specialists work with clinicians, families, and payers to answer coverage questions, obtain reimbursement for medically necessary supplies and services, and help with payment plans and medical assistance.

Tyler, 6, required two surgeries within 16 hours of birth that left him with an extremely short bowel and little chance of survival. Now, he is an active young boy who no longer needs g-tube feedings.

Finding a Balance

The most important yardstick by which to measure success is patient outcomes. Many of our patients have surpassed expectations by simply doing many of the ordinary things most kids do. And while there may not be a lot of empirical evidence to support the notion that kids with complex medical conditions have better outcomes at home, we're hard-pressed to find any organization or individual who works with these kids who doesn't believe it. There *is* a growing consensus that these children belong at home.

Measuring business success is slightly easier. We opened our doors in January 1990, broke even after ten months, and have been profitable ever since. Today PHS employs 140 people. The staff includes clinicians, pharmacists, dietitians, social workers, educators, billing and insurance experts, and equipment specialists who serve a total patient census of about 4,720 patients.

We found a niche and met a need. We also built a reputation as a trusted partner by hiring talented, experienced people who shared a commitment to providing unparalleled high-quality clinical care and customer service. As a company, we continually aspire to provide a higher level of service. We embrace new therapies, and we put policies in place to generate continuous performance improvement.

The Big Picture for Alternate-Site Infusion

PHS has built a business based on providing a full-spectrum of services under one roof for a narrow patient population—infusion therapy is just a component of the services in our model. The foundation of our success is our knowledge and experience with this type of patient and the core elements of care that we've developed to address the needs of children based on that expertise. We realize that there is a wide range of infusion provider business models in the industry today, and not all are suited for this type of patient specialization or service line diversification.

Emily

Emily, 9, was born with multiple congenital problems and struggled with basic functions such as moving, eating, and breathing. While she occasionally uses oxygen and will require more surgeries, she is taking dance.

Essential Pediatric Resources

- *Harriet Lane Handbook*
- *American Academy of Pediatrics Textbook of Pediatric Care*
- *Wong's Essentials of Pediatric Nursing*
- *Lexi-Comp's Pediatric Dosage Handbook*
- *The Teddy Bear Book Pediatric Injectable Drugs*

Depending on your local market, pediatrics may not be an easy area to tap into. It can present a "chicken and egg" scenario where it's difficult to get referrals without clinical expertise and a good reputation, but it's impossible to build a program based on clinical expertise—or a reputation for that matter--if you don't have enough referrals. Like forays into any other clinical specialty, providers moving into pediatrics should take into consideration each of the multiple factors unique to this area, create a niche based on clinical expertise, and possess a true passion for the patient (see the box on this page for a list of essential resources). In short, there is a right and a wrong way to do pediatrics.

The good news is there is more than one way to reach the pediatric patient population. In this new era of health care delivery, where provider affiliations, such as medical homes and accountable care organizations, are becoming increasingly important, business models can take a variety of shapes. While PHS's model covers a wider spectrum of services, others may want to provide services for certain points on the spectrum, infusion services only for example, and rely on partnerships to ensure access to additional services such as respiratory therapy and home medical equipment or nursing. You can effectively serve a market by allying with providers that fill related niches—as long as you know and trust your allies.

Regardless of your specialty or your partners, success depends on delivering quality care and obtaining reimbursement for your services. It's essential to help payers understand that it costs less to keep your patients at home--with a stronger potential for a positive outcomes--and to prove to referral sources that they can trust you with their patients.

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