



FACES *of* HOME HEALTH

Caring for Pediatric Patients and Family Caregivers Through Innovations in Home Health

Pediatric patients who receive home health care are a vulnerable population with specific and unique needs. Many pediatric home health patients have trouble communicating their health concerns due to the severity of their condition and their young age. Most children who need pediatric home health services are born with multiple comorbidities, severe intellectual and/or physical disabilities, or develop serious conditions as time progresses. Children who use pediatric home health services typically seek coverage for these services through Medicaid, private insurance, or state government programs. Without the use of skilled home health care, many of these patients may be separated from their families, as proper care would require institutionalization. Skilled home health care allows pediatric patients to receive the best possible care, while keeping families together in their homes and keeping patients connected to their health care providers.

Working with children with disabilities or severe, complex illnesses often comes with unique challenges. For example, learning to anticipate and read signals of distress is critical for clinicians caring for children.

Additionally, these pediatric patients often have difficulty with transportation to and from outpatient settings. Skilled home health care offers two critical functions in caring for children: (1) home health care allows skilled medical teams and caregivers to work directly with the patient in their home where they are more comfortable; and (2) clinicians are able to educate patient and family caregivers on treating the child within the environment in which they spend the most time.

As an example of the benefits of pediatric home health care for patients and their families, we profiled BAYADA Home Health Care, a national home health care provider that serves patients in over 22 states. BAYADA's specialties include home health, adult nursing, assistive care, pediatrics, hospice, and habilitation. BAYADA Pediatrics specializes in care for children from newborns to adolescents. Clinical care teams include home health nurses to assist with skilled medical services and home health aides to assist patients with limitations on activities of daily living. Other members of the care team include the registered nurse clinical manager, who supervises

Why develop specialized pediatric programs for home health?

Pediatric patients represent a vulnerable population often well suited for health care at home. The ability to receive care in the home stabilizes family relationships and gives parents peace of mind that they may not be able to receive if a child is being treated in a setting away from the home.

Children, however, pose different challenges for home health nurses than older adult populations. These patients have their own set of needs, circumstances, and environmental differences that make caring for them unique from the care given to adults. Training models, such as the two variations of BAYADA's SIM lab—high- and mid-fidelity—provide necessary education to home health nurses on how to meet the needs of this young, vulnerable population. Nurses trained using the SIM lab feel more confident when entering a patient's home, armed with the skills to properly administer care in the home, according to BAYADA Area Director Michael Ward, RN, MBA, A

Skilled home health care differs from a hospital setting, where peers surround nurses throughout the day. Instead, home health nurses are often on their own during periods of care, making hands-on skills training—like that provided in the BAYADA SIM labs—crucial to providing nurses the proper skills and confidence to care for pediatric patients at the highest possible level.

Pediatric home health programs are of critical value to families who have children with special needs, and who want to keep their family together under one roof. The Davis family is one example of how pediatric home health is keeping families together.

and oversees the clinical care and makes in-home visits, a client services manager to coordinate service, and an on-call manager to address concerns or questions after hours.

Clinician training is critical to addressing the home health needs of pediatric patients, and BAYADA has invested in developing specialized training and services for pediatric patients and their families. The BAYADA Pediatrics program includes innovative use of simulation training (SIM) labs, which take nurses through a series of testing exercises before being placed in the field. These labs, which act as a part of field testing, include life-sized, and life-like mannequins that simulate a child's reactions to their environment or disease and offer a safe way to train nurses to work with children.

In addition, like many home health care providers, BAYADA focuses on putting the patient and family at the center of care. By bringing care directly to the patient, the home health team is able to minimize isolation for the patient, and address health concerns within the patient's dominant environment. Through a combination of Medicaid and state and private insurance, families are able to receive comprehensive care for their children, and increase their child's ability to live in the community's mainstream regardless of individual physical or cognitive disabilities.

Born at 26 weeks, Kasey Davis was a premature baby and immediately received a tracheostomy, using a ventilator full-time to breathe. From birth, Kasey was fed solely through a feeding tube. Today, at age three, with the help of BAYADA nurses and the support of the Davis family, Kasey is off her ventilator, slowly learning to feed through her mouth, and had her tracheostomy tube removed through a permanent decannulation earlier this year. Kasey has been around doctors and nurses around-the-clock in her short life, and the comfort she and her parents feel with the BAYADA team has helped Kasey feel at ease during treatments that are often scary for younger children.

Andrea Grady, a registered nurse and field nurse with BAYADA, is Kasey's primary nurse. Andrea works with Kasey 8 hours a day, four days a week (she splits the additional 8 hours a day with other nurses on staff), acting as her nurse, and teacher—able to interpret Kasey's needs and keep her healthy.

Transitioning Pediatric Patients from Feeding Tubes to Eating

Early on, Kasey's ventilator prevented her from being fed by mouth. Now that she is off the ventilator, Grady is teaching Kasey to feed by mouth. For many



patients with similar conditions, this can be a difficult process, as children who have used a feeding tube since birth have not developed the skills or muscle movement to swallow. Kasey, because of her comfort with a feeding tube, has an aversion to touch for most foods. In



order to teach Kasey to feed by mouth, Grady uses a number of unique strategies to help the three-year old feel comfortable and ease the transition. For example, Grady has Kasey manipulate Play-Doh to get her comfortable with the sensation of food-like textures in her hands. Grady will also take finger foods and touch them to various parts of Kasey—her nose, chin, both cheeks—and have her kiss and brush her teeth with the food to first get Kasey acquainted to having solid food near her mouth. Next she'll work with Kasey to take small bites of the food before spitting it out to acclimate Kasey to biting and chewing solid foods. Like many children who have had a tracheostomy, Kasey likes foods that have an intense taste, such as salty and spicy foods.

In order to get Kasey comfortable with swallowing, Andrea puts liquid into a syringe and slowly drops the liquid, one-drop at a time, into Kasey's mouth, encouraging her to swallow. She also places mirrors around Kasey and shoots video of her, letting her see how she swallows, and demonstrating the technique with herself and Kasey's parents.

Teaching Verbal Skills to Pediatric Patients

With the ventilator, Kasey was unable to speak early on. In order to best connect with and understand Kasey, Grady decided to learn sign language alongside Kasey through a series of videos,

and practicing in her free time. Now, Grady continues her American Sign Language education along with Kasey, even though Kasey is fully verbal, as a means of continually developing her language skills in hopes of helping other patients in the future.

Partnerships Between the Home Health Team, Family, and Patient

Both Grady and the Davis family stressed the importance of finding an environment where everyone feels comfortable. For children like Kasey who receive extended, daily visits from home health,

the Davis family found at BAYADA a clinical team that they trust and with whom they feel comfortable leaving their child. The Davis family found that it is critically important to find a nurse who is not only highly skilled, but also a personality match. This allows for better channels of communication, increasing the quality of care provided and received.

Pediatric home health care is essential to allowing families to continue leading their lives together in their own homes, while feeling their special needs child is safe and well supported.

Information About Pediatric Populations

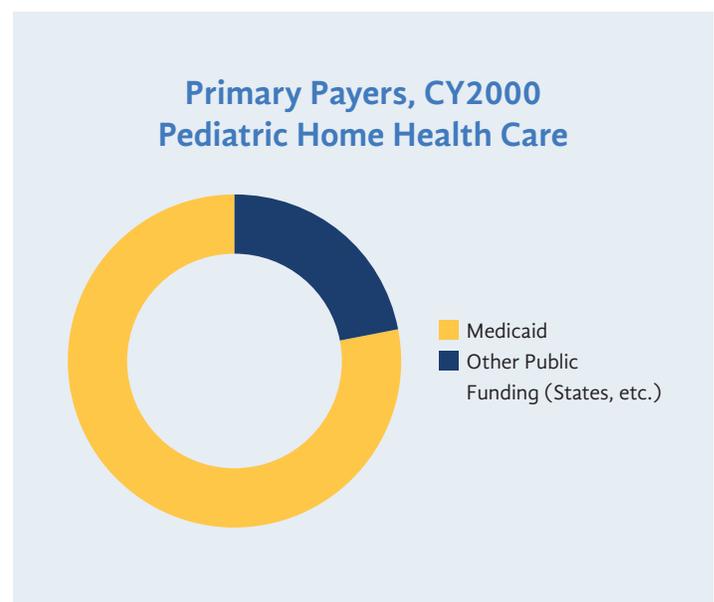
National estimates suggest that over sixty thousand children (approximately 67,200 in 2007) use home health services each year.¹ A 2006 report on pediatric home health patients from the American Academy of Pediatrics provides a snapshot of this special population:²

- The acuity, complexity, and diagnoses of pediatric patients vary widely, with the top four diagnoses as follows:
 - Cerebral palsy
 - Failure to thrive
 - Developmental delay
 - Preterm birth
- Young children are more likely than older children or adolescents to receive home-based care.

¹ Christine Caffery, et al., Home Health Care and Discharged Hospice Care Patients: United States, 2000 and 2007, 38 National Health Statistics Reports 9 (April 27, 2011), <http://www.cdc.gov/nchs/data/nhsr/nhsr038.pdf>.

² Committee on Child Health Financing, Section on Home Care, Financing of Pediatric Home Health Care, 118 PEDIATRICS 834-38 (Aug. 2006), <http://pediatrics.aappublications.org/content/118/2/834.full.pdf>.

As pediatric treatments have advanced in the health care system, home health services for pediatric patients have increased over time. Researchers in the PEDIATRICS report attributed the rise in pediatric home health patients in part to family preferences for the home setting over hospital care and the lower cost of the home setting compared to in-patient hospital care.³



³ Id. at 834-35.

Pediatric Patients Lack Access to Adequate Home Health Care Services

The 2006 PEDIATRICS paper found that pediatric home health patients lack adequate access to health care services, citing an insufficient supply of clinicians and ancillary personnel, shortages of home health nurses with pediatric experience, an inadequate payment system and overly restrictive private insurance and managed care policies.⁴

The National Survey of Children with Special Health Care Needs (NS-CSHCN) Chartbook for 2009 – 2010 further illustrates the health needs of children living with cognitive or physical disabilities.⁵ According to the survey, over 11 million children in the United States (15.1% of all children) have special health care needs⁶, and 23% of households with children include at least one child with a special health care need. The survey reports that preschool-aged children with special health care needs (from

⁴ Id. at 835.

⁵ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, The National Survey of Children with Special Health Care Needs Chartbook 2009–2010, U.S. Department of Health and Human Services, 5-6 (June 2013), <http://mchb.hrsa.gov/cshcn0910/more/pdf/nscshcn0910.pdf>.

⁶ “Special health needs” is defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” – see id. at 5.

birth to age five) have the greatest need for home health care services, followed by school-aged children and adolescents.⁷ Although Medicaid and some state government programs provide some coverage for pediatric home health care, many families with a special health care needs child pay out-of-pocket for home health care and other needed health care services.⁸

Best Practices for Pediatric Home Care Practice

The American Academy of Pediatrics offers best practice guidelines for pediatric home health care, which covers a variety of topics key for this special population⁹

- Home management of specific illnesses
- Use of medical technology and devices within the home
- Physician house calls
- Pain management
- Transporting medically fragile patients to new care settings
- Family issues and expectations

⁷ Id. at 43.

⁸ Id. at 51.

⁹ Available at <http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Section-on-home-care/Pages/Guidelines-for-Pediatric-Home-Health.aspx>.

Innovations in Training Pediatric Home Health Clinicians: SIM Lab Child Care Simulation

Recognizing the need for well-trained pediatric home health clinicians, BAYADA Home Health Care has invested in advanced labs focused on preparing nurses to serve pediatric patients. Currently, BAYADA uses two models of simulation

(SIM) labs to educate nurses in their pediatric programs, a high fidelity and mid-fidelity model. These labs give nurses practical, hands-on training to make the transition to the home easier.

High-Fidelity SIM Laboratory Training

- First introduced in 2011, the **BAYADA high-fidelity SIM lab is a full-service working training laboratory** that gives nurses hands-on training experience before treating pediatric patients in the home. Mannequins in the high-fidelity lab look, feel, and act like a live child, and are connected to a computer program that can be controlled to mimic certain symptoms. For instance, a nurse being trained in the high fidelity lab may encounter the mannequin experiencing difficulty breathing, blue lips, a seizure, or other conditions. This ability for nurses to be trained to treat real-world symptoms, before entering a patient's home, is a unique tool in pediatric home health.

Mid-Fidelity SIM Laboratory Mobile Training

- **In order to enhance the quality of patient care, and increase the lab's viability as important resource for BAYADA home health nurses, the company introduced a mobile mid-fidelity training model.** This model, according to Ward, better fits the goal of integrating clinical training with patients and families in the community. While the mannequins in the mid-fidelity model cannot mimic a live child, a snapshot of patient symptoms is instead provided on an iPad and nurses use these symptoms to treat unanimated mannequins. The program offers a cost-effective means of training nurses to respond in distress situations, and potentially offers a means to teach patient and family caregivers how to respond to situations when a nurse cannot be present. BAYADA aims to use the mid-fidelity model to increase access to quality pediatric home health for nurses and family caregivers. The ability to provide mobile, hands-on training to both home health nurses and family caregivers addresses an access barrier many patients and families currently face.

Both labs train nurses to respond to life-like scenarios before entering the home. This training model differs from the more widely used model of task-based training, followed by a home visit. Instead, scenario-based training gives nurses a more comprehensive training program to build confidence before being sent on an in-home training session. This confidence, says Ward, provides a better overall quality of care for patients. The SIM training allows nurses to go through rigorous training, learning how to correct errors in the lab rather than put a patient's life at risk.

“Due to the fidelity of the mannequin and the lab, we try to immerse the nursing team so that they really are caught up in responding,” explained Ward. “I don't think books or classroom time can teach that. You need to be in that emergency and applying that knowledge. The scenarios go through, measure and evaluate their knowledge, rather than just say what they would do in that situation.”

In the future, BAYADA hopes to use SIM labs for yearly competencies, and patient family training. The mid-fidelity SIM lab was created with mobility and accessibility in mind. With the eventual goal of a SIM in every office, BAYADA can provide hands-on training simulation to both nurses and patients' families who will care for the child on their own after the nurse leaves. This important step, connecting health care to the home and family, is one area where home health truly shows its value.