

Partnering With Families of Medically Complex Children Transitioning From the Hospital to Home

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Children with medical complexity are known to have increased safety concerns around discharge and their transition home.¹⁻³ These patients have multiple diagnoses, medications, and equipment and have high-acuity conditions that require close and constant monitoring. The home environment for these children resembles a hospital critical care unit to manage their chronic and acute conditions. Families are responsible to provide high-level care, including clinical assessment and life-saving interventions, to their children around the clock, similar to the care they would receive by expert clinicians on a high-acuity unit or ICU. The Creating and Applying Individualized Transition Plans: Learning Your New Normal (CAITLYNN) Program uses family experiences to address the increased care requirements and safety concerns associated with the transition from the hospital to the home setting.

A Parent Experience: Sue McCarthy

Our world seemed complete after the birth of our third child. We had 2 healthy boys at home and just welcomed our daughter, Caitlin.

At the age of 6 months, our daughter presented with severe gastroesophageal reflux and failure to thrive. She had a muscle biopsy, which confirmed she had

mitochondrial disease, and then at the age of 5 came a second diagnosis of Rett syndrome. For her, these diagnoses would be lifelong, affecting several organ systems and requiring multiple surgeries for life-saving interventions. Over the years, we found that for Caitlin even a small change in vitals required a hospital admission.

Caitlin had a gastrostomy tube placed when she was 10 months old. We then had to replace her bottles with a feeding pump and administer her nutrition through a surgically placed button in her belly. At the age of 22 months, she had a central line inserted in her chest to now feed her intravenously with a pump. This process required us to create a sterile workspace in our small home to store and prepare her intravenous nutrition bag and its additives. There were so many additives that needed to be drawn up and injected into that nutrition bag, and it was important not to contaminate anything, or my child could suffer a life-threatening blood infection.

Rett syndrome causes respiratory complications, so a suction machine was added along with oxygen and a bilevel positive airway pressure machine. Multiple bowel surgeries followed, which resulted in an ostomy bag being placed. She developed seizures that lasted over 12 minutes and required valium via multiple routes for administration.

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Ms McCarthy, Ms Currier, Ms Copp, and Ms Donovan all drafted portions of the initial manuscript, reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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At the end of each hospital admission, we were taught how to use any new medical equipment our daughter was prescribed and how to administer new medications via a tube or intravenous line, and we reviewed how to respond to a medical crisis. After successfully completing the bedside teach-back sessions with our nurse, I felt confident in my ability to use the equipment. We were given the discharge instructions, and off we went.

In the weeks, months, and years to follow I found myself surrounded by more medical equipment, most of which had to be plugged in with a multitude of extension cords and power strips, something I had not thought of when we were in the hospital. With 2 other children walking around, we worried about them tripping. Eventually we had to shift our kids' bedrooms around to accommodate the medical supplies, oxygen tank, blood pressure machine, infusion pumps, wheelchair, and shower chair and create a place for us to sit to make sure our daughter was safe and breathing. Slowly our home began to feel like a medical ICU.

Despite our confidence in using the equipment while she was an inpatient, we were dropped into a life that we had no preparation for and no idea how to navigate: a world filled with medical equipment, home care nursing, and so much uncertainty for our child's future. In addition to all the teaching and navigating this new normal, we had to work with multiple supply companies, manage multiple medical appointments, and provide home care nursing all while being parents to our other children. No hospital teach-back can prepare you for power outages, equipment failure, supply issues, or alarms sounding or for providing around-the-clock care or navigating the medically complex world.

I quickly realized there is more to home care than just teaching families how to use the equipment. As a parent, we are expected to assess and perform medical interventions at home to the same level as highly trained medical professionals in an ICU.

Caitlin's 17 years came with self-doubt and tears, but this became the most important job I had, and my child's life depended on it. We learned to navigate the bad days and keep Caitlin at home. Most of all, we had to figure out how to be a family that included a medically complex child.

CAITLYNN PROGRAM OVERVIEW

The CAITLYNN Program was developed to address gaps in the traditional discharge process, as shown in Fig 1. Our approach is to collaborate with the patient and family to assess the home environment before discharge, instead of the more common approach of postdischarge assessment.⁴ This allows our team to work closely with the family to navigate potential challenges before the patient enters or re-enters the home. The CAITLYNN Program aims to help families be successful and confident at home through individualized nursing-led transition planning that couples technology with nursing expertise. The program offers patient-specific home assessments, education, and recommendations for best practices. The interventions that make up the CAITLYNN Program are a companion to the standard discharge services that families receive. This service is offered with the intention of augmenting the discharge process families usually experience.

Dr Christiana Russ, Pediatric Hospitalist

In medicine, we talk a lot about transitions. The CAITLYNN Program takes a practical approach to the

logistics of taking a chronically ill child home. The use of technology, coupled with nursing expertise, can make a big difference to a family and help their sense of preparedness. The program is building on the experiences of patients, families, and the team to provide real care to real kids and families.

Patients

Target patients for the CAITLYNN Program include those with new diagnoses, new technology (including medical equipment), and/or social concerns.

Team

The CAITLYNN Program team is composed of both hospital staff and families. Our pediatric nurse practitioner guides our clinical team, which is composed of a parent of a child with complex medical needs, a respiratory therapist, nurse case management, a data analyst, and an innovation specialist. By having a parent on the team and collaborating with families of children with multiple medical complexities, we have a lens into the home environment that provides the entire team with a unique platform for intervention.

Home Assessment

Predischarge in-home visits are welcomed and completed with the family to assess the space, with their child in mind, for accessibility and feasibility. We approach the space by being mindful of the potential emergency response needs of the individual child and build out models to reflect those needs. We use emerging camera technology to capture 360° images of the home. We use these images to recreate their home environment then overlay the placement of medical equipment within the patient's own bedroom. This rendering is then shared with the patient and

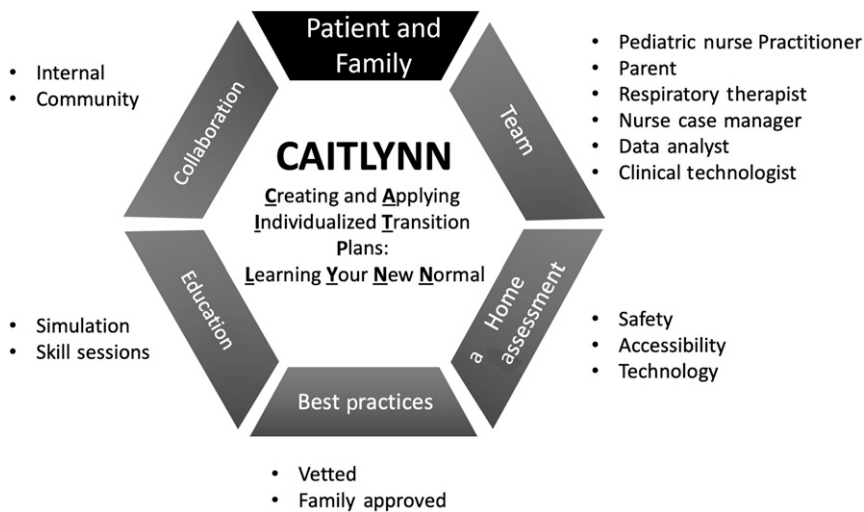


FIGURE 1
CAITLYNN Program elements.

family and also back with the clinical team after the family provides consent.

Using Massachusetts accessibility and safety guidelines,⁵ the team surveys the safety of the environment, including but not limited to the location of electrical outlets and heating vents, access to heat, and space restrictions. This is to promote the safe use of medical equipment at the point of care. Medical equipment manufacturers provide instructions for use, which includes clearance and voltage requirements, warnings, and contradictions to ensure safe use. The home assessment works to create a safe space while maintaining the aesthetics of a child's room.

A floor plan is created with suggestions for furniture placement and insight to proper placement of medical devices. The team takes into consideration the limitations of the physical space that may hinder a response to a medical emergency. An example of this is the distance from the caretaker's space to the child's bedroom and the line of view of the monitors. We aim to increase the patient and family's understanding of

safety in the home setting to achieve desired patient outcomes.

Best Practices

The team developed a checklist⁶ to help standardize our approach as we prepare each individual family for the transition to home. Our recommendations for best practices are vetted through our team and our medical colleagues and are derived from our extensive interviewing of patients with complex needs and their families. We work to adapt the home setting to enhance the comfort of the family and to promote those little moments with family that provide a sense of normalcy.

Families are offered a list of affordable product recommendations to provide organizational solutions to prepare for medical supplies and equipment in the home setting. A subset of products is shown in Fig 2. Additional emergency preparedness enhancements are also shared with families to anticipate unpredictable events, including a personalized 911 call reference script.

Education

Pre-discharge knowledge of the size and sounds made by medical equipment is provided in augmented

reality through the mARK app⁷ to help families anticipate new sounds in their environment. With formal education and practicing skills with clinical staff, families demonstrate competency for their child's specific medical interventions and emergency preparedness. If appropriate, the families are invited to take part in a medical simulation created specifically for their child's medical needs, held in a state-of-the-art medical simulation suite. This is a 2-hour educational session in which families practice responding to simulated medical emergencies using high-fidelity manikins and practice troubleshooting their new medical equipment.

Denise Currier, Pediatric Nurse Practitioner

We use simulation to prepare for real-life in-home medical scenarios that may occur with a family's particular child. For families, this experience has been shown to either boost confidence and reassurance in the ability to care for the child at home or facilitate a family coming to the realization that they are not ready and would prefer a transition to a rehabilitation facility. In the case of both outcomes, families have expressed satisfaction with their decisions.

Collaboration

Internal

Our care network consists of multiple programs currently providing post-discharge-from-the-hospital visits, which present disparate challenges from pre-discharge-from-the-hospital visits. Our interdisciplinary team continuously collaborates with these established programs and uses their experiences, challenges, and successes to iterate on the CAITLYNN Program's systems and processes.

Medical	Safety	Organization	Comfort
 Medical scissors	 Wi-Fi camera	 Shelving	 Handheld showerhead
 Hand sanitizer dispenser	 Surge protector	 Refrigerator for medications	 Decorations for age
 Medical gloves	 Clock	 Caregiver chair	 Lights

FIGURE 2
Subset of product recommendations.

Community

We have established relationships with local and national organizations that can provide the

family with additional services as needed. In addition to the 911 script, families are also connected to local utility companies and

emergency services in preparation for service outages. For families with siblings, changes to school bus drop off zones are requested to ensure that neither the medically complex child nor the sibling are ever at risk. Families are also connected to sibling services that offer child-life opportunities at home, which can help siblings cope with changes in family dynamics and provide emotional support peri-transition. The CAITLYNN Program connects the family to resources in their community that can help advocate for their child's needs.

CONCLUSIONS

A multidisciplinary approach is vital to the success of a program like the CAITLYNN Program. Our team relies on the expertise of families with experience in the complex medical system to truly understand the challenges and opportunities to provide support. We know that these are not easy transitions for families and that this population of children is likely to experience multiple transitions with new or progressive diagnoses, new medical equipment, and/or social concerns. As we continue to move this program forward, there are many additional aspects that we plan to develop, as shown in Fig 3.

Sue McCarthy

The opportunity to help others by sharing our lived experience is why I am so passionate about being part of the CAITLYNN Program team. We hope that Caitlin's legacy will help make other families' lives easier.

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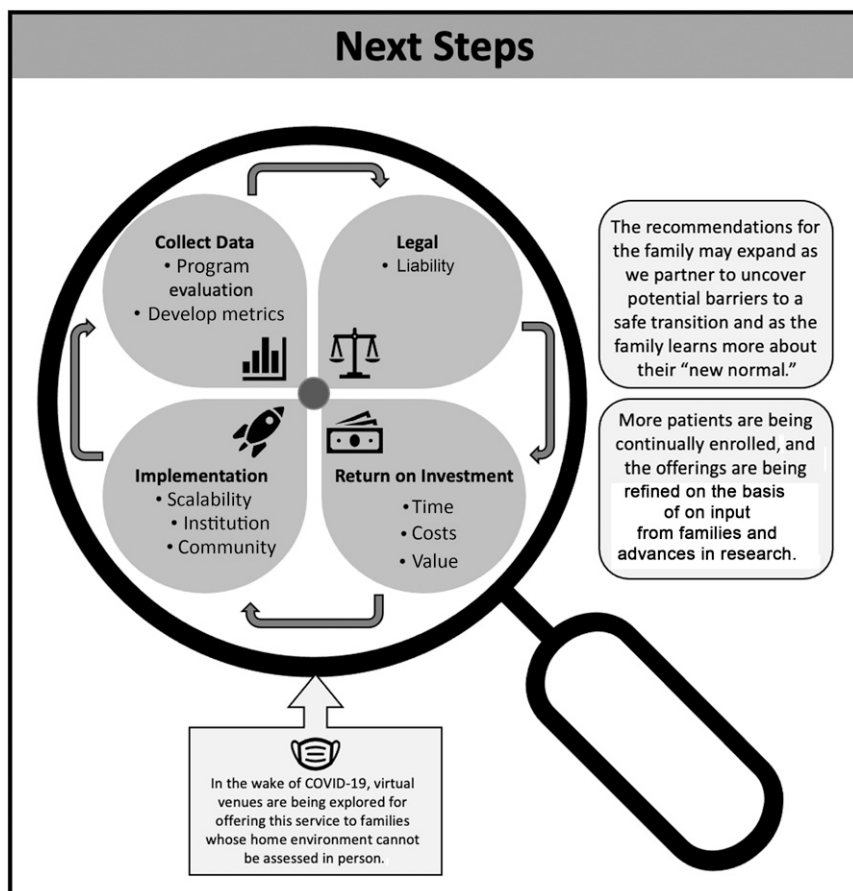


FIGURE 3
Data collection and next steps. COVID-19, coronavirus disease 2019.

RN, NEA-BC, CPHQ; the Intermediate Care Program at Boston Children's Hospital, Peter Weinstock, MD, PhD and Brianna O'Connell MS, CCLS; and the Simulation Program at Boston Children's Hospital.

ABBREVIATION

CAITLYNN: Creating and Applying Individualized Transition Plans: Learning Your New Normal

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