

Changing Palliative Care for Medically Complex Patients

Submitted by: Children's Nebraska

Silver Winner

Innovation Challenge

Overview

In a rural state with minimal access to pediatric care, children with medical complexity often have to travel hours for the specialty services offered at [Children's Nebraska](#). Many families voiced "feeling like they were on an island" without direct support from the hospital's palliative care team. Similarly, local emergency medical communities felt apprehension about taking care of medically complex children.

Recognizing a significant gap between community emergency services and the care of medically complex children, the Hand in Hand Pediatric Palliative Care Team (Hand in Hand) at Children's Nebraska, and the organization's Project Austin, collaborated to increase community emergency services awareness and education. The goal: to improve emergency care for this complex population. Through this partnership, the teams help children with serious illness, and their families, to establish and prioritize goals of medical care; assist with medical decision-making; alleviate pain and other symptoms to maximize quality of life; and provide support for physical, emotional, social, and spiritual needs. Together, the teams prevent and relieve distress, assist with communication, and promote quality of life throughout the illness trajectory while maintaining a patient- and family-centered view of medical care.

Impact

Nebraska is a rural state with minimal access to pediatric care. Children with medical complexity have minimal access to pediatric care in their home communities, requiring them to travel hours for specialty services offered at Children's Nebraska, which is located on the eastern border of the state. Due to this, Many families with medically complex children have voiced "feeling like they were on an island" without direct support from the hospital's team. Similarly, local emergency medical communities felt apprehensive about taking care of medically complex children.

A significant gap between community emergency services and the care of medically complex children was identified. The teams at Children's Nebraska realized that they could connect the hospital, patient/family, and community by arming local EMS and critical access EDs with knowledge and skills surrounding assessment and initial management, specific to each medically complex child. This proactive model of care created a unified and collaborative approach to the emergent care of medically complex children: providing safe, high-quality care for geographically-isolated families. They could feel part of a medical community.

Hand in Hand and Project Austin provide a constant source of support and guidance to children living with a

serious illness, and their families throughout the illness trajectory, while educating their local communities, who would otherwise have a limited skillset when assisting the medically complex. This collaboration between the hospital and the community empowers both families and their local emergency medical services teams. Together, the Hand in Hand and Project Austin teams create individualized emergency medical plans encompassing patient goals and symptom management. These plans are shared with the local EMS and Emergency Departments, making them extensions of the patient's specialty care team.

Since the onset of collaboration between Hand in Hand and Project Austin, more than 200 patients have received collaborative care, with a focus on the inclusion of familial goals and symptom management in potentially life-limiting illnesses in home-based settings. Such a focus on longitudinal care has helped many medically complex children maximize time at home in limited-resource settings.

Both teams continue to grow throughout Children's Nebraska with leadership support. Each program receives both inpatient and outpatient consultations, with Project Austin enrolling approximately 30 new patients every month and Hand in Hand enrolling an average of 16 patients per month.

In response to patient growth, both programs have expanded to meet the needs of communities with limited or no access to palliative care. Project Austin's services now include four nurse case managers and an outreach coordinator, with plans to integrate into Children's Nebraska's Complex Care Clinic, Neuromuscular Clinic, and Pulmonary Hypertension Clinic. Similarly, Hand in Hand has expanded to include two pediatric hospice and palliative medicine physicians, a nurse practitioner, a nurse case manager, three social workers, a program coordinator, a bereavement coordinator/chaplain, a child life specialist, and three integrative practitioners, who serve both inpatient and outpatient populations.

Outcomes

With formal collaboration between the two teams (beginning in 2019), the number of patients and families receiving the support of Project Austin and Hand in Hand has continued to grow, with the care of medically complex children tailored to the specific goals of the family. The teams continue to consult daily, fostering trust and community to support each medically complex child active in the two programs.

Emergency Department (ED) data at Children's Nebraska examined visits and hospital admissions before and after enrollment in Project Austin. Children's Nebraska saw a 23% reduction in ED visits and a 27% reduction in the number of inpatient stays. In addition, Children's Nebraska saw a 31%-61% decrease in hospital length of stay (dependent upon hospital unit) following enrollment. The impact of Project Austin has been profound, and the community response equally robust. Project Austin continues to educate communities on a patient-specific approach to pediatric advanced life support (PALS). It is not uncommon for EMS teams to go to patients' homes to better familiarize themselves with the patient and family.

Collaboration with the Hand in Hand Pediatric Palliative Care Team has helped further emphasize the humanization of complex medical care for some of the most fragile of their pediatric patients. With the guidance of

both teams, medically complex patients in resource-limited settings have been able to stay home longer and remain more comfortable in a manner that empowers local providers to be more comfortable with pediatric patients.

A specific example of the impact of Project Austin and the Hand in Hand team collaboration includes a 36-week preemie born with a critical airway and cardiac involvement, who was discharged to home with a tracheostomy and ventilator. The family resided in a rural Nebraska community with limited support and without access to local specialized pediatric care. Project Austin provided on-site education to local EMS, hospital, and home nursing. This education prompted a meet-and-greet between the family and their local EMS prior to a medical emergency. After an emergency, and throughout the infant's lengthy hospitalization, Hand in Hand was actively engaged with the family regarding medical decision-making and goals of care, developing a trusting relationship that continues to exist today. Project Austin and Hand in Hand continue to meet with this patient and family during outpatient clinic appointments, procedures, and hospitalizations to serve as a consistent team that has the family's goals at the forefront. They also remain in constant communication with non-pediatric community providers to help support the well-being of the child and family.

Hand in Hand fosters advancing growth, education, and advocacy for a statewide training opportunity, which focuses on pediatric palliative care and hospice practices, planned for 2024. Similarly, with the partnership and guidance of Project Austin, Hand in Hand is currently beginning partnerships with statewide hospice agencies to expand access to Concurrent Care Hospice.

Feasibility

The original design of Project Austin offered an external and internal manager, and a medical director collaborating to enroll patients as well as provide community education. The external and internal managers had extensive training in pediatric intensive care, trauma, transport, and outreach. This skill set was an integral and critical aspect of the design of Project Austin. With this background, a specific scope of service education could be provided to local emergency services and emergency departments.

To make the collaboration a success, each Project Austin team member played an integral role. The external manager built rapport and created partnerships with each EMS and ED system associated with a Project Austin patient. Through these partnerships, the external manager provided community emergency services with awareness, education, and support, creating a team that surrounded the patient. The internal manager created partnerships within Children's Nebraska, including nurse case managers, specialty physicians, and primary care providers. With these partnerships, medically complex children were identified and referred to Project Austin. The medical director assisted in creating disease-specific emergency medical treatment considerations. The three core team members created a robust program that since has enrolled more than 2,000 patients and over 750 EMS and referral EDs, working across eight states.

Throughout the creation and implementation of Project Austin, several roadblocks were identified and rectified. A common difficulty can be the continuity of providers, as this population of patients often sees a vast variety of

specialists. Project Austin and Hand in Hand provide consistency across the continuum of care by promoting open and frequent communication with all patient care team members through the electronic medical record. Furthermore, Project Austin is not revenue-generating, as services are not billable. They believe that all children deserve the services Project Austin offers regardless of their ability to pay. Project Austin is a free service offered to patients and collaborating EMS and EDs. Funding is provided by Children's Nebraska and The Children's Nebraska Foundation.

Robust interprofessional collaboration across the continuum in identifying and referring patients to Project Austin has been imperative to developing what the program is today. Interprofessional partnerships include clinical nurses, physicians, case managers, social workers, community EMS and EDs, etc. Building strong relationships with community EMS and EDs that are eager to receive support and training is another significant success factor in developing the program. All teams involved in the care of the medically complex are engaged to foster continuity and cohesive health care delivery. After all, this patient population can be amongst the most complex in Children's Nebraska's organization.

Hand in Hand was originally founded as a pilot program in 2006 in the Pediatric Intensive Care Unit (PICU), staffed with a physician, nurse case manager, and social worker. The pilot showed improvement in patient and family satisfaction, hospital staff resiliency, and cost benefit while providing an organized, dedicated delivery of palliative care to their diverse rural and urban pediatric populations. Hand in Hand subsequently became a fully-supported departmental entity and a recognized academic division within the Department of Pediatrics at Children's Nebraska. Hand in Hand remains the first and only fully dedicated pediatric palliative care program in the state. It has evolved into a cohesive, synergistic, interdisciplinary team to include three full-time providers, a nurse case manager, three social workers, a program coordinator, a bereavement coordinator/chaplain, a child life specialist, and integrative specialists, including massage therapy, music therapy, and healing touch.

The physicians and nurse practitioner on the Hand in Hand team provide billable services while the remainder of the collaborative team is not revenue-generating and is funded by Children's Nebraska and philanthropic groups. The core values of pediatric palliative care—including patient- and family-centered care to promote healing, attendance to suffering, and a focus on improving the lives of children living with a chronic, complex, or potentially life-limiting illness—is fully embraced and supported by leadership at Children's Nebraska.

Coordination between Project Austin and Hand in Hand provide continuity of care and consistency for their most vulnerable patients and their families.

Scalability

The Project Austin team is working diligently to make this a replicable program for pediatric hospitals throughout the nation. The hallmark of Project Austin is the Emergency Information Form (EIF), adapted from the American Academy of Pediatrics (AAP) and American College of Emergency Physicians (ACEP) Emergency Medical Plan, inclusive of familial goals of care.

The Emergency Medical Plan contains medical information pertinent to EMS and ED health care providers for the management of medical emergencies for a medically complex child. In addition to the EIF, a toolkit/playbook is being created, which will outline the program for other organizations to replicate and see positive outcomes. This toolkit was created to support other communities and health care organizations in implementing the Project Austin infrastructure and process. There is currently a draft toolkit with 30-40 education points. Children's Nebraska is also creating a smartphone app to move away from its current paper form. Using an app would mitigate variability between organizations and create streamlined access.

The second phase of the app will include education specific to the child and their medical condition for communities and EMS to easily utilize. In collaboration with Hand in Hand, the second phase of the app will also reference the child's hospice and advance directive information, if applicable. The potential to continue to update and evolve the app is limitless.

Both programs, with continued support from hospital leadership, have the potential to expand to additional clinic settings, see more diagnoses, and provide educational opportunities to medical staff regarding the care of medically complex children.

Equity

Project Austin and Hand in Hand are transformative for health care as they take acute care excellence beyond the walls of the hospital and into the rural community. Of the 93 counties in Nebraska, 50 counties are rural, and over a third of the state population reside in rural areas. Many of these rural areas have basic life support (BLS) and volunteer rescue services. This disparity limits the scope of practice and can increase the time allotted prior to EMS arrival on the scene in an emergency. The health care delivery system should not work in silos, as the patient's care team is a matrix of interwoven services from inpatient, outpatient, community, and home care. Creating intentional partnerships with internal and external key stakeholders willing to learn from one another positively influences the network surrounding each medically complex child.

Approximately 15% of the Project Austin and Hand in Hand population are non-English speaking. The two programs promote equity by providing comprehensive health care services to children, regardless of their background or circumstance, striving to address health disparities and ensure that every child has access to high-quality care. This includes providing language services and implementing culturally sensitive practices. By bridging this gap, these patients now have a unified emergency and medical system supporting them.

Health care equity is crucial for medically complex children to ensure they receive appropriate and timely care. This includes access to specialized medical services, therapies, and support systems to improve their quality of life. It also includes addressing disparities in health care outcomes and providing family-centered care to meet the unique needs of these children. By prioritizing their needs and ensuring equal access to care, Project Austin and Hand in Hand work together to improve their health outcomes and overall quality of life.

Project Austin continually meets with family members to discuss the feasibility of the program, utilization of forms, and feedback to provide to their local emergency services if need be. Should any feedback need to be addressed, outreach coordinators discuss and provide continued education to that family's community. In addition, local EMS services are in constant communication with outreach staff. This includes a quarterly EMS meeting to allow EMS services to discuss Project Austin cases, recent run reports, and advice about upcoming changes to the program. Hand in Hand and Project Austin meet formally each quarter and maintain open dialogue as part of a collaborative team regarding mutual patients and any changes to their status such as advance directive changes, goals of care, and hospice enrollment. The two teams fall under the Care Coordination Department at Children's Nebraska and maintain open communication and relationships to best serve shared patients and identify patients that might be appropriate for each other's programs. Project Austin and Hand in Hand aim to reduce health care disparities and improve health outcomes for all children in Nebraska and surrounding states.

Sustainability

The entire Project Austin program and Hand in Hand non-provider care are offered as free services to patients who meet qualifying criteria. As with any free service, sustainability can be a challenge. However, through proven outcomes, a value-based contract with one of the largest Medicaid carriers in the state was secured. The Medicaid company conducted financial analysis on a random sample of 27 patients covered by their services and enrolled in Project Austin. Data demonstrated a 1.2-million-dollar cost reduction after one year of enrollment in Project Austin. This aligns with the ACE Kids Act in better care coordination, keeping patients out of the hospital, and a decrease in spending.

Sustainability for Hand in Hand and Project Austin involves ensuring the provision of high-quality, compassionate care while managing resources efficiently. Key aspects include: educating health care professionals regarding pediatric palliative care and medical complexity to improve skills and knowledge, reducing turnover, and maintaining expertise; providing comprehensive support to families and EMS to help reduce stress and prevent unnecessary hospital readmissions; implementing a holistic approach that addresses the physical, emotional, and spiritual needs of children and families; and continued community engagement to create a network of support and resources for children with medical complexity.

The sustainability of both programs involves a multi-faceted approach, including dedicated funding from hospital leadership, interdisciplinary collaboration, staff training, community engagement, and ongoing evaluation of outcomes to ensure the unique needs of young patients and their families are met.

The Children's Nebraska team predicts the app's roll-out will show continued cost reduction, increased comfort and confidence in EMS and ED staff, and increased peace for the families enrolled. Eliminating the worry of ensuring the paper Emergency Information Form is available versus an electronic version on the app will continue to promote growth, awareness, and understanding when working with medically complex children. They anticipate a collaboration between Hand in Hand and Project Austin regarding the second phase of the app will increase communication amongst all parties, and ensure continuity of care and advance care planning for our shared patients.

Project Team

Mandy Pflaster, LCSW
Palliative Program Coordinator and
Medical Social Worker
Hand in Hand Palliative Care Team
Children's Nebraska
mpflaster@ChildrensNebraska.org

Madison Kingsley, RN, BSN, CPN
Nurse Case Manager
Project Austin
Children's Nebraska

Tiffany Simon, MSN, RN, CCRN
Program Manager
Project Austin
Children's Nebraska

Patrick Lloyd, DO
Palliative Physician
Hand in Hand Palliative Care Team
Children's Nebraska

About the Challenge

The John A. Hartford Foundation Tipping Point Challenge is a national competition to catalyze the spread of skills, ideas, and solutions that will improve health care delivery for all people living with a serious illness. It is sponsored by the [Center to Advance Palliative Care](#) and [The John A. Hartford Foundation](#).

For more information, visit tippingpointchallenge.capc.org.