Infant Transitional Care Program (ITCP)

Project Overview: The Infant Transitional Care Program (ITCP) is implementing an innovative model of care to optimize the health, quality of life, and well-being of infants with complex medical conditions (CMC) who are transitioning from the neonatal intensive care unit (NICU) into their homes and the community. This model employs elements of complex health care theory with the goal of enhancing systems of care that serve infants with CMC. This ITCP includes several innovative components, including: (1) restructuring the patient-centered medical home into a family-centered medical and neighborhood health home (FCMNHH); (2) establishing a consultative practice model for children with less severe medical complexities, (3) adapting principles of Health Care Transition to infants with complex care needs; (4) integrating community-based palliative care as a component of the system of care; and (5) equipping and empowering parents and families to assume leadership roles in every aspect of their children's care.

Lead Organizations

The University of Florida – Jacksonville Bower Lyman Center and Division of Neonatology

Wolfson's Children's Hospital

Principal Investigators

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Geographic Region

Five-county region of Northeast Florida

Project Period

August 2022-July 2027

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Population Served

The ITCP serves infants who reside in the five-county region of Northeast Florida, including Duval, Baker, Clay, Nassau, and St. Johns counties—including low-income and minoritized infants insured by Medicaid.

Collaborations

The ITCP integrates the resources of the University of Florida College of Medicine—Jacksonville Divisions of Community and Societal Pediatrics (DCSP) and Neonatology, with those of Wolfson Children's Hospital, Community PedsCare, and other community-based organizations.

The Division of Community and Societal Pediatrics (DCSP)

The Division of Community and Societal Pediatrics (DCSP) serves more than 1000 children and youth from birth through age 23. Consolidated in the Bower Lyman Center (BLC) for Children with Medical Complexities, programs include the Complex Care Clinic, Jacksonville Health and Transition Services, Inpatient Palliative Care service, and Physical Medicine and Rehabilitation (PM&R). The DCSP is also contracted to provide pediatric leadership for Community PedsCare (CPC), the regional provider of Pediatric Hospice and Palliative Care, and the Partnership for Child Health (PCH).

The Division of Neonatology

The Wolfson Children's Hospital NICU is the primary referral center for neonatal intensive care in north Florida and southern Georgia, serving as the only quaternary referral center for extremely preterm infants, infants with complex congenital, medical, and surgical disorders, and infants requiring extracorporeal membrane oxygenation (ECMO). The division provides neonatal services at six regional perinatal/delivery hospitals.

Family Engagement

The Family Advisory Board (FAB) engages parents whose infants are participating in the ITCP and additional parents identified in the NICU with a moderate or high-risk infant. The FAB prepares parents as leaders and advocates for their children using the principles of child rights, with a primary focus on trauma-responsive care and narrative medicine. Families play a leadership role by participating in the development, implementation, evaluation, and dissemination of the model of care.

Project Aims

- Implement and evaluate an innovative and evidence-informed family-centered model of care for transitioning neonates with complex medical conditions into the community.
- Empower parents to play a leadership role in the care of their children.
- Advance health equity by grounding the ITCP in the principles, standards and norms of child rights.
- Disseminate the findings through multiple peer reviewed manuscripts and presentations.

Notable Features

- **Sustainability:** The BLC has over a decade of experience building complex care practices that now care for over 1,000 children.
- **Collaborative care coordination:** Incorporates and integrates a collaborative team of care coordinators to facilitate the transition of infants from the NICU to the outpatient setting—establishing a continuum of care for ITCP infants.
- **Family empowerment:** Engage participating families to ensure that every aspect of the project reflects their voice and experience. Our goal is to ensure that caregivers are engaged from the time they meet their care coordination team in the NICU, through the critical months of transition and early follow-up, and throughout early childhood, when care is transitioned, once again, to general primary care physicians.
- **Health equity:** Adopt a child-rights based approach to care, by introducing health equity metrics, computerized platform for program development and evaluation, and by engaging family leaders. Family engagement will include the anonymous feedback to the ITCP, training in techniques that empower and support families, and the provision of materials related to cultural humility, racism, and trauma-informed care.

Evaluation Overview

The ITCP has implemented specific strategies to collect, analyze, and track process and outcomes data targeted to each objective. The process evaluation focuses on the development of the *Collaborative Care Coordination* model that links the inpatient, outpatient, and community venues where children live; family empowerment; the FCMNHH; and the pursuit of health equity. The outcome evaluation focuses on the capacity of the ITCP to ensure parents (1) are fully engaged in their children's care and contribute to care decisions; (2) are satisfied with the outcomes of bidirectional communication with other members of the health care team; (3) report a positive experience of care; (4) experience integrated care coordination and access to services; (5) feel empowered to care for their children; and (6) report improved health and health-related quality of life. The ITCP will utilize surveys derived from elements of several validated instruments, including the Consumer Assessment of Healthcare Providers and Systems (CAHPS), the Pediatric Integrated Care Survey (PICS), the Pediatric Quality of Life Inventory (PedsQL) and the GC platform, for formative and summative evaluation. Restorative practice circles will also be utilized to collect qualitative elements from families and project partners.

"As technology has transformed the "medical" care of sick newborns, we are seeking to transform the "human" care that is essential for their well-being—and that of the families in which they live. We are seeking to rediscover who we understand them to be, respond to them as infants infused with every child's right to life and optimal survival and development, realign the roles families play in the NICU and thereafter, recognize and respond to the trauma incurred by families, and establish nothing less than a new paradigm and precedent for the care of infants with complex medical conditions."

– Jeffrey Goldhagen, MD, MPH, University of Florida, College of Medicine, Jacksonville, Florida

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