



# Enhancing Integrated Health Homes for Children with Medical Complexity

**Project Overview:** The Dell Medical School at the University of Texas at Austin (Dell Med) and the Dell Children's Comprehensive Care clinic (CCC) are advancing integrated care for children with medical complexity (CMC) by (1) supporting expansion and continuous quality improvement of CCC's innovative practice model for CMC, (2) piloting an alternative payment model to help sustain the delivery model, and (3) evaluating and disseminating findings to inform policies that integrate cost-effective care for CMC and their families, promote health equity, and optimize health, quality of life, and well-being.

CCC is a primary care clinic in Austin dedicated to exclusively serving CMC, a population that requires significant medical, behavioral, and social services. Since 2018, CCC has improved health outcomes with support from a HRSA Collaborative Improvement and Innovation Network (CoIIN). This project builds on CCC's existing infrastructure to advance a more fully integrated health home for CMC.

## Lead Organizations

Dell Medical School at the University of Texas at Austin (Dell Med)

Dell Children's Comprehensive Care Clinic (CCC)

## Family Leads

CCC Family Workgroup members: Kathy McClelland, Maureen Benschoter, Michelle Burslem, Cindy Fleharty, Lauren Cloud, Carissa B. Vermillion, Farhana Khawar, Kate Holler, Kate Robinson

CCC Family Liaison: Sherry Santa

## Principal Investigator

Lisa Kirsch, MPAff, Dell Medical School, University of Texas Austin

## Geographic Region

Austin, Texas

## Project Period

August 2022-July 2027

## Contact

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## Population Served

CCC currently serves 840 children and youth with the most medically complex health needs. This project focuses on all patients and families served by CCC, of which 30% are Hispanic, 23% are non-English speaking, and 82% have Medicaid coverage.

## Collaborations

Through the CoIIN, CCC has built trusting relationships with partners dedicated to improving care for CMC, including clinic family leaders, Title V and Medicaid at Texas Health and Human Services (HHS), Blue Cross and Blue Shield of Texas (BCBS), Texas Parent to Parent, Dell Med, Dell Children's Medical Center, complex care clinics throughout Texas, palliative care providers, and other frontline providers (e.g., primary care providers, specialists, home health) and CloudForest Solutions, a technology vendor. Through this demonstration, CCC will work to strengthen relationships with previous and new partners to engage underrepresented groups, including working with VELA (a non-profit that supports primarily Spanish speaking parents of CMC), Sammy's House (day care center dedicated to children with medical fragility), the Texas chapter of the National Organization for Rare Disorders, other mission-aligned local non-profits, and non-medical partners (e.g., special education programs).

## Family Engagement

The CCC's north star is the parent and family voice. The clinic's work to engage families centers on an innovative model that allows the care team to intimately know families' stories and journeys. This is foundational to providing high-value medical care based on what matters to families.

At the core of the CCC are: 1) the Family Liaison, a clinic parent and 2) the Family Workgroup, highly-engaged parents of CMC who meet monthly to monitor progress, inform model improvements, and ensure family priorities remain paramount.

Veteran Family Workgroup members will mentor new family members, including racial/ethnic minorities, and the Project Team will evaluate barriers that may prevent underrepresented communities from participating in this quality improvement group. The Texas Parent to Parent Health Information Center, a Family Voices affiliate, will ensure meaningful family involvement at all stages of care model implementation and evaluation work.

## Project Aims

1. Empower parents to be equal partners in their child's care.
2. Understand and document barriers and challenges (both in service delivery and underlying policies) the CMC population experiences with the current system of care.
3. Optimize innovative technologies.
4. Expand Whole Child Visit pilot and support care integration through an alternative payment model. Whole Child Visits use telehealth to bring together the primary care team, specialists, and other providers biannually to develop a comprehensive care plan together with the child's family.
5. Assess the organizational capacity of CCC to reduce health disparities.

## Evaluation Overview

Quantitative, Qualitative, and Policy Analysis Workgroups that incorporate family voices and clinical, policy, and analytics expertise will drive evaluation work to inform continuous improvement efforts and show the model's impact on outcomes, equity, and costs. Quantitative analysis will draw on claims, electronic medical record, and acute care data captured by CCC. Qualitative outcome measurement will incorporate results of a survey instrument developed with the CCC Family Workgroup, focus group feedback, a journey mapping tool that helps identify and understand family touchpoints within the health care experience, and Photovoice, which is a tool that enables families to share and discuss images they have captured of their caregiving experience. To assess outcomes for all CCC patients, the evaluation will include a health equity assessment that uses the REaL (Race, Ethnicity, and Language) approach for stratifying data and the Intentional Equity in Quality Improvement questions recommended by the Institute for Healthcare Improvement.

## Notable Features

- **Technology:** Use the MY STORY application to engage with parents and caretakers of CMC, including those who are Spanish speaking. Parents use the app to upload pictures and videos of their children, keep a video journal, insert a narrative to define their child in their own words, and respond to survey questions from the clinic.
- **Empowered lay leaders:** CCC's Family Liaison and Family Workgroup, all of whom are clinic parents, partner closely with the clinic team on quality improvement. They are integral participants in this project, which aims to engage families from underserved communities in the Family Workgroup.

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**"The Whole Child Visit is really helpful and more comprehensive. I like the idea of everyone being on the "same page," especially school... I used to have to repeat goals and information and was afraid that I might miss something that needs to be shared. But this visit feels different than before, because it's more intentional about having everyone hear the same thing."**

*– Cindi Garza, Mother of a CCC patient, in response to a question on the Whole Child Visit survey*

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