

CDNN Abstract Submission

Title of Abstract: Transition for Complex Youth: How Families Adapt as Their Youth With Medical Complexity Ages Out of Child-Oriented Systems of Care

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ABSTRACT (250 words)

Problem: Youth with medical complexity (YMC) are a diverse group of young people who have multiple chronic conditions, functional limitations, and extensive care needs. Rapidly increasing numbers of YMC are aging out of child-oriented systems (health, education, and social service systems) and entering adult systems, where their needs have been largely neglected. Planning for and navigating through the transition to adulthood and to adult services requires immense time and energy. Yet, family caregivers are already overburdened by their youth's daily care needs. To better support these families, it is critical to understand how they manage this transition, including what challenges they face and how they confront these challenges.

Aim: This study aimed to understand how families of YMC adapt to the youth's transition to adulthood, and how this transition can be better supported.

Methods: A qualitative explanatory case study design was used. Data sources included semi-structured interviews, documents, field notes, and memos. Interview data was interpretively analyzed using reflexive thematic analysis, followed by theory-driven analysis. Documentary evidence was analyzed using directed content analysis.

Findings: 21 interviews were completed with 17 participants representing 11 families. The following themes were generated: (1) How do families imagine, pursue, and build a future? (2) What makes the transition hard? And (3) How do families adapt to transition?

Significance: Findings will inform future strategies to support better transitions in care for YMC and their families. These strategies should optimize families' natural adaptation processes by drawing on their strengths and supporting areas of greatest need.