Path-4CNC (Children's Complex Care Coalition of North Carolina) Complex Care Convenings 2021: Executive Summary

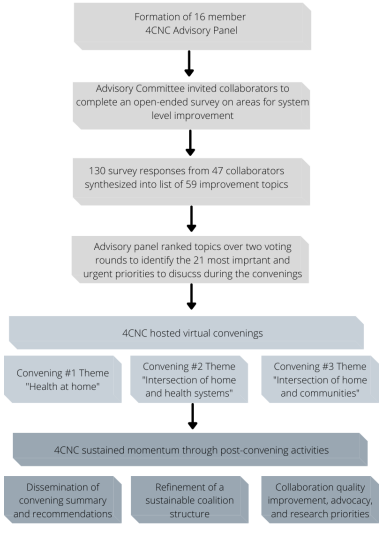
Overview

This summary synthesizes findings from the Path-4CNC virtual conference series focused on improving systems of care for children with complex health needs (CCHN) in North Carolina (NC). CCHN are those (a) with chronic medical and/or behavioral conditions that require ongoing health care and (b) whose families face social challenges (e.g., adverse social determinants of health, adverse childhood experiences) that complicate management of their health needs. At these virtual convenings held in January-March 2021, 90 stakeholders – including state and local agencies, health professionals, community organizations, and families of CCHN – from across NC: (a) identified challenges and strengths in current systems of care and (b) generated actionable recommendations for systems improvement to address the needs and priorities of CCHN, their families, and care providers. These recommendations can guide families, clinicians, researchers, policymakers, and other community partners aiming to advance health and well-being for CCHN.

Problem

Children with complex care health needs in NC continue to face barriers to care, unmet needs, and obstacles to coordinated services. As such, systems of care must improve to better address the needs and priorities of all CCHN and families. The Complex Care Ecosystem model developed by the National Center for Complex Health and Social Needs (National Center), an initiative of the Camden Coalition of Healthcare Providers, illustrates interconnections among multiple service sectors on which CCHN and families rely to meet daily needs. Ideally, care for CCHN should: (1) center on each child's and family's needs; (2) be high-quality and integrated across the ecosystem of services; and (3) improve outcomes that matter most to families. However, problems within sectors (e.g., resourcing, long waitlists) and between sectors (e.g., limited knowledge of available services, lack of data sharing and coordination) result in care fragmentation, confusion, and lower quality care. Also, CCHN who confront marginalization and racism (e.g., families of color, non-English speakers, rural communities) face systemic inequities in access to care and health outcomes. When individual-level care fragmentation and health inequities are broadly distributed – e.g., across 340,000+ Medicaid-insured CCHN in NC – the large scope and scale of limitations in complex care ecosystems and their impacts on families become evident.

Figure 1: Multi-step stakeholder-engaged prioritization process



Opportunity

Three factors motivated our formation of a statewide coalition of partners with expertise in systems of care for CCHN: (1) a need for systems improvement efforts guided by stakeholder perspectives, particularly by those with lived experience; (2) emerging understanding of how to conduct systems-level complex care initiatives; and (3) health policy shifts toward value-based care that position NC to improve complex care systems. A key goal of the newly formed Children's Complex Care Coalition of NC (4CNC) is to create a

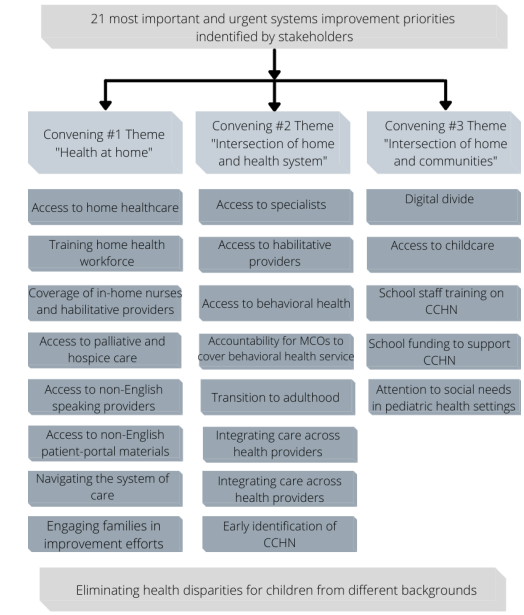
systems improvement agenda that reflects the priorities of families of CCHN and their service providers. These lived experiences should guide resource allocation, advocacy topics, and the focus of researchers and policymakers.

Process

To identify systems improvement priorities, we formed a 16-member Advisory Panel followed by a multi-step process consisting of: (a) open-ended surveys of families and providers; (b) analysis of survey responses within the National Standards for Systems of Care for Children and Youth with Special Health Care Needs framework; and (c) a modified Delphi consensus-building process with the 16-member Advisory Panel to identify the most important and urgent priority topics to address (Figure 1).

Path-4CNC Complex Care Convenings: The 21 consensus topics of highest importance and urgency informed agendas for three virtual convenings held in January-March 2021 that focused on the path to better health for CCHN: (1) at home; (2) at the intersection of home and health systems; and (3) at the intersection of home and community. In each 2.5-hour convening, 60-90 participants (1/3 family members of CCHN, 1/3 health professionals, 1/3 community/state agency partners) participated in small-group discussions facilitated by trained Advisory Panel members. Our convening planning team used detailed notes and transcriptions to organize small-group discussions into core themes, challenges, and recommendations.

Figure 2: Highest priority topics discussed across virtual convenings



Findings and Recommendations based on Virtual Convening Participants' Feedback

Content analysis of participants' small-group discussions identified seven major themes; key challenges and actionable recommendations were then mapped to each theme.

Themes	Challenges	Recommendations
Training and Education	Workforce shortage	Expand complex care training and diversity in the workforce
		Increase financial incentives for complex care workforce
	Need for provider training	Increase complex care provider training
Stigma	Misperceptions, prejudice, implicit bias	Expand professional training and education for providers
	Stigma, racism, and bias	Deploy individuals with lived experience
Family Support and Empowerment	Family voices and perspectives need to be elevated	Directly partner with families
	Family emotional needs and stressors not adequately addressed	Expand implementation of family-centered services
	Maintaining connections with families	Leverage technology to maintain connections over time - use multiple modalities (text, email, phone, etc)
Care Coordinati	Lack of a main care coordinator	Designate a single point of contact for care coordination

on	Integration of care services for medical, behavioral, and social needs	Coordinate services across the care continuum and between sectors
	Limited support for transitions of care	
Cross Sector Collaboration	Lack of awareness of available resources	Develop central, shared resources for coordination across sectors
	Siloed care sectors	Improve communication and coordination across the care continuum and between sectors
	Data and systems interoperability	Improve data sharing and interoperability
Access	Complicated and confusing application process for services	Training for families on how to access available programs
	Barriers to access and navigate systems	Expand transportation services for families in rural areas
		Provide accessible information for families and community based providers
	Digital divide	Provide technology and training to overcome digital barriers to access care
Funding and Reimbursement	Reimbursement for at-home care	Increase reimbursement and incentives for in-home care and community-based organizations to address social needs
	Funding professional development and systems improvement initiatives	
	Insurance coverage gaps	Close gaps with novel insurance options

Next Steps

Findings from the Path-4CNC virtual convenings highlight next step opportunities for key stakeholder groups to improve systems of care for CCHN and their families in NC:

- **Policymakers and advocates**
  - Reimburse families for in-home caregiving
  - Augment reimbursement, incentives, and training for complex care workforce and community-based organizations that address social determinants of health
  - Invest in and incentivize data linkages and interoperability between data systems and service sectors
  - Close the digital divide and sustain telehealth beyond the COVID-19 pandemic
- **Clinicians**
  - Partner with families and expand complex care-specific training
- **Researchers**
  - Implement, evaluate, refine, and scale care interventions – e.g., family partners as health navigators
  - Integrate families into project teams as partners in co-design and evaluation

4CNC will sustain momentum by:

- Maintaining connection between convening participants and stakeholders from across NC
- Connecting project leaders with patients and families with lived experience for project co-design and conduct
- Linking 4CNC's future work with strategic priorities and strengths of key state, regional, and community partners