

# Improving Systems of Care for Children with Complex Health Needs in North Carolina

Findings and Recommendations from Stakeholder Convenings hosted by the Children's Complex Care Coalition of North Carolina (4CNC)





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# EXECUTIVE SUMMARY

## Overview

This summary synthesizes findings from the Path-4CNC (Children’s Complex Care Coalition of North Carolina) 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 – inclusive of 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 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 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 300,000+ Medicaid-insured CCHN in NC – the large scope and scale of limitations in complex care ecosystems and their impacts on families become evident.



## 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 those with lived experience; (2) emerging understanding of how to conduct systems-level complex care initiatives; and (3) health policy shifts towards 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 focus of researchers and policymakers.

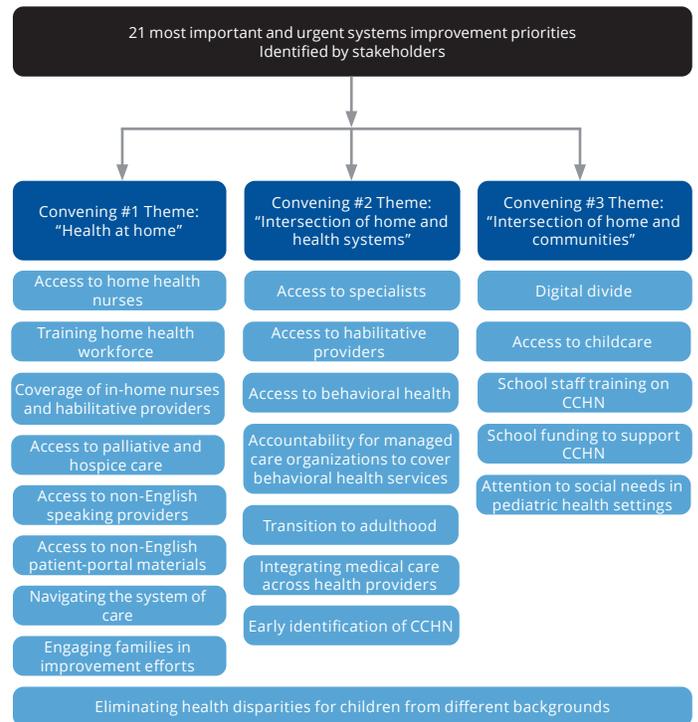
## Process

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,

*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 (Figure 1). 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.

## 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.



**FIGURE 1:** Highest priority topics discussed across virtual convenings

## Recommendations to address major themes and core challenges

Themes	Challenges	Recommendations
Training and Education	<b>Workforce shortage</b> (Lack of qualified and trained complex care providers, especially in underserved rural areas)	<b>Expand complex care training opportunities and diversity in the workforce</b> <ul style="list-style-type: none"> <li>• Specialized programs</li> <li>• Integration into existing programs</li> <li>• Increased exposure and networking</li> </ul>
	<b>Need for provider training</b> (Cultural competency, empathy, and care coordination)	<b>Use financial incentives to recruit and retain complex care workforce</b>
Stigma	<b>Misperceptions, prejudice, implicit bias</b> (among healthcare professionals)	<b>Offer training opportunities in complex care for child health providers</b> <ul style="list-style-type: none"> <li>• Empathy and cultural competency</li> <li>• Care coordination</li> <li>• Care transitions</li> </ul>
	<b>Stigma and bias</b> (Impacting families' access to care)	<b>Expand professional training and education for providers</b> <ul style="list-style-type: none"> <li>• Implicit bias</li> <li>• Awareness of stigma faced by families</li> </ul>
Family Support and Empowerment	<b>Family voices and perspectives need to be elevated</b>	<b>Deploy individuals with lived experience in roles throughout the system of care</b> <ul style="list-style-type: none"> <li>• Employ families of children with complex health needs (CCHN) as family partners and navigators</li> </ul>
	<b>Family emotional needs and stressors not adequately addressed</b>	<b>Directly partner with families</b> <ul style="list-style-type: none"> <li>• Participation in policymaking</li> <li>• Implementation of shared decision-making</li> <li>• Leadership of community-engaged initiatives</li> </ul>
	<b>Maintaining connections with families</b>	<b>Expand implementation of family-centered services</b> <ul style="list-style-type: none"> <li>• Parent-parent support groups</li> <li>• Family partner programs</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> </ul>
		<b>Leverage technology to maintain connections over time</b> <ul style="list-style-type: none"> <li>• Use multiple modalities (text, email, phone, etc)</li> </ul>

<b>Care Coordination</b>	<b>Lack of a main care coordinator</b> <ul style="list-style-type: none"> <li>• Who’s “driving the bus”</li> </ul>	<b>Designate a single point of contact for care coordination</b>
	<b>Integration of care services for medical, behavioral, and social needs</b>	<b>Coordinate services across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Integrate mental and physical health services</li> <li>• Leverage telehealth to improve access</li> <li>• Improve communication and coordination between healthcare and school sectors</li> <li>• Strengthen transitions of care from hospital-to-home and into adulthood</li> </ul>
	<b>Limited support for transitions of care</b> <ul style="list-style-type: none"> <li>• Transitions to adulthood</li> <li>• Hospital-to-home transitions</li> </ul>	
<b>Cross Sector Collaboration</b>	<b>Lack of awareness of available resources</b>	<b>Develop central, shared resources for coordination across sectors</b> <ul style="list-style-type: none"> <li>• Family partners and navigators</li> <li>• Centralized resource directory and referral systems</li> </ul>
	<b>Siloed care sectors</b> <ul style="list-style-type: none"> <li>• Limited communication between sectors</li> <li>• Limited data sharing</li> <li>• Lack of centralized, shared resources</li> <li>• Integration with school systems</li> </ul>	<b>Improve communication and coordination across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Strengthen communication systems for schools and expand school-based health workforce (e.g., social workers)</li> </ul>
	<b>Data and systems interoperability</b>	<b>Improve data sharing and interoperability</b>
<b>Access</b>	<b>Complicated and confusing application process for services</b>	<b>Training for families on how to access available programs</b>
	<b>Barriers to access and navigate systems</b> <ul style="list-style-type: none"> <li>• Limited services in rural areas</li> <li>• Use of medical jargon</li> <li>• Lack of interpretation and translation services (non-English speakers; visual or hearing impaired)</li> <li>• Accessing mental/behavioral health</li> </ul>	<b>Expand transportation services for families in rural areas</b> <b>Provide accessible information for families and enhanced access to services through community-based providers</b> <ul style="list-style-type: none"> <li>• Real-time access to interpreter services</li> <li>• Spanish translated medical forms and charts</li> <li>• Use of family-friendly language</li> <li>• Expand workforce for co-located mental health providers in the pediatric medical homes</li> </ul>
	<b>Digital divide</b> <ul style="list-style-type: none"> <li>• Limited access to technologies and devices necessary to navigate systems of care</li> </ul>	<b>Provide technology and training to overcome digital barriers to access care</b>

<b>Funding and Reimbursement</b>	<b>Reimbursement for at-home care</b>	<b>Increase reimbursement and incentives for in-home care and community-based organizations to address social needs</b>
	<ul style="list-style-type: none"> <li>• Home health/nursing</li> <li>• Unpaid family-delivered in-home care</li> <li>• Telehealth services</li> </ul>	
	<b>Funding professional development and systems improvement initiatives</b>	<ul style="list-style-type: none"> <li>• Family partner programs</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> </ul>
	<b>Insurance coverage gaps</b>	<b>Close gaps with novel insurance options</b>
		<ul style="list-style-type: none"> <li>• Medical-legal partnerships</li> </ul>

### 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. The following four cross-sector initiatives are examples of how stakeholder groups in NC can build on the convenings to address the most important and urgent priorities of those with lived experience in the system of care for CCHN.

#### Next Step Initiative Example 1: Make Families Partners, not just Clients, in the System of Care

Inclusion of families in all aspects of the system of care and development of formal roles for families could deliver health and economic benefits, and could alleviate workforce and coordination challenges faced by service sectors.

**ACTION A: Recognize and financially support the work of family members as in-home care providers and peer supports for other parents.**

**ACTION B: Invite and empower family representatives to participate in decision-making at all levels of the system of care.**

#### Next Step Initiative Example 2: “Professionalize” the Complex Care Workforce

Front-line service providers (e.g., private duty nursing, home health, families) provide the majority direct care for CCHN, yet access to training and professional networks to grow and thrive in their work are lacking.

**ACTION A: Enhance training and support for front-line care providers** – e.g., professional networking opportunities, training and technical assistance in partnership with children’s hospitals and academic centers.

**ACTION B: Incentivize careers focused on the care of CCHN** – e.g., loan repayment programs, supplemental payments for direct care providers.

**ACTION C: Develop and test new roles** – e.g., cross-sector integration facilitators and transition coaches who can serve as single points of contact.

### **Next Step Initiative Example 3: Create Shared Purpose to Improve the Availability, Quality, and Outcomes of Complex Care**

Families and service providers from across sectors experience challenges securing needed resources to meet CCHN needs. Innovative financial supports, collaborative partnerships that build complex care capacity, and shared resources are needed to improve equity in the availability, quality, and outcomes of community-based services across the diverse range of places where CCHN live.

**ACTION A: Enhance the capacity of community-based clinics to deliver complex care** – e.g., dedicated clinic-based care coordination staff, leverage telehealth for shared visits with both community providers and tertiary care specialists.

**ACTION B: Create tools that enhance visibility of existing resources and facilitate access to shared resources** – e.g., comprehensive resource directory, inter-agency collaboration and pooling of shared resources towards common objectives to enhance impact and reduce redundancies in care.

### **Next Step Initiative Example 4: Optimize Information Technology**

Information technology has potential to facilitate efficient linkages across the system of care for CCHN, break down siloes between information systems, and time and effort spent on sharing information using manual, paper-based methods.

**ACTION A: Invest in secure data-sharing and communication linkages between systems that commonly share information** – e.g., dedicated clinic-based care coordination staff, leverage telehealth for shared visits with both community providers and tertiary care specialists.

**ACTION B: Use new telehealth capabilities to link nodes in the system of care in real-time** – e.g., real-time telehealth video communication between referral providers and intake coordinators to simplify communication and reduce reliance on phone and fax.

**4CNC will sustain momentum generated by the Path-4CNC convenings by:**

- **Facilitating cross-sector collaboration between convening participants and stakeholders across NC that can move forward next step initiatives**
- **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/local institutional partners**

# INTRODUCTION

## Background

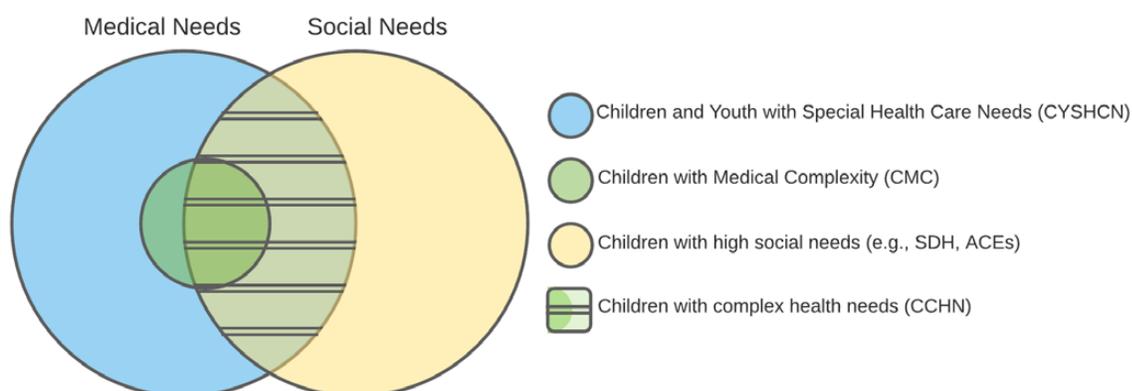
### Defining Children with Complex Health Needs

Children with complex health needs (CCHN) have high levels of need for health care and other services, and public spending for their care far eclipses that of other children.<sup>1,2</sup> The CCHN population is defined by the intersection of their medical and behavioral health needs with social needs for basic resources and community services. The **medical needs** of CCHN stem from the population's chronic health conditions (inclusive of chronic physical, behavioral, and developmental conditions). CCHN include representation from two well-described population groups that are distinguished by the presence of chronic conditions: children and youth with special healthcare needs (CYSHCN) and children with medical complexity (CMC). Approximately one in five children in the United States are CYSHCN, "who require health and related services for a chronic physical, developmental, behavioral, or emotional condition beyond what is typically required for children."<sup>3</sup> CMC are a subset of the CYSHCN population and represent 1-5% of all children. CMC require more intensive health care services due to complex chronic health conditions affecting multiple organ systems and limitations in basic body functions (e.g., breathing, eating) that often require long-term support from medical technology.<sup>4</sup>

The **social needs** of CCHN and their families stem from the population's experiences with adverse social conditions that negatively impact health. Social determinants of health (SDH) – the "conditions in which people live, learn, work, and play" – are central to the accrual of high social needs.<sup>5</sup> Some studies suggest that greater than 80% of the child population experiences adverse SDH which negatively impact their health – e.g., housing instability, food insecurity, and household financial strain.<sup>6,7</sup> Another important driver of high social needs common among children is adverse childhood experiences (ACEs): early life experiences associated with a variety of worse long-term health outcomes that affect children directly (e.g., physical abuse or neglect) and indirectly (e.g., parental substance abuse or incarceration) through their living environment.<sup>8</sup> ACEs and adverse SDH often are interwoven and represent commonly experienced adverse social conditions and experiences that together generate substantial social needs and worsen health outcomes for children and their families.

Although not all children with social needs are medically complex and not all children with chronic health conditions experience adverse social conditions, many children have both high medical and social needs. The intersection of populations with high medical needs (CYSHCN, CMC) and those with high social needs (children with adverse SDH and/or ACEs) provides a conceptual foundation for defining CCHN and understanding how to address their unique needs (Figure 1).

The overall prevalence of CCHN is increasing due to several factors: advances in neonatal care and life-saving technologies that allow more children with serious illness to survive and thrive, often with ongoing dependence on medical technology;<sup>9</sup> rising prevalence of childhood-onset chronic conditions such as asthma, obesity, diabetes, autism spectrum disorder, and ADHD;<sup>10</sup> and persistent child poverty and growing resource inequity that sustain the presence of adverse social conditions.<sup>1</sup> As a result, CCHN both: (a) account for disproportionately high health care costs and health service use, including hospitalizations, subspecialty care, and emergency department visits;<sup>11</sup> and (b) require disproportionate attention from community and social services to address unmet resource needs.<sup>12</sup>



**FIGURE 1:** Defining Children with Complex Health Needs

### Care coordination for children with complex health needs

CCHN typically require coordination of services from multiple medical and non-medical systems, including from the public health, social services, and education sectors.<sup>13</sup> Longitudinal care and coordination of care for CCHN are ideally delivered through the patient/family-centered medical home, a care model that aims to deliver accessible, high-quality, comprehensive, compassionate, continuous, patient/family-centered, culturally effective, and coordinated care.<sup>2</sup> Care coordination refers to a system that organizes care activities, facilitates health service delivery, and supports patient/family needs<sup>2,13,14</sup> across a “Complex Care Ecosystem” of providers and services.<sup>15</sup> When care coordination is done well, the outcome is **integrated care** – defined as “the seamless provision of health care and related services, from the perspective of the patient and family, across the entire care continuum. It [care integration] results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.”<sup>13</sup> Successful delivery of integrated care requires comprehensive team-based care<sup>16</sup> built on the foundation of the medical home with particular attention to communication and collaboration between the multiple participants in each CCHN’s complex care ecosystem.

Despite its importance, many CCHN lack access to a medical home and the team-based care and care integration it can provide.<sup>17</sup> As a result, care for many CCHN is fragmented, leaving families (inclusive of parents, guardians, and caregivers) to navigate multiple systems to secure and maintain necessary services for their children. Shouldering such a significant care coordination responsibility is stressful and isolating for families.<sup>18</sup>

### Impact of social complexity and health inequity

Coordination of services across medical and non-medical sectors (e.g., medical care, schools, community and social services) is a common challenge for families of CCHN. These challenges are made greater for CCHN who face adverse social conditions and health inequities. Adverse SDH and ACEs are adverse social conditions and experiences that can frequently complicate care delivery and coordination of medical and behavioral health needs, especially for CCHN. As a consequence, many CCHN and families have persistent unmet needs and suboptimal health outcomes.<sup>19,20</sup> Because ACEs and adverse SDH contribute to an early life environment of toxic stress that leads to negative long-term health consequences, it is critically important that CCHN and families faced with toxic stress are supported with resources to mitigate the harmful health effects of these social risk factors.

## INTRODUCTION

Comprehensive team-based care is central to identification and delivery of resources to support CCHN and families faced with high social needs stemming from adverse SDH and ACEs; effectively addressing the intersecting medical and social needs of CCHN and their families will have significant downstream societal benefits.<sup>16</sup>

Racism further compounds the challenges of managing complex medical and social needs.<sup>21</sup> Families of CCHN of color confront racism at multiple levels – structural, interpersonal, and internalized racism<sup>22</sup> – which leads to health inequities that impede access to care coordination within a medical home and lead to disparities in health outcomes by race and ethnicity.<sup>17,22</sup> Health inequity is a state in which individuals are unfairly “disadvantaged from achieving their full health potential because of social position or any other socially defined circumstance.”<sup>23</sup> Due to the pervasive effects of racism and bias on child health, the individual-level consequences of health inequity are most severe for the 50% of all children in the United States who are non-white.<sup>24</sup> Because 30% of CYSHCN have recently experienced racial/ethnic discrimination,<sup>25</sup> and CYSHCN are twice as likely as non-CYSHCN to experience high levels of ethnic discrimination,<sup>26</sup> efforts to eliminate the effects of racism on health and advance health equity for all CCHN are critical to system improvement efforts.<sup>22</sup>

### The Complex Care Ecosystem

A thriving **complex care ecosystem** is necessary to mitigate the fragmented care that many marginalized populations face. According to the National Center for Complex Health and Social Needs, the complex care ecosystem “includes consumers and families, health systems and practitioners, public health thinkers and doers, social service organizations, educators, first responders like police and fire.”<sup>15</sup> Within this ecosystem, organizations from a variety of sectors work together with families to provide ongoing, comprehensive, family-centered care while improving access to community resources and advocacy for the patient.<sup>27</sup> Additionally, it is essential to address the care needs of patients and families within the broader context of community health and social determinants of health over time. Combining the core components of integrated care and health equity within complex care ecosystems provides a conceptual foundation for approaches to improving systems of care for all CCHN.

## Landscape Analysis: Pediatric Complex Care Integration Initiatives

### THE NATIONAL LANDSCAPE

Current initiatives led by a range of organizations within the system of care for CCHN strive to provide enhanced support through care integration programs. Though these programs reside in different domains of the system of care, all aim to address comprehensive health needs and improve care quality and outcomes for CCHN and their families.

#### Initiatives within health care organizations

To foster care integration, many children’s hospitals have established “complex care” programs that provide intensive support and coordination across medical providers in different specialties in partnership with families.<sup>20,28</sup> By implementing many of the foundational principles of care coordination within the medical home,<sup>2</sup> these programs have improved patient/family experience and reduced healthcare utilization and costs. However, tertiary care center-based programs lack capacity to serve the entire CCHN population, leaving most CCHN without systematic support needed to coordinate services and providers. Furthermore, these complex care programs primarily focus

on medical care and are largely separated from community and social services that are essential components of daily care for many CCHN.

Other health care-focused initiatives reach beyond children’s hospital walls to integrate health services between hospital-based specialists and community-based providers, such as primary care medical homes or regional health care clinics. Care integration models in which children’s hospitals serve as coordinating centers for a network of community-based practices allow children to retain care from more accessible local providers. Direct communication and support of community-based providers in these networks by children’s hospital-based specialists can facilitate comprehensive and proactive care management, thus reducing emergency room visits and hospitalizations.<sup>29-31</sup> Studies of integrated care models for children have demonstrated cost savings and improvements in quality of life;<sup>32</sup> however, delivering well-coordinated, integrated care requires information sharing and communication across different electronic medical record systems,<sup>33</sup> is work-intensive, and costly to implement.

### **Initiatives of payers and care delivery partners: value-based care initiatives**

Payers and care delivery partners seek to improve care for CCHN by promoting value-based care initiatives that support integrated and comprehensive services across the range of sectors that affect health, including medical care, behavioral health, social services, and education.<sup>34</sup> Through provision of integrated care that ensures that CCHN have access to the right services at the right time, value-based care models aim to incentivize delivery of higher quality care at lower cost, rather than volume-based care in the traditional fee-for-service system.<sup>35,36</sup>

Multiple initiatives aimed at integrating care for children serve as examples of how to interweave the delivery of value-based care within a variety of payer contracts and healthcare systems. One promising initiative has been led by Kaiser Permanente Northwest, an integrated healthcare delivery system and payer. Kaiser Permanente Northwest has piloted a complex health management program – Pediatric Care Together<sup>37</sup> – to provide coordinated home and clinical services to its complex pediatric population and to integrate medical and social complexity into overall patient-level health assessments.

Partners for Kids (PFK) is another promising initiative.<sup>38</sup> PFK is an accountable care organization (ACO) in which the payer organization and care providers share medical and financial responsibility for keeping their population healthy.<sup>39</sup> The PFK ACO covers ~325,000 children accessing care through Medicaid in Southeastern Ohio. Through an embedded referral system, CCHN are assigned to a care navigation team that helps coordinate all providers involved in their care. By providing early, high-quality, coordinated care, the program aims to prevent later disease and reduce hospital visits. The program monitors its impacts through metrics such as ED visits, inpatient days, and ambulatory medication prescriptions.

Another promising integrated care initiative is the Children’s Care Network, a partnership among pediatric physicians and practices in Atlanta that has implemented value-based care initiatives. The Children’s Care Network “provides resources to enhance quality of care, improve outcomes, and reduce costs in the inpatient and outpatient settings.”<sup>40</sup> Through this clinically integrated network model, community pediatricians can provide their patients with better access to specialists, while specialists can ensure that their patients have access to the full spectrum of care through community pediatricians. Pediatricians in the network can expect to share data, technical resources, business support, and save on administrative costs.

### Initiatives involving state or federal public/private partnerships

Across the United States, state and federal-level initiatives provide enhanced care coordination and generate new knowledge about integrating care and health for CCHN. An example of a state-level integrated care program is the Oregon Pediatric Improvement Project (OPIP), a partnership of pediatric healthcare stakeholders in Oregon that aims to “create a meaningful, long-term collaboration of stakeholders invested in child health care quality.”<sup>41</sup> Towards this mission, OPIP works on quality initiatives in pediatric and adolescent health that integrate medical and community services, with projects relying on primary care providers to identify eligible patients. The program is housed in the Department of Pediatrics within Doernbecher Children’s Hospital at Oregon Health & Services University and is funded by grants and other governmental agencies.

At the federal level, the Center of Medicare and Medicaid Services (CMS) recently launched Integrated Care for Kids (InCK), a new value-based payment model that delivers child-centered care focusing on prevention, early identification, treatment, care coordination, and case management services.<sup>42</sup> By providing nearly \$126 million in federal grant support to implement the InCK model within eight healthcare partnerships in seven states across the country, CMS aims to improve the quality of care and reduce expenditures for children covered under Medicaid and the Children’s Health Insurance Program (CHIP).

### THE NORTH CAROLINA LANDSCAPE

According to the 2018-2019 National Survey of Children’s Health, 21.7 percent of all children aged 0-17 in North Carolina (NC) have special health care needs; the statewide CYSHCN population includes nearly half a million children.<sup>43</sup> A wide array of existing initiatives represent critical components of the system of care for CCHN in NC.

### Initiatives within health care organizations

Children’s hospitals across NC have also each implemented complex care programs to provide medically focused care integration for the most medically fragile CCHN. One example is the Center for Children with Complex and Chronic Conditions at Vidant Health in Greenville. This program has reduced hospital stays and costs of care for enrolled children through wrap-around services – including nursing, respiratory therapy, and social work – often delivered in a patient’s home.<sup>44</sup> Complex care programs based in other children’s hospitals in NC provide similar overall approaches to interdisciplinary care integration coupled with program-specific adaptations. For example, Wake Forest University/Brenner Children’s Hospital’s Enhanced Care Program includes a clinical focus on palliative care support and collaborations with regional home health agencies;<sup>45</sup> Duke Children’s Complex Care Service includes a clinical inpatient service line and a focus on mobile health innovations;<sup>46</sup> and UNC Children’s Complex Care Program provides comprehensive, consultative outpatient services for CMC across its large referral region. Condition-specific programs at NC children’s hospitals also provide similar services for children with individual, serious chronic conditions (e.g., cystic fibrosis, sickle cell disease, type 1 diabetes). Beyond children’s hospitals, some large community-based primary care medical homes in NC have been at the forefront of integrating care for health and social needs.<sup>47</sup> However, sustaining, scaling, and standardizing these efforts has been hampered by inadequate workforce and lack of funding for integration and coordination services.<sup>48</sup>

### Initiatives of payers and care-delivery partners

Blue Cross Blue Shield NC, the largest private insurer in North Carolina, has rapidly advanced value-based contracts with health care organizations around the state through its Blue Premier program.<sup>49</sup> While these contracts now include a substantial portion of people in the state, children – particularly CCHN – comprise a minority of enrollees in these programs. As a consequence, the included quality measures and interventions to address them may not target issues of highest relevance to CCHN and families.<sup>50</sup> North Carolina's ongoing shift in Medicaid from fee-for-service to managed care (Medicaid Transformation) is advancing focus on child-specific quality measures, including several of high relevance to CCHN and families. Notable measures highlighted within NC Medicaid Managed Care include access to complex care management services and proactive attention to adverse SDH integrated in contracts with Medicaid managed care organizations.<sup>51</sup>

### Initiatives through state-sponsored programs

NC Medicaid's Division of Health Benefits, Medicaid prepaid health plans, Title V and local health departments currently work together to deliver integrated care for CCHN. Three programs represent good examples of services offered to CCHN in North Carolina: Care Management for At-Risk Children (CMARC)<sup>52</sup> and the two largest Medicaid waiver programs for children in NC: the Community Alternatives Programs for Children (CAP/C) and the NC Innovations Waiver. Local health departments offer care management services from the CMARC program for at-risk children under the age of five; coordinate services among healthcare providers, community programs and supports; and provide family support programs. The Community Alternatives Programs for Children (CAP/C) and the NC Innovations Waiver are two of NC Medicaid's 1915(c) Home and Community-Based Services waiver programs.<sup>53,54</sup> CAP/C and Innovations focus on supporting children with complex medical problems and with intellectual and/or developmental disabilities (I/DD), respectively, by providing augmented services in home or community-based settings, thus delivering a cost-effective alternative to hospitalization.

NC also provides supplemental educational, child development, and caregiver support resources to meet the needs of CCHN. The Exceptional Children Division of the NC Department of Public Instruction provides appropriate individualized education programs (Early Intervention Part B Program) to help students with disabilities develop intellectually, physically, emotionally, and vocationally.<sup>55</sup> The North Carolina Division of Public Health's Early Intervention Branch leads the NC Infant-Toddler Program (Early Intervention Part C Program) to provide support and services for families with eligible children under three years old who are at risk for or have physical, developmental, social emotional and other special needs.<sup>56</sup> Finally, the NC Title V program in NC Department of Health and Human Services (DHHS) also supports and coordinates the NC Children with Special Health Care Needs Help Line. The Help Line is a free information and referral source for caregivers and professionals in multiple disciplines who work with infants, children, and youth who are at risk for chronic, physical, developmental, behavioral, or emotional conditions.<sup>57</sup>

### Community organizations and initiatives for family support

Multiple community organizations and additional initiatives help NC families to receive the information and support they need to care for their CCHN. A comprehensive listing of all agencies and organizations that support CCHN is beyond the scope of this report; however, family support and legal support are two prominent focus areas in the state.

## INTRODUCTION

Among the group of community organizations focused on direct family and parent support, one example is the Family Support Network of NC, which provides parent-to-parent support, information, and referral guidance for families with children under the age of 22 who have disabilities or special needs.<sup>58</sup> Family Voices, a national family-led organization of advocates for CYSHCN and children with disabilities, has two NC affiliates.<sup>59</sup> One Family Voices affiliate, Family Resource Center South Atlantic,<sup>60</sup> provides prevention and intervention services to strengthen families and communities in Wake County, Durham County, and surrounding communities. The other Family Voices affiliate in NC, Exceptional Children's Assistance Center,<sup>61</sup> provides information and support to help parents navigate the special education system as they care for their child up to the age of twenty-six. The Arc of North Carolina is a longstanding organization that provides advocacy and support services to people with I/DD and their families.<sup>62</sup>

Among the community organizations in NC that support legal needs of CCHN and their families, one prominent example is Legal Aid of North Carolina. Legal Aid NC is a statewide, nonprofit law firm that provides free legal help to low-income North Carolinians in civil cases involving basic human needs like safety, shelter, income, and more.<sup>63</sup> For the past 14 years, Legal Aid of NC's Medical-Legal Partnership Program has collaborated with health professionals in a variety of clinics, hospitals, and health systems to integrate access to "legal remedies" for social drivers of health, such as food, income, and housing security; access to education, health insurance, disability benefits, and other safety net supports, and family safety and stability.<sup>64</sup> Another example of a legal support organization is Disability Rights North Carolina, a legal advocacy agency that fights for the rights of people with disabilities in NC, handling cases involving discrimination, abuse, and other rights violations at no cost for families.<sup>65</sup>

### Challenges and Opportunities to Improve Complex Care Integration in NC

North Carolina Medicaid, which insures 43% of children in NC and 50% of CYSHCN in NC,<sup>66</sup> is transitioning to a value-based payment model through Medicaid Transformation.<sup>67,68</sup> Since July 2021, providers increasingly are reimbursed based on quality of care rather than the volume of care provided. This shift is aimed at better aligning incentives of health systems, payers, and providers with those of patients and families. Included in the NC Medicaid Transformation process are intensive efforts to address SDH, mitigate healthcare disparities, and improve care coordination for patients with complex needs.<sup>69</sup>

Despite North Carolina having a range of programs and resources available to support CCHN, the provision of care remains siloed within and across health and social sectors. There is limited cross-sector integration and collaboration between and among the state's existing complex care initiatives due to overlapping policies, unclear responsibilities, no uniform eligibility criteria, budget limitations, and an overall lack of data sharing.<sup>18</sup> As the many organizations committed to CCHN develop creative operational strategies tailored to their specific organizational needs, duplication of and gaps in services can occur and lead to insufficient family support and poor health outcomes. Unfortunately, because CCHN comprise a relatively small percentage of the overall child population in NC, these challenges often do not receive legislative or administrative priority.

One key demonstration project that directly confronts these challenges is the North Carolina Integrated Care for Kids (NC InCK) Model, which aims to improve care coordination while also reducing health expenditures and improving the quality of care for Medicaid-insured children under 21 years

of age.<sup>42,70</sup> The NC InCK Model – a partnership led by Duke Health System, University of North Carolina Health System, and the NC Department of Health and Human Services – is being implemented in five NC counties (Alamance, Orange, Durham, Granville, Vance) and includes approximately 87,000 Medicaid and CHIP beneficiaries under the age of 20. Key priorities of the NC InCK Model include implementation of individualized cross-sector plans of care and development of data linkages between the health and education sectors as well as other core child services, such as food, housing, welfare, and juvenile justice.

Now, as NC transitions rapidly towards value-based managed care, the stage is being set to broadly advance integrated and comprehensive care for CCHN.<sup>71</sup> New payer contracts, payment structures, renewed focus on integrating care for behavioral and mental health needs with overall medical care, and statewide policy changes that cover existing health service gaps and detangle information access systems present opportunities to improve systems of care for CCHN. In order to capitalize on these opportunities and align the ongoing rapid healthcare transformation in NC with the shared priorities of existing community-based organizations and initiatives and the patients/families they serve, collaboration across health and non-health sectors that serve CCHN and a cohesive strategic approach are critically needed.

### **Building a Coalition to Catalyze Cross-Sector Integration for CCHN in NC**

The following three key drivers motivated our efforts to facilitate collaboration on cross-sector care integration for CCHN in NC: (1) need for better information from those with lived experience on the key issues that system improvement efforts in the care for CCHN must address; (2) need for understanding the challenges and successes of existing organizational initiatives in NC; and (3) need to prioritize system of care improvement efforts in the context of health policy changes in NC. To address our team's key motivating drivers and information needs, we formed a broad coalition of partners from across NC with diverse experiences and interests in the system of care for CCHN. The goal for this new coalition – the Children's Complex Care Coalition of North Carolina (4CNC) – was to develop a working agenda for system of care improvements that reflects the priorities of those most heavily invested in the outcomes of such a system. In particular, one of 4CNC's central priorities is to guide system improvements towards meeting the needs and expressed priorities of families and front-line service providers of CCHN, whose lived experiences should inform allocation of resources, selection of topics for advocacy, and efforts of researchers and policymakers.

4CNC was created through a partnership with the National Center for Complex Health and Social Needs, a nationwide initiative aimed at improving outcomes for individuals with complex needs.<sup>72</sup> The project is a collaboration among Duke University, the University of North Carolina at Chapel Hill, Title V Program staff in the Women's and Children's Health Section of the North Carolina Division of Public Health, and Legal Aid of North Carolina. Four coalition leaders convened a 16-member coalition advisory panel (3 parents of CCHN, 3 state public health officials, 6 pediatricians from diverse practice settings, 1 Medicaid leader, and 3 representatives of child service and advocacy agencies) who worked over 6 months to recruit and engage community partners from around the state to share their perspectives and priorities for improvements to the system of care. A team of undergraduate and graduate student volunteers supported the coalition's work.

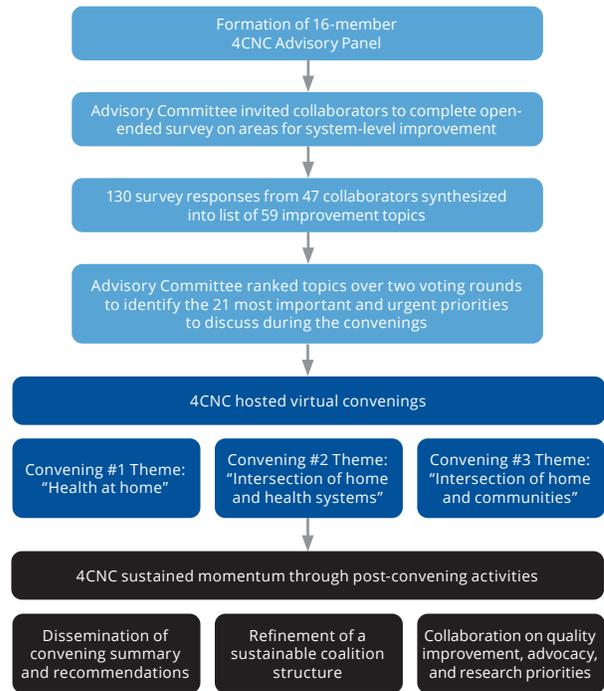
# METHODS

## Convening Topic Selection: Building Consensus through 4CNC

Consensus-building to identify the highest priority topics for discussion at the Path-4CNC convenings was the first in a multi-step, stakeholder-engaged prioritization process (Figure 1).

Between August 2020 and August 2021, we developed a master list of topics using multiple methods of stakeholder engagement and consensus building (Figure 2).

First, we partnered with the 16-member 4CNC advisory panel to solicit open-ended responses from stakeholders across NC with experience in the care of CCHN (primarily families and front-line service providers) about their priorities and ideas to improve the system of care and iteratively improved upon this list. We qualitatively analyzed survey responses to develop an initial list of priority topics. Members of the expert advisory panel then rated each topic on importance and urgency on a scale from 1 through 9 over the course of two rounds. Virtual meetings between rounds helped to clarify questions and discuss highlighted topics. Committee ratings were then grouped into three ranks (low, medium, high) for importance and urgency. The final 21 topics of highest importance and urgency (Figure 3) were integrated into the 4CNC priority agenda for improving the system of care for CCHN in NC.



**FIGURE 1:** Multi-step stakeholder-engaged prioritization process



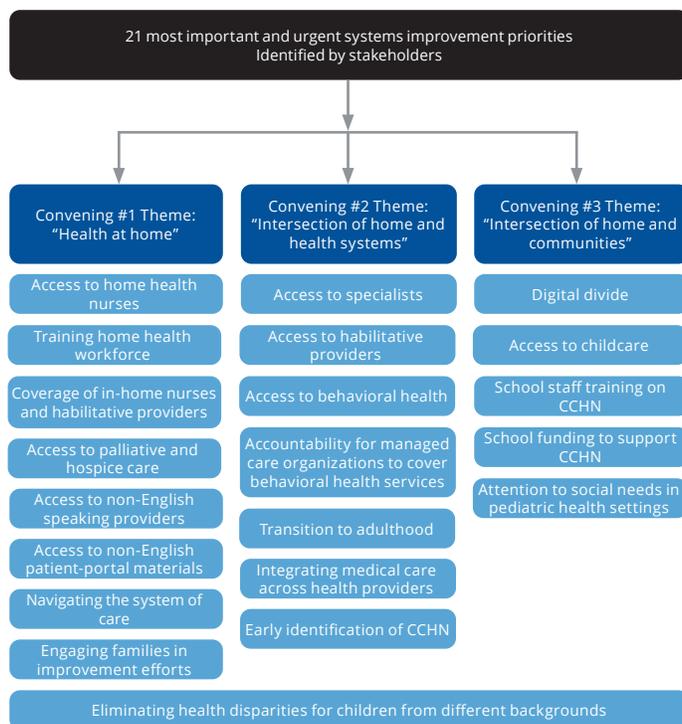
**FIGURE 2:** Consensus building steps to identify systems improvement priorities

Our initial goal was to host an in-person conference focused on improving the system of care for CCHN in NC. However, due to COVID-19 we adapted the sessions into a series of virtual convenings. Three virtual Path-4CNC convenings were held between January – March 2021. The first convening – “Path

to Better Health for Children with Complex Health Needs at Home” –was held on 27 January 2021. The second convening – “Path to Better Health for Children with Complex Health Needs at the Intersection of Home and Healthcare Systems” – was held on 24 February 2021. The final convening – “Path to Better Health for Children with Complex Health Needs at the Intersection of Home and Communities/Neighborhoods” – was held on 24 March 2021. Participants were recruited with the help of the advisory panel to aim for an ideal group of around 60-70 participants, a third of whom represented families, a third healthcare providers, and a third community and/or family advocacy agencies. Each advisory panel member invited up to five direct contacts with interest and experience in improving the system of care for CCHN in NC.

The agenda for each convening included a keynote presentation, a brief didactic session focused on practical topics of particular relevance to families of CCHN (“bite-size talks”), and a small group exercise to foster discussion and crowd-source ideas for improving the system of care (“gallery walk”). For each gallery walk session, participants were split into breakout rooms of approximately 12 individuals. Breakout room discussions were led by a facilitator who guided participants through the highest priority discussion topics for each convening and a scribe who recorded the group’s discussion on a PowerPoint slide. Each group started with a different topic, discussed the topic for 8-10 minutes, and rotated to the next discussion topic until all 4-5 key topics for each convening were discussed (Figure 4). As groups moved to slides that had already been started, participants had the opportunity to emphasize existing comments from other groups by using a star graphic.

To facilitate discussion, before each convening participants received one-page summaries with background information, a glossary of key terms, and the gallery walk breakout room topics. These materials were also uploaded to the Path-4CNC website so that they could be accessed after the convenings and shared more easily with participants’ contacts. To maximize accessibility for each convening, closed captioning in Spanish and American Sign Language interpretation were provided. We encouraged participants to share additional experiences and continue conversations through a moderated discussion board on the Path-4CNC website.<sup>73</sup>



**FIGURE 3:** Highest priority topics discussed across virtual convenings

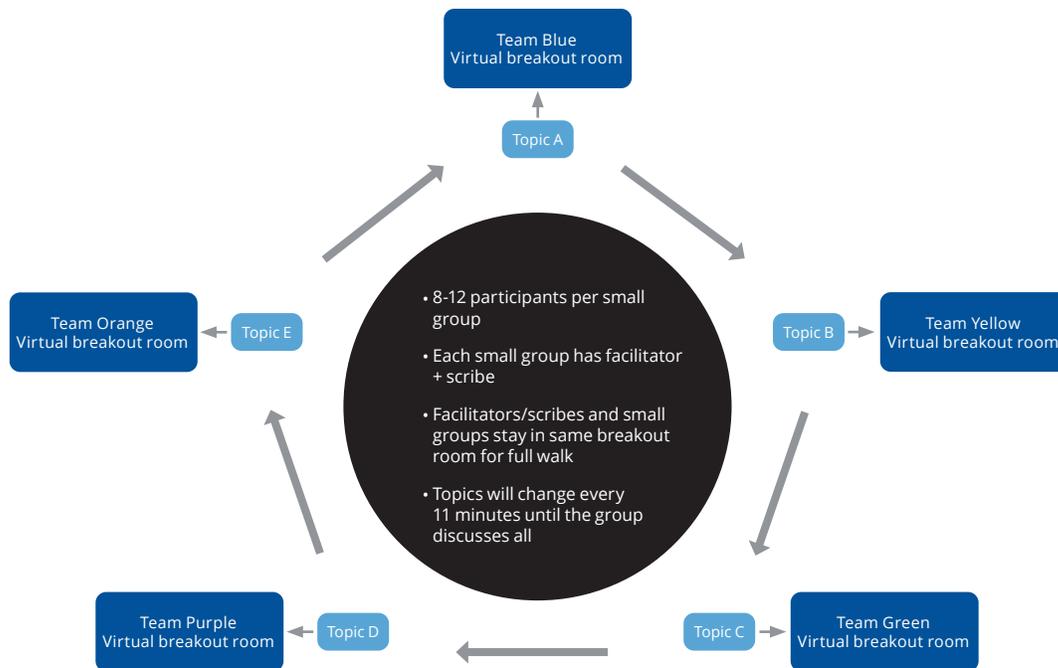
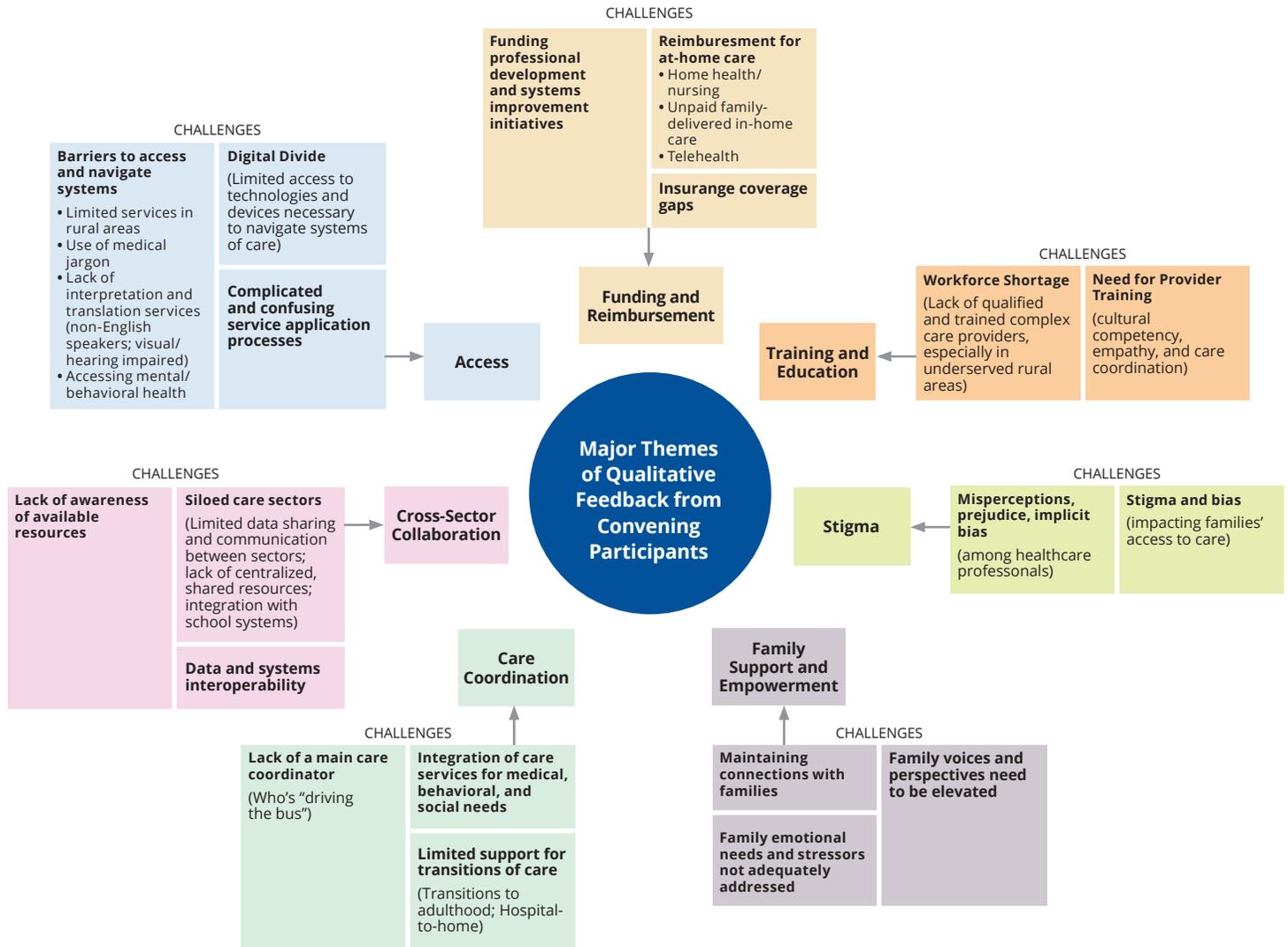


FIGURE 4: Gallery walk process

### Convening Topic Analysis

Breakout room discussions during each convening were recorded and transcribed. Team members worked in pairs to review verbatim transcriptions of convening discussions and identify common discussion themes. Names of resulting themes were modified through iterative discussion among all team members. Themes were summarized comprehensively and illustrated with exemplar quotes from participants.

## Major Themes and Core Challenges – Qualitative Feedback from Convening Participants



## Recommendations to address major themes and core challenges

Themes	Challenges	Recommendations
Training and Education	<b>Workforce shortage</b> (Lack of qualified and trained complex care providers, especially in underserved rural areas)	<b>Expand complex care training opportunities and diversity in the workforce</b> <ul style="list-style-type: none"> <li>Specialized programs</li> <li>Integration into existing programs</li> <li>Increased exposure and networking</li> </ul>
		<b>Use financial incentives to recruit and retain complex care workforce</b>
	<b>Need for provider training</b> (Cultural competency, empathy, and care coordination)	<b>Offer training opportunities in complex care for child health providers</b> <ul style="list-style-type: none"> <li>Empathy and cultural competency</li> <li>Care coordination</li> <li>Care transitions</li> </ul>
Stigma	<b>Misperceptions, prejudice, implicit bias</b> (among healthcare professionals)	<b>Expand professional training and education for providers</b> <ul style="list-style-type: none"> <li>Implicit bias</li> <li>Awareness of stigma faced by families</li> </ul>
	<b>Stigma and bias</b> (Impacting families' access to care)	<b>Deploy individuals with lived experience in roles throughout the system of care</b> <ul style="list-style-type: none"> <li>Employ families of children with complex health needs (CCHN) as family partners and navigators</li> </ul>
Family Support and Empowerment	<b>Family voices and perspectives need to be elevated</b>	<b>Directly partner with families</b> <ul style="list-style-type: none"> <li>Participation in policymaking</li> <li>Implementation of shared decision-making</li> <li>Leadership of community-engaged initiatives</li> </ul>
	<b>Family emotional needs and stressors not adequately addressed</b>	<b>Expand implementation of family-centered services</b> <ul style="list-style-type: none"> <li>Parent-parent support groups</li> <li>Family partner programs</li> <li>Co-location of care for all family members</li> <li>Medical-legal partnerships</li> </ul>
	<b>Maintaining connections with families</b>	<b>Leverage technology to maintain connections over time</b> <ul style="list-style-type: none"> <li>Use multiple modalities (text, email, phone, etc)</li> </ul>

<b>Care Coordination</b>	<b>Lack of a main care coordinator</b> <ul style="list-style-type: none"> <li>• Who's "driving the bus"</li> </ul>	<b>Designate a single point of contact for care coordination</b>
	<b>Integration of care services for medical, behavioral, and social needs</b>	<b>Coordinate services across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Integrate mental and physical health services</li> <li>• Leverage telehealth to improve access</li> <li>• Improve communication and coordination between healthcare and school sectors</li> <li>• Strengthen transitions of care from hospital-to-home and into adulthood</li> </ul>
	<b>Limited support for transitions of care</b> <ul style="list-style-type: none"> <li>• Transitions to adulthood</li> <li>• Hospital-to-home transitions</li> </ul>	
<b>Cross Sector Collaboration</b>	<b>Lack of awareness of available resources</b>	<b>Develop central, shared resources for coordination across sectors</b> <ul style="list-style-type: none"> <li>• Family partners and navigators</li> <li>• Centralized resource directory and referral systems</li> </ul>
	<b>Siloed care sectors</b> <ul style="list-style-type: none"> <li>• Limited communication between sectors</li> <li>• Limited data sharing</li> <li>• Lack of centralized, shared resources</li> <li>• Integration with school systems</li> </ul>	<b>Improve communication and coordination across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Strengthen communication systems for schools and expand school-based health workforce (e.g., social workers)</li> </ul>
	<b>Data and systems interoperability</b>	<b>Improve data sharing and interoperability</b>
<b>Access</b>	<b>Complicated and confusing application process for services</b>	<b>Training for families on how to access available programs</b>
	<b>Barriers to access and navigate systems</b> <ul style="list-style-type: none"> <li>• Limited services in rural areas</li> <li>• Use of medical jargon</li> <li>• Lack of interpretation and translation services (non-English speakers; visual or hearing impaired)</li> <li>• Accessing mental/behavioral health</li> </ul>	<b>Expand transportation services for families in rural areas</b>
	<b>Digital divide</b> <ul style="list-style-type: none"> <li>• Limited access to technologies and devices necessary to navigate systems of care</li> </ul>	<b>Provide accessible information for families and enhanced access to services through community-based providers</b> <ul style="list-style-type: none"> <li>• Real-time access to interpreter services</li> <li>• Spanish translated medical forms and charts</li> <li>• Use of family-friendly language</li> <li>• Expand workforce for co-located mental health providers in the pediatric medical homes</li> </ul>
		<b>Provide technology and training to overcome digital barriers to access care</b>

## RESULTS

<b>Funding and Reimbursement</b>	<b>Reimbursement for at-home care</b> <ul style="list-style-type: none"> <li>• Home health/nursing</li> <li>• Unpaid family-delivered in-home care</li> <li>• Telehealth services</li> </ul>	<b>Increase reimbursement and incentives for in-home care and community-based organizations to address social needs</b> <ul style="list-style-type: none"> <li>• Family partner programs</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> </ul>
	<b>Funding professional development and systems improvement initiatives</b>	
	<b>Insurance coverage gaps</b>	<b>Close gaps with novel insurance options</b> <ul style="list-style-type: none"> <li>• Medical-legal partnerships</li> </ul>

## Exemplar Quotes: Perspectives of Convening Participants

### THEME 1: Training and Education

Theme	Challenges	Recommendations
Training and Education	<b>Workforce shortage</b> (Lack of qualified and trained complex care providers, especially in underserved rural areas)	<b>Expand complex care training opportunities and diversity in the workforce</b> <ul style="list-style-type: none"> <li>• Specialized programs</li> <li>• Integration into existing programs</li> <li>• Increased exposure and networking</li> </ul>
		<b>Use financial incentives to recruit and retain complex care workforce</b>
	<b>Need for provider training</b> (Cultural competency, empathy, and care coordination)	<b>Offer training opportunities in complex care for child health providers</b> <ul style="list-style-type: none"> <li>• Empathy and cultural competency</li> <li>• Care coordination</li> <li>• Care transitions</li> </ul>

#### RECOMMENDATION 1

#### Expand complex care training opportunities

*“Certainly, workforce capacity is a current challenge... a longer-term solution that’s related to that is to build a better pipeline for the workforce starting in high school and working with community colleges to provide training opportunities for people to enter these fields.”*

*“I think the biggest issue is... that curriculum really needs to be overhauled. The training for nurse aides is focused on geriatric patients in nursing homes. There is almost no acknowledgement that a nurse aide would work anywhere else or with any other population.”*

*“There’s a need for specialized education that isn’t a degree. It may be a certificate. It may be some sort of shorter-term learning program, but I think that there needs to be more specialization... The same person can’t go out to the home of an elderly person with COPD and a baby from the NICU that needs an NG tube and feeding.”*

***“Build a better pipeline for the workforce.”***

*“[At home nurses] really become a part of your family. They’re in your home. And just, having training of these nurses, the understanding that you are letting them into your home, and maybe just having some more empathy training towards that... they need to understand that this is you opening up your most sacred place.”*

RECOMMENDATION 2

**Increase financial incentives for complex care workforce**

*“If we can’t pay living wages with potential for career advancement... we can’t expect people to do this kind of really difficult work without having some degree of a career track and a potential to earn a good living.”*

*“These are individuals who are some of the lowest paid in our mental health/behavioral health system, and yet they play such an integral role in working to ensure child and family outcomes, so thus you see high turnover in the system which can be so disruptive to the family and to the child.”*

RECOMMENDATION 3

**Increase complex care provider training**

*“Providers do not fully understand services and eligibility requirements.”*

*“Providers do not fully understand services and eligibility requirements. There’s long wait times for appointments and evaluations. There’s issues of geography, family, and understanding, and then provision of in-home services.”*

*“And then, the long-term solution is making sure that we are training our providers to understand referral, creating new positions for care navigation, and then making sure the community health support system and medical systems are collaborating.”*

THEME 2: **Stigma**

Theme	Challenges	Recommendations
Stigma	<b>Misperceptions, prejudice, implicit bias</b> (among healthcare professionals)	<b>Expand professional training and education for providers</b> <ul style="list-style-type: none"> <li>• Implicit bias</li> <li>• Awareness of stigma faced by families</li> </ul>
	<b>Stigma and bias</b> (Impacting families' access to care)	<b>Deploy individuals with lived experience in roles throughout the system of care</b> <ul style="list-style-type: none"> <li>• Employ families of children with complex health needs (CCHN) as family partners and navigators</li> </ul>

## RECOMMENDATION 1

**Expand professional training and education for providers**

*"I think one of the problems around palliative care is that even providers don't know how to explain it to families, so as soon as you say palliative or hospice, you really turn families off. So just some mass education in a better way to describe the services provided. They don't realize that there's, like, a slew of services. They only hear death and dying."*

*"I know – that some schools – and, even most childcare centers, thinking about the younger kids, preschools – when I worked there as a program coordinator, I was specifically told not to bring up anything – if we ever thought something was off, or wrong, or different with a child, we were not to say a thing at all – nothing... Don't recommend a service, don't say, "Hey, you can go here," because it's sensitive. We didn't want our customers unhappy that we think something's wrong with their kid, which I think is a great disservice to a lot of those kids."*

***"They don't realize that there's a slew of services."***

*"I think also regarding trying to engage families in those types of meetings whether it's an IEP meeting or even just let's sit down and talk about your child meeting, parents have to go to work during the day. Those meetings are usually scheduled during the day, yet the parents can't attend but the staff isn't willing to stay later so that it's trying to keep everybody engaged and involved, sometimes you just can't because you've got to be at work, and I think that poses a big challenge for some families. I think there's a lot more families that want to be involved but they just can't do it, for X, Y, and Z reasons."*

*"It's my experience that the doctors don't know all the resources, that's not their expertise, so they may or may not know anything in the community to send the family to."*

RECOMMENDATION 2

**Deploy individuals with lived experience**

*"I'm seeing a family chase all these hopes and dreams that their child will not be diagnosed with a behavioral health condition instead of being able to focus on getting services for their child and getting help and getting on these waitlists."*

***"If we're asking people to be involved in improvement, their time should be valued and should be having roles that are paid."***

*"Pay parents and families to be part of the system... if we're asking people to be involved in improvement... their time should be valued and should be having roles that are paid."*

*"That early intervention, the really learning how to access resources is so important, and oftentimes it does take somebody who's able to sit with them and be with them in their shoes to help them get past that hesitation."*

*"And similarly, there are, in my clinical work, I found some of the children that receive the least support from the school system are children with sickle cell disease, where there was in some situation – yes, part of it was ignorance about the disease, but part of it I'm sure was the component of unspoken racism and making this about the parents and the children that were completely unwarranted on the basis of the simple fact that the children were African American. And that was a really painful and frustrating situation that I'm sure still persists."*

## THEME 3: Family Support and Empowerment

Theme	Challenges	Recommendations
Family Support and Empowerment	Family voices and perspectives need to be elevated	<b>Directly partner with families</b> <ul style="list-style-type: none"> <li>• Participation in policymaking</li> <li>• Implementation of shared decision-making</li> <li>• Leadership of community-engaged initiatives</li> </ul>
	Family emotional needs and stressors not adequately addressed	<b>Expand implementation of family-centered services</b> <ul style="list-style-type: none"> <li>• Parent-parent support groups</li> <li>• Family partner programs</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> </ul>
	Maintaining connections with families	<b>Leverage technology to maintain connections over time</b> <ul style="list-style-type: none"> <li>• Use multiple modalities (text, email, phone, etc)</li> </ul>

## RECOMMENDATION 1

**Directly partner with patients and families**

*“One thing that I think is important – I’m looking at best practice and local examples – is they say to recognize the value of lived experience, which is true. I think one way to recognize that and just show value is to not expect them to volunteer to help. You need to have a way to reimburse families to engage families to help you with the work or we need to pay them for the work.”*

*“If I could fix one thing, it would be that agency folks recognize that parents and caregivers are experts of their own family, and that they recognize that they know their kids better than anybody... Because sometimes, I think our concerns are dismissed.”*

*“People aren’t empowered enough to know that their feedback is important and can and will help to shape the future for all individuals in their situation.”*

*“Leaving ourselves and our beliefs outside the room and focusing on what’s important to the patient or the family, and how can we best acknowledge that.”*

*“If we can ask the family with the appropriate amount of humility, we can get a lot of answers we might not be expecting.”*

***“Recognize that parents and caregivers are experts of their own family,... recognize that they know their kids better than anybody.”***

*“Make families co-creators of the policies, programs, and practices that impact them.”*

*“Listen to youth and family voices. Recognize that they’re not always the same.”*

***“Make families co-creators of the policies, programs, and practices that impact them.”***

*“...the rural communities, they do have a completely different experience in these systems, and their voice would be really helpful in advocating for the momentum of what their counties need.”*

*“People need to be paid. We’re saying their work is valuable. We’re saying they need to be trained to do it. But in many situations, those parents are expected to volunteer their time, which seems to me to be counterproductive if you’re saying, what you do is important and special and needs to be trained, but you gotta do it for free... our system needs to find a way to say, family input is important in our society, we show its value by paying for it and we’re asking people to give up their time, which has value.”*

### RECOMMENDATION 2

#### **Expand implementation of family-centered services**

*“We need more navigators that are parents, that are families that have this personal experience, and just kind of have their hands in a little bit of everything.”*

*“I think there also needs to be a family support group... these families go through a lot and they are burnt out. They need the resources of other families... the family support of another family has been helpful.”*

*“Not just providing a professional service but giving families access to other families with lived experience might help them understand that in a way that makes it resonate more.”*

*“You’re just trying to wrap your head around how your life is going to change... you receive all this information, pamphlets, fliers, one-pagers and you’re overwhelmed... I think family navigators who are family members would maybe be more sensitive to that and be able to read a parent better and be like okay, we’ll release a little bit at a time and say this is available too, and when you’re ready we’ll get there. But I remember feeling very overwhelmed in the beginning when we were trying to figure out what was going on.”*

*“If there’s screenings that are conducted by a physician or an integrated mental health provider in a clinic, then they can use systems navigation referral guidance to make sure parents are getting the support they need.”*

*“So often, the child is presenting the problem, but it’s a family issue. It may have more to do with the family structure and dynamic. I think that you have to be able somehow to talk to the family as well as the child if you’re gonna get to the root of the issue and change what’s going on.”*

*“The parent is often the vehicle through which I’m treating the child and working with that parent. Supporting her or his ability to provide care in their mental health is a big challenge.”*

### RECOMMENDATION 3

#### **Leverage technology to maintain connections over time**

*“Using different platforms to get information out... whether it’s a poster, whether it’s something audible, whether it’s an app versus a phone call.”*

*“Using different platforms to get information out.”*

THEME 4: Care Coordination

Theme	Challenges	Recommendations
Care Coordination	<b>Lack of a main care coordinator</b> <ul style="list-style-type: none"> <li>• Who’s “driving the bus”</li> </ul>	<b>Designate a single point of contact for care coordination</b>
	<b>Integration of care services for medical, behavioral, and social needs</b>	<b>Coordinate services across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Integrate mental and physical health services</li> <li>• Leverage telehealth to improve access</li> <li>• Improve communication and coordination between healthcare and school sectors</li> <li>• Strengthen transitions of care from hospital-to-home and into adulthood</li> </ul>
	<b>Limited support for transitions of care</b> <ul style="list-style-type: none"> <li>• Transitions to adulthood</li> <li>• Hospital-to-home transitions</li> </ul>	

RECOMMENDATION 1

**Designate a single point of contact for care coordination**

*“Two major physician caregivers in two different settings, each thinking the other was driving the bus”*

*“Their kids were 10 years old with complex needs. They just didn’t know there was stuff that could be provided for their child.”*

*“If it was someone’s sole responsibility to be aware of what’s going on, it would be really helpful.”*

*“I’ve worked with several families and each family does tell a similar story. They would like a one-stop shop... coordinated care is so important... it gets so overwhelming to try to navigate the systems.”*

***“If it was someone’s sole responsibility to be aware of what’s going on, it would be really helpful.”***

*“But I think trying to do coordinated teams, trying to have things in a more centralized location where there are multiple providers for some of these kids, just something to try and coordinate these appointments so that people aren’t missing a lot of work or missing a lot of school or those types of things.”*

## RECOMMENDATION 2

**Coordinate services across the care continuum and between sectors**

*“There needs to be better coordination with schools. We have a lot of families that fall through the gaps because they’re not getting care at school.”*

*“There are districts where there are no school social workers at all, or there’s one speech therapist that serves all of the schools, and so, certain kids can’t even get speech because the therapist can’t physically be in two places at once, and I think that’s a huge problem across the entire state.”*

*“Transportation is challenging in and of itself because what happens is that they’re coming from a rural county. They can only get transportation on certain days of the week or at certain times. Then, even families who have private vehicles, they only have one vehicle in the home and one of the parents needs it for work. So, that becomes an issue because they’re only available at certain times, and transportation definitely is a barrier to getting to their therapies.”*

*“It’s easy for those of us who don’t live in a rural county not to realize that there’s not even the available staff to serve these kids, who have the same needs as kids in less rural places, and I think we just need a lot more – support personnel, social workers, and nursing – across the state to be more equitable.”*

*“We have a lot of families that fall through the gaps because they’re not getting care at school.”*

THEME 5: Cross-Sector Collaboration

Theme	Challenges	Recommendations
Cross Sector Collaboration	<b>Lack of awareness of available resources</b>	<b>Develop central, shared resources for coordination across sectors</b> <ul style="list-style-type: none"> <li>• Family partners and navigators</li> <li>• Centralized resource directory and referral systems</li> </ul>
	<b>Siloed care sectors</b> <ul style="list-style-type: none"> <li>• Limited communication between sectors</li> <li>• Limited data sharing</li> <li>• Lack of centralized, shared resources</li> <li>• Integration with school systems</li> </ul>	<b>Improve communication and coordination across the care continuum and between sectors</b> <ul style="list-style-type: none"> <li>• Strengthen communication systems for schools and expand school-based health workforce (e.g., social workers)</li> </ul>
	<b>Data and systems interoperability</b>	<b>Improve data sharing and interoperability</b>

RECOMMENDATION 1

**Develop central, shared resources for coordination across sectors**

*“Every time there’s a change, a new service, or a new acronym, and you’re not in it all day, every day, you can’t keep up with it or know what’s going on.”*

*“Families don’t know they can even ask for that.”*

*“Every transition that our kiddos go through requires a whole new set of resources, and having someone that can get a family to the right point of contact, to the right providers, can save so much money for our systems, and also the quality of life for the child and family”*

*“I have a 16-year-old child with severe intellectual disabilities, and I cannot believe that sometimes parents have not ever heard of the waiver and have not started that process.”*

*“We’ve been on the Innovations Waiver for my daughter that’s now almost 25 since 2004, and I didn’t sign up until she was 6 or 7 because I thought, “Well, we don’t need it now.” Big mistake. This should be sent when the baby comes to your office – to a pediatrician. You just say, “Have you signed up for this?”, and you sign right when you’re a baby, and I would suggest that immediately.”*

*“I think back to when children were babies and you go in for each wellness check. You get a form that says, “These are the milestones that are coming, these are the shots that your child has,” just having a list of resources on that one form may be beneficial. That way, the providers don’t necessarily have to memorize what this program is, what that program is... There’s a lot of great programs out, but you don’t know they exist and you don’t know to go looking for them”*

## RECOMMENDATION 2

**Improve communication and coordination across the care continuum and between sectors**

*“I think about the school system and I think that someone in the school system, by age 3, 4, or 5, is doing a psychoeducational assessment, is identifying a learning disability or an intellectual disability, and that that is a potential but often missed opportunity to provide families information about other systems of services like the MCOs and like the waiver programs.”*

*“Children and families can fall through the cracks at any time whenever they change services. I believe that transition is a lifelong process, and that self-determination is all about learning how to be a really strong self-advocate. And this happens as children age, and they’re going through those developmental stages and milestones.”*

*“I think we need to consider coordinating care across providers. That should start with the family at the center. I think families are never the barrier to sharing information. It’s us in our different sectors trying to get around the laws that we feel like hold up information sharing, and the antiquated ways we have of sharing information with each other.”*

*“It has become a little bit harder with things now becoming more fragmented with where things are located. I think trying to do coordinated teams in a more centralized location with multiple providers for these kids would be beneficial.”*

*“We see the pulmonologist, the neurologist, the physical therapist, a complex care doctor, and a social worker. Having that one-stop shop for some of these kids that have an overarching diagnosis is ideal.”*

*“Access to information for medical professionals is important because not everyone is going to have a navigator in their office. Being able to access the resources in the community and learning how to collaborate with community support is great, so that even though the doctors may not have all the answers, they know where to go to get them.”*

*“We’re so far from meeting the appropriate ratio of nurse to child, or nurse to schools. All these great nurses are overworked, going between several schools, while they’re well trained to work with children with complex needs. Honestly, that’s a long-term solution in terms of advocacy with the general assembly to improve that ratio and provide the funding for them.”*

## RECOMMENDATION 3

**Improve data sharing and interoperability**

*“The ability to have data and systems communicate better... education, IDD, behavioral health, physical health, and all the other systems with collaboration.... that would actually make a huge difference in terms of family burden, because now we give it all to the parent... if we just could share that data more readily, it would reduce the burden.”*

THEME 6: Access

Theme	Challenges	Recommendations
Access	<b>Complicated and confusing application process for services</b>	<b>Training for families on how to access available programs</b>
	<b>Barriers to access and navigate systems</b> <ul style="list-style-type: none"> <li>Limited services in rural areas</li> <li>Use of medical jargon</li> <li>Lack of interpretation and translation services (non-English speakers; visual or hearing impaired)</li> <li>Accessing mental/behavioral health</li> </ul>	<b>Expand transportation services for families in rural areas</b>  <b>Provide accessible information for families and enhanced access to services through community-based providers</b> <ul style="list-style-type: none"> <li>Real-time access to interpreter services</li> <li>Spanish translated medical forms and charts</li> <li>Use of family-friendly language</li> <li>Expand workforce for co-located mental health providers in the pediatric medical homes</li> </ul>
	<b>Digital divide</b> <ul style="list-style-type: none"> <li>Limited access to technologies and devices necessary to navigate systems of care</li> </ul>	<b>Provide technology and training to overcome digital barriers to access care</b>

RECOMMENDATION 1

**Training for families on how to access available programs**

*“Just every time there’s a change, there’s a new service, a new acronym... if you’re not in it all day, every day, you can’t keep up with it.”*

*“How would they know the value of PT, OT, or Speech Therapy unless they’re taught? So not understanding it is not the issue. Not knowing it and not being exposed to it is the problem.”*

RECOMMENDATION 2

**Provide accessible information for families and community-based provider**

*“I’m thinking as a parent, when somebody says medical home what does that mean? Do I understand what that means? It’s just as important for the families to recognize what the model*

*is when you’re talking about it, so they understand what you’re talking about. You know what you’re talking about but if you use that language with a normal parent, would they understand what you’re talking about?”*

***“The world of medicine has a different language.”***

*“The world of medicine has a different language.”*

*“It sort of broadens this notion of equitable access to communication not just by someone’s spoken language. It would include things like health literacy.”*

*“In public health and in the medical field, you know, it’s a very different language... there’s all these words and acronyms and there’s all these letters after people’s names that’s very intimidating.”*

*“A better job of educating families is using language that everyone can understand. I know that everyone has their jargon, but if we can define it so that people know what you mean, it goes a long way.”*

*“There’s still so much material out there that people don’t understand. I actually went to an appointment with one of my sons this morning, and I’m sitting there thinking he didn’t know I was a practitioner, and if my husband was here, he’d have no idea what was going on.”*

*“I speak English, but there’s a lot of information – within the medical field that is so challenging. I remember when I was given the diagnosis for my child and everything else, that alone was so overwhelming because I couldn’t follow the terminology they were using. And so, for me to even say, “Hey, I have questions,” I need a whole day just to process those words, what is this, find the meanings, and then, let me come back, make an appointment, because then, I don’t know if I’m gonna have questions.”*

***“I speak English, but there’s a lot of information – within the medical field that is so challenging.”***

*“I think if we could have families access MyChart in Spanish, they would be able to cut so many phone calls... at the moment, it’s not all in Spanish.”*

*“There’s also people [who] need interpreters for sign language... People with hearing loss... that’s another way that we need to think about language access.”*

*“I think your current challenges are just magnified with your limited English families, other marginalized groups or populations.”*

### RECOMMENDATION 3

#### **Provide technology and training to overcome digital barriers to access care**

*“We really need investment in internet infrastructure. Get these rural communities the cell phone towers, satellites, whatever needed to get their children access to the health they deserve.”*

*“A lot of families don’t have their own transportation and already rely on transportation – the buses – to get their kids to school and transportation to get to work, so if the hotspot is at the library parking lot on a school bus, that’s great, but the kids still had no way to get there.”*

*"I have been asking myself the question during the pandemic at what point does high-speed internet connectivity become another one of the basic utilities that we think all families need access to? And, I think we may be past that point and struggling to catch up to the infrastructural changes that are needed to do it, but in my head, we're sort of already there, but it's like running water and electricity. People need access to the internet."*

***"At what point does high-speed internet connectivity become another one of the basic utilities?... People need access to the internet."***

*"The government has a plan for folks meeting certain income eligibility guidelines to be able to qualify for a much lower cost internet access. A program's come out recently on that. I know there's been a lot of financial assistance during COVID, but it seems like this is something beyond COVID, to make it more affordable so families can access it."*

*"A lot of kids use the assistive technology devices at their schools because they're tremendously expensive, and if parents buy them, A). They're expensive, and B). They're not being trained on them. And, the other thing is to assure that you don't just go buy an assistive technology device until you're sure it will work for your child's communication issues because you can spend a lot of money."*

*"I can remember hearing of a family member in a rural area, and this was early on in COVID where they didn't have the internet access at home. And so, they were driving around in their car, using their phone to find hotspots so that their children could still attempt to do their schoolwork... they didn't want people to know that they were struggling because they wanted their children to still have access and try to keep up with their schoolwork."*

## THEME 7: Funding, Reimbursement Structures, and Incentives

Theme	Challenges	Recommendations
Funding and Reimbursement	<b>Reimbursement for at-home care</b> <ul style="list-style-type: none"> <li>• Home health/nursing</li> <li>• Unpaid family-delivered in-home care</li> <li>• Telehealth services</li> </ul>	<b>Increase reimbursement and incentives for in-home care and community-based organizations to address social needs</b> <ul style="list-style-type: none"> <li>• Family partner programs</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> <li>• Co-location of care for all family members</li> <li>• Medical-legal partnerships</li> </ul>
	<b>Funding professional development and systems improvement initiatives</b>	
	<b>Insurance coverage gaps</b>	<b>Close gaps with novel insurance options</b> <ul style="list-style-type: none"> <li>• Medical-legal partnerships</li> </ul>

## RECOMMENDATION 1

**Increase reimbursement and incentives for in-home care**

*“We don’t have enough childcare vouchers that go to counties, so that’s the current challenge. The long-term solution would be for the General Assembly to increase childcare voucher funding.”*

*“Other states have created some flexibility for families by allowing either a parent or another family member to be certified as a nursing assistant or a homecare assistant, and be paid as a professional by that work.”*

*“Families’ time is just as important as [providers’] time... Is there a reimbursement mechanism, is there funding to help compensate families for the time that they put in?”*

*“Is there a reimbursement mechanism, is there funding to help compensate families for the time that they put in?”*

*“I think right now during COVID, some of the flexibility of being able to offer some services virtually, I hope that we’ll continue to see that telehealth coverage continue for many years to come, because that is also opening up, I think, some great opportunities.”*

## RECOMMENDATION 2

**Close gaps with novel insurance options**

*“Sometimes [parents] had to stop working in order to be able to qualify for the Medicaid services, to get the amount of services that their child needs in order to not regress.”*

*“It goes to the importance of thinking about something in the longer-term, like eventually having an option for families to buy into Medicaid if their child doesn’t qualify through a waiver and thinking really hard about how we allow people to be eligible for or to access the benefits of Medicaid.”*

## RESULTS

*“It would be great if there were some private/public partnerships to fund these services because so often if you’re the working poor and now you have insurance, but insurance doesn’t cover enough of it. Then there’s no one to pick up the slack because you don’t qualify for Medicaid or CHIP. I think that’s a big issue, so public/private partnerships would be great that targeted that.”*

*“Sometimes parents had to stop working in order to qualify for Medicaid services, to get the amount of services that their child needs in order to not regress.”*

## NEXT STEPS

Input from 60-90 attendees at the Path-4CNC series of statewide virtual convenings highlighted key challenges and recommendations across seven major themes. Multiple next step opportunities exist for key stakeholder groups to improve systems of care. Each group – from families and in-home service providers to policymakers and payers – has a critical role to play to equitably advance health and well-being for all CCHN and their families in NC. Key stakeholder groups in NC now have an opportunity to collaboratively address the challenges and implement the recommendations of Path-4CNC convening attendees. The following four cross-sector initiatives are examples of how stakeholder groups in NC can build on the convenings to address the most important and urgent priorities of those with lived experience in the system of care for CCHN. Each example includes inter-related actions and links to major themes from the convenings.

### NEXT STEP INITIATIVE EXAMPLE 1

#### **Make Families Partners, not just Clients, in the System of Care**

**Themes addressed – Family Support and Empowerment; Stigma; Cross-Sector Collaboration**

##### *Why this initiative is needed*

Participants in the Path-4CNC convenings emphasized the need to include CCHN and their families as partners in all aspects of the system of care. When families are treated as clients, decisions about the structure of service programs, the application procedures required to access them, and even the terminology used to describe them can often be made without input from those who access and use services. The result is that families of CCHN are frequently unaware of options to meet their needs and not sure where or how to start looking. When they do discover appropriate programs and services, the jumble of acronyms and endlessly differing application procedures can discourage even the most activated parent. Moreover, parents themselves are an underutilized and under-supported, but critical workforce in the system of care for CCHN. Many parents of medically and/or behaviorally complex CCHN provide daily, uncompensated care at the level of a nurse or nursing assistant. Others provide invaluable guidance, based on lived experience, to help families in similar situations navigate fragmented services and systems. Providing opportunities for family members to develop formal roles in the system of care could have health and economic benefits for children and families, and could alleviate some workforce and coordination challenges faced by service sectors.

**ACTION A: Recognize and financially support the work of family members as in-home care providers and peer supports for other parents.** Systems of care for CCHN rely on the efforts of families yet rarely support them. Family members with lived experience caring for CCHN can be acknowledged as critical members of the system of care by creating optional, paid roles for direct care and peer support. Creation of paid parental in-home caregiving roles can leverage the existing expertise and round-the-clock presence of parents. Providing parental in-home caregivers with training and integrating them into the system of care could also help address home health workforce shortages for CCHN and strengthen the family-centeredness of care teams. The depth of lived experience of families of CCHN can be further leveraged by creating parent-parent peer support and coaching roles. Peer support has been successfully utilized in prior studies of multiple CCHN groups to provide emotional support, assist with system navigation, advocate for resources, and facilitate caregiver activation for other parents of CCHN.<sup>77-79</sup> Building upon this evidence base, peer support programs are

## NEXT STEPS

now well-positioned for expansion and integration into the broader system of care. Doing so can be an opportunity to align family-centered interventions like peer support programs with the priorities of payers and health systems to improve patient/family experience as a core pillar of value-based care.

**ACTION B: Invite and empower family representatives to participate in decision-making at all levels of the system of care.** Representation throughout the system of care is critically important in order to elevate the voices of families of CCHN. Active participation is essential to empower families as change agents with the ability to positively influence the system of care. Furthermore, ensuring representation by diverse families who reflect the racial, ethnic, geographic, and socioeconomic diversity of CCHN in NC is essential to advance health equity for the statewide population. Family perspectives on the joys and challenges of direct caregiving and system navigation faced by families of CCHN in NC are essential for leaders in all sectors of the complex care ecosystem to hear. Making a place at policy, health system, community organization, and payer decision-making tables for families can ensure that their priorities are being addressed and systems of care are designed to serve the needs of the primary end-users: CCHN and their families. However, family representation should not be voluntary. Alignment with best practice recommendations to compensate families for their time is essential to honor the efforts of families and to reduce barriers to participation.<sup>80</sup>

### NEXT STEP INITIATIVE EXAMPLE 2

#### “Professionalize” the Complex Care Workforce

##### **THEMES ADDRESSED – Training and Education; Care Coordination; Funding and Reimbursement**

##### *Why this initiative is needed*

Strengthening the complex care workforce was a key priority expressed by participants in the Path-4CNC convenings. Currently, front-line service providers such as private-duty nurses and home health nursing assistants, habilitative and behavioral therapists, teachers, and families themselves provide the vast majority of direct, hands-on care for CCHN, yet many lack access to training opportunities and professional networks needed to grow and thrive in that work. Many also spend an inordinate amount of time struggling to obtain from or share with other service providers information they need to do their jobs well. As a result, turnover is high, morale is low, and quality of services for CCHN over time suffers.

**ACTION A: Enhance training and support for front-line care providers** by linking their agencies to a regional children’s hospital, academic center, or other institutional partner that can provide free or low-cost training opportunities, professional networking, opportunities for exchange on best practices, and technical assistance for commonly encountered situations (e.g., management of behavioral health needs in school settings for children with intellectual and development disabilities).

**ACTION B: Incentivize careers focused on the care of CCHN** through financial supports such as loan repayment programs and supplemental payments for direct service providers who care for CCHN, especially in high-need, under-resourced areas like rural communities. Making high-quality services available near where CCHN and families live is a shared interest for children’s hospitals and payers; these entities could partner with state and federal agencies to fund such initiatives.

**ACTION C: Develop and test new roles** such as cross-sector integration facilitators and transition

coaches who can serve as single points of contact and bridge the spaces in-between the health and related service agencies on which CCHN rely. Most existing coordination resources in NC are tied to individual programs or are charged with facilitating services and benefits in one specific sector (e.g., medical care). Professionals responsible for bridging care sectors could free up sector-specific personnel to focus on providing high-quality services, and could integrate the spectrum of services from a similar perspective to the family's. NC is particularly well-positioned to test such new professional roles for CCHN by learning from the work of North Carolina Integrated Care for Kids (NC InCK) as it tests the implementation of service integration consultants. A future direction that can build on these foundations is to expand care integration facilitation and transition coaching to CCHN and their families.

### NEXT STEP INITIATIVE EXAMPLE 3

## Create Shared Purpose to Improve the Availability, Quality, and Outcomes of Complex Care

### THEMES ADDRESSED – Access; Training and Education; Funding and Reimbursement

#### *Why this initiative is needed*

Family participants in the Path-4CNC convenings described countless shortages and waitlists for services for which children were nominally eligible, particularly among those living in rural areas of the state (e.g., respite care services, private duty nursing, NC Innovations Waiver program for children/youth with intellectual and developmental disabilities). On the other hand, front-line service providers – including behavioral therapists, palliative care nurses, and medical specialists – talked about how challenging it can be to provide services in areas where the population density does not financially support work focused on CCHN. In many of these areas, providers also lack the support and resources of large institutions that underwrite services in denser and wealthier areas of the state. Alternative payment models and value-based contracting may provide financial incentives for large health care organizations to invest in programs to address non-medical drivers of health for their patients. However, innovative financial supports, collaborative partnerships that build complex care capacity, and shared resources are needed to improve equity in the availability, quality, and outcomes of community-based services across the diverse range of places where CCHN live.

**ACTION A: Enhance the capacity of community-based clinics to deliver complex care,** both medical and behavioral. One strategy for doing so would be to provide training for community pediatric clinics on how to document and bill for care coordination work addressing medical care, behavioral health, and social determinants of health. Revenues from those activities could support dedicated care coordination staff and allow medical providers to spend relatively more time in the care of CCHN. Another strategy would be to leverage rapid advancements in telehealth infrastructure and reimbursement to implement provider-to-provider shared visits between a remote specialist located at a tertiary care center and a local primary care provider who has the patient in her clinic.

**ACTION B: Create tools that enhance visibility of existing resources and facilitate access to shared resources** for CCHN that are available across a range of care sites and communities. Currently, many community resources that could benefit CCHN and families are siloed from other service sectors and sites. For example, the state-supported program Care Management for At-Risk Children (CMARC) is separated from health system navigation provided by payer-employed care coordinators. As a

## NEXT STEPS

result, redundancies occur and confusion results. Consider the case of a single CCHN and family who concurrently receive care management outreach from a hospital/clinic coordinator, community agency employee, and payer representative. In such cases, parents describe confusion about who is able to do what, and many times describe feeling overwhelmed and confused.

One strategy to overcome these redundancies could be to create a comprehensive directory that is regularly updated, accessible online and on mobile devices, and transparent to patients, families, and all service providers. The NC Division of Public Health Women and Youth Branch's CYSHCN Helpline and website provide an existing foundation from which to further expand visibility of existing resources. A second strategy is to develop shared resources for use by multiple communities and organizations. NCCARE360 is a new online platform that aims to make referrals and access to social services more efficient across the state.<sup>74</sup> Building on this foundation to identify opportunities for multiple agencies in the same communities/regions (e.g., transportation, housing support) to form collaborations and pool shared resources towards common objectives can enhance impact and reduce redundancies.

### NEXT STEP INITIATIVE EXAMPLE 4 Optimize Information Technology

**Themes addressed – Family Support and Empowerment; Cross-Sector Collaboration; Access**

#### *Why this initiative is needed*

The unrealized potential of information technology to facilitate efficient linkages across the system of care for CCHN was a common concern for participants in the Path-4CNC convenings. Families and care providers described how siloed information systems (for school communication, health care, medical equipment companies, nursing agencies, insurance plans, state programs, etc.) generate massive amounts of additional work, especially when information needs to move between and among systems and/or service sectors. Furthermore, information transfer and communication between systems remains largely paper-based – e.g., printing and mailing or faxing paper copies of information. Reliance on manual, paper-based methods is inefficient because it fails to use existing digital information sources and it creates extra steps in the information-sharing process that require significant time and human effort. In turn, the required incremental effort becomes an important barrier for CCHN to access needed services and a source of endless frustrations for families and care providers.

**ACTION A: Invest in secure data-sharing and communication linkages between systems that commonly share information.** NCCARE360 is an example of the kind of software platform that can facilitate communication across sectors in the system of care and expedite delivery of services to CCHN and families. Developing and implementing NCCARE360 is a large-scale endeavor; but many smaller, between-system linkages are necessary and feasible. For example, one recent published effort created a direct information-sharing link among parents, teachers, and medical providers for children with ADHD by enhancing the health care center's electronic health record with a secure application linked to participants' email addresses.<sup>75</sup> Government agencies, payers, and large health care organizations could lead investments in the development of such linkages, which would benefit all participants in the system of care.

**ACTION B: Use new telehealth capabilities to link nodes in the system of care in real-time.**

Investments in video-enabled devices and communication infrastructure (e.g., broadband internet access) across multiple sectors during the COVID-19 pandemic have rapidly expanded opportunities for families, care providers, and coordination personnel to meet in a shared and secure virtual space, verify a client's identity, and even review/complete important documents together. For example, many participants in the Path-4CNC convenings expressed frustration about delays and inefficiencies in the process of obtaining referrals for medical and community services, such as specialty physician appointments and Medicaid waiver programs. Setting up on-demand, real-time video links between referring providers and referral intake coordinators could massively reduce the amount of time people on both sides of the referral spend leaving and returning voicemails, emails, and faxes. Doing so would require disruption to established workflows, but private companies have already implemented such direct access widely. Moreover, innovators in child health care have demonstrated that real-time telehealth connections can simplify between-agency communication and improve delivery of intended services for CCHN and families.<sup>76</sup>

## Sustaining the Momentum of 4CNC

4CNC aims to build on the momentum generated by the Path-4CNC convenings and continue our work towards better health and well-being for CCHN. We look forward to facilitating cross-sector collaborations between convening participants and stakeholders from across NC so that next step initiatives aligned with the stated goals and priorities of Path-4CNC convening participants can move forward. 4CNC will also build on networks established through the convenings to connect complex care leaders with patients and families so that initiatives are co-designed and positioned to address their priorities. Finally, we will continue to link 4CNC's future work with the strategic priorities and strengths of key institutional and community partners, thus generating a common purpose and leveraging shared resources and expertise towards the advancement of health and well-being for all CCHN in NC.

## CONCLUSIONS

The Path-4CNC series of virtual convenings applied principles of stakeholder engagement and participatory design to bring together the perspectives of diverse stakeholders from sectors across the complex care ecosystem in NC. Convening participants identified key challenges in the current system of care for CCHN in NC and generated actionable recommendations that can improve systems so that the health needs of CCHN, their families, and front-line service providers are addressed. Improvements in the ecosystem of care for CCHN will have collateral benefits in the care of child populations with similar health challenges, including CYSCHN, CMC, and children with high social needs.

Multiple next step initiatives have come into focus as exciting paths forward to build on the foundation of stakeholder recommendations generated during the Path-4CNC convenings. Continued efforts to maintain networking among change agents across the state who participated in the convenings, to facilitate cross-sector collaborations and lead next-step system improvement initiatives, and to sustain the momentum from the virtual convenings are key priorities of 4CNC. Ultimately, leveraging the learnings generated during the virtual convenings and pressing forward with patient/family-centered initiatives will be essential to equitably advance health and well-being for all CCHN in NC.

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## List of Acronyms

**4CNC:** Children’s Complex Care Coalition of North Carolina

**ACEs:** Adverse Childhood Experiences

**ACO:** Accountable Care Organization

**ADHD:** Attention Deficient Hyperactivity Disorder

**CAP/C:** Community Alternatives Program for Children

**CCHN:** Children with Complex Health Needs

**CHIP:** Children’s Health Insurance Program

**CMARC:** Care Management for At-Risk Children

**CMC:** Children with Medical Complexity

**CMS:** Centers for Medicare and Medicaid Services

**COVID-19:** Coronavirus Disease of 2019

**CYSHCN:** Children and Youth with Special Health Care Needs

**NC DHHS:** North Carolina Department of Health and Human Services

**ED:** Emergency Department

**I/DD:** Intellectual and/or Developmental Disability

**MCO:** Managed Care Organization

**NC InCK:** North Carolina Integrated Care for Kids

**OPIP:** Oregon Pediatric Improvement Partnership

**OT:** Occupational Therapy

**Path-4CNC:** The Path to Better Health for Children with Complex Health Needs of 4CNC

**PFK:** Partners for Kids

**PT:** Physical Therapy

**SDH:** Social Determinants of Health

## Glossary

**504 Plan:** a plan developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment.

**Behavioral Health Care:** Provides services to diagnose, treat, and manage mental health conditions, substance use disorders, and intellectual/developmental disabilities.

**CAP/C:** community based waiver program that is intended to support children with complex health needs who would otherwise be at risk for institutional level of care.

**Care Coordination:** Effective organization and use of resources to ensure access to comprehensive services for children with special health care needs and their families.

**Care Plans:** Co-created with families and their care team to plan, document, and accomplish care goals and coordinate care across services.

**Digital Divide:** the gap between those who have access to technology, the internet and digital literacy training and those who do not.

**Exceptional Children's Assistance Center:** a private, nonprofit parent organization, committed to improving the lives and education of ALL children through a special emphasis on children with disabilities and special healthcare needs

**EPIC:** software for holding medical health records

**Generalist:** An internist, family physician, or pediatrician who performs general medicine; one who treats most diseases that do not require surgery, including those related to obstetrics.

**Habilitative Providers:** Providers who focus on physical movements and help patients restore and improve movement and functioning. Examples include physical and occupational therapy and speech-language pathology.

**Hospice care:** focuses on the quality of life for people and families experiencing an advanced, life-limiting illness. Typically covered by both Medicaid and Medicare.

**Intellectual and Developmental Disabilities (I/DD):** disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development.

**In-home nursing:** health professionals act as primary caregivers at home. Medicare and Medicaid cover costs on a case-by-case basis. Usually a short-term amount of time.

**Individualized Education Plan (IEP):** a plan or program developed to ensure that a child with an identified disability who is attending an elementary or secondary educational institution receives specialized instruction and related services.

**Innovations Waiver:** Designed to meet the needs of Individuals with Intellectual and/or Developmental Disabilities (I/DD) who prefer to get long-term care services and support in their home or community, rather than in an institutional setting.

**Integrated Care Models:** Providers (often led by a primary care team) work together with families to provide a full array of services.

**Integrated Care for Kids (InCK):** a child-centered local service delivery and state payment model that aims to reduce expenditures and improve the quality of care for children under 21 years of age covered by Medicaid through prevention, early identification, and treatment of behavioral and physical health needs.

**Local Management Entities (LMEs):** Usually coupled with MCOs; these organizations are public managed care organizations that provide a comprehensive behavioral health services plan for people in need of mental health, developmental disability, or substance abuse services.

**Managed Care Organization (MCOs):** companies that agree to provide most Medicaid benefits to people in exchange for a monthly payment from the state.

**Medicaid Transformation:** In 2015, the NC enacted legislation directing the NC DHHS to transition Medicaid and NC Health Choice from fee-for-service to managed care; the state contracts with insurance companies, which are paid a predetermined set rate per enrolled person to provide all services.

**Medicaid:** A public benefits program jointly funded by state and federal dollars and administered by the state. Medicaid provides coverage for health care and health-related services to low-income children and youth with disabilities.

**Medical Home:** Provides comprehensive primary care by facilitating partnerships between patients, clinicians, medical staff, and families; produces higher quality care with improved cost efficiency.

**NCCARE360:** a developing statewide, electronic network supported by NC DHHS to connect those with identified social needs to available community resources.

**Palliative care:** medical care for individuals living with a serious illness and is focused on providing relief from symptoms. Private insurance typically covers the costs.

**Primary Care Provider (PCP):** a physician, nurse practitioner, clinical nurse specialist, or physician assistant who provides or coordinates with a patient to access a range of health care services.

**Respite care:** provides short-term relief (an afternoon or several days) for caregivers. Most insurance plans do not cover the costs of respite care.

**Social Determinants of Health:** conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks

**Social Needs:** adverse social conditions associated with worse health for which patients state a preference or priority for active assistance

**Social Needs Screening:** screens for five core health-related social needs, which include housing, food, transportation, utilities, and personal safety, using validated screening questions, as well as the additional needs of employment, education, childcare, and financial strain.

**Specialist:** Focuses on a specific area of medicine or a group of patients to diagnose, manage, prevent or treat certain types of conditions.

**Telemedicine:** the practice of caring for patients remotely when the provider and patient are not physically present with each other.

**Title V:** provides block grants to states to support Maternal and Child Health programs. These programs generally focus on provision of wrap-around and population-based services (e.g., immunization) and on assuring capacity.

**Transitions of Care (or Transition):** The movement of patients between health care practitioners, settings, and home as their condition and care needs change.

Appendix materials located [online](#) include:

- 1) One-page summary for each of the three Path-4CNC virtual convenings
- 2) Small group breakout (gallery walk) participant guides



