

# Catalyzing Cross-Sector Collaboration: Lessons from a Virtual Pediatric Complex Care Coalition

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## ABSTRACT

**Background:** Children with complex health needs (CCHN) have intersecting medical, behavioral health, and social needs. Unfortunately, fragmentation across health and social services sectors often results in uncoordinated care for CCHN and their families.

**Objective:** The purpose of this article is to describe the creation of a statewide cross-sector partnership, the Children’s Complex Care Coalition of North Carolina (4CNC), to identify and act on opportunities for system-level improvements in the care of CCHN.

**Methods:** We applied a virtual community engagement approach to form an advisory committee of cross-sector collaborators; systematically identify priorities most important and urgent to collaborators for improving systems of care; and host a series of virtual convenings involving over 90 attendees from across the state to operationalize collaborator-identified priorities into actionable next steps.

**Lessons Learned:** Key facilitators of success for the 4CNC partnership were investing time in building trusting relationships, particularly with families of CCHN, and aligning goals and priorities with existing local and regional efforts. Challenges included incorporating traditionally underrepresented perspectives, right-sizing virtual convening attendance and number of topics covered, and navigating technological difficulties in a virtual environment.

**Conclusions:** Health systems can catalyze the formation of cross-sector coalitions and community partnerships to advance complex care. Virtual convenings with interactive activities and participatory structures can be an efficient medium to connect coalition members and elicit actionable recommendations for system-level improvements that address the needs of community members.

**KEYWORDS:** Pediatrics, complex care; cross-sector partnerships; special health care needs; stakeholder engagement

## BACKGROUND

A small percentage of children disproportionately account for poor child health outcomes and high healthcare costs.<sup>1</sup> Similar to adults with complex health needs, children with complex health needs (CCHN) have intersecting medical and social needs that require services from the physical health, behavioral health, and social service sectors.<sup>2</sup> Unfortunately, such fragmentation results in higher healthcare utilization and worse quality care.<sup>3,4</sup> Importantly, the COVID-19 pandemic has accelerated the need for cross-sector collaboration to create local, family-centered ecosystems of complex care.

Duke Health and University of North Carolina (UNC) Health are two large academic, tertiary care pediatric centers in North Carolina (NC) that serve CCHN from across the state and southeastern United States. Mirroring national trends, a growing number of CCHN are being cared for at both institutions, and care for this population has a significant impact on families and the healthcare system.<sup>5</sup> In response to growing needs for child-specific systems of complex care, each institution has developed a structured complex care program to provide enhanced clinical care for CCHN and families. Together, these programs' interdisciplinary clinical teams currently care for over 300 of the most medically complex CCHN in NC by addressing health and social needs in a family-centered approach.<sup>6,7</sup> Since complex care program resources reside within their respective health systems, both Duke and UNC's programs are primarily focused on the delivery and coordination of healthcare services rather than the broader non-medical services needed to best support CCHN and their families.

While the shift towards value-based payment models has incentivized healthcare systems to develop programs for complex populations<sup>8</sup>, healthcare organizations are not well-positioned

to unilaterally integrate care across sectors at-scale for the estimated 400,000+ CCHN living in NC whose families report not receiving care in a well-functioning system.<sup>9</sup> First, CCHN live across a wide geographic distribution, while resources for enhanced care are concentrated around the handful of regionalized tertiary care centers. With over one-third of North Carolina's CCHN living in rural communities that face known disparities in access to care,<sup>10</sup> equitably meeting the needs of this population at scale requires systems of care that are grounded in CCHN's home communities. Second, healthcare organizations alone cannot provide the full range of medical and non-medical services to meet the diverse needs of CCHN and their families, such as home-based care, behavioral health supports, and resources for social needs.

Thus, partnerships with individuals and organizations in communities where CCHN live, learn, and play are essential. At the patient-level, relationships between health systems, community-based organizations, and government agencies can create referral processes to facilitate cross-sector linkages and care coordination for individual children and families.<sup>11,12</sup> At the community-level, health systems and their community collaborators can align efforts and invest in services to fill known care gaps for CCHN, and jointly advocate for policies to increase resources for CCHN.<sup>13</sup>

Recent health policy changes in NC and nationally present opportunities to advance system-level, cross-sector integration for CCHN.<sup>14</sup> First, in July 2021, NC Medicaid transitioned from a fee-for-service model to value-based, managed care contracts. Importantly, NC Medicaid's transformation acknowledges the importance of social needs towards overall health by requiring health plans to assess social determinants of health and to connect beneficiaries with community resources.<sup>15</sup> Second, Duke and UNC are leading the implementation of a 7-year, federally funded Integrated Care for Kids value-based payment and delivery model, working to

advance care integration across 10 child service sectors (physical and behavioral health, food, housing, early care and education, Title V, child welfare, mobile crisis response services, juvenile justice, and legal aid) for NC Medicaid enrollees in a five-county region.<sup>16</sup> Finally, federal passage of the Advancing Care for Exceptional Kids Act (ACE Kids, Public Law No. 116-16), to which states can opt in beginning October 1, 2022, adds even further urgency to develop innovative care delivery models for CCHN.

As state and federal policies incentivize new systems of care for children, new models are needed to foster intersectoral partnerships. One approach is cross-sector coalitions.<sup>17-21</sup> In this approach, collaborators work together to identify gaps in the current system, prioritize areas of highest need and greatest potential for impact, and co-plan projects related to quality improvement, advocacy, and research. In this paper, we describe our process for developing and maintaining a virtual statewide coalition of collaborators from across health and non-health service sectors to advance integrated systems of care for CCHN.

## **OBJECTIVES**

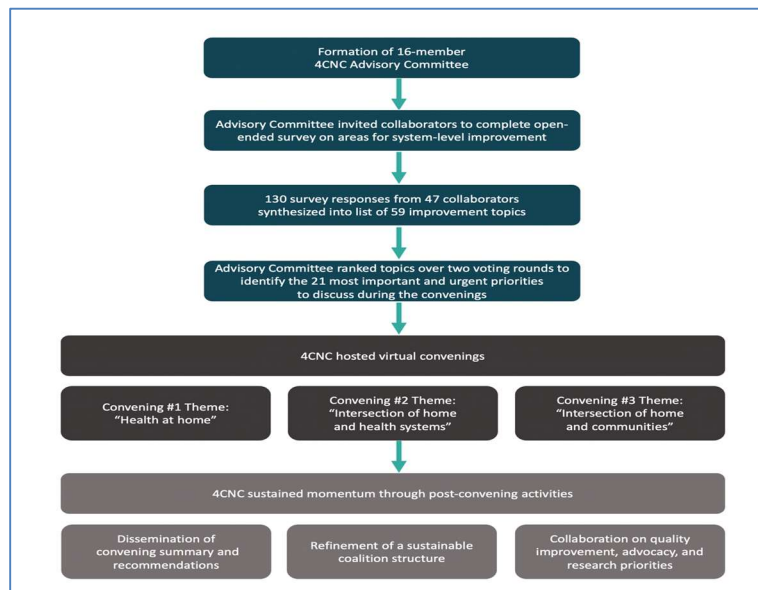
Our objective was to create a virtual coalition of partners from across NC to elicit actionable recommendations for improving systems of care for CCHN in the state. Specifically, we aimed to (1) form an advisory committee of cross-sector collaborators, (2) systematically identify priorities most important and urgent to NC collaborators for improving systems of care, (3) host a series of virtual convenings to operationalize collaborator-identified priorities into action, and (4) sustain momentum through continued dialogue and targeted improvement projects. We expect our process can serve as a roadmap for health systems and their

collaborators in other states to undertake similar efforts to advance health for CCHN and other complex populations.

## METHODS

Our coalition was initiated by pediatricians at Duke and UNC, who were one of six teams nationwide to receive funding and operational support from the National Center for Complex Health and Social Needs, which holds an annual request for proposals to select host organizations to hold a regional convening in their community.<sup>22</sup> Figure 1 outlines key steps in launching and developing the Children's Complex Care Coalition of North Carolina (4CNC). Our coalition consisted of four team leaders (two pediatricians, one program coordinator, and one graduate student), 16 advisory committee members, and 90+ participants who attended our virtual convenings.

**Figure 1. Overview of Our Coalition Process.**

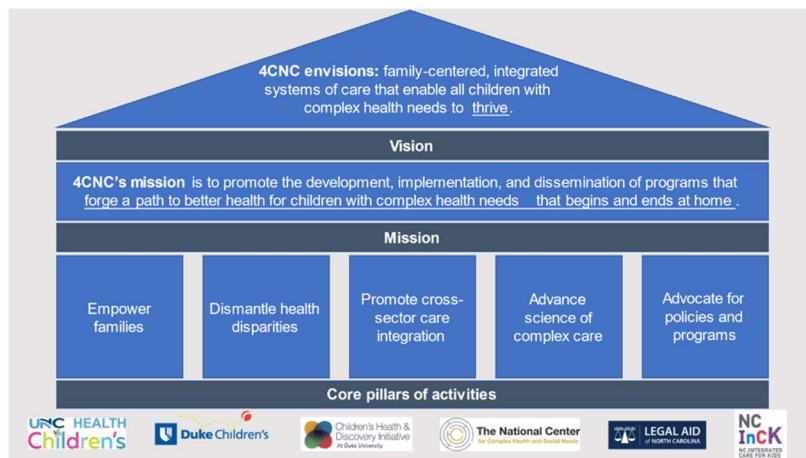




### *Forming an Advisory Committee*

Beginning in spring 2020, we took steps towards formation of a 16-member, multi-sector advisory committee. The starting point was connecting with key community partners from Legal Aid of North Carolina and Family Voices who have previously collaborated with two of our coalition leaders (D.M., N.d.) on projects at the state and national levels.<sup>23-25</sup> Next, we leveraged the professional networks of coalition leaders and key community partners at the local and state level (e.g., Title V program leadership in the NC Department of Public Health) to identify more partners with lived experience as parents and caregivers of CCHN or experience in clinical care, health policy, and community-based service sectors. By summer 2020, our final advisory committee was formed and included six pediatricians from diverse practice settings, three parents of CCHN, three representatives of child service and advocacy agencies, three state public health officials, and one Medicaid administrator. Our advisory committee met for one hour monthly between July 2020 and May 2021, with a smaller sub-committee meeting bi-weekly. The advisory committee helped develop the coalition's vision, mission, and core pillars of activities (Figure 2). Before our coalition could execute specific projects related to advocacy, research, and quality improvement, we decided to host a series of convenings to bring together diverse stakeholders from across sectors and the state, to build new connections, and to identify which specific topic areas were most important to address. Our advisory committee played a critical role in developing the participant list and participating in a consensus-development process that informed convening agendas and structure.

**Figure 2. Framework for Coalition Vision, Mission, and Core Pillars of Activities**



### *Engaging Collaborators to Identify Priorities for Convening Agenda*

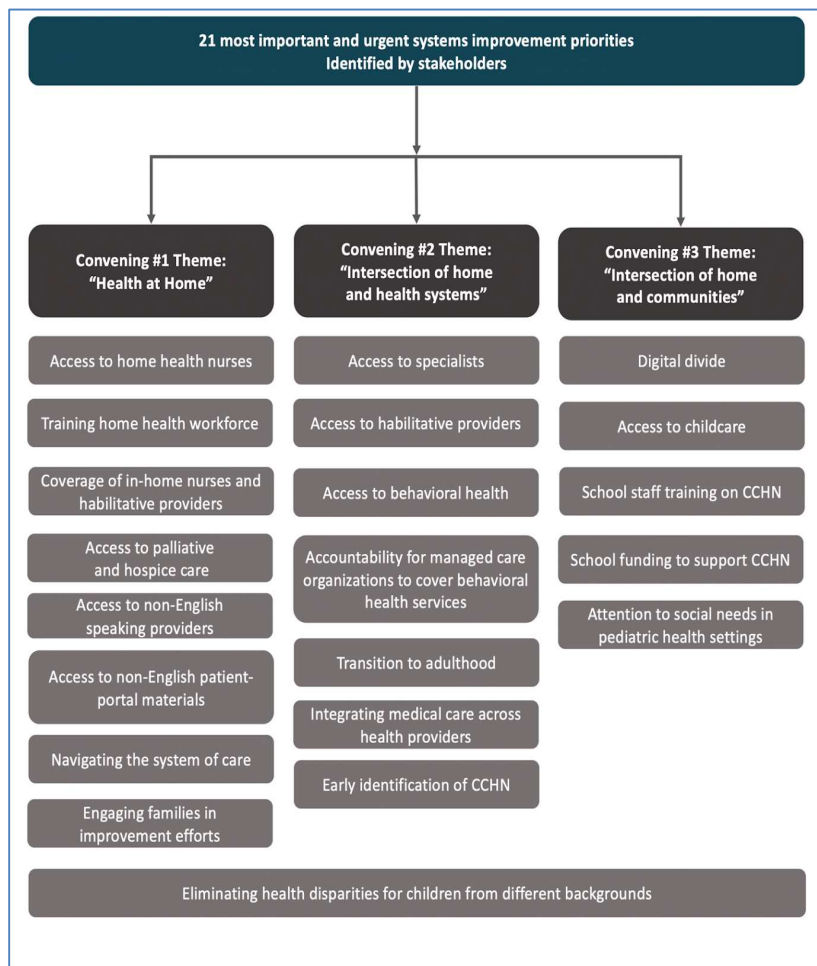
To create agendas focused on system-level improvements that reflected the priorities of families and professionals caring for CCHN, we conducted a multi-step, collaborator-engaged prioritization process. First, we asked our advisory committee to invite professional collaborators and parents of CCHN from across NC to complete a three-item, open-ended survey about the most important problems and strengths in existing systems of care for CCHN. We aimed to seek input from diverse voices across the state, including from both urban and rural areas, and in both English and Spanish. We received 130 individual, free text survey responses from 47 respondents who lived or worked in 31 of 100 counties in North Carolina (64% were parents or primary caregivers, 11% spoke Spanish as their primary language). We synthesized these into a list of 59 improvement topics. We mapped topics to domains of the “National Standards for Systems of Care for Children and Youth with Special Health Care Needs” to ground our efforts in a widely recognized framework.<sup>26</sup>

Next, the advisory committee rated each improvement topic's importance and urgency on a scale from 1 (lowest) – 9 (highest) over a two-round prioritization process. We hosted a virtual advisory committee meeting between each round so members could ask clarifying questions. After two rounds, we reached consensus on 21 topics, representing the most urgent and important systems improvement priorities identified by collaborators for CCHN in NC. A full description of the methods and outcomes of our stakeholder engagement process to identify these priorities can be found elsewhere.<sup>27</sup>

### *Hosting a Series of Convenings*

Our original intention had been to host a one-day, in-person convening. However, in response to the COVID-19 pandemic, we rapidly adapted to a fully virtual format with a plan to split the convening into three online sessions. The 21 topics informed our agendas for three virtual convenings. We grouped topics into overarching themes focused, respectively, on the path to better health for CCHN: (1) at home, (2) at the intersection of home and the health system, and (3) at the intersection of home and community (Figure 3).

**Figure 3. Distribution of Topics from Prioritization Process Across Three Convenings.**



We scheduled convenings from 2:00-4:30 p.m. on three days in January, February, and March 2021. We asked advisory committee members to invite 5-6 participants each from their professional networks to attend the convenings, because we estimated that our team could appropriately facilitate engagement with a maximum number of 70-90 attendees through a virtual platform. Our goal was to recruit participants so that in each convening, one-third of participants would be parents and caregivers of CCHN, one-third would be healthcare providers, and one-third would be professionals from community-based and governmental organizations.

Participants received a personalized email invitation (either from our program coordinator or from the advisory committee member who already knew the participant). Participants registered for the Zoom convenings via a form on our website that also provided additional background information.<sup>28</sup> In case participants had any difficulties with navigating our online registration form, we offered assistance from our program coordinator.

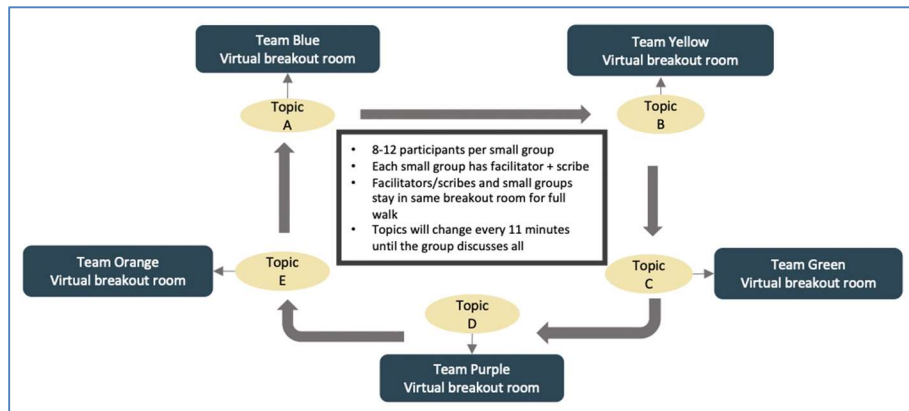
Before each convening, participants received (a) a one-page overview of the agenda with a glossary of key terms (Appendix 1) and (b) a one-page document describing the interactive activity (Appendix 2). Each convening followed the same 2.5-hour format: keynote speaker (30 minutes), interactive gallery walk activity (95 minutes), and “bite-size” talk (10 minutes). Our keynote speakers for the three convenings were a parent panel on caring for CCHN, a NC physician leading a Medicaid integrated care model and the state’s COVID-19 vaccine strategy, and a national expert on quality improvement and family engagement in pediatric complex care, respectively. We intentionally started our first convening with a parent panel to ground our approach to system-level improvement in the priorities and voices of families.

After each keynote presentation, we hosted a gallery walk, an interactive activity to facilitate participant discussion within five small groups that rotate through stations focused on specific topics.<sup>29</sup> At each station, small groups suggested responses to open-ended prompts that stemmed from the 21 priority topics (e.g., “How might we improve access to specialists for CCHN?”). Typically, when a gallery walk is conducted during an in-person meeting, groups respond to each prompt as they walk together from station to station; in our virtual convenings, each group remained together while the discussion topics rotated from one group to the next. Participants were split into small groups and placed into Zoom<sup>®</sup> breakout rooms. Each breakout

room had a facilitator (advisory committee member) and scribe (student volunteer). Each group rotated through 4-5 topic stations (Figure 4) and contributed ideas to a summative slide that catalogued all groups' combined responses in real-time (Appendix 3). After each group provided input about all of the topics, they returned to the first topic they discussed to summarize key takeaways based on review of combined responses from all groups to that prompt. We then closed the breakout rooms and reconvened as a large group. Each small group reported three takeaway points for the final topic they discussed. Guides for facilitators and scribes can be found in Appendix 4.

One week prior to the first convening, the leadership team, facilitators, and scribes met virtually via Zoom to review the guides, answer any questions about the activity, and participate in an abbreviated mock gallery walk activity to better understand the process and flow. We chose to use the gallery walk as an idea generation tool for two main reasons. First, one of our team leaders (SS) had experience with the format of the activity from previous stakeholder engagement projects. Second, compared to traditional breakout room approaches, the gallery walk activity allows participants to discuss multiple topics and build on the ideas of other groups that have already discussed a particular topic.

**Figure 4. Gallery Walk Process.**

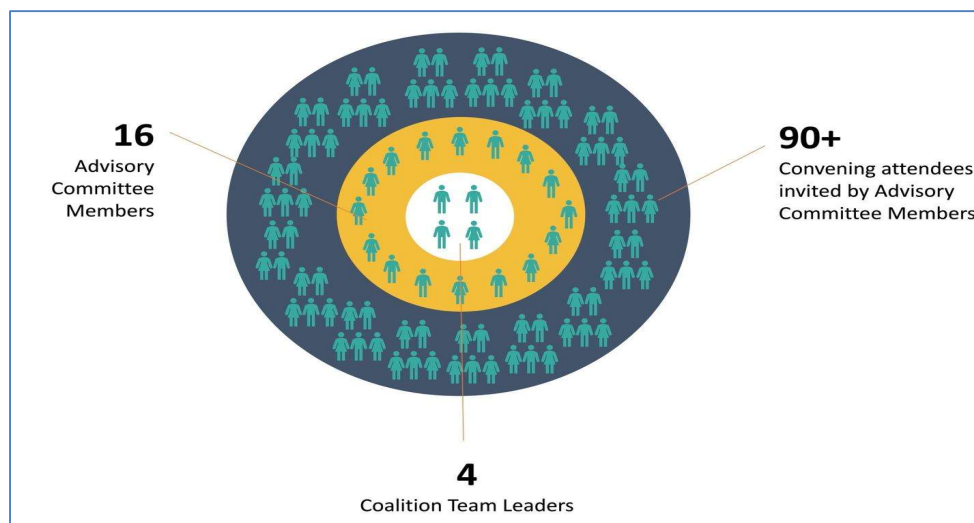


After the gallery walk activity, we ended each convening with a “bite-size” talk by members of our advisory committee on timely topics (i.e., virtual learning resources during the COVID-19 pandemic, information about NC’s transition to Medicaid managed care, and information about the newly created NC Medicaid Ombudsman program for help Medicaid enrollees ensure that they receive the care they need). Post-convening, we shared convening materials with participants, and encouraged sharing of reflections on our online discussion board. Since participants frequently shared links to additional resources during convenings in the Zoom chat, we compiled community resources onto a tab on our website. We also invited participants to complete a brief survey to indicate how they would like to continue to remain involved in the broader coalition (e.g., quality improvement projects, research studies, advocacy initiatives, community engagement efforts), which topical areas are of greatest interest to them (e.g., care coordination, health equity initiatives, access to specialty providers, home health, etc.), and if they have any suggestions or feedback for future directions of the coalition. This work was deemed exempt from review by the Duke Health Institutional Review Board.

## RESULTS

Regarding convening participants, 93 people attended Convening #1, 70 attended Convening #2, and 60 attended Convening #3. Across the convenings, our participants represented a diversity of sectors: 38% were from the healthcare sector; 22% were parents and family partners; 18% were from community-based organizations and social services; 11% were from government agencies; and 10% were undergraduate and graduate students. Figure 5 depicts the snowballing sampling technique we utilized to form our coalition, starting with the coalition leadership team consisting of two pediatricians, one program coordinator, and one graduate student. From there, we formed the multi-sector advisory committee, whose members were intentionally selected for diversity of background and expertise, invited diverse collaborators to participate in the multi-step prioritization process and to attend the convenings. After each convening, we collected feedback from participants via a brief survey about the convenings' strengths and improvement opportunities (Table 1). We used participant feedback to revise the format for subsequent sessions (e.g., we used participant recommendations from the first convening to adjust the timing of the gallery walk in the second convening).

**Figure 5. Impact of Snowballing Social Networks.**





**Table 1. Sample Post-Convening Participant Feedback**

<p><i>“Great focus on families and their lived experiences. The panel discussion was fantastic, and the breakout rooms allowed everyone to have a chance to talk, to offer suggestions, and to identify challenges.”</i></p>
<p><i>“Gallery Walk. Always wonderful to hear other agencies, organizations and professionals’ perspectives on the issues that are being focused on.”</i></p>
<p><i>“This was excellent--I found the gallery walk to be such a great way to parse through difficult issues without dumping lots of questions on a group at once. I also applaud your facilitators--they rocked!”</i></p>
<p><i>“More time for the gallery walk---we had such rich discussions, but had to truncate them. Also, big groups made it harder to hear everyone's input.”</i></p>
<p><i>“Breakout sessions were great! Glad to have the online forums because 8 minutes per topic was not enough; thank you for recognizing this and coming up with a solution ahead of time.”</i></p>
<p><i>“For continued participation and vested involvement - show how the data collected is making a difference and how it is being used.”</i></p>

## **Lessons Learned – Challenges**

### *Ensuring inclusion of traditionally underrepresented voices*

Efforts to re-design care delivery often center around the health system and providers.

We aimed to elevate the voices of families with lived experience from all backgrounds. First, we

compensated advisory committee members who participated as parents of CCHN \$50/hour for their time, including meeting attendance, preparation for the convening sessions, and presentations given during the convenings (in alignment with the compensation standards co-created by leaders in this field and a diverse group of parents).<sup>30</sup> To do this, we applied for supplemental funding from UNC's Translational and Clinical Sciences Institute through a stakeholder engagement voucher.

To broaden our reach during the recruitment stage, we asked our diverse advisory committee members to leverage their professional networks to personally invite families of CCHN who may be interested in participating in the convenings. During each convening, we also provided participants with closed-captioning and Spanish-language translation services to reduce barriers related to ability status and language. Because we anticipated that some participants might be uncomfortable having their comments recorded, our facilitators offered participants the opportunity to utilize the “chat” function so that the facilitators could read their comments aloud without attribution.

After the first convening, breakout room facilitators reported that despite their best efforts to encourage parents and caregivers to participate, the perspectives of family partners were often overshadowed by health professionals. For the subsequent convenings, our team encouraged group facilitators to flip the traditional power hierarchy (i.e., shift focus onto family voices, instead of medical providers). For example, between the first and second convenings, facilitators were coached to begin discussions with prompts for individuals with lived experience to share their stories.

Despite these efforts, we recognize that the virtual mode of convenings may have been less accessible to participants who lacked access to computing devices and stable broadband, particularly in rural areas. As we continue to sustain our coalition after the convenings, more complete demographic data collection from coalition members can help us evaluate the group's diversity and representativeness and drive intentional efforts to include more traditionally underrepresented voices.

#### *Right-sizing virtual attendance and number of topics covered*

It was challenging to identify the appropriate number and distribution of attendees and topics while reserving sufficient time for discussion in breakout rooms. We estimated that each breakout room should include up to 12 participants, and we attempted to diversify each group's make-up with participants from multiple sectors. However, limiting group sizes without bringing in more facilitators restricted the number of participants who could join the convenings. Furthermore, due to deviation in number of attendees from number of registrants, we had to manually reassign participants at the start of each convening to ensure balanced representation of sectors in each group.

Finally, after the first convening, we realized that we did not allocate enough time for discussion on each topic. Thus, for the subsequent convenings, we reduced the number of topics highlighted per breakout room (from 5 to 4), which incrementally increased discussion time per room (from 8 minutes up to 11 per topic).

#### *Navigating technological challenges in a virtual environment*

During our second convening, we encountered technology challenges. During the gallery walk activity, scribes were unable to update the summative slides (Google Slides<sup>®</sup>) with discussion notes in real-time. Using a group text message set up with scribes before the meeting, we were able to pivot in real-time by downloading the cloud-based summative slides for use locally on their computers (Microsoft PowerPoint<sup>®</sup>). We recommend that other groups aiming to adopt a virtual coalition model prepare contingency plans to allow for real-time adjustments to technology disruptions.

### **Lessons Learned – Successes**

For health systems interested in adopting our virtual coalition model for pediatric complex care or adapting our model to serve other populations<sup>31</sup>, we recommend the following foundational steps based off reflections and debriefs with our advisory committee:

- Invest time in building collaborative, trusting relationships to be the foundation of your coalition. Including diverse patient and family voices is essential.
- Partner with your collaborators to identify shared goals and prioritize those that are most important and urgent.
- Do not reinvent the wheel. Align goals and priorities with existing local, regional, and national efforts, and utilize existing resources and expertise. For example, explore available resource toolkits such as the one we have created from our work<sup>11</sup> and others from groups like the National Center for Complex Health & Social Needs.<sup>32</sup>
- Leverage trainees as valuable, skilled partners to assist with planning and executing virtual convenings. Our eight student volunteers constructed the coalition website and online

message board, developed the gallery walk activity, served as scribes and provided technical support during convenings, and led writing of a post-convening summative report.

## **Next Steps**

In the six months following the final convening, we wrote a comprehensive report describing our community-engaged coalition's efforts in detail as a mechanism for sharing our work and building new collaborations with partners.<sup>33</sup> We aim to continue cultivating partnerships with entities in our state who have shared interests in systems of care for patients with complex health needs, including community-based family support organizations, advocates for caregivers of children and adults with complex needs, state health policy leaders, and community-engaged research leaders at our academic centers. We also plan to evolve coalition into a sustainable group that can directly lead and meaningfully contribute to projects that impact systems of care for CCHN. For example, building on the convening findings around in-home caregiving, our coalition has partnered with the North Carolina Coalition on Aging and the North Carolina Serious Illness Coalition to work together on advocacy for better support of in-home caregivers across the lifespan. Together, we were recently awarded a one-year grant to support caregiver self-advocacy training. Each of our coalitions will work with partner community-based organizations to identify and select five caregivers who will be paid to participate in a series of trainings on leadership, advocacy, and policy engagement. Other specific steps to facilitate coalition sustainment include engaging convening collaborators through email newsletters, meetings, and a curated calendar of events, and developing a coalition networking directory to connect collaborators with shared interests. We also plan to develop a coalition incubator, in

which our advisory committee can support coalition participants interested in partnering on quality improvement, research, or advocacy projects.

## CONCLUSION

Health systems alone cannot fully meet the health and social needs of their complex patient populations. We convened a virtual coalition of families and collaborators from multiple service sectors across NC to explore collaboration opportunities to advance complex care for children in our state. In this case study, we highlight our process for coalition building during the COVID-19 pandemic, from developing a family-centered systems improvement agenda to hosting a series of interactive virtual convenings to setting the stage for sustainment of a community-engaged coalition focused on CCHN and their families.

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