

Children's Complex Care Coalition of North Carolina (4CNC)

Nearly one in five children in the United States (almost 14 million) are children and youth with special healthcare needs (CYSHCN). Because of these needs, CYSHCN often require hospital care. After a hospital stay, the transition back to home can be risky. Team leaders (Ming and deJong) have begun to conduct a comparative effectiveness randomized trial (H2H-CYSHCN Study) of high vs. low-intensity hospital-to-home transitional care for 480 hospitalized CYSHCN at Duke and UNC hospitals. Bass Connections team members participating in this project (4CNC) are working in three sub-teams whose work and academic products relate to that trial and/or to topics it addresses.

During the 2025-2026 academic year, 4CNC was divided into three sub-teams working on community engagement, caregiver support and engagement, and economic security and family policies.

Community Engagement

This sub-team continued to support the efforts of the H2H-CYSHCN Study's nine-member Community Advisory Board (CAB). The CAB has provided invaluable contributions to the study as caregivers to CYSHCN, including improvements to our recruitment script and qualitative interview guides. The CAB has three co-leaders and seven members and meets virtually once per month with live translation to accommodate both English- and Spanish-speaking members. In addition to supporting the CAB, this sub-team has also developed a practical guide that features lessons learned from recruiting and forming the CAB and from more than one year of facilitating the meetings. We hope that this guide will be useful to other groups as they work through the logistical aspects of community-engaged research.

Caregiver Support & Engagement

There is an adage that "What gets measured gets managed." This sub-team's work has been inspired by our desire to ensure that the CAB members have a positive experience participating in our research and has focused on two projects. The first is a systematic literature review of existing tools used to measure caregiver engagement with research initiatives. This will be used to identify the best tool for use with our CAB, by comparing available tools. We hope this research will be helpful to other researchers as they assess and evaluate their community engagement. The second project is a prospective data collection project to survey and conduct qualitative interviews with caregivers who have been involved in research initiatives at Duke to explore their experiences. The survey will allow for future psychometric analysis to validate a caregiver engagement survey developed by Family Voices, called the Family Engagement in Systems Assessment Tool (FESAT).

Economic Security & Family Policies

This sub-team is conducting a scoping review of federal and state policies in the United States that impact the economic security of families of children with disabilities. The work assesses the state of the literature on a comprehensive set of economic support

policies, including Temporary Assistance to Needy Families (TANF), Supplementary Security Income (SSI), Medicaid, housing assistance, Supplemental Nutrition Assistance Policy (SNAP), tax policy, and unpaid and paid leave policies. The goal of the work is to understand how these policies affect the economic well-being of families of children with disabilities along multiple dimensions, including income, wealth, poverty, financial burden, and food and housing insecurity. This review will pay special attention to whether the policies are effective (e.g., whether they improve economic well-being), whether they are being accessed by families of children with disabilities (uptake), and what barriers exist to full uptake and effectiveness.