

Community Living Committee Minutes

February 6, 2025 1:00 p.m. – 3:00 p.m.

Members Present: Carol Conway, Rhonda Cox, Jonathan D'Angelo, Dr. Joshua Gettinger, Deb Goda, Mary Mac Jenkins, Dr. Charlrean Mapson (Chair), Kay McMillan, Bethany Smith, Dr. Peggy Terhune, Ginger Yarbrough, Marjorie Serralles-Russell

Members Absent: Senator Sydney Batch, Debra Farrington, Brendon Hildreth

Staff Present: David Ingram, La'Quadia Smith, Talley Wells, Shar'ron Williams, Philip Woodward

Guests Present: Dr. Anne Dickerson, Beth Field, Dr. Tom Fish, Dr. Michelle Franklin, Dr. Alexis French, Sarah Potter, Isabella Russo

Introduction:

Dr. Charlrean Mapson led an icebreaker activity and made a motion to accept the draft November 2024 minutes. Deb Goda seconded the motion. The motion carried. Kay McMillan, Mary Mac Jenkins, Carol Conway, and Ginger Yarbrough abstained from voting because they were not present for the November committee meeting.

Fiscal Update:

Shar'ron Williams provided the fiscal update. She said NCCDD spent all of its money allotted in Federal Fiscal Year 2022, and there are no Community Living initiatives using Federal Fiscal Year 2023 funds. She pointed out that the Interaction Advisory Group has \$110,000 allotted to it for Year 1.

Initiative Updates:

I/DD Data

Dr. Michelle Franklin from the Duke-Margolis Center for Health Policy joined the meeting and shared the *I/DD Data* initiative Final Report on her screen. She thanked the members for their review of the draft report. She discussed the objectives and items that readers can comprehend and not simply compare, and she pointed out that this initiative generated 51 research questions. Carol Conway pointed out that 45 percent of people on a waitlist are getting a service, but they could be getting just one service out of 20 they are authorized to receive. When she said this would be good data to include, Ginger Yarbrough responded that the North Carolina Department of Health and Human Services (DHHS) hopes to add this type of data to the Innovations Waiver Dashboard as they refine it. Beth Field said the *Meet The Need NC* initiative has been looking for data that shows outcomes, so the initiative needs this data push. Michelle asked, what questions are still unanswered, and what are the next right steps? She also noted that

this information can easily be put into an infographic or a one-pager with bite-sized information amounts.

Dr. Joshua Gettinger said as a healthcare provider, it is important to combine evidence-based scientific data with stories and narratives. He pointed out the number of people on the Innovations Waiver and the number of people with I/DD not on the waiver and what this means to them. Mary Mac Jenkins asked if Community Alternatives Program for Children and for Disabled Adults (CAP/C and CAP/DA) recipients were included in the I/DD umbrella count, and Michelle responded that these numbers were difficult to compile. Mary Mac also expressed an interest in dental health, and Talley Wells suggested that Philip Woodward can arrange a presentation on this topic. Michelle expressed concern with the growth of the waitlist and added that there needs to be an assessment to ensure that people get what they need. The committee agreed that this report is ready to share publicly.

Community Living Mini-Grants

Chapters Ahead Inc

Dr. Tom Fish from Chapters Ahead Inc talked about the *Community Living Mini-Grants* initiative to establish Next Chapter Book Clubs in North Carolina, starting with Wingate University, where the book club now meets weekly. He said a book club is about friends, being in the community, and reading and that those three words together are very powerful. When the Ohio State University book club read Peter Pan, someone with I/DD said nobody had ever asked them how it would feel to fly or other similar questions to reflect on what they read. Tom discussed efforts to reach out to other Inclusive Post-Secondary Education programs, noting that Western Carolina University had challenges last fall with Hurricane Helene, but he had engaged in extensive discussions with North Carolina State University. He said the organization started a book club at Brunswick Community College and two additional book clubs, including one in Wilmington. He shared his belief that book clubs are vital because they provide an opportunity to make literacy a recognized, important part of people's cultural experience, pointing out how Justice Ruth Bader Ginsburg talked about the importance of culture in the lives of people with disabilities. Tom also suggested preferred terminology: refer to people learning to read as emergent readers instead of non-readers.

East Carolina University

Dr. Anne Dickerson of East Carolina University (ECU) joined to discuss the Community Living Mini-Grants initiative to develop checklists of transportation options for people with I/DD. She said that each checklist had at least three participants with I/DD participated in their development. She said the goal was to make sure the developers understand what each skill item is as well as the kind of transportation available. She said the National Science Foundation became interested in these checklists, and ECU received \$5,000 additional dollars through an I-Corps funding opportunity to enhance

the project and put the checklists on a website. She also said the Children's Hospital of Philadelphia is building a website with resources for individuals with autism and their caregivers, and the checklists are there. She indicated that the current website housing the checklists is temporary but is okay to share, and Anne will notify Philip Woodward when the new "Mobility Match" website is up. She also pointed out that other grants see the value in the checklists, and through promoting them, the checklists will improve.

Future Investment Discussion:

Charlean Mapson asked new member Mary Mac Jenkins to introduce herself. She said she has five-year-old twins and an eight-year-old son who is the reason that she got into advocacy for people with I/DD. She said he receives State Plan private duty nursing and Community Alternatives Program for Children (CAP/C) funding, and he has been on the Innovations Waiver waitlist since 2019. Joshua Gettinger asked Charlean what the difference is between being on the waitlist and suddenly being on the Innovations Waiver, and Charlean said her son received a waiver spot at age 14 after being on the waitlist since age three. She said it brought her peace of mind and a Direct Support Professional (DSP) to help provide care for her son. Mary Mac pointed out that her son has access to Early and Periodic Screening Diagnostic, and Treatment (EPSDT), but a lot of the pediatric population and their parents are not aware.

Wrap Up:

The timer set for the committee meeting breakout room ended, and the meeting was adjourned at 3:13 p.m.