**Community Living Committee Minutes**

**August 8, 2024 1:00 p.m. – 4:00 p.m.**

**Members Present:** Carol Conway, Rhonda Cox, Jonathan D’Angelo, Bryan Dooley, Debra Farrington, Dr. Joshua Gettinger, Brendon Hildreth, Dr. Gary Junker, Dr. Charlrean Mapson (Chair), Ryan Rotundo, Bethany Smith, Dr. Peggy Terhune

**Members Absent:** Senator Sydney Batch, Dale Stephenson

**Staff Present:** Pam Dempsey, David Ingram, Talley Wells, Shar’ron Williams, Philip Woodward

**Guests Present:** Melissa Black, Ali Climo, Dr. Anne Dickerson, Beth Field, Linda Kendall Fields, Stacy Morgan, Devika Rao, Tara Regan

**Introduction:**

Charlrean Mapson welcomed the committee and did an icebreaker asking each person to share which Olympic events they watch.

Carol Conway made a motion to approve the draft May Community Living Committee minutes. Gary Junker seconded the motion. The motion carried with unanimous approval.

**Fiscal Update:**

Shar’ron Williams provided the fiscal update with assistance from David Ingram because of audio issues. David pointed out that the Community Living Committee will not have as many initiatives after Federal Fiscal Year 2024. Carol Conway asked how much money is available for new projects, David responded $132,294 is available in FFY 2024 and $64,955 is available in FFY 2025.

**Initiative Updates:**

**After the Law: Guiding the I/DD Community to Supported Decision-Making**

Linda Kendall Fields of UNC Cares provided an update with Ali Climo and Melissa Black joining her. Linda said UNC Cares is part of the North Carolina Guardianship Association, and they are glad to see the Clerks of Court and public and private guardians grapple with the new Guardianship Rights law and the new materials that help them understand alternatives to guardianship. Ali shared a PowerPoint and discussed how UNC Cares plans to revamp the Rethinking Guardianship website to highlight less restrictive alternatives. Ali pointed out the Bill of Rights and the six domains of life, including the Community Living domain, where individuals can develop a supported decision-making (SDM) plan. Ali also played a video showing a sample SDM plan. The group discussed the possibility of making additional videos, and Linda said UNC Cares has worked on two videos but needs more funding to make more videos.

**Supported Living: A How-to Guidebook**

Janet Price-Ferrell from FIRSTwnc presented. She said she went into the Guidebook to try to write it in simple language, and she pulled out six major topics related to Supported Living. She said the initiative will create Instagram poster-like materials and will put the Guidebook into flipbook format that also works well on a smartphone where each page will have pictures, graphics, information, and a video. She also said they have created a video with a second video to be filmed later, and there is a handout to go with the Guidebook. Janet said the goal for completion is September 26th, when she will present at the Supported Living Level 2 & 3 Stakeholders meeting.

Carol Conway asked Janet to send samples and success stories. Janet pointed out how FIRSTwnc has five individuals receiving Level 3 services (the highest level), but she has had to fill only one shift this year. Janet said the biggest barrier to Supported Living is providers and confusion, including confusing information in the clinical coverage policy. Carol also asked if the parents have to be an employer of record, and Janet responded no because FIRSTwnc has an enhanced rate to pay its Direct Support Professionals $18 per hour. Jonathan D’Angelo suggested adding information about the Medicaid Buy-in because employment is becoming more important to people with I/DD, but they do not know about these programs. Joshua Gettinger asked how FIRSTwnc will disseminate the Guidebook and advertise it. Janet said the Guidebook will be visible on the FIRSTwnc website, and she and another staff person at FIRSTwnc should be able to update it. Janet said that as long as FIRSTwnc continues to provide Supported Living services, then updating the resources in the Guidebook will be easy.

**Community Living Mini-Grants**

**Autism Grown Up**

Tara Regan of Autism Grown Up presented about the organization developing the Life Course Library and three courses for it. She said each course will have three different modules, and the modules for the first course focus on life skills, self-efficacy, and different milestones. Tara said course two will contain workplace-focused resources, and course three will focus on navigating adulthood. She said these free courses include interactive activities for students and lesson plans for teachers. Janet Price-Ferrell commented that she will add this resource to the Supported Living Guidebook. Joshua Gettinger asked how many people have used this so far and how have they done. Tara replied that more than 500 people have accessed the website, two-thirds of them are repeat users, and people are filling out the survey for the second course, thinking of it as a checklist.

**East Carolina University**

Anne Dickerson, a professor of Occupational Therapy at East Carolina University, presented. She explained how this initiative is developing transportation skills checklists to match people to transportation options for three populations, and the initiative developed three because just one would be very long and complex:

1. People with autism spectrum disorder
2. People with intellectual disabilities
3. People with physical disabilities

Anne said the initiative is also working on a Spanish translation of each. Anne said she is open to working with anyone in North Carolina on these checklists, and she pointed out that she made some good contacts at the i2i Center for Integrative Health Spring Conference in June 2024 in Raleigh. Carol Conway suggested that Anne connect with the Alliance of Disability Advocates Center for Independent Living. Joshua Gettinger suggested making the checklists simpler because filling out lengthy forms is a barrier for some people. He shared, for example, how a very long mental health depression survey was cut down to two questions and how a pediatric symptom checklist was downsized from 35 to 17 questions. But Joshua also said this initiative marks a real advance, and the checklists are a great first attempt to address the issue of transportation. Anne replied that transportation is an activity of daily living that occupational therapists work with, but there are currently no community mobility tools. Ali Climo said UNC Cares is addressing barriers to community living for people with I/DD, including transportation, so she expressed seeing a potential opportunity for collaboration.

**Meet The Need NC**

Beth Field of the Leadership Alliance for Neurodevelopmental Disabilities (LAND) provided a PowerPoint presentation on the *Meet the Need NC* initiative. Stacy Morgan of the Mental Health Transformation Alliance (MHTA) and Cheryl Powell of the initiative’s Lived Experience Network Speaks (LENS) group joined Beth. Beth said the initiative has brought more and more people into the *Meet The Need NC* movement, and she mentioned how the initiative plans to do a lot of work during the 2025 Long Session of the North Carolina General Assembly. Cheryl pointed out that the goal is to move towards training people about the Innovations Waiver, including how to get it and what to do while waiting. She added that the initiative has created a tool but is still gathering a focus group to refine it. On the question of sustainability, Stacy shared how the MHTA always looks to diversify its funding by seeking out grant opportunities.

**Future Investment Discussion:**

**Proactive Approaches to Justice for People with I/DD RFA**

Philip Woodward provided an update on this Request for Applications (RFA) process and the RFA Application Review Committee’s recommendation. The committee discussed various questions such as who counts as “first responders,” the involvement of county jails, the court system, and how the state prisons see convictions for people who should have been diverted elsewhere in some way. The members also discussed Contingency #3 and wanting to see good outcomes result from this work.

Carol Conway made a motion to -

Accept the RFA Application Review Committee’s recommendation to approve funding to the Interaction Advisory Group in response to the RFA for Proactive Approaches to Justice for People with I/DD in an amount up to $110,000 per year with required minimum of 25% non-federal matching funds (minimum of $36,667), for Year 1 (of up to 3) beginning October 1, 2024 and ending September 30, 2025. An award to the Interaction Advisory Group is conditional based on the following contingencies:

**Contingencies:**

1. The Interaction Advisory Group will waive any fees to access the training portal during Year 3 or any year of this three-year initiative.
2. The Interaction Advisory Group will do outreach to diverse populations, including North Carolina's Hispanic and Latino I/DD community and North Carolina's black, indigenous, and people of color (BIPOC) I/DD community.
3. The Interaction Advisory Group will perform an effective pilot training in one or more concentrated areas of need that will become a model that can be used statewide.

Jonathan D’Angeloseconded the motion**.** The motion wasapproved by unanimous vote.

**Meet The Need NC Initiative Continuation Funding**

The committee discussed narrowing down the proposed Year 4 targets. Talley Wells shared that he feels that NCCDD benefits from the partnership with the *Meet The Need NC* initiative and that NCCDD staff, Marjorie Serralles-Russell and Bryan Dooley are still leading the conversation with the initiative’s leaders. The committee discussed increasing focus on outcomes more than the importance of the work. The committee also acknowledged that the Long Session of the North Carolina General Assembly starts approximately 40 days after the election, and the initiative can play a supportive role to NCCDD staff in developing relationships with new state leaders and legislators.

Jonathan D’Angelo made a motion to -

Approve continuation funding to the Mental Health Transformation Alliance (MHTA) for the NCCDD initiative entitled Meet The Need NC in an amount up to $150,000 per year with required minimum of 25% non-federal matching funds (minimum of $50,000), for Year 4 (of up to 4) beginning October 1, 2024 and ending September 30, 2025.

Gary Junker seconded the motion.  The motion was approved by unanimous vote.

**Future Investments**

Carol Conway raised the issue of preparing for NCCDD’s next Five-Year State Plan. She said she believes there are three segments of the I/DD community:

1. Severe intellectual disability
2. Mild developmental disability
3. Severe developmental disability

Jonathan D’Angelo mentioned how the system can benefit from outside oversight. Talley mentioned former NCCDD member Jonathan Ellis’s concerns about safety and the lack of a Direct Support Professionals and how the Council needs to find stories of people with I/DD living full and meaningful lives. Charlrean Mapson advocated for the importance of doing future planning when parents receive diagnoses that tell them they will not be here forever to support their child with I/DD.

**Wrap Up:**

The meeting was adjourned at 4:05 p.m.