**Community Living Committee Minutes**

**May 2, 2024 1:30 p.m. – 3:45 p.m.**

**Members Present:** Carol Conway, Debra Farrington, Dr. Joshua Gettinger, Dr. Gary Junker, Dr. Charlrean Mapson (Chair), Bethany Smith, Dr. Peggy Terhune

**Members Absent:** Senator Sydney Batch, Rhonda Cox, Jonathan D’Angelo, Brendon Hildreth, Ryan Rotundo, Dale Stephenson

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

**Guests Present:** Diane Coffey, Caryn Cook (ASL interpreter), Dr. Anne Dickerson, Sarah Ferguson (ASL interpreter), Beth Field, Tom Fish, Cory Gilden, Bentzion Groner, Linda Kendall Fields, April Kirby, Tammy Medlock, Stacy Morgan, Sarah Potter, Devika Rao, Tara Regan, Steve Strom, John Watson

**Introduction:**

Charlrean Mapson welcomed the committee and did an icebreaker asking each person to share their middle name.

Carol Conway made a motion to approve the draft February Community Living Committee minutes. Bethany Smith seconded the motion. The motion carried with unanimous approval.

**Fiscal Update:**

Shar’ron Williams provided the fiscal update.

**Initiative Updates:**

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

Linda Kendall Fields of UNC Cares provided an update. She said the new Guardianship Rights law took effect on January 1st, 2024 and is a big step forward in ensuring that people are not placed under unnecessary, undue guardianships. She thanked NCCDD for the American Rescue Act Plan (ARPA) funds and said that UNC Cares has become a sort of call center taking questions on the new law. Linda said the initiative is creating an interactive website, and she showed a prototype through her PowerPoint. She also said the initiative would like to create an app and applied for a highly competitive Innovate North Carolina grant but did not receive it. She said this initiative will focus on Healthcare Informed Decision-Making as an alternative to guardianship while creating a user-friendly Decision Tree where people are now asked by the courts what they can do instead of being in a guardianship arrangement. Linda described how users can click on the website to see information that pertains to their situation. She also mentioned that the initiative hired Karen Luken as a consultant for this work, and she said the initiative will also continue to work toward statutory reform. Johua Gettinger asked what happens when a person with I/DD turns 18 and how to reach high school counselors. Carol Conway asked if parents have more paperwork to fill out to prove that their child with I/DD cannot do something, and Linda said no, one section of the petition form changed, and it requires people to pause and consider before proceeding with submitting the petition for guardianship.

**Community Living Mini-Grants**

**Best Buddies International, Inc.**

Tammy Medlock of Best Buddies International, Inc. joined on ZoomGov. She proclaimed, “Everything we do is about empowering people with I/DD to be all that they want to be.” The Best Buddies program serves people with I/DD from Kindergarten through high school with inclusion training, a one-to-one friendship program in middle school, and a one-to-one friendship in the community and in the school in high school, a college program to help people with I/DD engage in their community, and a citizens program to match a person with I/DD and a person without I/DD who have mutual interests. She said the high school program starts with students at age 14 with creating a plan for what they want to do, their dream, their skillsets, and being their own guardian. She said these conversations prepare students for the organization’s jobs program where the goal is to help adults with I/DD find not just a job but a career. She explained how the goal of the Best Buddies program is true community inclusion. Joshua Gettinger asked if there is rural outreach, and Tammy said they have two staff with plans to hire three more to help the organization expand into more rural counties outside of Mecklenburg County.

**Bloom Fitness Corporation**

John Watson of Bloom Fitness Corporation joined on ZoomGov. He said the athletes participating in this program have no limits, and he said that making an emotional connection can help drive the athlete’s behavior, and Bloom Fitness has a 90 percent athlete retention rate. He pointed out how Bloom Fitness has had an app for two years, but it is clunky, so this initiative is assisting with a new app to make fitness more accessible to the athletes and their families. John also said the app will congratulate caregivers, too. He pointed out that Bloom Fitness has over 40 locations in Texas, Missouri, Florida, and North Carolina. Joshua Gettinger asked if people can download the app now individually, or do they need to be part of an exercise group. John replied that the app will be available in June as a free download.

**East Carolina University**

Anne Dickerson, a professor of Occupational Therapy at East Carolina University, joined on ZoomGov. She explained how this initiative is developing transportation skills checklists for three populations:

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

Each checklist focuses on strengths and weaknesses for the individual with I/DD and their family members to find the most appropriate transportation option available in their community for the individual to use. She said people with I/DD are providing feedback on the checklists, but she needs more people to do so. Bethany Smith expressed an interest in reviewing them, and Beth Field said the Meet The Need NC initiative has lived experience groups. Joshua Gettinger asked Anne if she is involved in advocacy to improve transportation options, and Anne replied that she is not, but she has some opportunities such as running a boot camp for individuals with autism to learn how to drive.

**The National Leadership Consortium**

Cory Gilden of The National Leadership Consortium joined on ZoomGov. She said this initiative is studying what’s working at five organizations that provide community living services in North Carolina to make a blueprint for success. She said there are no results yet, but they will analyze what they have found. The organizations are:

* Charles Lea Center, Inc.
* FIRSTwnc
* InReach
* Triangle Disability & Autism Services
* Monarch

**ZABS Place**

Bentzion Groner of ZABS Place discussed this initiative and its focus on employment. He said his organization found a desperate need for entry-level employees. He explained how the Skill Development and Job Tracking Portal will help people with I/DD create a public profile for employers and help them focus on interesting jobs that they want to do. He shared the story of Maria, a person with I/DD who wanted to work in a bakery but was turned down many times, but a bakery was willing to hire her, and she received a job there that she thrives in. Bentzion explained how ZABS Place is a labor of love that fits into the whole atmosphere of what happens after a person with I/DD turns 18. He described how if the system has rejected the person, ZABS Place can try to improve the system by providing the right nurturing and the right environment where the individual can succeed. Joshua Gettinger asked what the financial sustainability of this model is, and Bentzion said the funding for the portal comes from grants, but they plan to reach a point where they can charge a software service fee, and the initiative wants to prove the value of the service fee to employers. Bentzion also said that the software costs are minimal.

**Chapters Ahead Inc**

Tom Fish of Chapters Ahead Inc joined on ZoomGov. He mentioned this initiative setting up a Next Chapter Book Club for people with and without I/DD to read together at Wingate University, and this initiative will pursue opportunities to set up more Book Clubs. Philip Woodward mentioned that he has bookmarks promoting the organization and placed one in each committee folder.

**Meet The Need NC**

Beth Field of the Leadership Alliance for Neurodevelopmental Disabilities (LAND) provided a recorded video with a PowerPoint presentation on the *Meet the Need NC* initiative. This presentation included the goals this initiative plans to accomplish by September 2024. Beth Field mentioned gathering an advisory collaborative across disabilities, levels of need, age, regions, and marginalized populations helping the initiative have a ripple effect to extend knowledge. Talley Wells mentioned how this initiative is helping NCCDD prepare for a listening session with the Legislative I/DD Caucus on May 14th. Beth said that Representative Zack Hawkins has asked 20 people with lived experience to come speak, and the event will include a press release and a press conference.

Joshua Gettinger said that, based on Beth’s report, this initiative seems to have experienced breakthroughs during the past three months. Beth said yes, the initiative’s progress is making people look back on where it started. Charlrean Mapson mentioned how former NCCDD member Cheryl Powell invited her to do a podcast, and Philip Woodward said he would share the podcast link with committee members.

**Future Investment Discussion:**

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

Philip Woodward said NCCDD posted this Request for Applications (RFA) on April 15th and held an RFA Grant Application Workshop on April 22nd where nine organizations participated. He said applications are due by May 31st, and he will form an RFA Application Review Committee with Charlrean Mapson, Jonathan D’Angelo, and Carol Conway as interested members of it.

**Supporting Parent Advocates**

Carol Conway established an organization called Parent Advocates for Adult Children with Intellectual and/or Developmental Disabilities in North Carolina (PACID), and she pointed out that the entity refers parents aggressively instead of merely sharing a link with them and asks the parents to follow up with PACID if something does not work. She expressed having trouble finding other people around the state to develop PACID-like entities, but she wants to educate more people than merely the usual people participating in these conversations. She also said she can only take 20 more e-mail addresses on her listserv before it maxes out. She asked if NCCDD can do something to seed PACID-like entities. Talley mentioned the Family Support Network of North Carolina (FSN), and Carol said FSN provides one-to-one support where one family with a child with a specific disability will help another similar family. Talley wondered if NCCDD’s new leadership network initiative could do something similar to what PACID does and how the leadership alumni can assist. Philip Woodward suggested FIRSTwnc, but Carol said Janet Price-Ferrell at FIRSTwnc told her she does not have enough time to commit to doing this.

**Wrap Up**

The meeting was adjourned at 4:00 p.m.