

## **Community Living Committee Minutes**

**November 7, 2024 9:00 a.m. – 12:00 p.m.**

**Members Present:** Rhonda Cox, Jonathan D'Angelo, Bryan Dooley, Dr. Joshua Gettinger, Deb Goda, Dr. Gary Junker, Dr. Charlrean Mapson (Chair), Ryan Rotundo, Bethany Smith, Dr. Peggy Terhune, Kat Boeck, Bryan Dooley, Tony Hall, Olivia Rose Scott, Marjorie Serralles-Russell, Sandy Terrell

**Members Absent:** Senator Sydney Batch, Carol Conway, Debra Farrington, Brendon Hildreth, Dale Stephenson

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

**Guests Present:** Caryn Cook (ASL interpreter), Sarah Ferguson (ASL interpreter), Beth Field, Tom Fish, Dr. Michelle Franklin, Dr. Alexis French, Jennifer Marquez, Janet Price-Ferrell, Isabella Russo, John Watson

### **Introduction:**

After the members joined and the meeting commenced, the committee agreed to discuss initiative reports first.

### **Initiative Updates:**

#### **I/DD Data**

Talley Wells recognized the presence of Duke-Margolis Center for Health Policy staff and North Carolina Department of Health and Human Services (DHHS) staff and suggested that the committee discuss this initiative first. He pointed out that NCCDD's policy leaders have expressed an interest in I/DD data. Marjorie Serralles-Russell joined the meeting and said stories are wonderful, but NCCDD needs data to go with them, and she thanked the Duke-Margolis staff for helping NCCDD get to this point. Talley pointed out that DHHS is interested in this data, but it needs to be correct data, as DHHS is careful about any data that it shares. Dr. Michelle Franklin observed that she has not seen this many things come together for a report like this. The group discussed the sources of the data and clarifying these sources to obtain a more accurate picture of the overall data. This discussion included how difficult it is to calculate how many people in North Carolina have I/DD and what constitutes an intellectual or other developmental disability. One person present asked, what are the unique I/DD needs, and what is not unique but not yet addressed? Another person pointed out the quandary of people waiting for years only to be told that they do not qualify for Innovations Waiver services. Dr. Joshua Gettinger asked a question

regarding how NCCDD can consider using this report for maximum systems change impact.

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

Janet Price-Ferrell from FIRSTwnc followed up on her presentation to the full Council about the Supported Living how-to Guidebook. Joshua Gettinger said he liked it and asked how it will be updated. Janet responded that it is on the FIRSTwnc website where NCCDD owns it, but FIRSTwnc will be able to maintain for a \$14 per year domain fee. Talley Wells suggested the possibility of having a conversation with Steve Strom at Money Follows the Person about maintaining the Guidebook. Philip Woodward said he will share the videos when they are ready. In response to a member question, Janet said the flipbook version can be downloaded and printed, but she suggested printing it with a date stamp because some of the information may change. Joshua asked how people will find it. Peggy Terhune said she will send it to the Public Relations people who work at Monarch and suggested that NCCDD do some sort of Public Service Announcement (PSA) campaign such as television commercials to promote it.

### **Community Living Mini-Grants**

#### **Best Buddies International, Inc.**

Kelsey Warlick from Best Buddies International, Inc. joined virtually. She said this initiative hired a transition manager who got into the school system in May, and it focused on a person-centered approach to transition planning while providing 22 different workshops that impacted 43 students with I/DD ages 14-22. She thanked NCCDD for this funding and said it will bring the organization closer to achieving their overarching goal of equipping participants with skills gained through the Best Buddies Transition program, and this will help make the students active members of their communities, make meaningful connections, help them develop networks with employers in different community resources, and help with natural supports within the school and workplace settings. She pointed out that the initiative has worked with the North Carolina Division of Employment and Independence for People with Disabilities (formerly the Division of Vocational Rehabilitation Services) and job coaches who can place the students in jobs that they can sustain as their careers.

#### **Bloom Fitness Corporation**

John Watson from Bloom Fitness Corporation joined virtually. He talked about this initiative successfully finishing the development of a fitness app that is free for athletes with I/DD and for their caregivers to be able to support these athletes. He said Bloom Fitness Corporation's goal is for athletes to choose a lifetime of fitness, and they have a

90% athlete retention rate. He asked the Council how they can roll this app out for more people to use and benefit from. John also mentioned a couple of athletes with I/DD who will create instructional videos on how to use the app.

### **The National Leadership Consortium**

Cory Gilden and Caitlin Bailey from The National Leadership Consortium joined virtually and shared a PowerPoint presentation. She said they did a deep dive into organizations that deliver individualized, community-based services and supports in hopes of making suggestions to other organizations to help them more of these types of services. She added that The National Leadership Consortium set out to better understand the barriers and facilitators to community living for people with I/DD. She mentioned that these organizations build relationships with other service providers to share experiences and ideas to solve problems. She pointed out at some organizations did fundraising to make everyday operations smoother, and this was worth their investment. Cory said external facilitators included building partnerships with Local Management Entities/Managed Care Organizations (LME/MCOs) and corporations. She pointed out how they learned that these organizations either need more funding or need the funding that they receive to be more flexible. Cory also shared a Unique Approaches slide that showed not necessarily best practices but things that help these organizations, including encouraging frontline management to become involved in the daily work and encouraging good employee mental health. She also shared the infographics that this initiative created from the organizational studies and urged the members to read the full 75-page report for more information.

### **August Minutes:**

Charlrean Mapson made a motion to approve the August 2024 meeting minutes, and Bethany Smith seconded this motion. The minutes were approved unanimously.

### **Fiscal Update:**

Shar'ron Williams provided the fiscal update.

### **Hurricane Helene Response and Needs:**

The committee discussed Hurricane Helene and its response. Ryan Rotundo said he property was okay, but the water rose 27 feet high near his sister's apartment. He recognized the value of natural supports, saying that his sister stayed with him, her mother, and her father during the storm. Rhonda Cox talked about participating in calls led by the State of North Carolina and identifying high-needs populations. She shared how Vaya Health had 6,555 individuals to establish contact with and how some Vaya

Health staff who were displaced worked out of the living room of a fellow staff member. She mentioned 170 individuals with additional support needs and thanked the North Carolina Division of Mental Health, Developmental Disabilities and Substance Use Services (DMH/DD/SUS) and Kelly Crosbie for helping to figure out their support. She said the two biggest needs are for potable water and for housing, especially low-barrier, low-income housing. Rhonda also said some areas need heaters and food. She said an I.V. bag business was destroyed, and it will take up to three years to get some basic things back. Jonathan D'Angelo asked her what the three lessons learned are, and Rhonda replied:

1. Providers must have disaster plans.
2. How do providers communicate and agencies before and after the storm?
3. The time to prepare for an emergency is when it doesn't happen.

She asked if Vaya Health needs to spend time with its members to ask what would make their response to the hurricane different?

Gary Junker mentioned how the North Carolina Department of Adult Correction evacuated 4,000 justice-involved people on 40 buses to Spruce Pine. He said 70 percent of these people have substance use issues or I/DD, and 80 percent have a chronic condition.

Talley Wells pointed out that the biggest lesson learned from the daily calls was the independent living apartments where people did not need support until after the hurricane had passed. He asked how we can impact the Innovations Waiver and keep track of everyone needing services. Rhonda pointed out that Vaya Health being spread out was an asset – its call center never went down during or after the storm. Gary Junker pointed out the importance of personal stories and having a plan, saying it is harder to rescue someone than it is to escape ahead of the storm. Olivia Rose Scott asked how can the Council help individuals with I/DD be prepared and suggested a curriculum. Jonathan said on the first call after the storm, some policies were created “on the fly.” Talley said that calls with LaCosta Parker from NC Medicaid and the Centers for Medicare & Medicaid Services (CMS) helped with these policies. Bryan Dooley mentioned the roles that Centers for Independent Living (CILs) play in helping people with disabilities.

### **Future Investment Discussion:**

Deb Goda shared comments around federal versus state definitions in the Duke University I/DD Data initiative report. She said the Tailored Plans do not spend \$184 thousand for each individual; the average spent per year is closer to \$90 thousand. Jonathan D'Angelo asked if we can obtain an average dollar cost per year for individuals receiving Tailored Plan services. Rhonda Cox pointed out that it is easy to misinterpret data and added that Vaya Health has been doing something to serve people with I/DD for 50 years. She pointed out that North Carolina will have five Standard Plans and four Tailored Plans. Bethany Smith shared that, in her experience, the Tailored Plan provides limited access to providers in Pitt County. One member

suggested that providers should be mandated to participate in the Tailored Plans. Rhonda responded that Medicaid is more complex and can be an administrative burden to providers. She pointed out that providers have the right to choose to participate in a healthcare plan. Joshua Gettinger pointed out that the United States has a badly fragmented healthcare system. Bethany expressed concerns with the different variations of Medicaid and said it is not fair for a provider to reject a Tailored Plan when they accept all of the Standard Plans.

Philip Woodward read comments that Carol Conway shared about mini-grants versus long-term grants and also about addressing issues facing high-needs individuals who will not be able to live independently in the community or enjoy the rewards of employment and post-secondary education. Philip pointed out how Carol said these individuals face the most risk of abuse and neglect.

### **Wrap Up:**

The meeting was adjourned at 12:08 p.m.