**UC AHEC Community Advisory Committee Meeting Meeting Notes June 11, 2024**

**Members:** Pat Achoe/UC College of Pharmacy, Tera Archbold/UC Blue Ash, Amy Clark/AHEC Scholar, Tina Dothard Peterson/UC College of Allied Health Sciences, Donna Green/UC College of Nursing, Yvonne Kaszubowski/Warren County Career Center, Beth Kress/Heartland Hospice, Tiffany Mattingly/The Health Collaborative, Connor Whitford/M4

**Special Guest:** Dr. Emily Johnson, Freeman Center for Intellectual and Developmental Disabilities, UC Health

**Staff:** Dr. Sarah Pickle, Sharron DiMario, Taylor O’Shaughnessy

Tiffany opened the meeting and welcomed two new members - Connor Whitford, a fourth-year UC medical student and Amy Clark, a second-year AHEC Scholar. She also reminded the group of its mission.

**Presentation on the Freeman Center for Intellectual and Developmental Disabilities:** Dr. Johnson shared information about the Freeman Center, a multidisciplinary clinic providing primary care, behavioral health and community and wrap-around support services (Medicaid waivers, state and local community services, dietician, etc.) for its patients and collaboration with UC specialists. Prior to joining the Center, Emily was the medical director for a federally qualified health center in Colorado. She also has lived experience, having both a brother and son with Down’s Syndrome.

She explained that with Medicaid waivers, patients can live independently with home nursing and other therapies. In this case, a client waives his/her right to institutional care. These waivers allow long-term services and supports, such as group and foster home settings. The services differ by state since Medicaid eligibility criteria differs by state. With better integration of home-based services and primary care, this means a better patient experience. Coordination between a number of agencies and services is necessary for patients with IDD.

She shared the challenges around eligibility. The patient must be diagnosed before age 22 with a disability. Disabilities can also be acquired, as in the case of traumatic brain injury. This is especially challenging for immigrants who have had poor access to care and are not eligible for services because of documentation.

Compounding the challenges in caregiving, there is high turnover and low availability of providers in home and community-based services – the pay is low and the hours often long and erratic.

Regardless of spending levels, waivers for home and community-based services must remain budget neutral. There are waiting lists, and many are not able to access services at all. There is a hidden population of which 80% are diagnosed with IDD. The data is poor about why people fall into that group. Mild intellectual disability is often hard to diagnose. There are also large proportions of incarcerated persons and those in the criminal justice system that go undiagnosed.

States decide how to allocate these services and in 2018, Ohio changed to a needs-based services process. People who are doing well may not get services at all. This is of special concern for aging parents with IDD children who are trying to plan ahead . Sometimes, they have to create a crisis to access services. Services also vary by county since much of the funding is property tax based. For example, what the waivers cover is the same, Hamilton County residents have more choices than those in Butler and Warren Counties. In more rural counties, fewer services are available, and transportation is inadequate.

While integration and transitions of care are critical, in this population the transition between hospital and home can be problematic. Everything needs an order, and they are often not written down by caregivers. Patients often move between one residential service to another. A ‘transfer document’ between settings would be helpful. Dr. Johnson shared that policy makers could help set up a better process and reduce the paperwork burden.

We know there are disparities in race/ethnicity, with non-white patients having less access to services in this incredibly complex system. To be successful requires a number of connections. There are also language barriers.

Coordination of care is the ideal opportunity for advancement and innovation, but we are not sure what this really looks like. There is some evidence that Medicaid waivers in elderly populations and long-term supports and services, like the PACE program, show this works in reducing hospitalizations.   
  
Supporting the direct service workforce has potential to meet the needs of multiple populations – those that need work and training for immigrant workers (who make up 27% of the workforce.) Some work is being done in Ohio to support this.

As for housing, it is best for patients not to be isolated, but integrated and involved and have meaningful relationships, allowing them to work if they want to. This includes employing people with autism and other IDD.

Tiffany mentioned a coordination of communication platform called “The Right Care Now” project that summarizes health information for people and provides questions to direct care staff. Dr. Johnson mentioned there are Five Fatal conditions that need to be monitored – constipation, seizures, aspiration, reflux, and dehydration.

Pat shared that Kroger, P&G, 5/3 are engaged in providing employment for this population. For example, Kroger employs persons with IDD in entry-level internships and they are now working in higher level positions. Adapted University experiences are also available at UC and UK.

Dr. Pickle asked if an AI tool could review patients’ charts and create a comprehensive care plan authorized by a physician. The Freeman Center would be the ‘spoke’ and the rest of the team is multi-disciplinary and serves as the ‘hub.’

Tiffany also shared that local hospitals have asked for help from the Collaborative to facilitate care with patients who have severe mental illness or IDD. This is a Medicaid requirement.

She also shared that the Collaborative serves hospitals’ emergency preparedness and response coordination. The World Institute on Disabilities has identified The Collaborative as one of three task forces in the country to build out processes underrepresented populations (IDD, LGBTQ+, mobility, vision and hearing-impaired, people in recovery and English as a Second Language) when disasters strike. The group has been meeting for six months. She asked the advisory committee to support sharing two surveys on this issue.

Connor asked how he could educate himself on how to connect patients with resources, since there is very limited training on this in med school. Dr. Johnson said that knowing what a Medicaid waiver is and information about state and county developmental disabilities boards is helpful.

Taylor shared a short survey about the newsletter in the chat.

The next meeting of the UC AHEC Community Advisory Committee is Tuesday, September 10 from 7:00 -8:00 pm on Zoom.