Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities

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Leadership Education in Neurodevelopmental and related Disabilities

Background

The Research and Training Center on Community Living (2019) estimates that in the U.S. there are approximately 7.4 million adults living with an intellectual and developmental disability (IDD) . Advancements in medical treatment and care have significantly improved health outcomes and increased longevity of life for those with IDD (Centers for Disease Control and Prevention [CDC], 2019; Levi et al., 2020). There is, however, an increased risk of obesity, hypertension, physical inactivity, and smoking for adults with IDD and they have a higher risk of experiencing difficulty with accessing health services (CDC, 2019).

Transitioning from pediatric to adult medical services can be arduous for individuals living with IDD and their families and can lead to a delay in receiving the needed primary and specialty health services (CCD, 2019, Hart, 2020; Levi et al., 2020). There are few coordinated adult service providers available for adults with IDD, including in the Greater Cincinnati area. The University of Cincinnati (UC) Health Transition Care Clinic has been instrumental in reducing the health gap experienced by adults with IDD.

In January 2022, UC Health announced an expansion of the clinic. The Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities (Freeman Center) honors Timothy Freeman, MD, long-time Assistant Professor in the Department of Family and Community Medicine.

For more than 30 years, Dr. Freeman has focused his medical practice on the care of adults with intellectual and developmental disabilities. He is a pioneer in this field, caring for those with intellectual and developmental disabilities long before there was national recognition of the need for improved health care for this population.

UC Health

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Objectives/Problem Statement

1. What are the most pressing needs of the IDD adult community (including the perspective of the people with IDD, their families, and other stakeholders involved in their care)?
2. How can the role of the Center for IDD Community Navigator most effectively be utilized to support adult patients and their families?
3. What resources will be most helpful for the Center for IDD Community Navigator's role?

Methods

- Background information: several meetings were held with Dr. Lauren Wang to determine the responsibilities and previous efforts.
- Interviews with Stakeholders:
  - Comparing Community Navigator and Service Support Administrator (SSA) Role:
    - Developed interview questions for SSA, family members, and individuals with a disability.
      - Summary of the questions:

  - Tell us about you:
    - general details about yourself
    - your family
    - your roles/services/support that you provide for your clients
  - What gaps could a navigator at the Center for IDD fill?
  - How could a navigator directly support you?
  - How might a Navigator support people who are not connected to the developmental disabilities system?
  - Does an SSA work on developing a future plan of care/goals/plans? Does this plan include the family? How is this completed?
  - What are some specific priority areas that you wish you had more support or services? Share 3.
  - Other thoughts/feedback/comments?

  - Results of interviews were analyzed to find common themes.
- Researched local community supports and potential collaborators based on common knowledge and anecdotal information regarding resource needs for individuals and families in the IDD community.

In addition to addressing the research questions, we also addressed the need to:

- Research national Universities for best practice:
  - Initial research was completed by Dr. Wang prior to SEBM project
  - Interest was in models that were connected to UCEDD, a university, and a healthcare system, with a focus on adults.

Results

- Interviews held (via Zoom or phone) to gather information.
  - Interviews held with (3) local Service Support Administrators (SSA) and other county board staff.
  - Interviews with (2) individuals with IDD and (2) families.

Overall Themes of Reponses:

- Systemic Barriers
  - Funding
  - Role clarification
  - Inflexibility of systems of care
  - Siloed supports
  - Gatekeeping
  - Lack of communication and collaboration between systems

- Unmet Needs of Adults with Disabilities:
  - Housing
  - Transportation
  - Intentional future planning
  - Trained medical staff (including nursing homes)
  - Adaptive medical equipment for adults

- Engaging those who are not currently connected to supports
- Flexible supports that allow for slow intentional transitions that fit the person's needs

- Resource Document developed to provide to the future Community Navigator.
- The top 5 universities that held critical components for wrap-around services were identified and included:
  - University of Oregon Center for Excellence
  - Georgia State University Center for Leadership in Disability
  - University of Illinois-Chicago
  - West Chester Center for Human Development (New York)
  - Indiana Institute on Disability and Community

"I need help learning about what I don't know." ~parent of an adult with disabilities

Discussion

- While we had initial objectives determined, by nature of working with a center in early development, we found the need to frequently pivot our efforts.
- To avoid duplication of services we explored the difference between a Community Navigator role and a Service Support Administrator for the local counties. An additional outcome was highlighting the benefits of a Community Navigator and encouraging future collaborations.
- It was also determined that due to minimal communication between medical providers and community social services, the Community Navigator is better positioned to assist individuals and families with referrals and navigating healthcare systems.
- Based on the research of other healthcare centers, the Freeman Center will be a unique, leading expert of coordinated care for adults with IDD as they age.

Conclusions & Next Steps

Conclusion:
The data gathered supports the continued development and eventual hiring of a Community Navigator for the Freeman Center. The position should strive to decrease barriers identified and work to bring a positive impact to the center, individuals with IDD and their families, medical staff, and community partners.

Recommendations for Next Steps:

- A **needs assessment** is recommended to gain perspective from a larger and more diverse group of people in the community.
- Reporting data out to key stakeholders.

Acknowledgement

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We also want to honor the legacy of Dr. Freeman who was instrumental in developing the UC Health Transition Care Clinic and the UC Health Intellectual and Developmental Disability Program. He taught, mentored and inspired hundreds of physicians during his career. His incredible passion in treating people with intellectual and developmental disabilities and improving their health and quality of life has been truly remarkable.