

Understanding the Needs and Services of those Transitioning to the Adult Healthcare System: The Freeman Center

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Background

- What is healthcare transition?**
- A **purposeful** and **planned process** moving from the pediatric to adult healthcare system
 - Adult healthcare is moving to more holistic life course approaches instead of purely medical¹
 - **Community navigators** connect patients with care teams and help remove barriers to accessing care and services
 - Focus on patients' needs for optimal care
 - Clearer understanding of healthcare environment
- What does the research say?**
- Significant challenges (e.g., access to range of services) and barriers (e.g., finding qualified providers) exist for adolescents and young adults with intellectual and developmental disabilities (I/DD) and their families related to various transition areas^{1,2}
 - Individuals with disabilities describe the transition process as feeling “fragmented, unclear, and lacking coordination”³
 - Similarly, healthcare providers experience barriers in assisting with the transition process for adolescents with I/DD¹

- What is the Freeman Center?**
- The University of Cincinnati's Freeman Center for Intellectual and Developmental Disabilities provides healthcare for adults with I/DD
 - The Freeman Center is an **interdisciplinary** center of excellence that provides **specialized, coordinated, patient-centered** care
 - One of the few national centers equipped to reduce healthcare gaps experienced by this underserved population
 - Currently provides primary care, behavioral health and psychiatry, physical medicine and rehabilitation, nurse care coordination, dietary support, clinical pharmacy, social work, community navigation, PT/OT/ST, healthcare transition planning, in-person and virtual appointments, condition-specific health consultations, and specialty care referrals
 - Listens to the voices of patients about needed services to determine benefit of community navigators to improve care

Objective

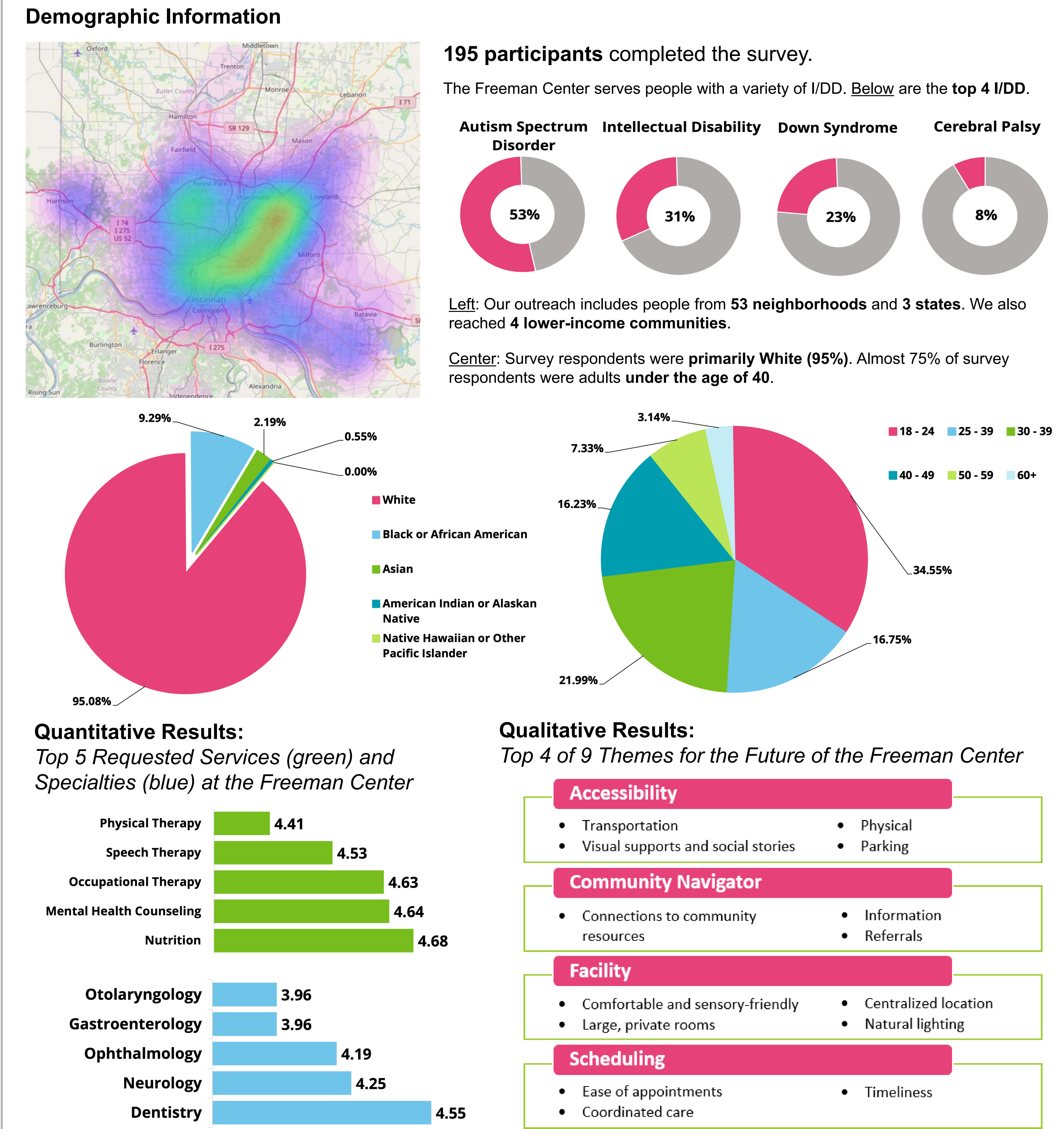
- Obtain and analyze information from relevant stakeholders about preferences and needs for services and supports at the Freeman Center to improve care for adults with I/DD.

Methods

- Participants**
- Recruited individuals with I/DD, their families and caregivers, and medical providers throughout Ohio
 - Emphasis on actively recruiting **minoritized** groups
 - Reached out to community organizations
 - Mapped zip code data to determine distribution of responses from low-income neighborhoods
 - Analyzed data separately to ensure representation

- Data Collection**
- Online survey gauging **patient needs** and **hopes for the future** of the Freeman Center
 - Quantitative analyses included averaging 6-point Likert scales about services and supports
 - Qualitative analyses included consensus coding and thematic analysis of open-ended responses about needs and preferences
 - A handout including preliminary survey results distributed to stakeholders to increase participation

Results



Acknowledgements

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References

1. Hill, A., Wilde, S., & Tickle, A. (2019). Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS): a meta-synthesis of parental and professional perspectives. *Child and Adolescent Mental Health*, 24(4), 295-306.
2. Leeb, R. T., Danielson, M. L., Bitsko, R. H., Cree, R. A., Godfred-Cato, S., ... & Lebrun-Harris, L. A. (2020). Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders—United States, 2016–2017. *Morbidity and Mortality Weekly Report*, 69(34), 1156.
3. Brown, M., Macarthur, J., Higgins, A., & Chouliara, Z. (2019). Transitions from child to adult health care for young people with intellectual disabilities: a systematic review. *Journal of advanced nursing*, 75(11), 2418-2434.

Discussion

- Demographic Information**
- Survey respondents were predominately White
 - This is **unrepresentative** of the populations the Freeman Center serves
 - May affect generalizability and interpretability
 - The range of ages and disabilities served highlights the Freeman Center's ability to provide **specialized** and **coordinated care** to this underserved population
- Quantitative Results**
- Survey respondents expressed interest in centrally located **therapy services, behavioral supports, and specialty providers**
- Qualitative Results**
- Survey respondents identified 9 major themes for the future of the Freeman Center
 - This information is beneficial in communicating with stakeholders about **future changes**

- Challenges**
- Recruitment
 - Despite explicit efforts, it was **difficult to engage** minoritized communities
 - Relied on participants to accurately complete the survey without supports from the research team, such as phone call reminders
 - Institutional Barriers
 - Our research is dictated by **external factors**, such as time constraints and approval processes

Conclusion

- Patients desire **coordinated** healthcare in a **supportive** and **accessible** facility, emphasizing **specialized services and resources**

Next Steps

- Further **increase diversity** of respondents
 - Continue to reach out to community organizations
 - Translate the survey to Spanish
 - Engage with local communities in their neighborhoods
 - One of the few national centers equipped to reduce healthcare gaps experienced by this underserved population
- Distribute finalized **handout** with findings to families and stakeholders
- Develop survey investigating specific needs and services of a **community navigator** at the Freeman Center
- Ensure the Freeman Center considers the results of the survey when planning for its future through **consultation**

Information about the Freeman Center

Access to our survey about the Freeman Center