

Freeman Center for intellectual and developmental disabilities: Patient-centered interdisciplinary care

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ABSTRACT

Objectives: Adults with intellectual or developmental disabilities (IDD) face substantial barriers to accessing high-quality, patient-centered care. This paper describes the development and evolution of the Freeman Center, an integrated, interdisciplinary center developed using feedback from adults with IDD and their family members. **Methods:** We evaluated the reach of the Freeman Center services and described the patient population. **Results:** As of November, 2022, 1068 patients were seen at the Freeman Center. These patients represent about 5 % of all people with IDD in Hamilton County Ohio, where the Freeman Center is located. On average in 2022, the Freeman Center provided approximately 380 primary care visits, 47 psychiatry visits, and 85 combined primary care and psychiatry service visits per month. **Conclusions:** Patient demographic characteristics are largely consistent with the general population of Hamilton County, indicating patients are representative of the county the clinic primarily serves. Further work is needed to evaluate patient outcomes at the Freeman Center.

1. Introduction

Adults with intellectual and developmental disabilities (IDD) are a heterogeneous population with unique healthcare challenges. In the US, 1–3 % of the overall population are estimated to have IDD.¹ The seven million nonelderly adults with disabilities in the US represent 15 % of total Medicaid enrollment and 42 % of the total program spending.² Despite this investment, individuals with IDD continue to have worse outcomes, most evident in the 20-year disparity in life expectancy between this population and the general population.³ This group also disproportionately utilizes tertiary services, such as the emergency room and inpatient hospitalizations^{4–7} and consistently reports lower satisfaction with and lower quality of care.^{8–13} This disparity in care was magnified by the COVID-19 pandemic as, “having an intellectual disability was the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality.”¹⁴

Individuals with IDD experience increased barriers to care such as multiple co-occurring health conditions, higher risk for complications, communication barriers, a lack of trained providers, and environmental barriers to care. Relative to the general population, adults with IDD are more likely to have multiple physical health conditions and mental

health conditions^{15–18}; are more likely to experience abuse, neglect, and exploitation^{19,20}; and are more likely to experience adverse side effects and decreased quality of life from polypharmacy.^{21–23} Compounding these complications, accessing appropriate care is difficult for adults with IDD, with only 57.53 % receiving annual health examination.²⁴ Additionally, communication barriers may impact adults with IDD’s independence in making an appointment, arriving to and checking in for an appointment, participating in a visit, and integrating information after a visit; these communication barriers limit accessibility and effectiveness of care for individuals with IDD.^{10,25–28} Further, a knowledge and comfort gap amongst healthcare providers is well established.^{9,25,28–30} Indeed, only 40.7 % of physicians report being “very confident” in their ability to provide the same quality of care to patients with a disability, and only 56.5 % “strongly agreed” that they welcomed patients with a disability in their practices.³¹ Finally, the healthcare environment itself is often identified as a barrier to care due to physical features (ie., office locations that require stairs or elevators or clinic rooms that are inaccessible to mobility devices) and sensory features (waiting room stimuli, unpredictable waiting times, etc.).^{10,29,30,32}

As a result of these barriers to care, it is critical to develop evidence-based systems and approaches dedicated to providing better care to this

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growing population.³³ There is a critical need to develop models of physical and mental healthcare delivery that minimize barriers to care and maximize health outcomes and quality of life for adults with IDD. Funding agencies like the Patient-Centered Outcomes Research Institute (PCORI) have prioritized funding for comparative effectiveness trials for models of primary care for people with IDD, but there is currently a dearth of existing evidence-based models of care.

One potential solution to better provide care for adults with IDD is interdisciplinary teams, consisting of a group of providers from multiple different healthcare professions.¹⁷ Interdisciplinary healthcare teams can provide comprehensive, holistic care and address the developmental needs and improve the health outcomes of adult patients with IDD.^{34–37} Here we describe the program and initial evaluation of the University of Cincinnati Health Timothy Freeman, MD Center for Intellectual and Developmental Disabilities. This is a center focused on providing patient-centered, interdisciplinary, team-based comprehensive care for adults with IDD. In addition to improving clinical outcomes, The Freeman Center creates opportunities for community partnerships and improving education on IDD for healthcare providers.

1.1. Program description

In 2018, the University of Cincinnati (UC) Health Transition Care Clinic (TCC) was created to serve transition age youth with IDD aging out of the pediatric system. The initial model of care developed for the TCC was for providers to see the patient, address issues specific to transition, and connect the patient to other providers in the community.

Around this time, the larger healthcare organization in which the TCC is housed was working to implement integrated behavioral health care within the primary care system. Individuals with IDD were identified as a population that may benefit from the integration of medical and psychiatric care. A psychiatrist with training in neurodevelopmental disorders joined the TCC and developed a collaborative care model specific to the population. Collaborative care is a specific type of integrated care that utilizes the principles of the “chronic care model” and allows the psychiatric consultant to provide indirect consultation on a panel of patients while only directly interacting with a select few.³⁸ Individuals were seen in the clinic by a primary care physician who identified active behavioral health needs. Primary care physicians could then place a referral to the collaborating psychiatrist for direct evaluation or expert chart review with the goal of treatment recommendations.

1.1.1. Feedback from patients and families

To better accommodate the needs of the community, we established an advisory board of patients, family members, community members, and health care workers. Patients and families wanted patient-centered care from providers with experience in caring for individuals with IDD. They expressed a preference for continued care within the TCC instead of transitioning to other providers in the community. They also described how insurance acceptance rates and lack of comfort among community physicians furthered the already significant barriers that they faced. The top priorities identified by the advisory board included: having providers trained in caring for individuals with IDD, increasing access to specialty services, improving care coordination, having intentionally designed space to meet the needs of the population, and the need to have a “home” within the healthcare system. These priorities served as a framework for further developing a clinic specializing in the care of individuals with IDD.

1.1.2. Program evolution

With the growing demand for services, the TCC was discontinued and replaced by a medical home model. This model was determined to better address healthcare needs established by the advisory board. In this model individuals with IDD would be able to receive primary care, psychiatric care, and support services within a single clinic. With

support from the UC health system, patients would also have access to specialty medical services.

In 2022, the Timothy Freeman, MD Center for Intellectual and Developmental Disabilities was officially established. This was achieved through the support from UC Health system, community organizations, and philanthropic donations. The Freeman Center was named in honor of Dr. Freeman, who was a family medicine physician who started seeing patients with IDD at UC Health in 1987. He was a pioneer in this field, caring for this patient population before it was recognized by the medical community as a population requiring specialized services. He trained and mentored numerous medical students and resident physicians in a variety of fields throughout his thirty plus year career. The development of a center encompassed his dream of providing medical care, training future physicians, contributing to research, and building collaborations within the community.

The Freeman Center is currently located within the UC Health Primary Care Network. The clinical team is composed of two family medicine physicians, two family medicine/psychiatry physicians, one family medicine nurse practitioner, and one physical medicine and rehabilitation physician. The Freeman Center also provides access to registered nurse care management, behavioral health care management, a behavior support specialist, counseling services, a dietitian, and a pharmacist. [Supplemental Fig. 1](#) provides a timeline to illustrate when services were added to the Freeman Center.

1.1.3. Community partnership

A central focus of The Freeman Center is to remain deeply rooted in the community and to work to help address unmet needs outside of the clinic walls. A collaboration was formed between The Freeman Center and Hamilton County Developmental Disabilities Services. Hamilton County Developmental Disability Services is the state funded agency that provides support services to individuals with disabilities within the community. The collaboration allowed The Freeman Center to provide behavior supports for patients at the time of their appointments. The behavior support specialist works to train staff, ensure the clinic environment is welcoming and sensory friendly, reduce anxiety during visits and medical procedures like blood draws or vaccines, and troubleshoot difficult situations with families that may occur outside of medical visits. The interdisciplinary team meets monthly to support mutual patients and facilitate early intervention for patients at risk of incarceration or admission to a developmental center.

The Freeman Center additionally receives ongoing guidance and support from the advisory board and steering committee. The steering committee is made up of patients, families, and community members and continues to provide input on the future direction of the Freeman Center to ensure the needs of the community continue to be met and that efforts remain patient and community-centered, while the advisory board is composed of stakeholders who provide higher level input on strategic development.

1.1.4. Promoting education

The disparities in access to care for individuals with disabilities reflects an increased need for healthcare providers comfortable with providing care to this population. The Freeman Center is committed to growing the number of healthcare providers who are well-equipped to provide patient-centered care for adults with IDD. The affiliation with an academic health system has allowed The Freeman Center to participate in the education of medical students and medical residents at the University of Cincinnati College of Medicine and The University of Cincinnati Medical Center in clinical settings. Learners work with staff in The Freeman Center to develop critical skills needed to provide competent care for individuals with disabilities. In addition to clinical experiences The Freeman Center providers have worked to implement formal curricular changes to medical education, promoting competencies associated with working with the IDD population. Topics within the developed curriculum include: communication, transitions of care,

access to care, guardianship, alternatives to guardianship, and patient-centered care. The Freeman Center providers serve as instructors of the curriculum and are involved as co-investigators for grant funding opportunities.

2. Methods

2.1. Data source

We sought to evaluate the reach of the Freeman Center since its inception. De-identified, patient-level data were obtained from the Freeman Center for Health Informatics at UC. Patients were identified based on the creation of an episode of care at the Freeman Center within the electronic health record, and specific IDD diagnoses were identified by diagnoses documented in the problem list and medical history. The data used in this study contained de-identified individual-level healthcare records for patients at the Freeman Center between 1 January 2018 and 30 November 2022.

2.2. Variable definitions

We determined the number of patients seen and their available demographic characteristics from institutional data. Demographic variables including age, sex, insurance type, and county were extracted from the patient’s most recent date of service. To characterize the IDD diagnoses of patients at the Freeman Center, we characterized the number of patients with intellectual disability, autism, Down syndrome, cerebral palsy, spina bifida, attention-deficit hyperactivity disorder, and rare genetic syndromes (i.e., Angelman Syndrome, Williams Syndrome) based on the presence of diagnosis codes for visits during the observation period. To characterize the co-occurring conditions of patients at the Freeman Center, we identified the number of patients with obesity, hypertension, depression, anxiety, bipolar depression, obsessive-compulsive disorder, and conduct disorder. Diagnosis codes used to identify IDD and co-occurring conditions can be found in [Supplemental Table 1](#).

2.3. Statistical analysis

Descriptive statistics were used to summarize the demographic characteristics of patients. Categorical variables are reported as frequencies and percentages. Continuous variables are reported as medians and interquartile ranges (IQR). Additionally, descriptive statistics were used to calculate the number of visits by provider type over time. SAS software version 9.4 was used for all analyses.

2.4. Ethical approval

Our institutional review board (IRB) reviewed this study and determined it to be IRB-exempt due to the use of limited data sets.

3. Results

Data from 1068 unique patients were included in this sample. [Table 1](#) provides patient demographic information. Most patients were male (62.2%) and resided in Hamilton County, where the Center is located (77.1%). Patient ages ranged from 2 to 82 years, with a median age of 38 years (IQR = 26, 52). The plurality of patients were 18–29 years old (n = 331, 31.0%). The most common IDD diagnosis was other/unspecified ID (43.1%) followed by autism (33.8%). The most common co-occurring conditions were anxiety (34.2%) and hypertension (28.5%).

[Fig. 1](#) illustrates the number of visits per month and [Table 2](#) provides the annual number of visits by different services provided at the Freeman Center. Each month since 2018, the Freeman Center has seen over 200 patients for primary care with a steady increase in annual

Table 1
Demographic characteristics of patients at the Freeman Center.

Characteristic	Freeman Center patients (N = 1068)
Male, N(%)	664 (62.2)
Hamilton county, N(%)	823 (77.1)
Age category, N(%)	
< 18 years	21 (2.0)
18–29 years	331 (31.0)
30–39 years	223 (20.9)
40–49 years	177 (16.6)
50–59 years	143 (13.4)
60 + years	173 (16.2)
Race, N(%)	
Asian	10 (0.9)
Black, African American	312 (29.2)
Multiracial	15 (1.4)
White	702 (65.7)
Other or unknown ^a	29 (2.7)
Hispanic or Latino ethnicity, N(%)	25 (2.3)
IDD diagnosis, ^b N(%)	
Intellectual disability	
Mild	62 (5.8)
Moderate	30 (2.8)
Severe/profound	19 (1.8)
Other/unspecified	460 (43.1)
Autism	361 (33.8)
Down syndrome	141 (13.2)
Cerebral palsy	173 (16.2)
Spina bifida	26 (2.4)
ADHD or ADD	94 (8.8)
Rare genetic syndromes ^c	13 (1.2)
Co-occurring conditions, ^b N(%)	
Obesity	273 (25.6)
Hypertension	304 (28.5)
Depression	153 (14.3)
Anxiety	365 (34.2)
Bipolar depression	78 (7.3)
Obsessive-compulsive disorder	102 (9.6)
Conduct disorder	162 (15.2)

Note: ADHD = attention-deficit hyperactivity disorder; ADD = attention-deficit disorder; ^aOther race includes Indigenous American, Indigenous Hawaiian or other Pacific Islander, patient refusals to report race, and patients reporting their race as “other”; ^bIDD diagnoses and co-occurring conditions are not mutually exclusive categories, and a single individual may be represented in more than one row; ^cFrequency counts for rare genetic syndromes, including Angelman syndrome and Williams syndrome, were combined to protect patient confidentiality.

visits from 3234 visits in 2018 to 4571 visits in 2022. The number of psychiatry visits has grown steadily since this service was introduced in September 2019; there were 162 psychiatry visits in 2020 (the first full year this service was available) and 560 visits in 2022. Of note, one primary care provider also is a psychiatrist and provides both services to their patients. As a result, visits to this provider were represented in [Fig. 1](#) and [Table 2](#) separately as they represent a combined primary care and psychiatry service. The number of visits to this provider have also steadily increased from 31 visits in 2020 (the first full year this provider was at the Freeman Center) to 1021 visits in 2022.

4. Discussion

Given the high rate of co-occurring medical and psychiatric conditions and barriers unique to the population, adults with IDD represent a unique patient population whose needs are often unmet by the healthcare system. This paper outlined the development, evolution, and initial evaluation of the Freeman Center, a clinic focused on providing patient-centered, interdisciplinary, team-based comprehensive care for adults with IDD.

Using an estimated prevalence of two percent, Hamilton County, Ohio would be expected to be home to approximately 16,614 people

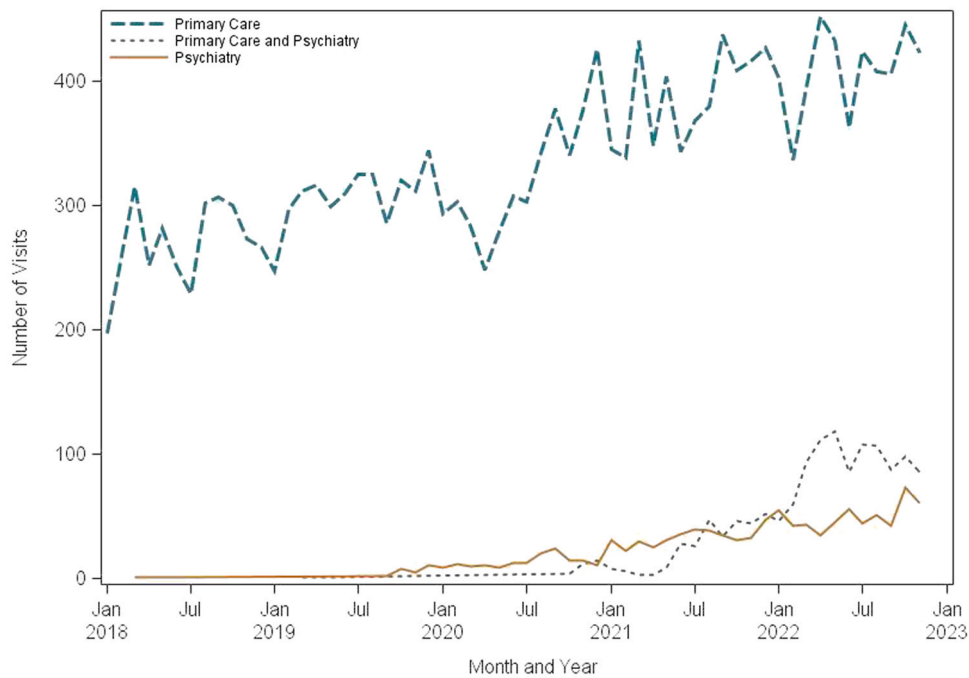


Fig. 1. Number of visits to the Freeman Center for IDD by month.

Table 2

Number of visits to the Freeman Center for IDD by year.

Service	Year				
	2018	2019	2020	2021	2022
Primary care	3234	3693	3880	4650	4571
Primary care and psychiatry	0	3	31	306	1021
Psychiatry	0	26	162	400	560

with IDD.^{1,39} Our data demonstrates that the Freeman Center currently cares for 5% of this population, and capacity is growing. The demographics of Freeman Center patients are largely consistent with the general population of Hamilton County, Ohio.^{39,40} However, ages of our patients are younger compared to the general population,⁴⁰ which may be reflective of previous reports of premature mortality in adults with IDD.^{3,41,42} Further, approximately one-third of all individuals with diagnosed IDD at the Freeman Center also have an autism diagnosis, which is consistent with population-level data on the prevalence of autism among people with IDD.⁴³

Data presented here is also consistent with previous research that has identified greater rates of some co-occurring mental and physical health conditions among people with IDD compared to the general population.^{17,44–46} Approximately 34.2% of Freeman Center patients experience anxiety and 14.3% experience depression. In contrast, approximately 26.4% of the general population of Ohio experiences anxiety/depression and 8.8% experienced a major depressive episode in the previous year.⁴⁷

In other cases, however, our data reflected lower prevalence of some health conditions among Freeman Center patients than would be expected in the general population. For example, we identified lower rates of obesity in this population compared to the general population (25.6% vs 35.5%).⁴⁸ Additionally, 28.5% of Freeman Center patients in this cohort are diagnosed with hypertension, compared with 35.7% in the general, non-elderly Ohio adult population.⁴⁹ This is consistent with previous research, which interestingly shows that individuals with IDD have rates of hypertension that are similar to or lower than the general population.^{50–52}

4.1. Methodologic considerations

Strengths of this paper include data collection from prior to the formal inception of the Freeman Center, allowing for a robust understanding of the needs served. Further, identifying both the initial concept for the Freeman Center and showing the evolution will hopefully be useful to other healthcare providers and healthcare systems aiming to serve this population. The overall consistency of our data with previous research indicates that the Freeman Center, while not yet at scale, is appropriately reaching the IDD population of Cincinnati. Limitations include incomplete data on severity of ID (most common IDD diagnosis and severity was other/unspecified ID at 43.1%).

4.2. Next steps

To continue to minimize barriers to care for adults with IDD, the Freeman Center plans to continue to add additional specialty services and grow the overall capacity of our health system. We aim to hire a community navigator to serve as a liaison to various counties we serve and the numerous community organizations/resources that are already instrumental in the lives and care of our patients. We also plan to evaluate the impact of this service and other community partnerships. Given patient and caregiver comfort in the Freeman Center, we hope to expand services to allow more holistic care for our patients, including partnering with Physical Therapy, Occupational Therapy, Speech Therapy, Nutrition, and Social Work. Given the great need for further medical expertise, we aim to establish a one-year fellowship program in developmental medicine, with plans to our first class in 2025. Future plans also involve evaluating the outcomes of the fellowship and the Freeman Center’s other educational initiatives. Finally, we are looking to move to a more intentionally designed space that is equipped for a variety of physical disabilities, has appropriate sensory modifications, and room to expand to other services such as dentistry.

5. Conclusion

The heterogeneous population of individuals with IDD, often have significant unmet health needs. Increased rates of co-occurring mental and physical health conditions and considerable barriers to care

contribute to poorer outcomes and increased mortality compared to the general population. This paper shares the development and evolution of, as well as early data from, an interdisciplinary and innovative center dedicated to providing holistic care to individuals with IDD. Early data shows demographics and co-occurring condition rates consistent with previous research, which is reassuring that patients are equitably entering care at The Freeman Center. Importantly, the Freeman Center provides a critical resource for teens and young adults with IDD transitioning out of the pediatric healthcare system as there is a paucity of adult providers equipped and willing to care for this vulnerable population. Although young adults with IDD frequently continue to receive care in the pediatric system beyond a typical age of transition, it is important that we further develop a caring and competent adult system to care for this population as they continue to live longer. Future directions include enhancing the scope of care, training future IDD specialists and care providers, and decreasing barriers to care through IDD-focused environmental design with the goal of improving outcomes and decreasing health disparities for individuals with IDD.

CRedit authorship contribution statement

Joshua Smith: Writing – original draft. **Brittany Hand:** Conceptualization, Methodology, Formal analysis, Visualization, Writing – original draft. **Emily Johnson:** Writing – review & editing, Supervision. **Cory Keeton:** Writing – review & editing, Supervision. **Lauren Wang:** Conceptualization, Visualization, Supervision, Project administration.

Ethics statement

We attest that this work has been carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and is aligned with the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals.

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Data Availability

The data that has been used is confidential.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr. Lauren Wang is the medical director of the Freeman Center.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2023.100003](https://doi.org/10.1016/j.hctj.2023.100003).

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