

A Consultation Model for Intellectual and Developmental Disability Care

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Purpose: To provide an overview of an innovative, consultative care model for patients with Intellectual and Developmental Disabilities (IDD) within a Family Medicine department.

Methods: We conducted a retrospective chart review of all patients seen in the clinic between 2017 to 2023 to identify patient demographics (eg, age), clinical needs (eg, diagnoses and referral needs), and administrative characteristics (eg, Medicaid status). We also conducted a spatial analysis to evaluate each patient's estimated travel distance and time to the clinic.

Results: The number of patients seen in the IDD clinic totaled 184, with 65% male patients ($n = 120$) and a mean age of 31.29 years ($SD = 16.27$). More than half of patients, 65%, were insured by Medicaid ($n = 119$), and almost half received services paid for by the state Medicaid waiver (43%, $n = 80$). Many patients lived with family (64%, $n = 117$) and reported family guardianship (55%, $n = 101$). The spatial analysis identified that the majority of patients, 86% ($n = 159$) were nonrural residents based on Rural-Urban Continuum Codes. The mean distance traveled was 20.41 ($SD = 21.36$) miles with a mean travel time of 27.08 minutes ($SD = 21.78$). Following the consultations, 38% received outgoing referrals. Referral locations included psychiatry (8%), neurology (3%), behavioral health counseling (3%), and other medical services (17%).

Conclusion: This study demonstrates the diverse characteristics of patients with IDD receiving care through a consultative-based model of care. This model appeared to provide services for patients from a wide geographic catchment area that may not have otherwise had health care access. (J Am Board Fam Med 2025;38:180–187.)

Keywords: Access to Care, Autism Spectrum Disorders, Intellectual Disability, Interdisciplinary Health Team, Organizational Innovation, Population Health, Practice-based Research, Primary Health Care, Referral and Consultation, Retrospective Studies, Spatial Analysis, Quality of Care, Vulnerable Populations

Caring for patients with an intellectual or developmental disability (IDD) is often overwhelming for primary care clinicians who may lack specialized training related to caring for these patients.¹

Physicians consistently report barriers to IDD care including a lack of knowledge about patients with IDD, insufficient time for appointments, cumbersome paperwork and documentation, and challenges surrounding care coordination. Physicians also reported feeling underprepared to care for IDD patients in terms of education and training.^{2,3} Multiple studies have reported disparities in care for patients with IDD,^{1,4} often resulting from clinicians' knowledge gaps and lack of confidence in their ability

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to provide sufficient care.^{5,6} Despite similar prevalence in the general population, chronic conditions often go undiagnosed in adults with IDD,⁷ and patients both present to the emergency department and are hospitalized more frequently for conditions that are generally preventable when accessing high-quality primary care.^{8,9} A lack of focus on health promotion also leads to lower rates of preventive screenings and higher rates of chronic disease.^{10–13} The barriers to treating patients with IDD in the traditional primary care setting, suggests an IDD-specific model of care may be needed, and residency programs in IDD have been found to help.^{14–16}

In 2016, we partnered with the local Medicaid payor (Vaya Health) in Western North Carolina to implement a novel primary care consultative model to provide opportunities for family medicine trainees to work with patients with Intellectual and Developmental Disabilities (IDD). The program was piloted in 2017 before expanding in subsequent years. The clinic's goal is threefold: 1) improve the health of patients with IDD in our region 2) serve as a resource to primary care clinicians who may not feel comfortable with or capable of providing sufficient care for patients with IDD 3) provide training opportunities for family medicine resident physicians in treating patients with IDD.

The consultative clinic model is novel in that it provides patients with IDD a single consultation appointment in which they can receive standard-of-care health care from a clinician who is knowledgeable about their IDD and comprehensive care-coordination. Care-coordination is achieved through the consolidation of the patient's medical records from myriad clinicians and necessary referrals as identified during the evaluation to ensure the patient's continued access to care. The clinic primarily relies on referrals from other clinicians, though patients are able to schedule directly as well. Clinic appointments followed a unique workflow to allow for improved care coordination. On scheduling a patient with IDD, a records request is sent to Vaya Health for psychological assessments, a medication list, and care management plans. During an hour-long appointment, patients and caregivers meet with both a resident and faculty physician to address their concerns and conduct an overall assessment. Patients leave with a list of recommendations and a consult letter written to their primary care

clinician. If they do not have a primary care clinician, they are assigned one within the organizations' Family/Internal Medicine practice or referred to clinician in the community who has experience working with IDD patients.

The present study describes our IDD consultation clinic regarding the patients seen, their needs, and the distance to care covered by this model. The goal of this study is to provide clinicians with an overview of patients treated in this model as a means to address physician uncertainty about patients with IDD. We were particularly interested in the characteristics of individuals served, health care needs, and the geographic reach of the consultation model, defined as the patients' proximity to location where consultative services are offered. Our hope is that this information, paired with the above description of our clinic workflow, will allow clinicians to make an informed decision regarding the adoption of a similar care model in their clinic.

Methods

Study Sample and Procedure

We conducted a cross-sectional retrospective chart review of all patients seen in the IDD Clinic situated in the Family Medicine Department at the Mountain Area Health Education Center (MAHEC) from the start of the clinic (August 2017) to the time the study was initiated (April 2023). We were particularly interested in examining the most frequently reported needs for patients and families, rates of diagnoses, and the referrals and services most commonly seen in the IDD clinic. For this reason, a longitudinal data collection form (ie, a patient registry) was created to document key information about patients seen in the IDD clinic soon after the clinic was opened. After patient visits, the lead author (RP) manually extracted data from Electronic Health Records (EHR) to this electronic registry via a data collection form in REDCap, creating one record per patient describing the patient and their IDD consultation visit. This study was evaluated by the Mission Hospital Institutional Review Board and deemed not human subjects research.

Measures

The data collection form included patient demographic, clinical and administrative characteristics. The demographic information was collected as

documented in the EHR and included visit year, age at last visit, sex, address, and insurance coverage (Medicaid, Medicare, Private, Dual/Other, Uninsured/Self-pay). Demographic data specific to this population included being on the North Carolina's Home and Community-Based Services Waiver (Innovations) waiver or waitlist status (receiving Innovations, waiting on the registry of unmet needs (RUN), screened but not on the RUN, not screened, or unknown), patient living situation (family home, independent, supportive living, adult/family care home, intermediate care facility (ICF), alternative family living (AFL), skilled nursing facility, other), and legal guardianship status (self, full family, limited family, full paid, limited paid). We also recorded patients' insurance coverage and a care manager's involvement.

For spatial analysis using the patient addresses, we classified patients as living in rural or urban areas and calculated their estimated travel distance and time to the clinic. Rurality was defined using the Rural-Urban Continuum codes for the ZIP code in which they live, with codes of 4 or greater being classified as rural. Travel time and distance were estimated by querying the Google Maps API using the street addresses of the patients and the clinic. This method estimates travel time using average (ie, time independent) traffic and road conditions and the most efficient route. For patients with a P.O. Box address, distance and travel time were routed from the center of the ZIP code.

Clinical characteristics included their primary and secondary diagnoses (IDD, autism spectrum disorder, congenital/chromosomal disorders, Down syndrome, cerebral palsy, or other IDD-related diagnoses), outgoing referrals made, referral type, and if the patient had received sufficient dental care (adequate, inadequate, no care). Using data reported by the patient during the consultation visit, dental care adequacy was defined as having any dental care in the past year (adequate), having an identified dentist but not recently receiving care (inadequate), or having no care and no dentist on file (no care). The types of outgoing referrals included physical therapy, occupational therapy, speech therapy, behavioral health counseling, psychiatry, orthopedics, endocrinology, pulmonology, neurology, cardiology, otolaryngology, other medical services, and legal counseling through the medical-legal partnership in the family clinic.

Finally, we collected administrative characteristics including previsit planning, records receipt from the LME/MCO, patient referral source, and the reason for the referral. The referral place and reason were recorded as free-text and then grouped after data collection. Referral sources were grouped into developmental pediatrics, internal MAHEC referrals, MAHEC Psychiatry referrals, other family medicine practices, other pediatrics, and unknown. Referral reasons were grouped into advanced care planning, behavior change, behavioral health, gastrointestinal issues, health maintenance, menses management/contraception, overall assessment, service coordination, transfer of care, and transition planning.

Statistical Analysis

We described the patients and clinic using univariate statistics. All data cleaning and analysis was performed in SAS Studio (v 3.7; SAS Institute, Cary, NC). In addition, ArcGIS (v.10.8.1; ESRI, Redlands, CA) was used to create a map of where patients were located. Any data missing during the initial chart review was rectified with a second wave of review during the data analysis process, allowing for a complete case analysis (0% missing).

Results

Demographic Characteristics

From August 2017 to April 2023, the MAHEC Intellectual and Developmental Disabilities Clinic in Family Medicine saw a total of 184 patients (Table 1). Ages ranged from 7 to 89, with a median age of 24, and mean age of 31. Out of 184 patients, 65% (n = 120) were male, and 35% (n = 64) were female. Rural dwelling patients comprised 14% of the total (n = 25), while 86% (n = 159) were from nonrural areas. Nearly two-thirds, 64%, were living in a family home (n = 117), while 5% (n = 9) were living independently, 2% were in supportive living (n = 3), and 2% were in an adult/family care home (n = 4). The remainder of patients lived in an ICF (5%, n=9), an AFL (22%, n = 40), or another living arrangement (1.1%, n = 2).

Patients with self-guardianship comprised over 25% of IDD patients, over half had full family guardianship (n = 101, 55%), and 6 had limited family guardianship (3%). The majority of patients, (n = 119, 65%) were covered by Medicaid, 14% were covered by Medicare (n = 25), 11% were

Table 1. Patient Demographics

	N	%
Total	184	100.0
Appointment year		
2017	11	6.0
2018	37	20.1
2019	52	28.3
2020	23	12.5
2021	20	10.9
2022	31	16.8
2023	10	5.4
Patient sex		
Male	120	65.2
Female	64	34.8
Rurality		
Non-rural	159	86.4
Rural	25	13.6
Insurance		
Medicaid	119	64.7
Medicare	25	13.6
Private	21	11.4
Dual eligible/other	48	26.1
Uninsured/self	1	0.5
LME/MCO patient	135	73.4
Registry of unmet needs		
Not screened	24	13.0
Received waiver	80	43.5
Not on registry	17	9.2
On registry	25	13.6
Unknown	38	20.7
Living situation		
Family home	117	63.6
Independent	9	4.9
Supportive living	3	1.6
Adult/family care home	4	2.2
ICF	9	4.9
AFL	40	21.7
Other	2	1.1
Guardianship		
Self	51	27.7
Full family	101	54.9
Limited family	6	3.3
Full paid	25	13.6
Limited paid	1	0.5
Age, mean (SD)	31.29	16.3
Age, median (IQR)	24.00	18.5
Distance, mean (SD)	20.41	21.4
Distance, median (IQR)	12.50	21.3
Travel time, mean (SD)	27.08	21.8
Travel time, median (IQR)	20.00	19.0

Note: Insurance categories are not independent and do not sum to 100%.

Abbreviations: AFL, Alternative family living; ICF, Intermediate care facility; LME/MCO, Local management entity/managed care organization; SD, Standard deviation; IQR, Inter-quartile range.

covered by private insurance ($n = 21$), 26% were dual-eligible ($n = 48$), and 1 was uninsured (0.5%). The catchment area for the clinic was quite large, covering 16 counties as seen in Figure 1. The majority of patients ($n = 116$; 63%) lived in the same county as the clinic; however, the distance from the clinic ranged from 1.5 to 110 miles, with a mean travel time of 27 minutes ($SD = 21.8$) and a median travel time of 20 minutes ($IQR = 19$).

Clinical Characteristics

The most common primary diagnoses included ASD ($n = 69$, 38%), IDD ($n = 49$, 27%), and cerebral palsy ($n = 28$, 15%; Table 2). While the majority of patients ($n = 95$, 52%) had no secondary diagnosis, of those patients with a secondary diagnosis, IDD was the most common ($n = 66$, 36%). Less than half of patients received outgoing referrals ($n = 70$, 38%) for a variety of services. The most common documented referral type was psychiatry ($n = 15$, 8%), though a number of patients received referrals to other medical services not captured in our data collection ($n = 32$, 17%). Finally, less than a third of all patients had received adequate dental care ($n = 40$, 22%) at the time of their visit.

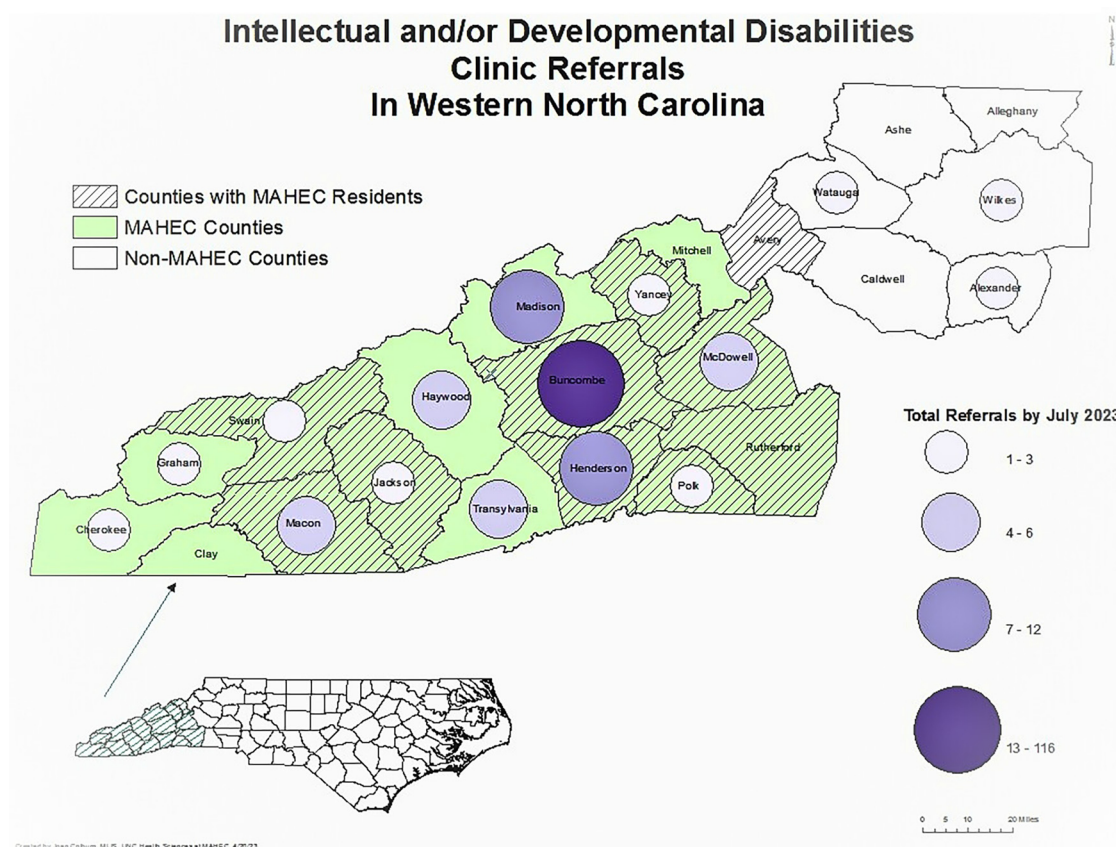
Administrative Characteristics

A majority of patients seen were patients of the local LME/MCO ($n = 135$, 73%), and we received records from the LME/MCO for approximately half of those patients ($n = 88$, 65%; Table 2). Most patients were either on the Innovations waiver ($n = 80$, 43%) or the RUN ($n = 25$, 14%), however several patients were either not screened ($n = 24$, 13%) or their waiver status was otherwise unknown ($n = 38$, 21%). Reasons for referral to the program were available for 181/184 (98.4%) of the patients, and included advance care planning (1%), behavioral health or psychiatric needs (14%), care coordination (14.9%), consults (45.3%), establishing care (2.7%), medication management (1.6%), and transfer of care (23.8%). Results indicate that only 4 (3.7%) of the patients residing in Buncombe County needed behavioral health or psychiatric care compared with 17% of patients who were residents outside of Buncombe County.

Discussion

This study describes the patients seen in a consultative IDD model, and the range of patients seen suggests that the model has succeeded in providing

Figure 1. Map of the 23-county catchment area for the Intellectual/Developmental Disabilities Referral Clinic in western North Carolina. Counties are shaded to reflect the catchment area of the Mountain Area Health Education Center (MAHEC; green), counties with medical residents trained at the referral clinic (patterned), and counties without a MAHEC affiliation (white). Bubble size and color reflect the density of referrals made from that county during the study period.



care for patients in rural/surrounding areas where it would otherwise not be available. Between August 2017 and April 2023, we saw 184 patients from 16 counties using one main medical consultant. Patients received services for a wide range of needs including transitioning to adult care, connection to services, and addressing specific health care needs that may have otherwise gone unmanaged.

Strengths of this clinic have included our collaboration with our LME/MCO given that nearly 75% of our patients were covered through Medicaid. The LME/MCO not only provided appropriate medical and care management records before visits but also maintained ongoing care coordination meetings with our medical team to discuss challenges related to care navigation, Medicaid transformation in the state, and barriers patients face as they seek both medical and behavioral health care. In addition, while outside the scope of the present article, the

dispersion of primary care physicians trained in IDD at this clinic may increase access to IDD-related services even further than the consultation clinic itself does. Graduates of our residency program now practice in 10 counties within our referral area and may be better equipped to serve these patients after having received IDD-specific educational sessions covering a range of topics during their clinic participation. Future research is needed to evaluate the potential workforce development impacts of this clinic. Finally, while our visit volume decreased during the height of the COVID pandemic, we believe this was due largely to shifts in staffing rather than a reflection of the clinic.

Despite providing care for a number of patients, several challenges persist. Initially, our goal was to have staff trained by our LME/MCO to assist with previsit planning and care coordination; however

Table 2. Patient Clinical Characteristics

	N	%
Total	184	100.0
Incoming referral place		
Developmental pediatrics	7	3.8
MAHEC (non-psychiatry)	70	38.0
MAHEC psychiatry	2	1.1
Missing/unknown	65	35.3
Other family medicine	32	17.4
Other pediatrics	8	4.4
Incoming referral reason		
Advanced care planning	2	1.1
Behavior change	15	8.2
Behavioral health	6	3.3
GI Issues	2	1.1
Health maintenance	9	4.9
Menses management	2	1.1
Overall assessment	80	43.5
Service coordination	26	14.1
Transfer of care	31	16.8
Transition planning	11	5.9
Primary diagnosis		
IDD	49	26.6
ASD	69	37.5
Congenital/chromosomal	14	7.6
Down syndrome	17	9.3
Cerebral palsy	28	15.2
Other DD	7	3.8
Secondary diagnosis		
IDD	66	35.9
ASD	7	3.8
Congenital/chromosomal	5	2.7
Down syndrome	4	2.2
Cerebral palsy	3	1.6
Other DD	4	2.2
None	95	51.6
Patient records received	88	47.8
Outgoing referral made	70	38.0
Physical therapy	5	2.7
Occupational therapy	3	1.6
Speech therapy	3	1.6
Behavioral health counseling	6	3.3
Psychiatry	15	8.2
Orthopedics	4	2.2
Endocrinology	1	0.5
Pulmonary	3	1.6
Neurology	6	3.3
Cardiology	1	0.5
Ear/nose/throat	4	2.2
Other medical service	32	17.4
Legal services	2	1.1

*Continued***Table 2. Continued**

	N	%
Dental care		
No	72	39.1
Yes, inadequate	72	39.1
Yes, adequate	40	21.8

Note: Outgoing referral categories are not independent and do not sum to the total number of patients receiving referrals.

Abbreviations: ASD, Autism spectrum disorder; IDD, Intellectual and developmental disabilities; MAHEC, Mountain area health education center.

staffing challenges exacerbated by the pandemic made staff retention difficult, and as such, previsit planning was eliminated as an attainable goal. This is reflected in our receiving patient records before consultation for less than half of patients. Communication of the clinic services to other clinicians also proved challenging in terms of making meaningful connections with referral sources and setting expectations for our consultative model. We received many inappropriate referrals, including those for psychological assessment or complex psychiatric treatment (reported as behavioral health in Table 2). In addition, many of the care gaps identified are beyond the scope of what can be accomplished in primary care, such as dental and behavioral health services that accept new Medicaid patients with disabilities.^{17–19} Lastly, many patients who would qualify for services paid for through the North Carolina Innovations waiver face an average waitlist time of 9 years to become enrolled,²⁰ in addition to shortages of staff to provide these services once enrolled. North Carolina has been undergoing Medicaid transformation for several years but has faced many roadblocks to implementation, leading to confusion and communication challenges for both patients and clinicians.²¹

Spatial analysis of patient residence revealed that the consultation model seems to reach the surrounding counties and an additional cluster of counties to the west. We are unable to directly assess the patient choice component of how patients arrive at this IDD clinic with our data; however, the referral reasons included in our data suggest that these patients may have desired IDD-specific services that were not necessarily available to them elsewhere. This seems to be a plausible explanation, as another federally qualified health center serving

those counties does not have services available for adult IDD patients. This may also be related to the challenge of obtaining referrals from primary care clinicians outside of our organization, resulting in most of our patients being self-referred or referred by care managers who are more proximate. From a service system perspective, most of our patients depend on services that would be managed by our LME/MCO. Anecdotally, many patients either had never heard of the LME/MCO, were reluctant to work with them, or were unable to navigate the process to enroll onto the waitlist for services. Patients who qualify for, but are not yet receiving services, may have very few resources for system navigation and rarely qualify for care management; however, the state is in the process of a Medicaid transformation that is expected to improve access through adding multiple services (eg, care coordination) to tailored plans for patients with IDD 2024.

Limitations

This study has limitations worth consideration. First, this is a cross-sectional study in that each patient was seen only once and therefore we were unable to examine patient outcomes associated with the model, such as how many referrals resulted in patient visits. Future studies will be needed to ascertain the degree to which the additional care provided in this model improves patient health. Second, the use of registry data carries certain limitations. There were unanticipated referrals that were not included in the data set, including genetic and imaging specialists, which were coded as “other medical clinicians.” Future studies should examine the impact of this consultation model using different data sources, such as electronic health records or insurance claims. Finally, some of our measures include the potential for bias. In particular, travel time estimates and rurality may have measurement error. Some patients only provided a P.O. Box for their address, and travel estimates for those patients were routed from the centroid of their zip code. Similarly, rurality was defined by zip code, but this measure of rurality may suppress within-zip code heterogeneity that exists in this region. For example, Buncombe and Henderson counties both contain urban centers surrounded by rural areas that are in the same zip code but have disparate experiences of urbanicity.

Conclusions

The IDD consultative care model implemented in our clinic provided care for a diverse patient population from a variety of referral sites with a range of clinical needs. This consultative model was not without challenges, however. Expectations from patients and referring clinicians were sometimes incongruous with services offered, and clinician shortages led to difficulties with both incoming and outgoing referrals. Despite these challenges, the overall goal of providing IDD care was accomplished as demonstrated by the broad reach of these consultative services. In total, our clinic saw patients from 16 counties, with some patients traveling over 100 miles to receive care they would otherwise not have accessed. Clinicians seeking to increase the IDD care within their region should consider adoption of a similar consultative model.

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