

2024 APPAM Fall Research Conference

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**ENHANCING HEALTH OUTCOMES FOR
INDIVIDUALS WITH INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES: EVIDENCE-
BASED PRACTICES AND POLICY
RECOMMENDATIONS FROM THE ASK
RESEARCH PROJECT**

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Abstract

Purpose: This mixed-methods study examined the experiences of families in Florida navigating the support service system for individuals with intellectual and developmental disabilities. Access to appropriate services is crucial for individuals with IDD, yet families often encounter barriers. This research aims to understand these barriers and facilitators, focusing on diverse communities, including Haitian American, Hispanic American, and African/Black American populations.

Methods: The study employed a cross-sectional qualitative design, using structured interviews and small group listening sessions with family members and caregivers of individuals with IDD. Additionally, a quantitative survey was incorporated to provide an alternative option for individuals to participate. In-person listening sessions were held at community events and forums, while virtual interviews were conducted via Zoom for individual convenience. Data were manually recorded during sessions conducted in English, per participant preference.

Data & Main Results: Both quantitative and qualitative data analysis techniques identified key themes related to accessing IDD support services. Challenges emerged regarding information and navigation, with families relying on informal networks due to a lack of centralized information. Geographic disparities in service availability were significant, particularly in rural areas. Cultural and linguistic barriers affected families from diverse backgrounds, highlighting the need for culturally competent services. Transitions between service settings and long-term planning also presented difficulties.

These findings underscore the complexities families face accessing IDD support services and inform strategies for improved service delivery, addressing cultural competency, and promoting positive outcomes for individuals with IDD and their families.

Keywords: intellectual and developmental disabilities, support services, family experiences, Florida, access

1. Introduction

Supporting individuals with intellectual and developmental disabilities and their families requires a comprehensive understanding of their needs and the effectiveness of available services. Access to appropriate services is crucial for promoting independence, well-being, and community inclusion for individuals with IDD. However, families often encounter challenges navigating the complex service system, including fragmented information sources, geographic disparities in service availability, and difficulties during critical transition periods.

This study examined the experiences of families in Florida as they seek and utilize support services for their loved ones with IDD. The research focuses on understanding the barriers and facilitators families encounter when accessing services, with a particular emphasis on reaching diverse communities, including Haitian American, Hispanic American, and African/Black American populations. Existing research highlights the importance of culturally competent service delivery and the need to address disparities in access based on race, ethnicity, and language (e.g., National Council on Disability, 2011). Studies have also documented the challenges families face in navigating the IDD service system, including lack of information, complex eligibility criteria, and long waiting lists (e.g., Braddock et al., 2005). This study builds upon existing research by examining the specific experiences of diverse families in Florida and identifying strategies to improve service access and delivery. The findings have important implications for policymakers, service providers, and advocates working to create a more equitable and effective system of support for individuals with IDD and their families.

2. Methods

This study employed both a cross-sectional qualitative and quantitative design to explore the experiences of families and caregivers of individuals with intellectual and developmental disabilities in Florida. The research focused on understanding the pathways families use to access support services and the challenges and facilitators they encounter.

2.1 Participants

There were 706 respondents over the first two years of the project (2022-2024). Participation included completing an online survey, virtual interview, or in-person listening session.

The study included diverse family members and caregivers of individuals with IDD, with a focus on expanding participation from Haitian American, Hispanic American, and African/Black American communities, as well as other marginalized groups, as shown in Table 1.

Table 1: Participant Ethnicity

White	Black (incl. Haitian, African American)	Hispanic or Latino	Mixed Race	Asian or Asian American	Native Hawaiian or Pacific Islander	American Indian or Alaska Native	Unknown
448 (63%)	97 (14%)	98 (14%)	11 (2%)	22 (3%)	3 (0%)	6 (1%)	21 (3%)

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Using the existing 15 Family Care Council areas, the population was consolidated and aggregated by the geographic areas shown in Table 2.

Table 2: Breakdown of Participant Demographics by Family Care Council Areas

FCC Area	Counties	Respondents
Area 1	Escambia, Santa Rosa, Okaloosa, and Walton counties	23 (3%)
Area 2	Bay, Jackson, Calhoun, Jefferson, Franklin, Leon, Gadsden, Liberty, Gulf, Holmes, Washington, and Wakulla counties	34 (5%)
Area 3	Madison, Taylor, Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, and Union counties	44 (6%)
Area 4	Baker, Duval, Nassau, and St. John counties	59 (8%)
Suncoast West	Pasco and Pinellas counties	48 (7%)
Suncoast East	DeSoto, Hillsborough, Manatee, and Sarasota counties	13 (2%)
Area 7	Brevard, Seminole, Orange, and Osceola counties	15 (2%)
Area 8	Charlotte, Collier, Glades, Hendry, and Lee counties	42 (6%)
Area 9	Palm Beach County	37 (5%)
Area 10	Broward County	61 (9%)
Area 11	Dade and Monroe counties	81 (11%)
Area 12	Flagler and Volusia counties	28 (4%)
Area 13	Citrus, Hernando, Lake, Marion, and Sumter counties	36 (5%)
Area 14	Hardee, Highlands, and Polk counties	36 (5%)
Area 15	Indian River, Martin, Okeechobee, and St. Lucie counties	20 (3%)

Participants primarily identified as female, a parent, and were aged between 26-51. Most respondents reported that the primary diagnoses of their loved with an IDD was autism, ADHD, a sensory disorder, or a combination thereof. Additionally, data showed that the ages of the persons with IDD that were discussed were under 25.

2.2 Data Collection

Data were collected through structured interviews, small group listening sessions, and an online survey. Small group listening sessions were conducted in person at community events or local leadership group public forums, with a maximum of three participants per session. Structured interviews were conducted virtually via Zoom to accommodate individual availability. Both interviews and listening sessions were conducted in English, based on participant preference. Data were manually recorded by the interviewer/moderator during the sessions. The online survey was offered in English, Kreyol, Spanish, and French.

2.3 Data Analysis

Qualitative data analysis techniques were used to identify key themes and patterns related to accessing IDD support services. This involved a systematic process of coding and categorizing data to develop a comprehensive understanding of family experiences through thematic analysis.

3. Results

This section presents the key findings from the qualitative data analysis regarding families' experiences accessing IDD support services in Florida. The results are organized around key themes that emerged from the interviews and listening sessions.

3.1 Information and Navigation

Families described encountering challenges in finding and navigating information about available services. Many relied on informal networks, such as friends and family, for information, highlighting the lack of a centralized and easily accessible information source. Several participants expressed frustration with the complexity of the service system and the difficulty in understanding eligibility criteria.

3.2 Service Access and Availability

Geographic disparities in service availability emerged as a significant concern. Families in rural areas reported limited access to certain services, requiring them to travel long distances to receive support. Long waiting lists for services were also frequently mentioned, creating significant delays in accessing needed supports.

3.3 Cultural and Linguistic Barriers

Families from diverse cultural and linguistic backgrounds reported encountering barriers related to language access and cultural understanding. Some participants expressed a need for service providers who could communicate effectively in their preferred language and who understood their cultural values and practices.

3.4 Transitions and Long-Term Planning

Families highlighted the challenges they faced during transition periods, particularly the transition from school to adult services. Many expressed concerns about the lack of support during this transition and the difficulty in navigating the adult service system. Long-term care planning also emerged as a significant concern, with families expressing a need for more information and guidance on planning for the future.

4. Discussion

This study's findings offer valuable insights into the challenges and facilitators families experience when accessing IDD support services in Florida. The identified themes of information and navigation difficulties, service access and availability disparities, cultural and linguistic barriers, and concerns about transitions and long-term planning align with existing research highlighting the complexities of navigating the IDD service system (Philip, 2024).

The reliance on informal networks for information underscores the need for a centralized, user-friendly, and culturally competent information hub. Developing such a resource could empower families with the knowledge and tools to effectively navigate the service system and access appropriate supports (Hewitt et al., 2013). Furthermore, addressing the geographic disparities in service availability requires strategic investment in underserved areas and exploring innovative service delivery models, such as telehealth, to reach families in remote locations (Lamptey, 2021).

The findings related to cultural and linguistic barriers emphasize the importance of culturally competent service delivery. Training service providers on cultural awareness and providing language access services can improve the quality and effectiveness of support for diverse families (Williams et al., 2013). Additionally, engaging families from diverse backgrounds in the design and implementation of services can ensure that services are responsive to their unique needs and preferences (Lumsden & Black, 2020).

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The challenges families face during transitions, particularly from school to adult services, highlight the need for improved transition planning and support. Developing comprehensive transition plans that address individual needs and preferences, and providing ongoing support during the transition process, can facilitate a smoother and more successful transition to adult life (Young et al., 2017). Similarly, addressing families' concerns about long-term care planning requires providing accessible information and resources on guardianship, supported decision-making, and future planning options (Lindahl et al., 2019).

These findings have important implications for policy and practice. Investing in a centralized information hub, addressing service access disparities, promoting culturally competent service delivery, and enhancing transition planning and long-term care supports are crucial steps towards creating a more equitable and effective system of care for individuals with IDD and their families. Future research should explore the effectiveness of specific interventions aimed at addressing these challenges and improving service delivery.

5. Conclusions

This study provides valuable insights into the experiences of families navigating the IDD support service system in Florida. The findings highlight the ongoing challenges families face in accessing information, navigating complex eligibility criteria, and securing timely and appropriate services. The study underscores the need for a more user-friendly, culturally competent, and geographically equitable service system. Key recommendations stemming from this research include:

- Developing a centralized and accessible information hub for families seeking IDD support services.
- Addressing geographic disparities in service availability through strategic investment and innovative service delivery models.
- Promoting culturally and linguistically competent service provision to meet the diverse needs of families.
- Enhancing transition planning and support, particularly during the transition from school to adult services.
- Providing families with accessible information and resources on long-term care planning options.

By addressing these key areas, policymakers and service providers can create a more supportive and effective system of care that empowers individuals with IDD and their families to thrive. This research contributes to a growing body of literature highlighting the importance of family-centered care and the need for ongoing efforts to improve the accessibility and quality of IDD support services. Further research should explore the long-term impacts of these recommendations and investigate the effectiveness of specific interventions aimed at addressing the identified challenges.

6. Abbreviations

IDD – Intellectual and Developmental Disabilities

FCC – Family Care Council

ADHD – Attention Deficit Hyperactivity Disorder

7. Competing interests

The authors declare no financial or non-financial competing interests related to the research presented in this manuscript.

8. Ethics approval and consent to participate

This study was conducted with the approval of the Biomedical Research Alliance of New York Institutional Review Board (IRB# 232396, Protocol# 24-079-1131). Informed consent to participate in interviews and listening sessions was obtained from all participants prior to data collection.

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