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Access to Services Through Knowledge (ASK) Research Project Final Research Study Findings Report

An investigation into how families and caregivers of persons with intellectual and developmental disabilities find, prioritize, and utilize care and service options within Florida

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Part I: Introduction

In 2022, the National Association for the Dually Diagnosed (NADD) was contracted by the Florida Developmental Disabilities Council (FDDC) to conduct an Access to Services through Knowledge (ASK) State of Florida Research Project designed to identify key information, services, and community resources for persons with intellectual and developmental disabilities (I/DD) to be utilized throughout their lifespan. Specifically, this project investigated families' perspectives on identifying I/DD community resources used by them. To achieve this, the NADD Research Team completed a study aimed at identifying resources used by family members and caregivers of persons with I/DD, including the ways they identify and share information, assist each other with information, refer people to useful resources, and utilize existing web-based platforms.

Florida has dozens of private and public organizations and governmental agencies that provide resources, services, and support for persons with I/DD and their families. In July 2022, the state's Agency for Persons with Disabilities (APD) allocated nearly \$2 billion in funding to be directed toward strengthening the I/DD service system, an increase from \$1.29 billion in 2021. The most common long-term support services and resources families and persons with I/DD seek include legal support, medical and dental provider care, education, employment support, insurance, and Medicaid program coverages.

Even with the increase in state funding allocated for I/DD services, more information is needed on how families of persons with I/DD access, utilize, and educate themselves about the support services available to them, and the effectiveness of those services. Furthermore, it is important to learn how local communities engage and share information to better expand access to services. This information may be used to refine or develop tools to support or improve interventions that target this community (Heller & Factor, 2008). Families/caregivers of children with I/DD face multiple psychosocial, environmental, and economic risks, including stress, anxiety, loneliness, health risks, increased poverty, lack of awareness, and more (Coulman et al., 2022b; Heller & Factor, 2008; Milberger et al., 2022). There is an overarching need to identify holistic approaches that account for unique family perspectives, values, and cultures as they relate to caregiving. Assessments of the needs of individuals with I/DD—and the needs of the family unit as a whole—pave a better path forward to mitigating some of the stressors inherent in caregiving roles. To improve or enhance existing services, knowledge, and access to resources for caregivers of individuals with I/DD in the state of Florida, the FDDC partnered with the NADD to conduct the following mixed-methods research study over a 12-month period.

Part II: Research Design and Methodology

Design and Rationale

The NADD Research Team conducted an extensive statewide (Florida) review of existing research, programs, and policies within state, institutional, and organizational agencies to determine existing pathways that are widely utilized by various family and

caregiver groups of persons with I/DD. The goal of this evaluation was to develop direct and impactful survey and interview questionnaires that could allow participants to share their stories and lived experiences in looking for, accessing, and utilizing I/DD support and services in Florida. This information, coupled with the completed literature review, provides a comprehensive look at ways in which future care and support options may be improved to better serve the I/DD populations across Florida.

Methodology

The NADD Research Team utilized a mixed-methods design (i.e., qualitative, and quantitative) to collect information from family members of persons with I/DD within Florida and nationwide. This population was selected to identify pathways individuals with I/DD and their caregivers use to research, obtain, and utilize specialized support services across their lifespan. The research tools included two phases: (1) an online survey of family members on their experiences, followed by (2) in-person and virtual structured interviews with respondents who indicated an interest in providing more information. Additionally, members of the NADD Research Team attended the FDDC's annual *Developmental Disabilities Awareness Day* in Tallahassee in Spring 2023 where they spoke to family members of the Partners in Policymaking group about their experiences finding, sharing, and utilizing I/DD resources within their community. This town hall-style session was informal and provided an opportunity to further expand the content collected as part of the project.

This study sought to answer some fundamental questions regarding knowledge of existing resources, how they are accessed, and their availability (including filling the gap(s) that exists between differing counties and agencies). These questions included:

- What types of resources do family members of persons with I/DD currently utilize?
- How do families of persons with I/DD learn about and access available resources within their local community (i.e., where do they go to find services)?
- How do families of persons with I/DD support each other in locating and sharing information about available support services or other resources (locally or statewide)?
- In what ways do cultural perspectives (including spiritual practices and language) influence a person's understanding of available I/DD resources available to them?

Based on these questions, the NADD Research team used purposive sampling within the survey and interviews to determine the perceptions of families of persons with I/DD relative to the availability, accessibility, and efficacy of supports and services to assess what programs and resources are used most often, and which of these services they feel provide the best opportunities for lifelong care. The data from the interviews

and survey also provided information about perceived barriers and potential improvements needed to mitigate these barriers.

The respondents from the targeted survey and interviews represented diverse geographic, economic, social, cultural, and educational backgrounds. The information gathered from their participation has been synthesized, in conjunction with the expansive literature review, and provided as a holistic view of what is currently utilized and accessible in Florida, as well as what additional opportunities for success may be incorporated based on similar studies conducted elsewhere in the United States. The intent of the research synthesis was to make the findings from multiple different studies and reports more generalizable and applicable. The aim of the research synthesis was to generate new knowledge by combining and comparing the results of multiple sources on the topic of resource availability, accessibility, and efficacy for persons with I/DD who live in Florida across their lifespan.

Participant Recruitment and Selection Logic

Participants of the study were required to electronically sign a consent form to participate, confirming their eligibility to participate by meeting specific requirements: (1) Must be 18 years of age or older; (2) Must be a family member (sibling, parent, child, grandparent, spouse), caregiver, legal guardian, and/or conservator for a person with I/DD; (3) Must live in Florida; (4) Must speak and understand English, Spanish, Kreyol, or Kreyol French; and (5) Must have used or are planning to use I/DD resources or support services (pre-enrolled persons were permitted to participate).

Based on the population size of I/DD persons currently living in Florida—approximately 430,000—the NADD Research Team sought to garner approximately 400 responses from the online survey and approximately 20 structured interviews. These interviews were completed via the Zoom audio/video platform and in person, depending on the participant's preference. The total number of project participants was 507, inclusive of the survey and interviews.

To ensure diversity among its participants, the NADD Research Team continuously evaluated and revised the deployment strategies for sharing the survey and interview invitations based on the respondents' demographic data and to accommodate the needs of individual respondents. More specifically, if there was insufficient participation from certain regions, age ranges, or genders (for example), then the NADD Research Team conducted targeted outreach to access these populations directly.

The survey and interviews were provided in English, Spanish, Kreyol, and French, and the NADD Research Team incorporated bilingual and non-native family members, guardians, and caregivers to participate in a setting of their choice. Professional, native-speaking interpreters and translators were utilized to ensure linguistic competency and accuracy. It was imperative that traditionally underserved populations were included in this study to gather information about barriers they perceived or resources they felt were most useful to guarantee that the support services and

engagement that families of persons with I/DD utilize are useful to their individual circumstances. Including this cultural component provided important information on preferred communication and knowledge pathways that may help to better align and inform I/DD communities in the future, inclusive of linguistic and cultural affiliation.

The NADD Research Team utilized targeted social media, NADD membership and networks, email distribution lists developed by the FDDC and Project Steering Committee, and additional outreach to recruit families of persons with I/DD throughout Florida. Additional marketing designed to elicit participation from family members, caregivers, legal guardians, and conservators was directed toward the various statewide agencies and organizations within Florida that provide services, resources, and engagement to the I/DD communities. These included (but were not limited to) the Agency for Persons with Disabilities (APD), Department of Children and Families, ABLE United, Department of Education, Florida Vocational Rehabilitation, FDDC, Department of Elder Affairs, Department of Health, Florida Health Start Coalition of SW Florida, Agency for Health Care Administration, Disability Rights Florida, Family Care Councils and the Center for Autism and Related Disabilities.

Part III: Background & Literature Review

Call for Holistic Model of Interventions

Individuals with I/DD are primarily identified via assessments of impairments in cognitive, social, and/or adaptive behavior before age 18. Recent prevalence estimates indicate that 8.56% of children in the United States have a diagnosis of I/DD (Zablotsky et al., 2023). Less is known about the prevalence of I/DD in adults, including their health status, with the most recent estimates completed almost 30 years ago in the National Health Interview Survey on Disability of 1994-1995 (Haverkamp et al., 2019; Krahn et al., 2023; Ward et al., 2015). A 2019 review by Anderson et al. further underscored the need for improved surveillance of support needs, service utilization patterns, and other health-related outcomes for adults with I/DD. Research indicates individuals with dual diagnoses—who have coexisting mental health issues—require more support than individuals without diagnosed disabilities. Many families of individuals with I/DD face lifelong challenges with accessing help and struggle to access services due to various family and community constraints (Weiss & Lunsky, 2010; Werner et al., 2019). Identifying individuals and surveying their needs for comprehensive medical and mental healthcare is a critical step toward improving the well-being of families and their loved ones of all ages with I/DD.

Family and community factors influence the likelihood of accessing needed services, including general medical, mental health, and crisis intervention care (Adams & Young, 2021). At the family level, concerns such as perceived stigma about having a loved one with a disability, risks of encountering cultural and racial disparities, and uncertainty about how to access needed services may hamper attempts at outreach. Community barriers include such issues as uncertainty or mistrust regarding the quality of care, and adequate training of service providers to ensure effective treatment for the unique

needs of individuals with dual diagnoses. Identifying best practices and determining existing gaps in resources are essential to improve the quality of life for individuals.

Evidence from surveys of families suggests interventions for caregivers of individuals with I/DD are inconsistent and disjointed. Many families express feeling ill-equipped or unable to manage the comprehensive care requirements for an individual with an I/DD diagnosis without additional support (United States Department of Health and Human Services, 2021). A recent review of family perceptions of care underscores the need for respect for people with I/DD and their families as visible and valued members of society. Holistic approaches to care should include physical, emotional, and mental health for the family unit (Krahn et al., 2023). Other factors include general and individualized approaches to care that incorporate culture and diversity.

Compounding the complex web of services is that the United States' disability policy tends to focus on individuals rather than the collective family/caregiver unit (Heller & Factor, 2008). The emphasis on home- and community-based placements for individuals diagnosed with IDD leads to increased reliance on families for care coordination and delivery; therefore, it is important to provide much-needed support to assist them with these roles. The call for a collaborative approach to caring for those with I/DD requires partnerships with caregivers, paid providers, policymakers, and the individuals themselves in their communities (Moore & Kates, 2022; Dreyfus & Dowse, 2018; Rieck et al., 2019). Gaining a better understanding of families' needs and barriers to accessing supports is a critically important step toward promoting their health and well-being.

Williamson and Perkins (2014) posit that a holistic perspective is needed to design caregiver resources, programs, and policies consistent with the ecological framework of caregiving that advocates for services aimed at supporting the complex family unit using a tailored approach. Results from a study that explored the concept of natural supports (e.g., the family unit) for those with I/DD found that individuals with I/DD who have natural supports experience better quality of life and lower service expenditures compared to those without natural supports (Friedman, 2021).

Natural supports refer to social and community connections that promote the integration of services, meaningful opportunities, relationships, and emotional well-being. Interventions and resources are needed to address parental or family well-being and practices that support the development of children with I/DD. Promoting natural supports and interdependence aligns with the ecological model for increasing information-sharing and providing resources to caregivers of individuals with I/DD. The goal is to improve awareness of and access to services beyond those provided by paid providers, in the spirit of community. Caregivers and other family members alike (e.g., siblings of individuals with I/DD) stand to benefit from expanded access to information, resources, and education to navigate systems effectively (Burke et al., 2018). To better meet the complex needs involved in caring for those with I/DD, a focus should be on ways to streamline access to services, provide knowledge about

available resources, connectedness, and empowerment to effect meaningful system change (Burke et al., 2018; Friedman, 2021; Tibbetts, 2015; Williamson & Perkins, 2014).

Access to Services, Information, and Programs

Adopting the lens of families as both consumers and providers is necessary to increase access to services, information, and programs. While further research is needed to understand the various access issues of demography, there is a need to recognize the challenges families or caregivers of individuals with I/DD face in accessing services, particularly during transitional stages of life (Milberger et al., 2022).

Parents encounter difficulties accessing community and family supports, navigating hierarchical systems, and finding care modalities that address the medical and behavioral aspects of neurodevelopmental disorders (NDD) (Currie & Szabo, 2020). Dreyfus and Dowse (2018) investigated the experience of parents who have a family member with I/DD and found that, often, they face significant demands in navigating systems to secure resources for their family's social care. Time and effort burdens, power differentials, and lack of emotional energy often impede access to quality services for their family member with I/DD. Positive characteristics associated with access to services include communication, support systems, collaboration, education, and luck. Conversely, lack of information, limited support and validation from professionals, and issues related to waitlists and logistics impeded access and led to negative experiences for caregivers of individuals with I/DD according to Tibbetts (2015).

Factors Underlying Access of Caregivers of Individuals with I/DD to Services and Information

Cultural Competency

The beliefs and understandings about disabilities within a particular culture influence how families access support for a child with I/DD. Cultural factors, such as religious or spiritual beliefs, can affect a family's acceptance of a diagnosis like autism spectrum disorder (ASD). For example, some Muslim families may believe that having a child with ASD is a sign of worthiness, while some Asian families may perceive diagnoses of an intellectual or developmental disability as a stigma (Jegatheeson et al., 2010). Resources to balance access and information should include a focus on cultural competence and services that are sensitive to cultural needs and beliefs (Tibbetts, 2015).

In addition, it is important to assess service effectiveness based on engagement from and participation of caregivers of individuals with I/DD. Steward et al. (2023) reports on the importance of access to services in the language spoken in the family home, and delivery of culturally competent services as prominent themes when breaking down barriers to services for new Americans who access healthcare. Racial, ethnic, and immigration-related disparities may negatively impact awareness of services,

connections to service delivery, and access to disability-related benefits. There is a need for research to clarify the processes by which families seek services, overcome health disparities, and develop collaborative efforts based on individual backgrounds, disabilities, and cultural sensitivities.

Integrating culturally responsive resources can enhance equitable and inclusive opportunities for individuals with I/DD, especially those from racially and ethnically marginalized backgrounds (Shogren et al., 2021). It is critical to understand that socioeconomic variables, quality education, and personal biases contribute to disproportionality in special education for culturally and linguistically diverse (CLD) students. Lack of essential information, structural inequalities, and interagency coordination further impede a collaborative approach to transition planning and support services that go beyond simply complying with the Individuals with Disabilities Education Act (2004).

Individualized pathways have the potential to set and achieve meaningful goals related to caring for individuals with I/DD and preparing them for adult life (Young, 2022). Another related concept should be the delivery of services that build individual strengths, including knowledge and skills to promote greater independence as well as self-determination to enhance equitable, inclusive opportunities. The integration of the family's values offers opportunities for appropriate assessments and instruction while honoring their culture or background (Shogren et al., 2021).

Assessments of needs should also account for inclusive practices to support individuals who identify as LGBTQ+. For example, there is the need to modify healthcare protocols, forms, training, and policies to address the needs of individuals with I/DD who identify as LGBTQ+. Education and information should include a curriculum on the intersection between LGBTQ+ and I/DD populations. This approach supports the notion of individualized pathways to better navigate information and services to promote well-being and decrease stress (Echezona-Johnson, 2022).

Family Support

A critical factor in caring for individuals with I/DD is the relationship between the caregiver or the family unit and the person with the diagnosis of I/DD. However, ongoing challenges in everyday living (e.g., lack of cognition, lower levels of prosocial behavior, or increased, persistent physical health challenges), impact the quality of the relationships.

There is a need to offer early intervention and continuing resources that bolster parenting practices and parent/caregiver relationships to support parental well-being and increase knowledge about services that address social, health, and educational inequalities (Coulman et al., 2022b). Training modalities must be considered. For instance, while an online training program for parents increased their knowledge about behavioral principles, there were minimal changes in their parenting practices (Terol et al., 2022). Training, whether virtual or in-person, should consider cultural adaptations,

changing family structures, and financial resources (Heller & Factor, 2008; Terol et al., 2022).

The report by Heller and Factor (2008) further advocates for services and resources to support caregivers' social lives and economic situations. There is a need for economic support, mental health resources, and access to support services because the health risks for parents or other caregivers of adults with I/DD have been largely overlooked in research and policy initiatives (Heller & Factor, 2008). Research shows that caregiving for a family member with I/DD can have physical, mental, and economic impacts on caregivers. Caregivers of those with I/DD may benefit from systems navigation training programs and peer mentorship models that can significantly improve caregiver and family well-being, including mental health and economic resources (Milberger et al., 2022).

Mental Health Resources

The relationship with services and supports impacts caregiver mental health (Williamson & Perkins, 2014). Caregivers of people with I/DD are particularly vulnerable to emotional health problems like anxiety, depression, and guilt, as well as physical health issues such as chronic fatigue, sleep deprivation, and physical ailments like back and shoulder pain (Lee et al., 2022).

In their study, Burke et al., (2018) demonstrated that participants expressed a need for more resources related to specific areas such as geographic regions, sibling stress, and mental health. Related are mental health recommendations for specific demographics (e.g., LGBTQ+ individuals), ethnicity, and parental role. For instance, Latina mothers of adults with I/DD have higher depressive symptoms and lower optimism compared to Anglo mothers. Fathers are more pessimistic and less likely to use coping strategies than mothers.

Maternal age at the time of birth and the caregiver's age also affects caregiver burden. Older maternal age and caregivers over 55 years old report experiencing less burden than younger mothers (Echezona-Johnson, 2022; Williamson & Perkins, 2014). Also, the severity of disability and complexity of needs are related to higher caregiver stress and burden (Williamson & Perkins, 2014). Coulman et al. (2022b) affirms that parents of children with I/DD often experience elevated levels of stress, depression, and other mental and physical health problems.

Caregivers with unmet service needs or who require more services experience higher stress according to Williamson and Perkins (2014). The work of Echezona-Johnson (2022) suggests that it is essential to provide support strategies to help them achieve greater well-being. Family support services, such as respite, transportation, and education can be helpful in reducing caregiver stress, allowing them to have a life outside of caregiving, and sustaining their caregiver role (Williamson et al., 2016).

The use of interventions that reduce minority stress and promote positive psychology, such as the PERMA model (Positive Emotion, Engagement, Relationships, Meaning, and

Accomplishment), may be effective (Echezona-Johnson, 2022). In addition, peer mentorship may reduce caregiver stress, burden, and depression, and improve satisfaction with health and overall quality of life. The findings by Milberger et al. (2022) support the need for systems navigation training programs and peer mentorship models to significantly improve caregiver and family well-being. In addition, flexibility in the availability and delivery of family support services is emphasized, as these should align with the individual needs of the caregiver and their loved one with I/DD. Caregivers with larger and more satisfying social relationships tend to report better morale and experience less caregiving stress. Therefore, there is a need for further research to examine social support among caregivers (Lee et al., 2022).

Economic Support

Families of children with I/DD face multiple social and economic risks, including higher rates of poverty (Coulman et al., 2022b; Heller & Factor, 2008). Families of individuals with I/DD incur significant out-of-pocket costs for care. The economic impacts of disability severity, caregiving demands, and minority status need further investigation (Heller & Fuller, 2008).

Caregiver assessments that consider diverse challenges, supports, and resources are required to better understand caregiver needs. While various caregiver assessment tools are available, few have been used specifically for caregivers of adults with I/DD in the United States. Further adversely impacting the financial resources of caregivers with children with I/DD (especially adult children) is a national system that fails to prioritize the caregiver or caregiver unit. The United States Senate Commission on Long-Term Care recommends expanding assessment requirements to include family caregiver needs. Understanding and responding to the needs of family caregivers is a public health issue, and additional funding should be allocated for caregiver resources. A holistic approach is needed in designing caregiver programs and policies, considering the ecological model (Williamson & Perkins, 2014). For instance, while families generally adapt well to having a child with I/DD over time, there are substantial effects on families' economic status, mental health, and social connections, especially for mothers.

Research also must consider trends related to minority families and families living in poverty, which now make up nearly 13% of families in the United States (Heller & Factor, 2008). The work of Lee et al. (2022) emphasizes the significant financial hardships, including needing time off from work and being unemployed or underemployed due to caregiving roles. Therefore, it is essential to continue researching the demography of families with individuals with I/DD to better inform public policies and establish system navigation that accounts for changing family structures, cultural factors, and financial resources (Heller & Factor, 2008). A related need is improved advocacy and networking with other families, engaging policymakers, and decision-makers, and striving for collaboration to obtain necessary supports and services, particularly in the context of Managed Long-Term Services and Supports (MLTSS) (Williamson & Perkins, 2014).

Collaboration

Feelings of social isolation and loneliness are common among caregivers of loved ones with I/DD. Currie and Szabo (2020) describe the complexity of caregiving for a family member with complex health needs, including constant uncertainty and an overwhelming sense of helplessness and grief day-to-day. The experiences of families with a loved one diagnosed with I/DD are often invisible, misunderstood, and stigmatizing. Social isolation and exclusion lead to self-doubt rather than confidence and self-reliance (Currie & Szabo, 2020; Dreyfus & Dowse, 2018). These experiences diminish caregivers' capacity for innovation and peer support. Sharing insights on their needs and improving access to supports leads to improved outcomes for both individuals with disabilities and their families (Dreyfus & Dowse, 2018).

A large percentage of parents of individuals with I/DD express dissatisfaction with the support provided (Jansen et al., 2012). It is important to understand how caregivers of children with disabilities navigate their lives in a world that can be both oppressive and transformative (Rieck et al., 2019). Listening to the voices of people with disabilities and recognizing them as experts who can contribute to improving services, initiatives, and policies is necessary to alleviate burdens and remove barriers that hinder community support.

The concept of family-centered care emphasizes placing the needs of the child at the center of care, in collaboration with the family, the providers, and the community (Jansen et al., 2012). Rieck et al. (2019) shares the story of Linda, the mother of a child diagnosed with a disability, to demonstrate the importance of community support for both the family and the individual with special needs. In the narrative, Linda expresses her desire for a close-knit community where members are interdependent and responsible for each other, particularly vulnerable individuals.

Many parents of children with profound intellectual and multiple disabilities (PIMD) require higher levels of medical and ancillary services. Yet, a majority express dissatisfaction with the support provided (Jansen et al., 2012). Caregivers of individuals with I/DD face daunting challenges in navigating a disjointed system to secure resources for their family member (Dreyfus & Dowse, 2018).

In their qualitative study, Currie and Szabo (2020) mention the difficulty in managing medical appointments, medications, and behavioral outbursts, which can be all-consuming. Partnerships between professionals and parents are key elements of community and collaboration (Jansen et al., 2012; Mulligan et al., 2014). Families highly involved in coordinating services received more services and reported better perceptions of provider competence and family satisfaction (Williamson & Perkins, 2014). Using collaborative care models and care coordinators, Currie and Szabo (2020) suggest that providers should discuss and validate the day-to-day struggles of families with loved ones with I/DD and promote new narratives of parenting that address their complex needs and unique values.

Dreyfus and Dowse (2018) suggests the development of personalized social care services for families of loved ones with I/DD to meet the demands and logistics of caring for them and supporting their efforts to coordinate and advocate for the family member's needs. Advocacy and networking are natural products of community and parent-provider partnerships. Flexibility in the availability and delivery of family support services should align with the individual needs of the caregiver and the loved one with I/DD and include goal-based tools (Mulligan et al., 2014). Williamson et al. (2016) notes that caregivers play a crucial role in advocating for their loved ones by networking with other families, engaging policymakers and decision-makers, and striving to obtain necessary support and services.

Social Networks

Formal and informal support networks establish connections and empower caregivers and other family members of individuals with I/DD. Building inclusive communities and establishing forums to create stronger connections enhance information-sharing, open opportunities for coaching and technical support, and lead to improved knowledge of ways to navigate the system of healthcare and service delivery (Burke et al., 2018). Programs such as sibling leadership programs, ambassador programs, and parental coping strategies can provide the skills needed to empower the caregiver and promote connectedness to others in similar situations (Burke et al., 2018; Friedman, 2021). The concept of interdependence aligns with a focus on informal community support and provides a source of social reinforcement for caregivers (Friedman, 2021; Hall et al., 2022).

Research suggests that building stronger social networks can enhance caregiver resilience and overall quality-of-life outcomes. Jackson et al. (2018) reported that parents express a need for someone to listen and understand without trying to offer advice or solutions. As noted previously, caregivers with larger and more satisfying social relationships tended to have better morale and experience less caregiving stress (Lee et al., 2022). Support groups, for instance, offer the ability for caregivers of individuals with I/DD to laugh together instead of crying (Jackson et al., 2018).

Parents express that networking with other parents in similar situations provides reassurance, relief, empowerment, and encouragement. Some parents suggested that participation in support groups is a way to learn from peers, share strategies, and be proactive in support of their loved one. However, the perceptions of support groups as a valuable resource depend on whether they address the parents' needs, which in some cases depend on their child's disability, support group design, or like-mindedness. While 32% of parents reported that support groups did not meet their needs, most parents (60%) value support groups for providing an opportunity to connect with parents who share similar experiences of having a child with a specific I/DD. In general, 26% of parents reported feeling better or anticipated feeling better after attending a support group. Still another 16% noted that, due to strong family and friend supports, they did not need a support group (Jackson et al., 2018). Whether peers, family, friends, or trusted professionals, support networks contribute to positive experiences with service access and delivery (Tibbetts, 2015).

National Assessment of Existing State-Level Policies and Programs

Both state and federal agencies that support people with I/DD understand the importance of helping families who have a family member with I/DD. Supports include information, resources, and services. Following are initiatives various states, universities, systems, and national groups have developed to support these families.

In 2011, the Johnson Foundation at Wingspread's Family Support Summit in Wisconsin brought together a diverse group of leaders to make recommendations on the types of supports families need, to provide direction and inform guidelines on policies, and to advance a national agenda for supporting families. The result of this meeting is documented in *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities* (Administration on Intellectual and Developmental Disabilities, 2011). The full report is available online:

<https://dzp4370ojv4q1.cloudfront.net/wp-content/uploads/sites/74/2017/05/Wingspread.pdf>

That report launched a wave of new work, ranging from federal funding from the Administration on Community Living to develop a Framework for Supporting Families, to a state-level increase in policy programs and funding of services. In 2021, the University of Missouri—Kansas City (UMKC) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) reconvened a summit to identify accomplishments made since 2011 and to make further recommendations on policies and programs that support families so that their loved ones can live the full community-inclusive lives they envision. The full report on this summit, written by NASDDDS and UMKC is titled *Continuing the Conversation: A National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. The authors also wrote a highlighted summary of the summit which is available online:

<https://supportstofamilies.org/national-agenda/2022-agenda/>.

Important in all these findings is the need for families to find information and resources and for state and advocacy groups to look at how families get information. It is also essential to assess the impact of services on the families and their members. Below are several examples of national and state strategies to assess the impact of supporting families.

National Core Indicators

The National Core Indicators—Intellectual and Developmental Disabilities (NCI-I/DD) is a nationally recognized measurement tool that state offices of I/DD services use to measure and improve the performance of state-funded services. The NCI-I/DD uses a suite of tools ranging from in-person surveys of people receiving services to written and online surveys of families of people receiving I/DD services. All but two states in the United States use NCI surveys, and their regular participation has contributed to a robust national dataset. The survey results are compiled for each state and can also be compared to the national data. Over time, NCI provides states with a quality metric tool to understand the impact of public policy and set qualitative outcome

benchmarks. NCI-I/DD is co-managed with the Human Services Research Institute (HSRI) and the NASDDDS.

There are three NCI-I/DD Family Surveys: (1) the Adult Family Survey, (2) the Family/Guardian Survey, and (3) the Child Family Survey.

- The Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management.
- The Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does *not* live in the family home and receives at least one service other than case management.
- The Child Family Survey is administered to families who have a child with an intellectual or developmental disability who lives in the family home and receives at least one service in addition to case management from the state I/DD agency. A Child Family Survey could be completed for an individual up to 22 years of age if still receiving “child” services.

Florida participates in the NCI-I/DD and conducted an Adult Family Survey in 2020–2021. The full report can be found on the National Core Indicators website:

<https://ncireports.verityanalytics.org/PublicIntegration/ViewIntegration/NCIReports/AFS/2020-21/FL>.

States that are interested in obtaining more detail or additional information may add state-specific questions to a survey. By adding questions to the existing NCI-I/DD tool, they can avoid creating additional surveys, which can sometimes lead to respondent fatigue. This system also allows the data to be analyzed by the national NCI team. However, because it is state-specific, there are no national data trends.

The State of Washington and the Washington Council on Developmental Disabilities have successfully used the NCI family surveys to look at how families perceive services for their family member with I/DD and determine how the family member is informed of services. By gathering information about these questions annually, the state can monitor how the answers to these questions change over time. In addition to the nationwide survey, Washington State adds additional questions that are pertinent to them. These state-specific questions cannot be normed to a national average, but in asking them every year they are able to look for changes and trends over time. Below are the additional questions that Washington asked in the Adult Family Survey in 2021–2022.

- Is your family member a member of a federally recognized American Indian tribe and/or Native Village?

- Where do you get information about services and supports for your families?
- Have you received information on how to identify and report instances of abuse, neglect, and exploitation?
- Are you satisfied with your family member's service provider(s)?

States wishing to ask additional state-specific questions can work through HSRI. Each state can ask 10 questions at no additional cost to the NCI fee and thereafter is charged \$100 per additional question.

University Centers for Excellence in Developmental Disabilities Education Research (UCEDD)

Since 1963, University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) have been involved in program design, development, and evaluation of systems that promote people with disabilities to participate fully in their communities. At present, there are 67 UCEDDs, with at least one in every state within the United States' territory. Situated in universities, these centers facilitate the distribution of disability-related information between the university and the community.

The core funding of the UCEDDs is administered by the Office of Intellectual and Developmental Disabilities.

Several UCEDDs have focused their efforts on supporting families.

Missouri's UCEDD: The Institute for Human Development at the University of Missouri—Kansas City

One example of a UCEDD focusing on supporting families is the University of Missouri—Kansas City's Institute for Human Development. It offers the LifeCourse Nexus framework, which was created to help individuals and families of all ages and abilities develop a vision for a good life, think about what they need to know and do, identify how to find, or develop supports, and discover what it takes to live the lives they want to live. The framework is designed to be the keystone for supporting a community of learning that champions transformational change through knowledge exchange, capacity building, and collaborative engagement.

LifeCourse Nexus grew out of a 2012 grant to UMKC and NASDDDS from the Federal Administration on Community Living to collaborate with state I/DD systems to build on the work started at Missouri's UCEDD, UMKC Institute for Human Development. During a five-year period, partnerships between state I/DD directors, state Council on Developmental Disabilities directors, and other key state stakeholders worked to create LifeCourse Nexus.

UMKC has since developed a robust learning community. Charting the LifeCourse (a part of LifeCourse Nexus) is a community of learning that brings people together to

work toward transformational change within organizations, systems, and communities to support “good lives for all people.”

The LifeCourse Nexus serves as the central location for the network of people who want to share, learn, and develop strategies for supporting families. The Charting the LifeCourse framework and tools create a common language for shaping and supporting innovation in policy, practice, procedure, and culture.

Many state teams have formed and use this platform to find resources that can help in their own strategic planning. Information on LifeCourse Nexus can be found at <https://www.lifecoursetools.com>.

Oklahoma's UCEDD: The Center for Learning and Leadership

The Center for Learning Leadership (CLL), Oklahoma's UCEDD, is another example of a UCEDD focused on supporting families.

Hosted by the University of Oklahoma Health Sciences Center, the CLL/UCEDD works in partnership to bring the perspectives of people with disabilities, their family members, and the professionals who support them into the planning, implementation, and evaluation of interdisciplinary education programs, community services, research, and dissemination activities. Their commitment to partnerships enables the UCEDD to use the identified issues, ideas, and perspectives of self-advocates, providers, faculty, students, and families as the basis for planning to promote systems change, advocacy, and capacity building in the state.

The Oklahoma UCEDD supports both family and self-advocate leaders through mentoring, stipends, and technical assistance to the Family Leadership Council of Oklahoma and the Oklahoma Self-Advocacy Network. It facilitates meetings of both groups and works in partnership to bring family and self-advocate perspectives into consideration for policies and programs. It replicates a successful family partnership model approach with self-advocates that includes both formal and informal mentoring and training with a goal to increase self-confidence and capacity for individuals to advocate for themselves and others.

Family-to-Family Resource Centers

The Health Resources and Service Administration (HRSA) is an agency of the United States Department of Health and Human Services. Its overall mission is to provide equitable healthcare to the nation's highest-needs communities. One of their programs is the Family-to-Family Health Information Centers. Every state has a grant from this project, but the target group varies by state. Some states have allocated a portion of these resources to develop a Family-to-Family Resource Center.

Missouri Family-to-Family Resource Center (MoF2F)

An example of such a program is the Missouri Family-to-Family Resource Center (MoF2F) run by the University of Missouri—Kansas City UCEDD. They provide three

types of services: information and referral, parent-to-parent, and leadership development opportunities. Center staff also helps locate needed disability-related services and materials on disabilities and disability-related topics.

The MoF2F is family-driven with family members participating in all components and activities of the project. Families and youth serve as volunteers providing peer support and serving in advisory roles, and the MoF2F staff itself consists of family members of people with disabilities.

MoF2F's quarterly family-to-family stakeholder meetings facilitate a strong network of support for Missouri families. Meetings create an information and network exchange among stakeholders and promote the development of products and activities to meet identified unmet needs. Self-advocates and family members volunteer by reviewing products, developing content, serving as peer support mentors, hosting conference exhibits, and serving on advisory boards.

The MoF2F provides information and peer support to over 1,000 people each year, and it has presented its services to over 10,000 attendees at 74 different locations, such as statewide disability conferences, parent groups, meetings, regional centers, and workshops.

Information about the MoF2F project can be found through the following links: <https://mofamilytofamily.org> and <https://ihd.umkc.edu/missouri-family-to-family-resource-center/>.

Family Networks: Peer-to-Peer Support

Believing that peer support is essential to family knowledge and empowerment, several states have funded family peer networks, thereby helping families to be the best advocates for their family member with disabilities. One important aspect of these networks is that they are not eligibility-based, but rather support both families who do and do not use formal disabilities services systems. These networks often act as resource and information platforms and a mechanism to share personal family experiences.

Oregon

One example is the Oregon Consortium of Family Networks (OCFN), which is funded through the state I/DD services through the Council on Developmental Disabilities. Comprised of seven nonprofit organizations across the state led by local family members, the OCFN provides support and resources to families.

OCFN plays several important roles, such as helping families build connections and supporting them to raise children in their family home; building community capacity; and creating natural supports that foster living a whole life while also reducing the need for paid services. Information on the OCFN can be found at: <https://www.ocdd.org/families-supporting-families/>.

Connecticut

Connecticut is another state that invests in families and works to make sure families and other stakeholders know about available resources and services. One way the state does this is through its hosting of annual advocacy forums with the state director of Developmental Disabilities Services. More information on these community forums is available at: <https://portal.ct.gov/DDS/General/DDS-Stakeholder-Updates/2023-DDS-Stakeholder-Updates>.

Connecticut also works with families that may not formally be a part of its state-funded services due to eligibility restrictions but can nonetheless benefit from information and resources to help navigate supports. The State of Connecticut Department of Developmental Services has established a helpline for this purpose. Information about the helpline can be found at: <https://portal.ct.gov/DDS/Family/Family-Individuals-and-Families/DDS-Help-Line>.

Ohio

For these various services and resources to be used, it is important to make sure that the resources are easily accessible and understandable for the intended audience. The State of Ohio's Department of Disabilities website does this well by prominently featuring information for families. The website has a tab entitled "You and Your Family" where families can find important information and resources. Ohio frequently updates the site with videos and other information. The website can be found at: <https://dodd.ohio.gov/your-family>.

Part IV: Summary of Findings

The NADD Research Team collected insights and perspectives from various family members and caregivers of persons with I/DD across Florida. This information was extracted through multiple data collection streams to ensure a representative sample of the population was represented. Sessions included an online survey, informal town hall-style discussions, and virtual and in-person interviews provided in multiple languages.

2023 FDDC Developmental Disabilities Awareness Day

On March 13, 2023, members of the NADD Research Team attended the FDDC's Developmental Disabilities Awareness Day in Tallahassee, Florida. The purpose of this event was to invite stakeholders, family members, and self-advocates within I/DD communities across Florida to participate in legislative sessions to raise important issues. As part of the multiday activities, Jeanne Farr, Dr. Mark Harvey, and Dr. Dosia Paclawskyj hosted an open forum for those interested in sharing their experiences and stories directly with the team.

Many attendees noted that they found participation in the Partners in Policymaking program to be beneficial, especially families seeking more expansive help and support for older youth, young adults, and beyond. Others noted that national organizations

with state or regional chapters in Florida, such as the National Alliance on Mental Illness, the Center for Autism and Related Disabilities, and the Florida Mental Health Advocacy Committee, provided dependable resources for support, which is important, as many persons with I/DD often have co-occurring mental health conditions.

Furthermore, some families indicated economic support provided by the Florida Empowerment Scholarship (which includes options for behavioral therapy), and Hope Street helped them fill unmet financial needs. Hope Street is a religious-based organization located in various cities around Florida that provides Christian faith-based support and services for families in need.

Spiritual communities, social media, word-of-mouth from friends and family, and culturally sensitive supports were also described by families as frequently utilized as the abundance of information on the internet or through local and state searches tended to be overwhelming and not catered to the individual needs of the family or advocate seeking help or guidance. Overall, the consensus was that access to resources was limited and difficult to obtain as children grew, switched schools, and progressed to adulthood. Several participants noted that expanded training opportunities for pediatricians and family members, local public service announcements and direct marketing, and a single-source website that consolidates and organizes resources by need, age, etc. would play a significant role in improving outcomes for persons with I/DD and their families and caregivers.

Online Survey

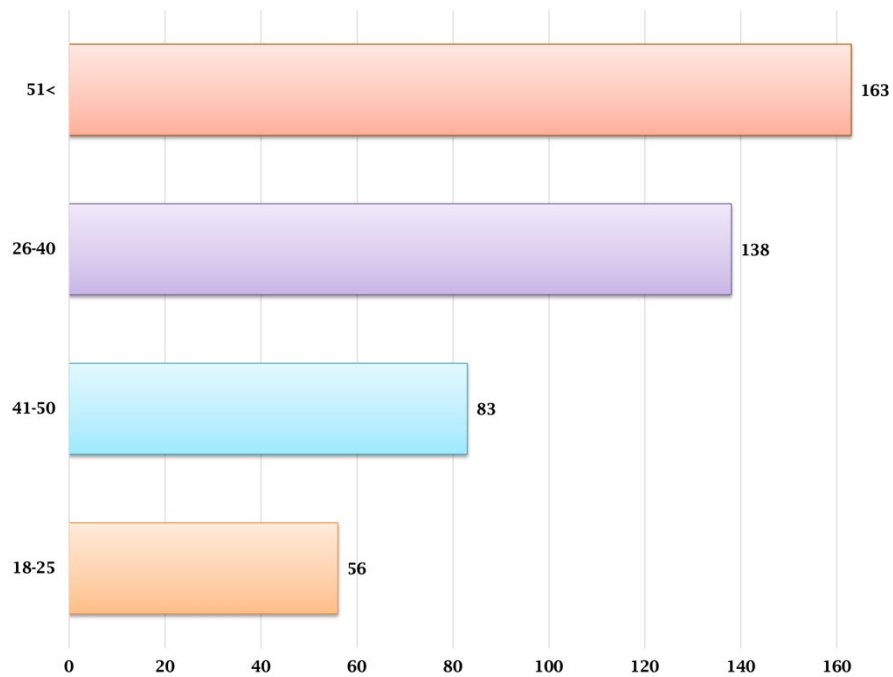
Demographics

There were 1,182 respondents to the online survey, with 464 participants (or 39%) completing it. The survey was active from January 25, 2023, to May 31, 2023. Most of the participants were from Miami-Dade, Broward, Orange, Palm Beach, Duval, Polk, and Hillsborough counties, representing approximately 50% of the population sample. In total, 50 counties were identified out of the 67 within the state.

All participants were required to be at least 18 years of age. As seen in **Figure 1**, most respondents (37%) were 51+, with ages 26-40 (31%), 41-50 (19%), and 18-25 (13%) following in order, respectively.

Figure 1

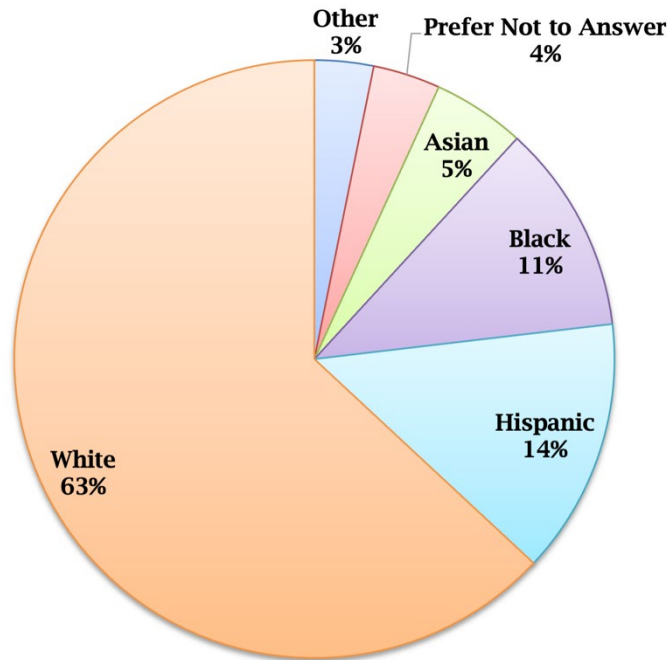
Age Range of Participants by Number of Respondents



Most of the participants identified as either White (278), Hispanic Americans (61), or African/Haitian Americans (50), as shown in **Figure 2**.

Figure 2

Ethnicity of Respondents by % of Participant Population

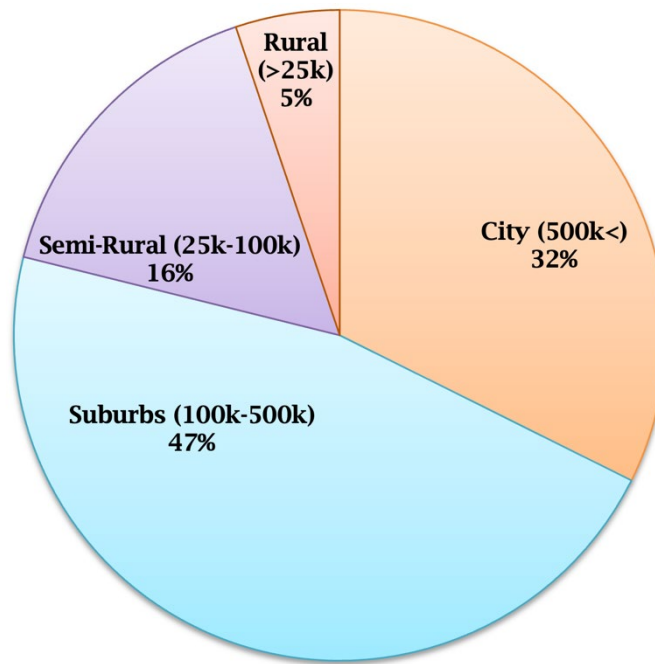


Note. Respondents who selected “Other” consisted of 14 total individuals who identified as Mixed Race (5), Polynesian (4), American Indian (4), Middle Eastern (2), and South American (1).

Many of the respondents (79%) lived in suburban or urban areas (100,000 or more residents), as shown in **Figure 3**.

Figure 3

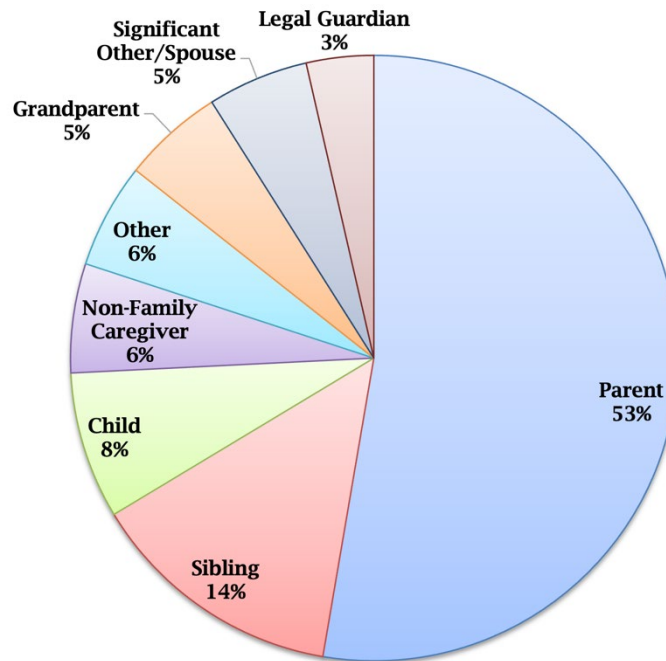
Population Density by Community Type



More than half of the participants (53%) identified as a parent of a person with I/DD, with grandparents, siblings, and children accounting for the rest of the representatives of the immediate family. Spouses, legal guardians, and non-family caregivers made up the remaining composition of respondents. **Figure 4** provides a visual comparison of the affiliations identified by the participants relative to those they cared for with I/DD.

Figure 4

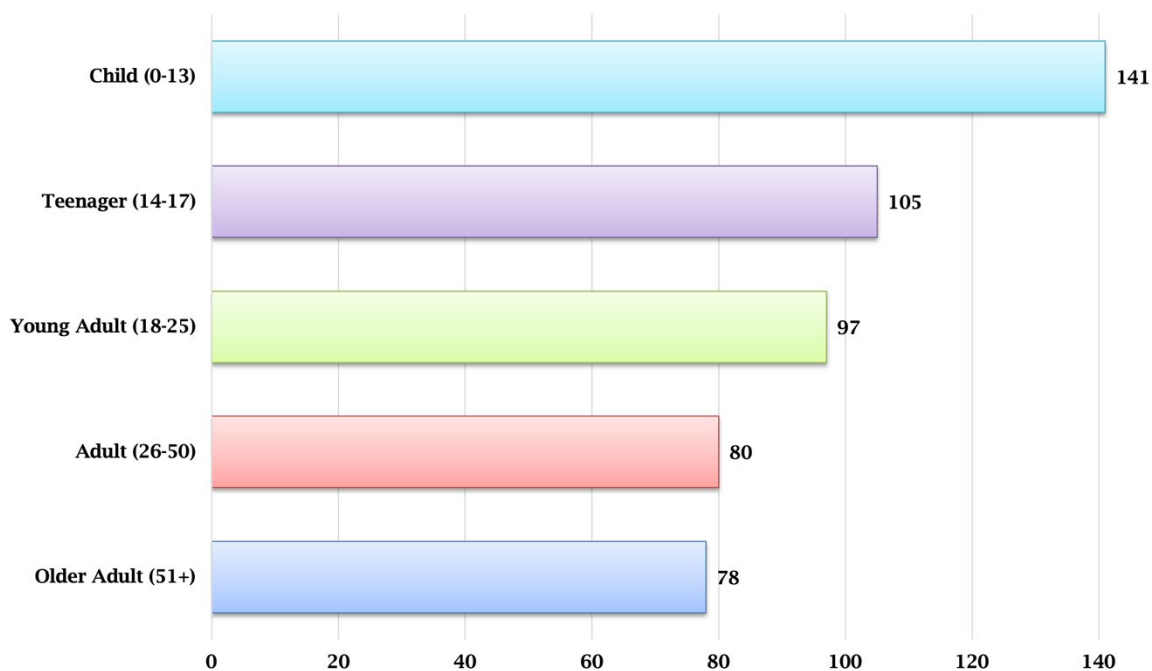
Respondents' Relationship to Person with I/DD



Most respondents noted that they had been responsible for the care of their loved one with I/DD for up to 20 years (roughly 70%) with nearly 30% stating that they had served as a caregiver or guardian for their loved one for more than 20 years. Unsurprisingly, as **Figure 5** shows, these individuals were aged 25 and under (roughly 63%) while an additional 31% were aged between 26 and 50. Roughly 18% of the remaining persons were older (over 51 years of age).

Figure 5

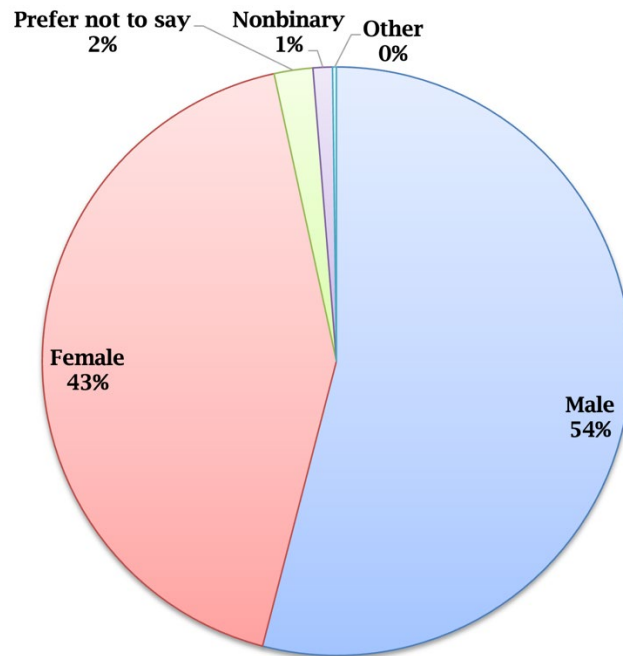
Age Range of Person with I/DD



More than 55% of those cared for were male and nearly 45% were female (**Figure 6**). Very few (less than 2%) of participants did not choose to identify the gender of the person they cared for in their responses.

Figure 6

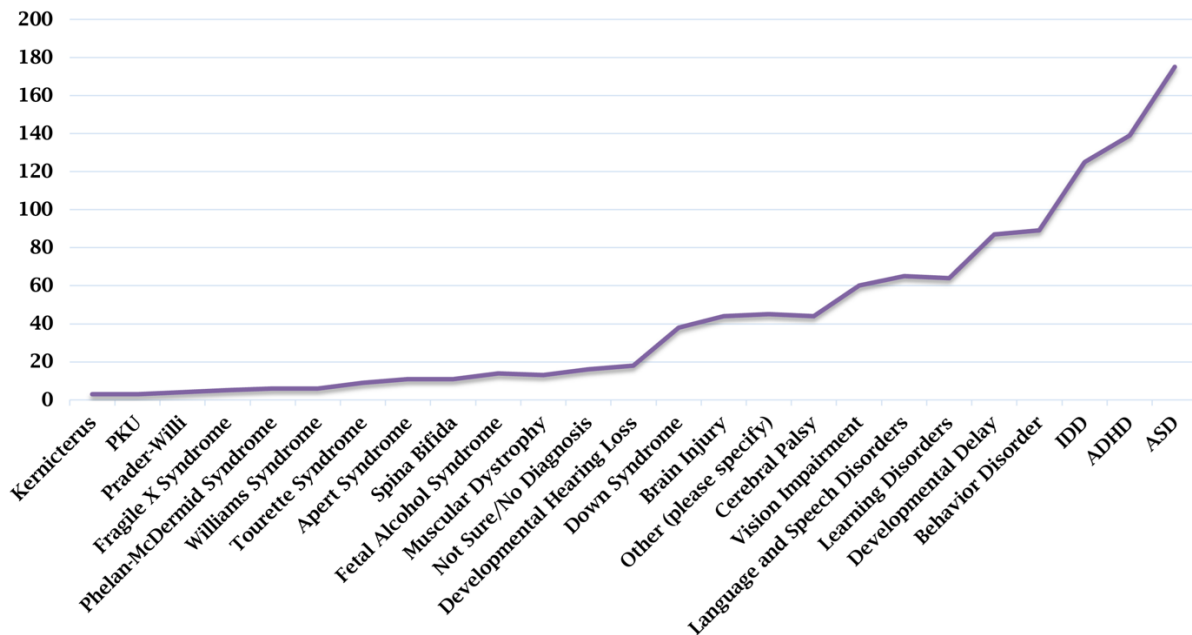
Gender of Person with I/DD



There were 23 specific diagnoses identified by participants, with the most common being ASD (41%), ADHD (34%), I/DD (29%), behavior disorder (21%), development delay (21%), language and speech disorder (16%), learning disorder (15%), vision impairment (13%), and cerebral palsy (11%), as shown in **Figure 7**.

Figure 7

Diagnosis(es) Identified by Number of Participants



Note. Many respondents selected multiple diagnoses suggesting that there are likely multiple conditions that require different facets of treatment, care, and support. Persons who selected “Other” included: dementia, seizure disorder, oppositional defiant disorder, paralysis, Ehlers-Danlos syndrome, genetic mutations, sclerosis, other physical or social impairments, schizophrenia, and bipolar disorder.

Knowledge Pathway

Figure 8 shows how respondents rated their knowledge of current programs or resources available for their loved one with I/DD. Most respondents categorized their knowledge as good, okay, or excellent (51%, collectively). However, 36% stated that they felt their knowledge of what was available to them could be better, with an additional 9% admitting that they knew little to nothing about available I/DD resources and services within their local community.

Figure 8

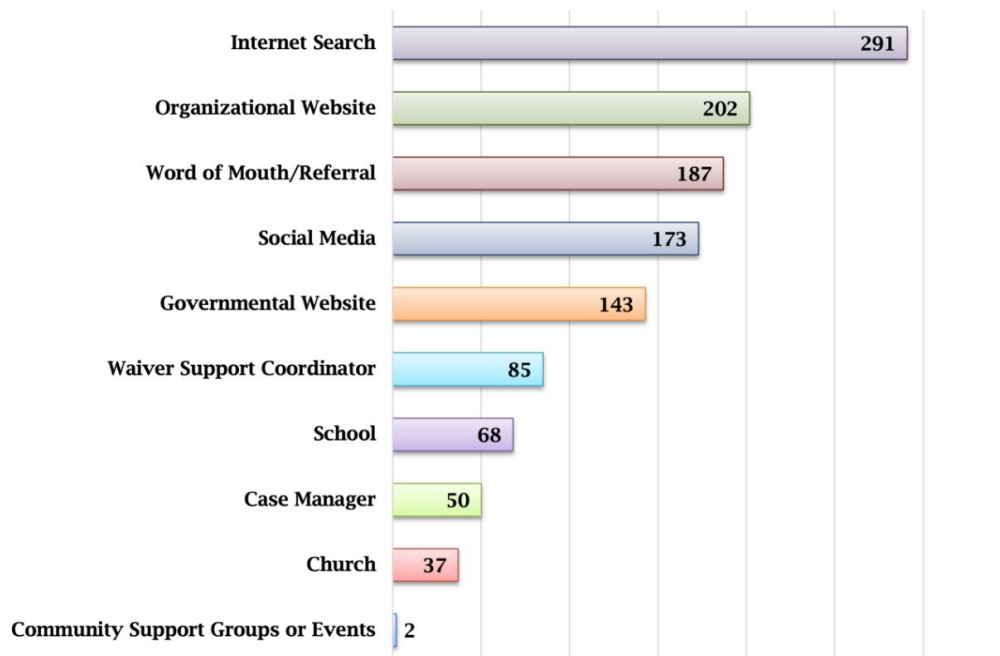
Participants' Confidence in Knowledge of I/DD Support and Services



Nearly 70% of respondents noted that a basic internet search (e.g., Google) was their go-to tool to find information about I/DD services and support options within their community, county, or within Florida. Notably, many respondents (48%) navigated directly to various organizational websites, such as the APD or FDDC, to find the information they needed. Further, social media, word-of-mouth or provider referral, and religious/educational/agency referrals and suggestions were widely used by many of the respondents, as shown in **Figure 9**.

Figure 9

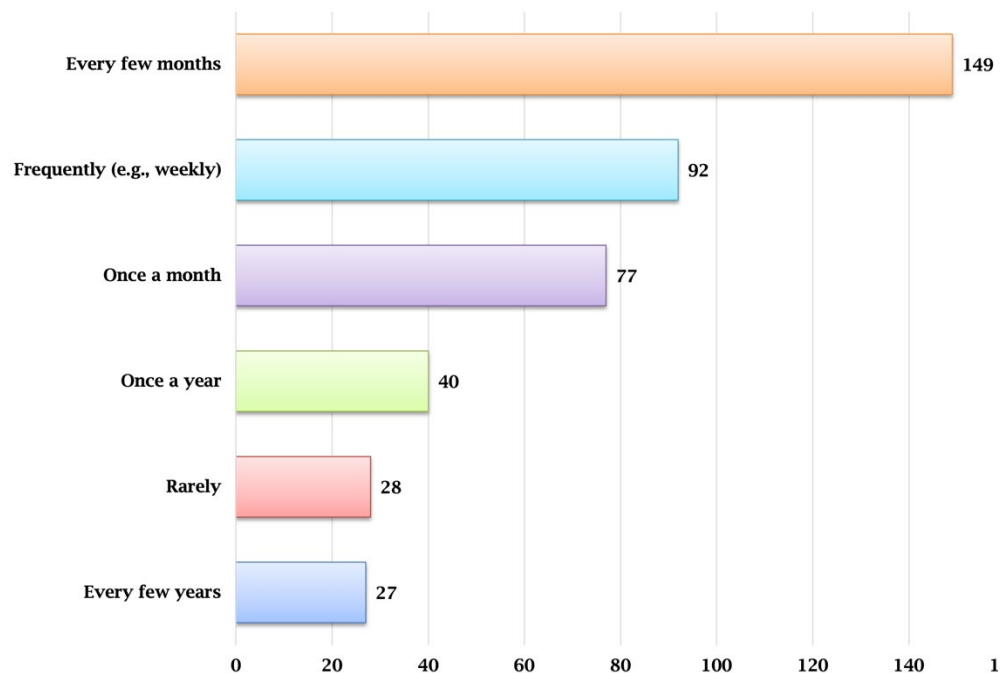
Tools Used to Learn about New or Existing Resources and Supports



Pertaining to how often respondents reviewed or looked for new resources, support, or care options, many respondents stated that they looked as frequently as every week (22%) to every few months (35%) to make sure they were well-informed (**Figure 10**). A few participants admitted they rarely or never looked for new information once they found the care or support that worked best for their situation at the time.

Figure 10

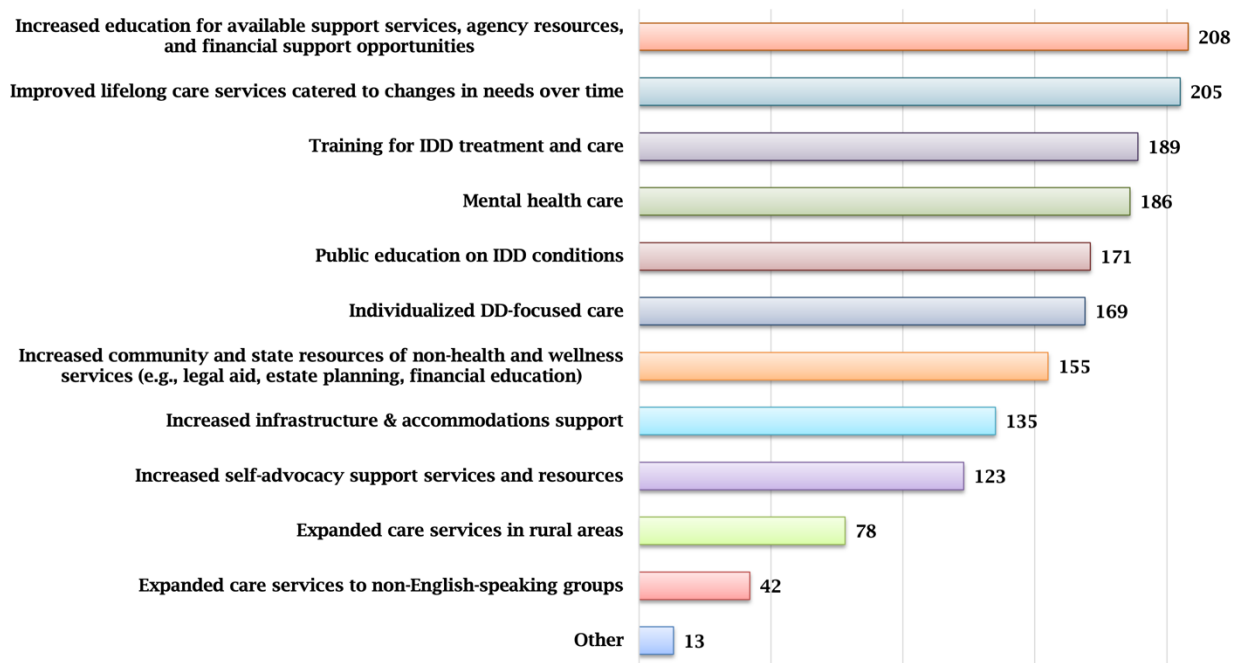
Frequency with Which Resources Are Investigated or Utilized



Respondents were asked to name specific care and support services they felt needed improvement or that should be incorporated into their local community resource options. Of the many options to choose from, 50% stated lifelong care and support were a top priority in need of expanded reach. Additional high-priority items included increased opportunities for education and training for family members (45%), collaborative mental healthcare (45%), and extensive public education on I/DD symptoms in their community. Individualized care, changes in infrastructure opportunities to accommodate I/DD needs and capabilities (including geographic barriers for rural communities), and cultural accommodations for non-English-speaking groups encompassed the remaining opportunities suggested. **Figure 11** shows how each of these categories was prioritized based on the aggregated information provided by the participants.

Figure 11

Additional Tools and Support Required



Note. Categories contained in the “other” selection included reduced or eliminated waitlists, increased access to long-term adult housing and/or group home options, reduced out-of-pocket expenses, and dental care treatment.

The APD, Medicare/Medicaid services, and various state agencies and disability-focused organizations were identified as the most helpful resources for various participants, depending on the disability identified, the age of the person they cared for, and the geographic area where they resided. For example, respondents in more populated areas relied heavily on state agencies, while rural and non-English-speaking communities appeared to prioritize national organizations and nonprofits for support.

Overall, participants noted that, for proper care and improvement in systems for families of persons with I/DD, they needed better information pathways and opportunities for caregivers and family members to get information in a more streamlined way.

Resources and Support Services Utilized

As shown in **Table 1**, over 80% of respondents grouped the resources and services they had adopted, using from five to 10 support or care services at a time. Some participants (approximately 16%) noted that they did not know how many resources they had used, or that they had used none in recent years, although the reason for not using them was not disclosed.

Table 1

% of Respondents Using Resources by Type & Frequency (per Year)

	None	1-2	3-5	6-10	10+
Financial Planning	15%	21%	18%	28%	18%
Health & Wellness	7%	15%	39%	22%	18%
Mental Healthcare	5%	23%	33%	27%	12%
Education	12%	20%	32%	19%	18%
Elder Care/Retirement	12%	16%	40%	14%	18%
Legal Aid	9%	17%	30%	26%	19%
Social Services Skills	8%	18%	38%	18%	18%
Insurance	8%	23%	30%	21%	18%
Community Engagement	5%	22%	32%	11%	30%
Self-Advocacy	14%	14%	31%	17%	24%
Independent Living	9%	22%	25%	13%	31%
Transportation	15%	27%	27%	10%	20%
Sex Education/Gender Identity	-	44%	11%	33%	11%
Benefits	7%	23%	28%	15%	28%

Note. Of those who used resources, most (nearly 67%) commented that they utilized these services or care options at least five times each year. Additionally, most (at least 20% each) of these resources were closely associated with general healthcare, mental healthcare, education, benefits, and social services support for their loved one with I/DD. Resources identified by the respondents as being the easiest to access and utilize centered around general healthcare (31%), education (28%), mental healthcare (22%), and insurance (18%). Notably, resources focusing on sex education or gender identity, self-advocacy, housing/independent living, and community engagement were at the bottom of the list, representing an average of less than 7% of responses, collectively.

Respondents were asked to identify community resources they trusted, and how they shared or found information about trusted supports within their communication network. Most respondents expressed more trust in their own research on the web, organization or government agency information, social media (e.g., Facebook), and word-of-mouth from family or friends. **Table 2** provides a visual representation of services and referral sources identified per the respondents who actively engage in their local community support groups.

Table 2

% of Participants Finding Local Resources by Preferred Sources/Referrals

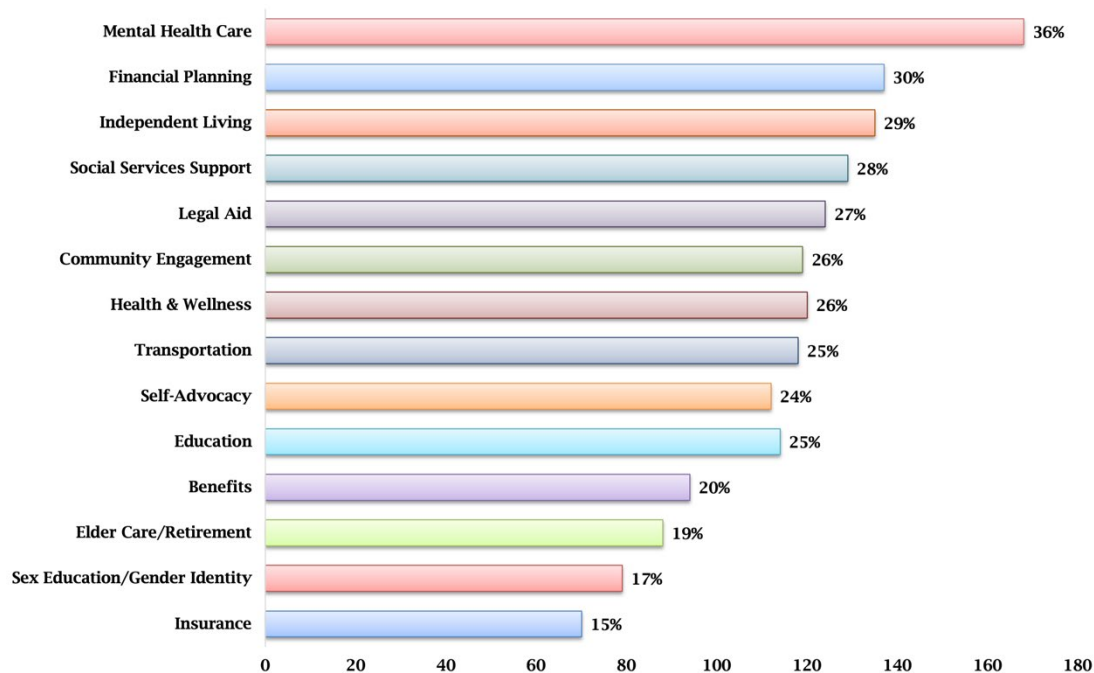
	Web	Org.	Social Media	Gov. Agency	Word-of-Mouth	Church	School	Case Mgr.	Waiver Support
Financial Planning	76%	47%	50%	41%	35%	14%	14%	9%	14%
Health & Wellness	73%	59%	42%	38%	44%	11%	15%	15%	24%
Mental Health	69%	56%	43%	38%	36%	12%	18%	16%	14%
Education	76%	50%	57%	30%	45%	13%	32%	12%	17%
Elder Care	64%	52%	42%	48%	36%	12%	20%	10%	16%
Legal Aid	72%	57%	51%	55%	40%	15%	28%	15%	13%
Social Services Skills	72%	57%	37%	38%	49%	8%	14%	20%	28%
Insurance	81%	65%	47%	36%	53%	16%	26%	19%	23%
Community Engagement	78%	68%	57%	41%	54%	8%	22%	32%	32%
Self-Advocacy	62%	66%	45%	52%	41%	17%	21%	21%	31%
Independent Living	74%	68%	52%	48%	48%	13%	16%	19%	42%
Transportation	78%	57%	34%	31%	50%	12%	16%	19%	22%
Sex Education/Gender Identity	67%	44%	67%	44%	78%	11%	44%	22%	33%
Benefits	82%	49%	43%	36%	55%	3%	12%	9%	25%

Note. The data above symbolizes responses selected for each care and support category and does not account for all participants. Some participants selected multiple categories and some selected only one, therefore the percentages represent a proportion of respondents for each care category selected.

Additionally, prioritization of resources that were more important than others is shown in **Figure 12**, with health and wellness (31%), education (28%), and mental healthcare (22%) accounting for approximately one-third of all high-priority needs for families and caregivers of persons with I/DD.

Figure 12

Services Prioritized Annually by % of Respondents

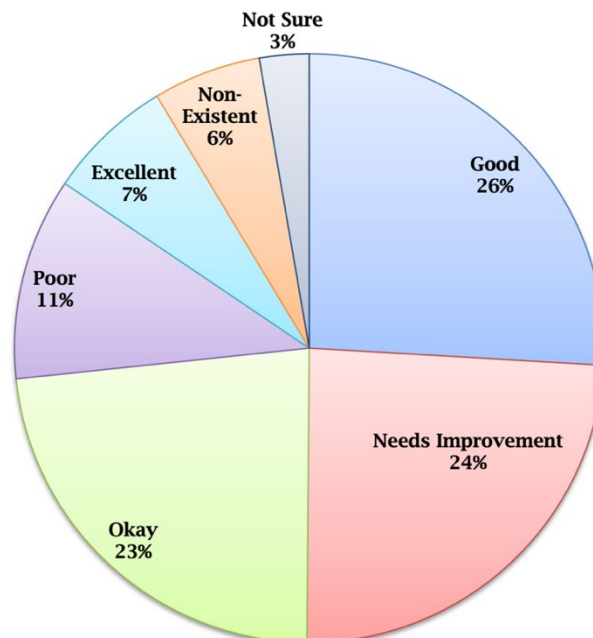


Note. Only 38% of respondents noted they were part of a community-led or family-centric support group. Of these, most respondents (nearly 30%) noted they found groups through social media or family member referrals. Within these groups, the participants stated that they primarily offered resources and referrals specific to general healthcare (15%), mental healthcare (15%), and education (17%). Less than 10% (each) of the remaining topics included: family planning, community engagement, social services support, self-advocacy, elder care, benefits, legal advice, and transportation services.

Although many participants noted that mental healthcare was available within their community, nearly 43% commented that resources for a collective I/DD and co-occurring mental health condition were limited or nonexistent. Support services emphasizing independence and self-care were also listed as missing or limited, alluding to the fact that self-advocacy was not a priority within many of the counties represented by this study. Based on the responses about resource availability, many respondents (roughly 70%) noted that they felt that the care and support options within their local communities were poor, insufficient, or needed improvement. Less than 7% of participants considered their local community resources excellent/sufficient, as shown in **Figure 13**.

Figure 13

Usefulness of Available Local Resources



Community Support and Information Sharing

Understanding how families and caregivers of persons with I/DD get the information they need about new and existing I/DD support options is critical to improving knowledge and resource pathways. To further understand this issue, the age of caregivers must be considered to better focus resources and information to provide a more holistic view of how age impacts source discovery.

Based on the age range of participants, **Table 3** shows a visual representation of the various sources utilized and the prevalence among the age ranges disclosed, at an aggregate of each respective generation (approximately).

Table 3

Preferred I/DD Referral Sources (by Respondents' Age Range)

	18-25	26-40	41-50	51+
Internet Search Engine	33	101	61	113
Organization's Website	21	72	43	75
Social Media	26	63	37	51
Government Website	19	45	27	56
Friend or Family	18	51	44	77
Church	7	15	5	10
School	8	24	19	18
Case Manager	2	16	17	15
Waiver Support Coordinator	3	11	13	59

While many participants across the generational boundaries turned to the internet to find the information they needed on I/DD, a significant number of respondents aged 51 and over indicated they turned directly to organizational and governmental websites for service and care support. Further, the lack of utilization of spiritual communities, schools, case managers, and waiver support coordinators by younger generations may indicate a shift in reliance and trust in self-service research rather than third-party referrals.

Generally, participants felt improvements to the current pathways and accessibility options for families and caregivers of persons with I/DD were needed. Major themes were derived from these responses, with many relating to expanded and updated information, individualized services and support, improved education, collaborative resources, and simplified processes for families.

The data collected from this study showed community size directly impacted resource capacity and availability. **Table 4** includes a breakdown of how community size correlated to participants' views of available services and supports for specific types of need, based on geographic size and their knowledge of available support and care options.

Table 4

Services and Supports Available by Community Size (per % of Respondents)

	Urban or City	Suburban	Semi- Rural	Rural or Unincorporated
Financial Planning	43%	45%	9%	3%
Health & Wellness	36%	45%	13%	5%
Mental Health	39%	41%	16%	3%
Education	39%	46%	13%	3%
Elder Care	28%	46%	22%	2%
Legal Aid	40%	47%	13%	-
Social Services Skills	33%	42%	17%	6%
Insurance	34%	45%	17%	4%
Community Engagement	19%	49%	27%	5%
Self-Advocacy	34%	34%	24%	7%
Independent Living	28%	56%	13%	3%
Transportation	32%	53%	12%	3%
Sex Education/Gender Identity	44%	44%	11%	-
Benefits	36%	48%	15%	2%

Concurrently, **Table 5** provides a view of community size and its relationship to how the existing resources are viewed as useful. Interestingly, though there was an assumption that more populated communities (i.e., urban, suburban) would have higher availability and accessibility of resources, there were significantly high levels of respondents who selected “nonexistent” or “needs improvement” within these community categories. This alludes to the fact that even within well-populated areas, I/DD resources may be scarce or unavailable.

Table 5

I/DD Resource Usability by Community Size (by % of Respondents)

	Nonexistent	Needs Improvement	Satisfactory	Good	Excellent
Urban/City	34%	27%	34%	34%	34%
Suburban	39%	53%	45%	44%	50%
Semi-Rural	17%	16%	14%	18%	11%
Rural/Unincorporated	10%	4%	7%	4%	5%

Note. This data is representative of the total population that participated in this study, with roughly 79% of the participants residing in urban (>500,000) or suburban (100,000 to 500,000) population settings. Therefore, the data does not reflect an even distribution of respondents across all community sizes. Further, many respondents selected multiple options for rating their resources and it is likely their views changed depending on the resource type, leading to over 100% saturation within some of the community size categories.

Cultural Insight

The survey was administered in four languages: English, French, Kreyol, and Spanish. Only two respondents took the survey in a language other than English, which was Spanish. There were no participants who elected to take the survey in French or Kreyol. Although most of the survey was completed in English, participants represented various cultural and linguistic backgrounds (see **Figure 2**). When asked which languages they felt most comfortable speaking and reading, 96% stated English, 17% stated Spanish, 3% stated Kreyol, and 1% stated French. It’s worth noting that some respondents selected multiple languages, suggesting a multilingual approach was preferred.

Relating to the accessibility to resources and care options available in languages other than English, 67% of respondents indicated satisfaction with the current language options provided, although 13% were unaware of all the resources available or did not provide a firm answer.

Regarding questions about whether spiritual or cultural views should be accommodated within the I/DD resource and support community, only 7% noted that there were significant norms that required special accommodations. These included alternatives to in-home care for cultures that view this as inappropriate (especially for young women), Christian-centered support that emphasizes ideals that embrace the church and the various teachings of scripture within health and wellness concepts and dissolving the cultural barriers surrounding I/DD that have inhibited proper care by families and caregivers who do not acknowledge I/DD as a medical condition needing treatment.

Respondents were asked to identify any norms or perceptions their culture or family follows relating to how they seek treatment for medical and clinical care (specifically around I/DD). Approximately 8% noted that topics about misinformation and embarrassment were most common, especially at a generational level. Younger generations indicated they appreciated and educated themselves on changes to the general knowledge of I/DD, while older generations tended to follow assumptions that I/DD is a private matter. This was particularly evident for persons who identified as Black (Haitian) and Hispanic.

Considering that perceptions of I/DD resource efficacy may be influenced by ethnic identity, it is important to also use a cross-analysis to help visualize what, if any, correlations exist. For example, **Table 6** shows the percentage of respondents from each ethnic community who indicated they knew about I/DD resources available to them, with a majority of the population noting that services could be improved.

Table 6

Knowledge of Existing I/DD Resource Availability by Ethnicity

	Non-Existent	Could Be Better	Okay	Good	Excellent	Not Sure
American Indian	25%	50%	-	-	25%	-
Asian	9%	50%	14%	23%	-	4%
Black or African American (incl. Haitian American)	8%	35%	24%	27%	2%	4%
Hispanic American	8%	47%	21%	15%	6%	3%
Polynesian	-	50%	-	-	50%	-
White	9%	34%	17%	27%	13%	-
Prefer not to answer	25%	19%	6%	25%	13%	12%

Note. The percentages embody those who submitted responses to the question and account for an estimated view of each resource type they use, by ethnic group and their rating of self-knowledge. The total population represented by this table, therefore, does not represent 100% response rate of all participants in this study.

Table 7 depicts the I/DD resources prioritized based on the ethnicity of the respondents, with the internet representing at least 50% of respondents across all racial and ethnic groups.

Table 7

I/DD Referral Sources by Ethnicity

	Amer. Indian	Asian	Black (incl. Haitian)	Hispanic	Polynesian	White	Mixed Race
Internet	100%	50%	64%	60%	50%	74%	86%
Organization Website	50%	50%	46%	48%	50%	48%	50%
Social Media	50%	18%	48%	53%	-	38%	43%
Government Website	-	41%	40%	35%	-	33%	29%
Friend/Family	25%	23%	44%	35%	100%	47%	36%
Church	-	9%	12%	13%	-	7%	-
School	25%	23%	24%	18%	-	14%	14%
Case Manager	-	9%	10%	13%	50%	12%	14%
Waiver Support Coordinator	25%	5%	12%	18%	50%	23%	7%

Most of the participants (an average of roughly 45% per group), noted that the I/DD resources and support options within their communities were nonexistent or needed improvement (**Table 8**). Subsequently, although there may be sufficient resources available within their local community, from the perspectives of the various ethnic groups represented by the community, the usability of existing resources needs to be enhanced.

Table 8

I/DD Resource Usability by Ethnicity

	Nonexistent	Needs Improvement	Okay	Good	Excellent
American Indian	25%	50%	-	-	25%
Asian	10%	52%	14%	24%	-
Black (incl. Haitian)	8%	37%	24%	29%	2%
Hispanic	8%	48%	22%	15%	7%
Polynesian	50%	-	-	-	50%
White	9%	34%	17%	27%	13%
Mixed Race	9%	45%	18%	18%	9%
Prefer not to answer	29%	21%	7%	29%	14%

Note. While many respondents felt current information pathways and resource availability needed improvement, it was surprising to note that in traditionally marginalized ethnic groups (e.g., Black, and Hispanic) more than 25% of each population group categorized these existing systems as “okay” or better.

Virtual and In-Person Interviews

Secondary IRB approval was received on May 15, 2023, to conduct in-person and virtual interviews. Recruitment emails and social media outreach initially launched on May 17, 2023, and continued through June 28, 2023. The last session was completed on June 30, 2023. The first participant request was received on May 22, 2023.

There were 108 requests to participate or learn more about the project. Of these, 21 were completed, 11 were no-shows, 12 opted out due to various reasons, 86 were pre-screened, and 44 electronically signed the Adult Consent Form.

Demographics

There were 13 counties represented by the 21 completed sessions. These counties included: Brevard, Broward, Duval, Hillsborough, Lake, Lee, Martin, Miami-Dade, Orange, Palm Beach, Pinellas, Santa Rosa, and Seminole. Nineteen of the 21 sessions completed were virtual (via Zoom) and two were in-person (taking place in Wildwood

and Miami, Florida). Participants predominantly stated a preference for a virtual session over an in-person session due to time constraints with work and/or childcare.

Of the respondents completing sessions, 19 were female and two were male. All participants provided their perspectives based on their role as a parent or legal guardian for a child or dependent with I/DD. The respondents were also predominantly Caucasian, however there were identified representations from the Black, Haitian, and Hispanic groups.

All completed sessions were conducted in English at the request of the participants. There was additional interest from Indian-Asian and Pacific Islander representatives, though they never completed a session.

Summary of Interview Findings

Qualitative data were analyzed using Emotional Coding, Process Coding, and In Vivo Coding to provide breadth and depth of participant feedback. Emotional Coding is of particular benefit for this study because participants' emotions provide a lens for their perspectives related to accessing caregiver services for their loved one(s) with I/DD and provide insight into their lived experiences. Process Coding supported understanding of how caregivers access information or secure resources for their loved one(s). The accompanying use of In Vivo Coding allowed the voice of the caregiver to persist, honoring the need to include caregiver input into improving access to, knowledge of, and services to support their roles in caring for their loved ones with I/DD.

Emotional Coding

Emotions associated with access to services for those caring for persons with I/DD ranged from frustration to disappointment. Of the participants interviewed, over half indicated seeking services and accessing information about caring for their loved one with I/DD was frustrating, disappointing, and overwhelming.

A mother of an adult son with I/DD said that it is “a nightmare trying to access services and support.” This sentiment was echoed repeatedly when participants characterized their emotional journey when searching for and connecting with services that were disjointed regardless of diagnosis.

A mother struggled to find resources when she moved to Florida with her two children with I/DD. She was frustrated with the lack of information about services and resources. This led to disappointment with accessing services in the state of Florida, which was different from her experience in Georgia, where she had lived previously.

Another transplant from Ohio to Florida was more direct, stating that “Florida lacks services” for caregivers of people with I/DD. Her frustration included having to navigate a web of disconnected resources. She said that there is no place for caregivers to go to a central location to access information about services and other resources

adding that “the greatest hurdle in moving to Jacksonville, Florida, is the lack of services for I/DD loved ones.”

Anger often accompanied the emotions of frustration and disappointment. A self-proclaimed advocate of persons with I/DD said when her daughter was born with Down syndrome, she called in every favor ever owed to her. Admitting that anger fueled her motivation to be an advocate, she said that “there are no services to assist in [her daughter’s] growth.” “The state of Florida has nothing for me and my child,” she added.

As an advocate, and in a professional position to network at a high level, this mother is working with the University of Central Florida (UCF) to develop a mobile application or navigator for people with Down syndrome because she sees the state and her county as lacking resources and innovation. She said, “If you can have an app that tracks your menstrual cycle, then you can certainly design an app to track therapies, conditions, and milestones for people with Down syndrome.” Other participants also leaned into innovation and collaboration because of system-wide disappointment.

Another mother of a child with Down syndrome suggested she would like to see a “hub-and-spoke online state program to allow for proactive searches in one place.” With a background in marketing, this mother suggested that FDDC design an online decision-tree resource to address various resources (e.g., education, financial, medical, and legal). Using algorithms to navigate the site would prompt caregivers for events related to milestones. She said that it would be great to have an online resource that nudged her to access services at age-appropriate opportunities such as participating in Special Olympics.

Another participant who accessed the FDDC website said that it was not helpful and hard to navigate. She said, “The FDDC website is disorganized” but cited the Centers for Medicare & Medicaid Services’ site as a model for easy navigation. Similarly, another mother expressed her desire for online resources that should be organized by category, topic, or need.

To overcome frustration in accessing credible information to support their loved one(s) with I/DD, participants cited a need for reliable online resources that are not supported by advertisements. A mother of a three-year-old with a diagnosis of nonverbal autism said that because research can be overwhelming, she would like to see a robust, authoritative online resource, and “not just links to random websites or a site that just wants your money.” According to one mother, there is a need for strong SEO copywriting to satisfy users to ease frustration: “Every time you navigate to this site, it can provide you with educational information and specific services.”

Process Coding

The themes most frequently discussed when it came to accessing resources were self-reliance and resourcefulness with a bit of luck thrown in. All participants commented that “Dr. Google” was their number-one resource in trying to find services for their

loved one. Regardless of culture or diagnosis, the search for and access to services is complicated. Information is scattered, said one participant who had to find services pre-internet for her now-adult daughter. “The internet was a game-changer,” she said.

But for many other participants, the internet is difficult to navigate. For others, online resources must be validated or verified by trusted sources, with one participant saying that she uses the internet but with caution, relying more on social networks.

In general, there is no known “resource depot” for caregivers to go to for services including parental coaching, physician referrals, and educational, legal, and financial resources. As a result of not having a “go-to” source, participants often expressed confusion and felt overwhelmed and isolated.

Other online resources that increased knowledge and helped participants access services included:

- Parents of Kids with Intellectual Disabilities on Facebook
- Disability Support Network on Facebook
- Family Support Groups on Facebook
- A Day in the Life of Gabe video series
- Other online communities specific to a diagnosis, e.g., Autism Speaks

For one Haitian mother of a child diagnosed with autism, TikTok was a resource because “in the Haitian culture you’re not supposed to say anything and keep quiet about disabilities.” However, as the story of “Linda” is highlighted in the research section of this report, caregivers need to hear from others who share their cultural sensitivities. She said, “People need to hear more stories like mine.”

In Vivo Coding

The words that families and caregivers used was vital to capture their lived experiences accurately. This is particularly important when speaking with multiple populations represented by different cultural, socioeconomic, and educational backgrounds. Dialect and how an individual describes a situation is expressive since the meaning of words can vary, even within communities that appear similar. Although many families expressed analogous views of supports and services they had utilized, how they described their experience navigating the systems was telling, creating a story that is individualized but relatable to other families or caregivers facing similar circumstances.

Innovation and Self-Reliance

Despite a lack of coordinated and validated resources, many of the participants designed their own innovative ways to raise awareness about resources and provide information about accessing services and finding information. For instance, a mother of a daughter with quadriplegia cerebral palsy said that she and her friend launched a podcast, “2 Moms and Some Labels,” to fill the void of information and bring awareness to resources and services because of ongoing trouble trying to find support

from the state. Like many of the participants, she said that there is a lack of services and support as a child grows.

This sentiment was acknowledged by two other mothers who expressed a desire for access to information and resources during transitional periods, e.g., from elementary to high school or from school to vocational opportunities. It would be nice to have a “resource folder” that includes “information about SSI, school systems, behavioral health clinics,” according to one mother of a child with complex medical issues related to their I/DD diagnosis. In other words, she would like to see the state have a one-stop shop for resources like the one she found with Bright Feats, which is supported by the Abilities Workshop, Inc., established in 2019 to help the special-needs community cultivate a path forward.

Another mother said she relied on diagnosis-specific webinars for education, information, and support. The Down Syndrome Foundation, Down Syndrome Association, and Autism Speaks were valuable resources cited by participants who utilized webinars, podcasts, and online training opportunities.

Two participants expressed the desire for partnerships in offering programming such as legal issues, financial resources, estate planning, and resource sharing. These participants shared their experiences with UCF, which hosts panel discussions with experts and family members. UCF has held information sessions on topics such as legal issues, estate planning, parenting tips, and information about support groups. One participant credited the Scott Center for Autism Treatment at Florida Tech, and UCF for a program that helped “mainstream kids with autism.”

One participant in an interview commented:

“Don’t sit around and do nothing while you are waiting on a waitlist for services. Go out there and do stuff in the meantime and utilize that time appropriately.”

In addition to internet searches and innovative ways to access services for their loved one(s) with I/DD, all participants conveyed that online networking, social media support, word-of-mouth, and happenstance opened the door to accessing information and services.

Although Google often was the first way to access information and find resources, many participants also relied on the Family Café, Partners in Policymaking, Family Care Council, and national organizations such as the Down Syndrome Association. As one participant said:

“I rely on my ‘tribe’ (the Down Syndrome Association) as my child grows. I look to this community as a collaborative environment. I need this because you can’t do it alone. There are no services to assist in her growth. The State of Florida has nothing for me and my child.”

Family Café

One participant shared that as a caregiver of someone with I/DD, “it’s a tough journey” with the burden of endless searches for trusted information. Many participants rely on the Family Café for access to information, services, and resources.

One mother says she has utilized the Family Café for networking over the past 24 years because there is no “easy map” to get through it all. One participant said that the Family Café was her “go-to” for information, sharing, and accessing resources.

Other channels where participants accessed information included:

- Partners in Policymaking
- Family Care Council
- Boys and Girls Clubs
- Churches/Spiritual Communities
- State Advisory Council on Special Education
- Early Steps
- Child Find
- Nathaniel’s Hope
- Charlotte Behavioral Program

Chance Encounters

Complementing the evidence presented in the research, participants often found out about accessing resources by chance. One-third of participants suggested that serendipity resulted in access to resources and information/services that might be available to them as caregivers of people with I/DD.

In the case of an African American mother of three children diagnosed with autism, a chance meeting with a librarian helped her get started. She said that it is okay to ask strangers for help.

For another mother of Hispanic origin, a chance encounter with a waitress whose son had autism was her entry into accessing services. For one mother, “word of mouth” was the most prevalent way to seek, find, and access services. Her advice was to “reach out. You can only get help if you seek it, as it will never come to you.”

Most participants interviewed said that the paid provider network was not informed about what resources might be available. In one participant's experience, school was no help, pediatricians were dismissive, and other leads on resources were dead ends.

Additionally, language was a barrier. In only two cases did participants relay that doctors were of help. Most participants relied on community and social connections to access services and get information.

A male participant was the only one who relayed that, in his experience, medical providers were the most helpful in accessing resources. He also relied mostly on family members rather than outside resources.

Community and Peer Support

For many respondents, isolation is a byproduct of caring for a person with I/DD. One mother said she would like to see respite care services because she needs a break every now and then. She said with emotion, “I can’t be with [my child] all the time.” She added that it must be okay to say that “you can’t do it alone.” For this parent and other caregivers, there was a feeling of lost time.

Some participants also shared that stress was a factor in caring for their loved one(s) with I/DD. However, most of the caregivers emphasized the need for connection, networking, and partnerships, emphasizing the importance of interdependence as demonstrated in the research.

Like one participant who emphasized that it is important to lean on parents who “have been in the trenches,” many participants valued community and peer support when researching resources. In addition to providing avenues to access information about how to best care for their loved one(s) with I/DD, peers are necessary to support each other in their journeys. Like the mother who leans on her “tribe,” all participants relied on one form or another of personal support.

A male caregiver relied on peers, the Family Network on Disabilities, and the school system for information about how to access services and what resources are available. His advice is to “look to your peers for answers and look to them for questions you have not asked yet.” He suggested that it is necessary to find community support and “if you cannot find any support whatsoever, then create the support and resources.” Another participant shared similar advice, saying that a caregiver can find “little golden nuggets of wisdom from other parents.”

Summary

The qualitative interviews demonstrated that caregivers of people with I/DD experience a combination of uplifting and challenging emotions. Sometimes access to information is buried in bureaucracy and difficult to access due to disjointed, complex, and unvalidated information, particularly online. Paid providers were not helpful resources for information, rather, peers and networking, either online or in-person, offered comfort, camaraderie, and access to trusted information and resources.

While the internet plays a key role in accessing information, it is often difficult to navigate and may not be trusted as an authoritative resource. There was a desire to access information in a one-stop portal that provided more than links to other resources. Participants wanted personalized information unique to their loved one(s). They wanted to know they were not alone.

Additional Conversations

The NADD Research Team completed additional conversations with various family members throughout Florida. These caregivers represented minority and multicultural population groups, including Black, Hispanic, White, and mixed race. Although there were both native Spanish-speaking participants and English-speaking participants, all conversations were conducted in English.

There were over a dozen total conversations conducted. Participants included family members, caregivers, legal guardians, and conservators (identified collectively as “caregivers” for this report). These participants represented various regions of Florida. Conversations took place in Melbourne, Kissimmee, Palm Beach, Sarasota, Orlando, West Palm Beach, Jupiter, and Miami.

These additional conversations allowed caregivers of persons with I/DD to share their perspectives related to supporting their loved one(s) with an I/DD. Specifically aimed at understanding their views on resources and support services, barriers that prevented them from accessing services, ways in which they learned about services, and what community organizations they used, the conversations were open-ended and took place in August and September 2023. Participation was voluntary.

Services and Resources

In many cases, caregivers of loved ones with I/DD struggled with obtaining services including education, medical, vocational training, and independent living. In contrast to the in-person and interview attendees, these caregivers represented an older population of those with I/DD and demonstrated a need for resources related to transitioning at various points in development. Child Find, Medicaid, the Arc, Easter Seals, Partners in Policymaking, Family Café, and the Family Care Council were helpful in finding or accessing services and resources. However, like the participants of the in-person interviews and virtual interviews, respondents indicated the State of Florida was not helpful, and caregivers shared their frustration about a system that was siloed and hard to navigate.

Head Start consistently was named as a starting point for many participants when seeking services and finding resources. Often schools and paid medical providers did not have information about services and resources for persons with I/DD nor did they seem to have any interest in supporting their loved one(s) according to many of the participants.

In one case, the Florida Parent Center, which is now the Florida Network on Disabilities (FND) provided an entry point for services and resources. This resource was particularly helpful in educating caregivers about disability statutes and laws.

While two caregivers pointed to the use of the Family Care Council, many of them found it to be a dead end. As one adopted parent of a loved one with Down syndrome noted, there are no appointments being made; it is “death by attrition.” The overall

sentiment from participants of these casual conversations was that it is difficult to get these services.

According to one African American mother whose daughter is now 40 years old, it “took years to get services.” She added that in many cases, she felt that she “got the runaround from everyone.”

Some caregivers used APD, but indicated the program was often laden with yearslong waitlists. One mother talked about using the Florida Alliance for Assistive Services and Technology program, which provides assistive technology to Floridians with disabilities. The program offers a range of helpful activities, e.g., device loans, demonstrations, and training for assistive technology.

Ease of Access

Like the in-person and virtual interviews, the repeated refrain from participants in the casual conversations was frustration when navigating a disjointed and complex system. Since all participants shared that they relied on their own research to find information and access resources, often having to self-educate, there is a need for a centralized directory of services. A mother of two children with I/DD suggested helping families with a list called “Where do you begin?”

Most agreed that there was no centralized list of resources for caregivers of persons with I/DD. There is a need for a “step-by-step process” according to some participants. One mother suggested that “websites need to have a resource button.”

One participant suggested that the FDDC website have a link to the Family Care Council and design a more resource-driven website. Another commented that the State should have a multiplatform approach(e.g., Facebook, Instagram, etc.), because to help families “you have to go where the people are.” Respondents noted that these online resources must be parent friendly.

While a directory of services would be helpful, the State must recognize that there are varying levels of computer know-how. In one case, a participant said she was “not computer-savvy” and would like someone to explain system navigation to her. She also indicated a preference to speak with a real person and not rely on computer robots.

Two participants suggested that the website must be in layperson’s terms, sharing what resources are available and what choices caregivers might have. Another participant agreed and said that confusion is compounded because of the jargon.

In addition to confusion and frustration resulting from siloed information, two significant barriers to access included:

- Lack of awareness about resources and services.
- Lack of understanding about how to access services.

Community and Peer Support

Since paid providers and other system networks, e.g., schools, do not offer support according to most participants, support groups were common ways to share information and seek counsel. One mother suggested there was a need for support groups for fathers as well, particularly those who would not reach out due to cultural barriers. In the case of one mother, a virtual support group allowed her to meet like-minded people from across the United States. However, as one participant cautioned, “parents do not [always] take advantage of support groups,” asking, “How do you get parents to show up?”

Facebook groups are helpful in identifying resources, according to a few caregivers. In one instance, a parent discussed the value of the Down syndrome organization in Palm Beach County as an exemplar in supporting caregivers by hosting monthly educational events, offering music classes, and instructing parents on how to complete forms such as Med Waiver.

In addition, some participants suggested that a peer-mentoring program would be valuable. Mentoring would help answer questions such as “What is normal?” Another participant said that parents are overwhelmed with medical and developmental needs so “it is hard for them to reach out for help while dealing with life.” One mother said that she loved to mentor new parents. She advises parents on how to advocate for their child and helps them locate resources. One participant said that parent advocacy groups, not governments, make changes.

One mother was hired by an advocacy group after she sued the school district. This mother’s suggestion is for parents to “advocate for your kids and don’t feel bad about issues with the systems; they are there to help.” One mother’s advice to parents is to “trust your gut.” She added, “If you have to be a pain in the butt, be a pain in the butt.”

As in the in-person interviews and virtual interviews, many of these respondents stumbled upon information serendipitously. As part of her job, one mother found out what other parents were doing by accessing a network of moms. Another mother met a teacher who was on the Florida Developmental Disability Council. She became her mentor and provided her with resources for early intervention and the application for Med Waiver. This same mother started a preschool program through her local church. Another participant said she had a personal mentor relationship with a 70-year-old nurse. “I still call her for guidance and advice,” she added. Many participants shared that there is a need for community and a need to build friendships.

Other ways in which caregivers seek support include:

- Friendship Circle
- Family Care Council
- Family Café
- Informal networks
- Partners in Policymaking
- Family members

Other comments:

- Schools and daycares need training on disabilities.
- Faith-based daycares are helpful for people with strong belief systems.
- Lack of standards for extracurricular activities and sports hinders participation by persons with I/DD.
- Transition programs and skills training through the Arc are valuable. In addition, the Arc offers opportunities for socialization, residential living options, and training.
- Employment opportunities and summer activities are needed.
- Caregivers would welcome information about the mental health aspects of caring for an individual with I/DD.
- There are concerns about when loved ones with I/DD transition to adulthood.
 - Does the family need a special-needs trust?
 - How do you set up a guardianship?
 - What training is available to prepare those with I/DD for living independently?
- There is a need for assistance with financing support services and living devices that insurance does not cover, e.g., sleep-safe beds.
- There is a need for special-needs attorneys, specialized therapists, live-in support, support for older parents, marriage support, affordable housing, and behavioral services.

Part V: Discussion of Findings

Overall, most participants noted that they utilized social media and Google as leading resources to obtain information and next steps for services and care support for their loved one(s) with I/DD. Several participants commented that social media groups they participated in were most helpful in providing not only general information about available resources but also support to help cope with “stress” and “mental strain” coinciding with caring for their loved one(s) with I/DD.

Many participants noted that they hadn’t really considered or looked extensively into long-term care for when their child is older due to being consumed with their current needs or barriers incurred. There were also a few participants who commented that they felt that State agencies or organizations were prioritizing general treatment and care, and that they didn’t feel their child was receiving or would receive the proper care they needed according to their individual circumstances. This appeared to be further compounded in areas that were rural or that had more minority and low-income communities within them.

Finally, the issue of money and American Disabilities Act (ADA) designation seemed to create a barrier to access to care due to a lack of designation acknowledgment by the ADA for specific I/DD diagnoses.

Recurring Themes

Through the survey and various interviews, several recurring themes were derived from the lived experiences of the family members and caregivers who had utilized different avenues to find information on available services and care options for their loved one(s) with I/DD. These themes represented both positive and negative experiences and were somewhat specific to ethnicity, community size, and the age of the parent, guardian, or caregiver.

The positive themes expressed by the respondents primarily emphasized the use of family support groups, social media, Partners in Policymaking, Family Café, the UCEDDs, and self-guided internet research. The negative themes were mostly attributed to state and local agencies and organizations and their lack of a streamlined process for families to find resources, affordability, accessibility of services in remote or less-populated areas, and a lack of a centralized source of information that is easy to find and understand. Most participants shared a distrust or dissatisfaction with the way the system is now and were worried about the quality of life their child or loved one(s) with I/DD would have once they were no longer able to care for them. Further, several parents of children with severe I/DD appeared to prioritize the care of their child over their own health and welfare, stating that the quality of life for their child superseded any health emergencies they themselves would have.

Range of Services Needed by Families

Caregivers of loved ones with I/DD shared a wide range of services that they used or needed to better care for their loved ones. Oftentimes needs aligned with the age of the loved one with I/DD or the specific need of the caregiver. Parents of younger children require information about schools, daycare, therapies, paid providers, support for siblings, training, parent coaching, and mentoring. Caregivers of older children or adults with I/DD needed information about transitioning from “child” to “adult” because, as one mother said, resources tend to go away when the child turns 18, but individuals with developmental disorders “are children forever.”

Other services requested included guardianship, special-needs trusts, affordable housing, vocational training, and independent living skills. In general, there was a consistent request for special-needs attorneys, specialized therapists, live-in support, support for older parents, marriage support, financial assistance, and wellness or social support.

Difficulty Navigating Disparate and Complex Online Resources

Results of the online survey and analysis of in-person interviews revealed a need for a more coordinated and systematic way for caregivers of people with I/DD to access resources, find information, and seek support at both the individual and community levels. Overall, respondents voiced the need for the State of Florida to provide a holistic approach to accessing disparate services for caregivers of loved ones with I/DD. Since the internet was resoundingly the most prevalent way that caregivers searched for information, resources, and services, caregivers expressed the desire to

have a single-source, authoritative portal, or online presence, to easily navigate resources and access information to better care for their loved one.

Consistent with the research findings, caregivers were burdened with complex systems navigation to access support services, find resources specific to their loved one's needs and life stage, and find collaborative partnerships. Time, effort, and awareness burdens impeded access to services.

Community and Social Networks

Regardless of diagnosis and despite cultural differences, there is an express need for peer support, organizational advocacy, and State-led collaboration. Although natural supports provided social and community connections to services, there was a desire to have a more holistic approach to accessing services. Resource packets or individualized pathways would be helpful to caregivers who did not know where to begin or where to go in caring for their loved one(s). Care and support from like-minded people would help facilitate uncertainty and trust issues. Online and in-person support groups, coaching and mentoring, and peer-led workshops or webinars would be helpful resources while staving off feelings of isolation and frustration.

Significant Stories

There were many stories shared that epitomized the experiences of family members and caregivers of persons with I/DD in Florida. Some of the most impactful are provided here.

- A parent of a child with Down syndrome found significant support within her local community in the way of dinners and resource referrals to build a local community they could lean on. They noted that their child's primary care physician wasn't informed enough to provide insight or support for Down syndrome treatment external to immediate medical needs. The respondent did note that as her daughter grew, resources and community care services dwindled and she looked to national organizations for guidance, such as the Down Syndrome Association, which she only discovered through a flyer at her child's pediatrician's office.
- Another parent noted that interactions with the local WIC office proved to be very helpful in finding resources for her child with I/DD for families with low income or no/limited insurance. Due to limitations with income and insurance coverage, she had few options for medical or clinical care for her child, relying heavily on providers and clinicians who had coinciding hours of operation or accepted payment plans. She noted that these providers lacked expanded resources to accommodate her child's I/DD conditions and needs, and she hasn't been able to find resources, support, or care services for her child that cater to the I/DD support she requires.

- Another parent stated that their child had both Down syndrome and a rare malformation of the brain called Dandy-Walker syndrome. Although her child's primary pediatrician has been competent to treat the Down syndrome diagnosis, the respondent noted it has been difficult to find a fully capable support and care team to cater to all conditions her child has been diagnosed with. She, too, has looked to social media for assistance and guidance and has joined several online support groups that have provided support that was lacking or unavailable within her community or through medical care services.
- Another participant was older (60) with an adult son (39) of whom she has guardianship. She is not aware or familiar with the waiver programs or adult-specific resources available for her son. She is also not sure where to start to get long-term care for him once she is no longer able to care for him. She was very frustrated with State governmental and organizational agencies, especially APD, as she felt that only seemed to cater to children with I/DD and had limited to no support options for adults with I/DD.
- Another parent talked about the evolution of their child's needs from when they were first diagnosed through grade school. She noted that her most trusted resource has been a nurse practitioner at her child's pediatrician's office who has been successful in referring clinical and alternative provider care for her child, including speech pathology and ongoing therapy support for the family. She stated that seeking resources and support on her own has been difficult and she's nervous about the next phase of her child's transition to middle school since the school system will be different and the current classroom accommodations may not be available.
- Another parent, who noted that they had obtained an advanced degree in a related field, still stated that they felt "inadequate" and "unsure" of where to go for information on resources specific to their child's condition. They noted that as their child aged, it became more and more difficult to find information to help through the transition periods of school, treatment, and ongoing care. They ended up relying heavily on Partners in Policymaking and the State Advisory Council on Special Education, but even as educated and informed as they were, navigating the resources was cumbersome.
- Another Partners in Policymaking graduate noted that a chance encounter with a waitress who also had a child with I/DD opened the door for much-needed services and support around legal aid and behavioral health information. However, even with the additional support they've been able to obtain, they are still worried and unsure how their child will maintain a good quality of life when they're no longer around to care for them.

Several parents and caregivers noted that mental health and wellness for the parent, guardian, or caregiver needs to be included in the resource and support list as families search for proper care services. As noted by one parent,

“Mom and Dad would like to have someone who could care for the kids during the day so they could have some time/relief for themselves, even if the free time is to learn more about the I/DD.”

Additionally, a mother felt insignificant in her role as a caretaker of someone with I/DD, stating,

“I’ve done enough work to earn another graduate degree but still don’t feel like an effective advocate for my son.”

In response to a lack of collaboration among different providers and clinicians, a parent commented,

“Why aren’t parents handed a list of professionals? . . . [We] need more coordination of services. There’s so much inefficiency.”

While a parent of a child with Down syndrome noted,

“I rely on my ‘tribe’ [the Down syndrome Association] as my child grows. I look to this community as a collaborative environment. I need this because you can’t do it alone. There are no services to assist in her growth. The State of Florida has nothing for me and my child.”

And a transplant from out of state found,

“The greatest hurdle in moving to Jacksonville, Florida, is the lack of services for I/DD loved ones. It’s as if after he turned 22 years old, that was it—no more services readily available.”

Further, many attributed financial constraints and the limitations imposed by Medicaid services as contributing factors to resource limitations within their communities. For instance, a parent described trying to find a proper pharmacy within their community to fill a prescription, and if it weren’t for the assistance of someone at a local grocery store, they would not have been able to find where they needed to go. They pointed out that when they contacted their local public health office and tried to look the information up online, they were met with a dead end and little guidance from the staff and website.

To combat these barriers and hardships, many families have sought solace in one another, relying on peer support groups to fill the gaps left by agency and organizational shortcomings.

As one parent noted regarding self-empowerment,

“Online networking has helped her gain information and now she wants to help others. She and her friend launched a podcast to be a support for moms of I/DD.”

Other parents attributed the success they’ve found in searching for appropriate supports through similar self-motivation measures. As one suggested,

“Don’t get discouraged when things take time (e.g., doctor’s visits)—it’s normal. It’s not personal.”

Additionally, another parent implored,

“Reach out. You can only get help if you seek it, as it will never come to you. . . . See your case worker as an access towards other resources. They are there to help you and are a key tool in improving the quality of life of not only your children but you as well.”

What is clear through all these comments is that parents and families of persons with I/DD want to—and should—find resources and services that are easily identifiable, and that finding kinship among other families navigating similar pathways creates an opportunity to improve resource use and recommendations.

Simply put by a family member,

“Don’t sit around and do nothing while you are waiting on a waitlist for services; go out there and do stuff in the meantime and utilize that time appropriately.”

One participant who identified as a Haitian American living in South Florida noted the difficulties in overcoming the social taboos associated with the Haitian culture’s views of I/DD and mental health. As a mother of a child with I/DD, she admitted that it took her a while to acknowledge and embrace the needs of her child as she “didn’t want to label him,” or was reminded by family that, “in the Haitian culture, you’re not supposed to say anything and keep quiet about disabilities.” It was only after adopting a new way of thinking, which was influenced by listening to other families and doing her own research, that she decided that her story needed to be heard and that nothing should prohibit her child from receiving the proper care and support they deserve.

Part VI: Conclusion

The purpose of this study was to investigate how families and caregivers of persons with I/DD living in Florida learn about, access, and share resources and support options within their local communities. The data collected and the literature examined found that access to information, supports, and services is influenced by a variety of barriers. These barriers include delays in service delivery, health of family members,

geographical location, cultural norms, primary language, age, I/DD diagnoses, family and caregiver health, and economic factors.

Parents desire more openness and support from others who can relate to their experiences (Currie & Szabo, 2020). Caregivers require skills-building, social networks, expanded education on resource availability, and strategies to break down access barriers (Gilson et al., 2017). Peer mentorship and systems navigation are critical to improving caregiver and family well-being, particularly during transitional stages of life (Milberger et al., 2022). Finally, caregivers of individuals with I/DD require a collaborative approach to care with special attention to cultural competence using a family-centered care model (Echezona-Johnson, 2022; Jansen et al., 2012; Stewart et al., 2023; Tibbetts, 2015).

Investments by federal and state agencies described herein recognize the critical role families play in supporting a person with I/DD to live fully and successfully in their community. Accessible, family-friendly information about supports and services is crucial so families can obtain and utilize needed services. Families expressed frustration with the amount of time they spent searching for information about services and the difficulty they experienced navigating online resource information. It is important to evaluate how families receive information and how they feel about the information they receive. This is made possible by services such as National Core Indicators and Family-to-Family networks.

Though there is an abundance of programs and services available throughout Florida, many appear to be hard to find or limited in their capacity to provide proper support due to the geographic or economic limitations of the communities and residents within them. Parents reported dissatisfaction with the quality of existing services, a lack of respite services, and few social and recreational programs.

Recommendations

Based upon our analysis of existing research, the survey and interview data collected, and the information shared during the *Developmental Disabilities Awareness Day* town hall-style session, we make the following recommendations to improve access to needed I/DD services, to promote continuous quality improvement, and to ensure that services and supports are provided in a culturally responsive manner.

In this study, the importance of social supports, particularly parent-to-parent networks, was clearly expressed by participants. Family members also reported that social networking sites were valuable sources of useful information. Efforts should be made to develop, promote, and assist family support networks by providing physical locations, facilitation, childcare, translation, and promotion through a variety of media. Parent training and networking organizations like Partners in Policymaking and the Down Syndrome Society, were noted to be invaluable supports for families to learn about their family member's disability, resources and services, and evidence-based practices.

Web-based information concerning I/DD and related services and supports is often difficult to access and navigate. Governmental and service organizations should involve consumers of services in the design and ongoing evaluation of web-based information and documents. Information provided by text or phone messages can reach families who lack internet service or computers. In some communities, traditional forms of media (e.g., newspapers, radio, TV) are the preferred methods of obtaining information.

Families often must negotiate multiple service systems to obtain comprehensive supports and services for their family member(s) with I/DD. Investment in the development of single, “one-stop” points of access for services most often needed by families and persons with I/DD, based in local communities, or easily accessible by web-based portal or phone, would reduce the burden of effort and time expended by families and individuals.

Governmental agencies and service organizations should engage in rigorous efforts to ensure that policies, communications, and services are culturally informed and responsive. This may include making efforts to recruit bilingual/bicultural personnel from underserved communities and locating services in areas to improve access in more remote communities. Training in culturally responsive practices should be infused with ongoing professional development programs for government agencies and service-providing personnel.

Our research supports the need to modify healthcare protocols, forms, training, and policies to address the needs of individuals with I/DD who identify as LGBTQ+. Education and information should include a curriculum on the intersection between LGBTQ+ and I/DD populations. This policy recommendation promotes access and equity to person-centered services and supports for individuals with I/DD who identify as LGBTQ+ and their families.

Family members and direct service caregivers are the primary support for individuals with I/DD across the lifespan. Attention needs to be focused on the healthcare needs of these individuals, including mental healthcare for the physical and emotional stress many persons with I/DD (and their families) experience. Often affordability and availability prevent family members and caregivers from receiving the care they need. Healthcare, including mental healthcare, should be made readily available and funding provided to ensure these essential support providers maintain the optimum wellness needed to provide care for a child or adult with I/DD.

Our review of the research literature, analysis of survey and interview data, and evaluation of the town hall-style information shared suggest that training in the diagnosis, identification of comorbid conditions, and evidence-based practices for the care and treatment of individuals with I/DD is needed for providers of healthcare and mental healthcare. The reviewed research suggests that this is a national problem that requires a review of professional training programs to ensure that adequate curricula and practicum/internship experiences are required in professional programs leading

to clinical licensure. Family members reported that informed healthcare providers were often their most useful support in accessing needed care and services.

Finally, our study suggests that there may be gaps in services as individuals and families move through the lifespan. Efforts should be focused on providing support to families at times of developmental transition points, particularly the transition from school to adult life. Individuals with I/DD are experiencing greater life expectancy, and particular attention is needed to develop the supports and services individuals with I/DD will require as they grow older. Parents/caregivers express concerns about who will be responsible for ensuring quality, person-centered care when they are no longer able to.

This study provided a deep background and rich context to continue building knowledge toward the establishment of an Access to Services through Knowledge (ASK) information and resource delivery system for the community of people with intellectual and developmental disabilities of all ages.

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