

September 2022

FDDC-NADD Dual Diagnosis Study

Final Research Study Report

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This project is provided by the Florida Developmental Disabilities Council, Inc., supported in part by grant numbers 1901FLSCDD-01 and 2001FLSCDD-01 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

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Part I: Introduction and Background

In May 2021, the National Association for the Dually Diagnosed (NADD) was awarded a grant by the Florida Developmental Disabilities Council (FDDC) to conduct research to better understand the strengths and challenges related to supporting people with the dual diagnosis of intellectual and developmental disabilities (IDD) and mental health conditions. This research would result in the development of a Florida statewide strategic plan. The aim of the plan is to provide a roadmap for strategies that support the social and emotional wellness of people with intellectual or developmental disabilities and mental health conditions (IDD/MH) across their lifespan.

This research examined existing programs, policies, and practices related to service approaches, including crisis prevention and intervention, for persons with IDD. Interviews and surveys incorporated insight directly from medical and clinical providers, law enforcement professionals, educators, family members, case managers, self-advocates, and direct support professionals.

As part of this study, NADD conducted an exploratory assessment that shows that supporting individuals with a dual diagnosis has been a challenge for states for many years. Struggles often emanate from siloed systems within states, perceptions about individuals with IDD and their ability to benefit from mental health treatment, and a lack of clinical and direct support capacity. State agencies developing and improving systems for individuals with IDD describe supporting people with co-occurring IDD and mental health support needs as one of the most complex challenges directors encounter.

Background

According to the Eunice Kennedy Shriver National Institute of Child Health and Human Development (2021), IDD impacts “intellectual functioning or intelligence and adaptive behavior that creates lifelong challenges that manifest into impairments that are intellectual, physical, or both.” Intellectual and developmental disabilities can impact an individual’s nervous system, sensory system, and metabolism and can progress into degenerative conditions as a person ages (NICHCY, 2011). Some IDD’s are a result of a genetic syndrome, such as Fragile X syndrome or Down syndrome. Others have been introduced through exposure to toxins, viral contagions, or trauma. Additionally, malformations, infections, and labor- or delivery-related complications have been associated with IDD diagnoses (Schaepper et al., 2021). Schaepper et al. (2021) note that several co-occurring conditions specific to mental health and neurodevelopmental disorders have frequently accompanied IDD, such as autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), impulse control disorder, depression, and anxiety.

The Centers for Disease Control and Prevention (2022) state that 18% of the 4.5 million adults in Florida have a disability with co-occurring mental health conditions that impact their ability to concentrate, make decisions, interact

within their community, and live independently. Of those, more than half reported not receiving any needed mental health treatment due to high costs; lack of insurance coverage; and insufficient mental health professionals, services, or resources (National Alliance on Mental Illness, 2021). The Florida Behavioral Health Association (2019) notes that suicide rates and hospitalizations for persons in Florida with mental health conditions are significantly higher than the United States (US) average, with Florida ranking first in the nation for rates of suicide and self-harm.

Current research collectively indicates that the number of individuals with IDD experiencing mental health crises in Florida (and nationally) has been increasing steadily for decades (Heekin, 2016). To analyze the strengths and weaknesses of current mental health support systems, policies, and treatment approaches, and to learn about promising practices for individuals with IDD, a mixed-methods research study was conducted. This study provided an opportunity for stakeholders within the IDD and mental health communities to provide insights and identify policies and practices that may better address the specific needs of persons who are dually diagnosed. This was undertaken with the aim of promoting mental wellness, resilience, and the capacity to respond effectively when a mental health crisis occurs.

An analysis of current published research guided the development of online survey and virtual interview content. The online surveys focused on the experiences and insights of providers, clinicians, law enforcement professionals, educators, case managers, family members, and direct support professionals. Survey questions addressed their experiences with training, collaboration, education, internal policies, and systemic procedures relating to supporting individuals with IDD and mental health conditions.

The virtual interviews were designed to obtain first-person narratives of self-advocates and their caregivers (specifically family members). The in-depth interviews were conducted to learn more about their experiences of being directly involved in a crisis, paying particular attention to practices that promote positive outcomes prior to a crisis, and those that were helpful during and following a mental health incident.

Overview of Crisis Intervention Policies and Procedures in Florida

Many states use some form of civil commitment—a statutorily created and court-ordered form of compulsory treatment—to compel patients to undergo mental health treatment, including medication. These policies are intended to promote public safety and to ensure that those who need treatment receive it. Despite its widespread use, involuntary treatment has been an intensely debated issue in mental health law for several decades. Both in Florida and nationally, the available data suggest that the number of individuals with dual diagnoses (particularly children and youth) needing crisis management is

increasing annually (Testa & West, 2010). A primary goal of this research (which focused on Florida) was to develop a plan that would promote the social and mental wellness of people with IDD experiencing mental health conditions, thereby reducing crises and avoiding involuntary interventions.

Legislation

In 1971, the Florida Legislature passed the Florida Mental Health Act (“Act”), commonly referred to as the “Baker Act,” in recognition of Maxine Baker, a state representative from Miami who sponsored the bill. The Baker Act allowed for the creation of mental health programs designed to “reduce the occurrence, severity, duration, and disabling aspects of mental, emotional, and behavioral disorders” (H.B. 383 (Section 394.453), 2021). The assumption behind this legislation was that individuals who require the use of the Baker Act have lost the power of self-control and are likely to inflict harm on themselves or on others. It is the intent of the legislation that the Baker Act be used only in situations where the person has a mental illness and meets all the remaining criteria for voluntary or involuntary admission. The Florida Legislature has regularly revised the Act and, in doing so, has revised the Act’s legislative intent.

In 1997, the Supreme Court of Florida Commission on Fairness organized an evaluation of the 1971 Baker Act to ascertain whether the Act, as implemented, met its goals and purpose described by the law. They found that the state of Florida had failed to develop adequate community programs to meet the needs of citizens with IDD. Over half a million people were reported to suffer from mental illness, and close to 20,000 petitions were filed for involuntary civil commitments. The Commission found that the system moved slowly, resulting in detentions and involuntary civil commitments becoming lengthier and leading to an increased number of cases of abuse. The tension between fiscally driven policies and clinically desirable outcomes was identified as the fundamental cause of these systemic problems. The Baker Act Commission concluded that the law lacks a clear description of timeframes; that court hearings lacked due process; that a county’s public defender did not always represent patients with mental health conditions; and that the quality of this representation was not uniform. These problems led to the unsafe and unfair treatment of patients with mental illness in the Baker Act system.

Mental Health Awareness and Support

A Rand Corporation study suggests there is no empirical evidence that a court order is necessary to achieve treatment compliance and desirable outcomes or that a court order, in and of itself, has any independent effect on outcomes (Ridgely et al., 2001). Individuals with an intellectual disability are more likely than the general population to have a co-occurring mental health condition (Schaepper et al., 2021). Appropriate and person-centered care is not always available, making individuals with complex care needs more vulnerable to ineffective crisis management and involuntary treatment interventions.

In Florida, a recent amendment to the Baker Act established a permissible collaboration between the Department of Health and the Department of Education to supervise the administration of the school health services program for public and charter schools. Under this partnership, the Baker Act requires each county health department to design a school health services plan with the district school board and the local health advisory committee. Among other mandatory components of the school health services plan, the plan must provide immediate notification to the parent of a student being removed from school, a school-sponsored activity, or school-sponsored transportation and taken to a Baker Act receiving facility (Christy et al., 2020). Principals may delay notification if they believe it is in the student's best interest and if they have submitted the necessary report. Prior to involving law enforcement, the principal or their designee must verify that de-escalation strategies have been used and that outreach to a mobile response team has occurred, unless the principal has a reasonable belief that any delay in removing the student will increase the likelihood of harm to the student or others. The criteria for implementing the Baker Act include an involuntary examination under the name of the Act and may be initiated by a circuit court judge, an authorized mental health professional, or a certified law enforcement officer (Goldstein, 2018).

The Marjory Stoneman Douglas High School Public Safety Act creates the Mental Health Assistance Allocation within the Florida Education Finance Program. The Baker Act is designed to assist school districts in establishing or expanding school-based mental health care, training educators and other staff in detecting and responding to mental health issues, and connecting children, youth, and families who may experience behavioral health issues with appropriate services. For the 2020-21 school year, \$100 million was appropriated for the allocation, with a minimum of \$100,000 allocated based on each district's proportionate share of the state's total unweighted full-time equivalent student enrollment. Districts receiving the allocation are entitled to a proportionate share of the school district's allocation. The plan must focus on a multi-tiered support system to deliver evidence-based mental health care assessments, diagnosis, intervention, and treatment for students. Supports and services under the allocation must be coordinated with a student's primary mental health care provider and other mental health providers involved in the student's care (Christy et al., 2020).

Part II: Research Design and Methodology

Design and Rationale

The NADD Research Team conducted analyses of policies, training approaches, collaborative partnerships, resource access, and service systems designed to meet the needs of individuals with intellectual and developmental disabilities and mental health concerns. The analyses incorporated surveys, virtual interviews, and a study of national trends and promising practices. An aspect of the study examined the experiences of individuals and families involved in a crisis intervention. Collectively, this multifaceted approach to gathering information contributed to the breadth and scope of this research study, resulting in important insights that can inform future policy and practice. These primarily related to the strengths, challenges, and opportunities in support systems, policies, and treatment approaches in place to meet the mental health needs of persons with IDD.

Methodology

The research team used a mixed-methods design involving both qualitative and quantitative methods to analyze the current policies and systems within Florida and other states in response to individuals with dual diagnoses who receive specialized support services. The study sought to answer some fundamental questions regarding policies and practices and to identify gaps between agencies, including:

- What do we know about existing systems (policies and implementation)?
- What examples of evidence-based, promising practices are in place in Florida and other states?
- What do persons with IDD and their families have to tell us about their crisis management experiences and needs?
- What do service providers have to tell us about their experiences and needs?
- What is needed to move service systems toward improved outcomes for people receiving services?

Using purposive sampling, the research team conducted targeted surveys with mental health professionals, health care providers, educators, law enforcement professionals, and service providers. The research team also interviewed persons with IDD, their families, and support professionals to learn more about their experience of positive support, crisis prevention, and intervention

including involuntary interventions. The research team then synthesized the results of the multiple data sources analyzed during the literature and policy review, the survey results, and the interviews.

Participant Recruitment and Selection Logic

Persons with IDD (self-advocates), their family members and caregivers, clinicians, medical providers, educators, law enforcement professionals, case managers, and direct support professionals were the participants in this study.

Recruitment was conducted electronically using email recruitment flyers and social media outlets throughout Florida and nationally. Recruitment outreach was through existing partnerships with IDD and mental health organizations, the NADD listserv database, the project's stakeholder team and their networks. All participants were provided a link embedded within the recruitment announcement that directed them to the online SurveyMonkey landing page (for the surveys) or, in the case of interviews, to the Calendly pre-screening appointment request form. The recruitment flyers detailed the inclusion requirements necessary for participation. The SurveyMonkey landing page incorporated a consent form and provided contact information for persons to email the NADD Research Team if they had questions. The survey was provided in three languages: English, Spanish, and Haitian-Creole. Translations were provided for all correspondence, recruitment, consent forms, and the survey questionnaire. The translations were preliminarily converted using the Poedit software application and validated through Lingvanex Translator.

For persons who registered for the pre-screening sessions via the Calendly request form, each session was conducted before an interview and comprised several preliminary mental and behavioral health assessment questions to determine an individual's readiness to participate in the study. Family members, caregivers, and self-advocates participated in a pre-screening session. The screening ensured that individuals would only be interviewed if the NADD Research Team's designated Trauma-Informed Care Specialist determined that their involvement in the study would not impose any significant emotional or behavioral risks. All persons who were pre-screened passed and were permitted to move on to the interview phase. Both the pre-screening and formal interviews were conducted in English via the Zoom audio/video platform. All participants consented to allow the interviewer to audio record the sessions to allow for accurate transcription of their responses. Participants received digitally executed copies of both consent forms prior to their interviews.

Ethical Considerations

The anonymity and confidentiality of all participants of this study were and will continue to be protected. The NADD Research Team took precautions to ensure the survey responses were completely anonymized by disabling any IP tracking, excluding personal information from the survey, and not requiring contact information. Although all interview participants had to provide contact

information as part of the interview coordination process, no further identifiable information was requested from them. Participants were assigned an acronym following each interview. The recordings were only shared with the approved transcriber and qualitative coder. No individuals outside of the NADD Research Team had or will have access to any of the information collected from any participant as part of this project.

To address potential conflicts of interest or additional ethical issues, the NADD Research Team obtained approval from the Biomedical Research Alliance of New York before collecting any data. This screening process included the use of an electronic consent form for both the surveys and interviews and an electronic audio recording consent form for the interviews. Participants were provided copies of all digitally signed consent forms and information on how to request a copy from the NADD Research Team directly.

Participation was voluntary, and survey participants and interviewees were permitted to withdraw from the study at any time. The NADD Research Team set up a dedicated email address which was regularly monitored to provide access to information and coordination throughout the interview and survey deployment periods. No individuals or groups on the stakeholder team conducted any interviews, nor did they have access to participant responses or recruitment tracking lists. None of these individuals were involved in the data analysis or writing relating to the description of the findings.

The data collected from the surveys and interviews, including the pre-screening assessment forms, tracker logs, and any notes taken, are stored securely on NADD's cloud drive and are only accessible by the research team members. This information will be downloaded to an external hard drive and stored in a locked filing cabinet for no less than 5 years following the end of the project in September 2022. The data will be destroyed at the end of this 5-year period using a digital shredding process.

Part III: Literature Review

The NADD Research Team conducted a rigorous review of the existing research on mental illness in persons with IDD. This research examined prevalence data, best practices in promoting mental wellness and crisis response, the quality of current support systems for individuals and families, availability of education and training for support providers and law enforcement, and policies guiding service delivery in homes, schools, and communities.

Although there has been extensive research done on IDD and mental illness individually, very few studies have examined these conditions as possibly concurrent diagnoses. For example, a meta-analysis of children and adolescents' mental health services revealed a significantly higher prevalence of psychiatric symptoms in children and youth with IDD, ranging from 38% to 49%. The review also found a significantly higher prevalence of formal

psychiatric diagnoses in children and adolescents with IDD. The commonly reported psychiatric disorders included ADHD, anxiety, conduct disorder and externalizing behaviors, and depressive disorders (Buckley et al., 2020). Further, Lin et al. (2021) found that more than 95% of individuals with IDD evaluated as part of a national healthcare assessment in the United Kingdom had co-occurring mental health disorders, some of which had been misdiagnosed or inadequately managed. The authors posit that this mismanagement may have been responsible for the high premature mortality rate for persons with IDD compared to persons without. The data show there is a correlation between IDD and mental health conditions and that there is a need to exclusively investigate their interrelationships to better inform policies and practices moving forward.

Existing Policies and Systems

A recent investigation into the developmental disability systems and services in New York (e.g., the New York State Office for People with Developmental Disabilities) highlights the need to improve the opportunities for persons with IDD/MH to obtain treatment for a range of medical, clinical, and health-related conditions (Cervantes et al., 2022). The authors noted that the confusion and discord between mental health providers and developmental disability agencies often led to insufficient referrals or incorrect treatment measures. To address this issue, an integrated system composed of a comprehensive education structure, mental health treatment network, and developmental disability system that work collaboratively to provide effective support across all symptoms and conditions needs to be developed at the state level.

Within the judicial system, Robst et al. (2011) discovered a correlation between arrests and mental health crisis intervention events. Their findings suggest that the emergency examination provision of Florida's involuntary civil commitment statute is associated with an increased risk of arrest. This connection suggests that the principal aims of civil commitment are not being met. In the quarter after an involuntary examination, people are more likely to use outpatient services and should therefore get arrested less often. The services may be ineffective because they are the wrong kind or the wrong frequency. Some services may increase arrests for technical violations. However, it is unclear whether this is because of increased oversight of the individual or because the services are ineffective.

Totsika et al. (2022) outlined several risk factors correlated with increased mental health issues for individuals diagnosed with IDD, including socioeconomic factors and genetic influences. Malnutrition, insufficient home stimulation, infections, negative parent interactions, prenatal substance use, and health problems increased mental health diagnoses. Diagnosis of mental health conditions in individuals with IDD is complicated by communication deficits, cognitive discrepancies, and the IDD diagnoses themselves (e.g., depression may be attributed to withdrawal behavior exhibited by many individuals with ASD). Estimates of mental health issues for individuals diagnosed with IDD are double compared to individuals without an IDD

diagnosis. And almost every mental health condition is estimated to be highest for individuals with IDD caused by a genetic disorder.

Arias et al. (2021) discovered that one of the most frequently diagnosed disorders in children with intellectual disabilities is oppositional defiant disorder (ODD). Its prevalence varies from 12% to more than 50%, depending on the child's age and comorbidities. The disparity of results suggests that some underlying problems should be further investigated. These problems include age, small samples, different measuring instruments and diagnostic procedures, and diagnostic algorithms that were initially designed for children without an intellectual disability. Furthermore, given the possible overlap between some ODD symptoms and the challenging behaviors that are especially prevalent in children with an intellectual disability, the validity of behavioral indicators needs to be thoroughly analyzed (Arias et al., 2021). Appleton et al. (2019) made a similar finding when they discovered that individuals (children and adults alike) with both symptoms of ASD and intellectual disability show higher levels of anxiety, mania, and mood disturbance than individuals with just symptoms of intellectual disability alone. Despite these findings, little focus has been given to this group and their mental health.

Finally, people with dual diagnoses are less likely to be supported by provider organizations (Friedman, 2021). This disparity is probably because provider-owned or operated settings are supposed to be more community-based than institutions. However, they often poorly support people with dual diagnoses. The mechanisms behind these findings may demonstrate “transinstitutionalization,” or the systemic movement of patients from one type of institution to another, particularly in the cases of individuals with a dual diagnosis. Whatever the case, inclusivity within the definition of “community” needs to be expanded to incorporate all aspects of a population, especially the most vulnerable individuals.

Promising Evidence-Based Practices Currently in Place

One indicator of a successful state system for supporting individuals with IDD and mental health issues could be recidivism as it relates to institutionalization. Lulinski and Heller (2021) surveyed 65 agencies regarding the transition of 2,499 individuals from institutions to community-based settings. These investigators found that individuals with IDD who returned to more restrictive environments were younger, had higher intelligence quotients, and were more likely to have a dual diagnosis. Mental health service personnel reported that nearly 91% sought assistance from local police, 911, and emergency medical personnel due to aggression toward others, themselves, or property. Additionally, higher satisfaction scores were associated with private sector services and university-based services; lower satisfaction scores related to state-sponsored services despite widespread use. The agency size also correlated with recidivism; larger agencies with more people living in supported residential services tended to have higher recidivism rates and lower quality-of-life indicators. Lulinski and Heller (2021) offered four key concepts from their

analysis: The state needs to (1) increase technical assistance and crisis responses to behavioral issues, (2) enhance training in mental and behavioral health services, (3) improve interagency collaboration, and (4) increase reimbursement rates to providers (p.). O’Donoghue and colleagues found that recovery-oriented service models have positively impacted clinical outcomes and care experiences. Namely, there was an increase in community treatment orders following the reconfiguration of community mental health services; however, there was also a non-significant trend in reducing readmitted people (O’Donoghue et al., 2016).

Within their investigation, Totsika et al. (2022) identified applied behavior analysis and parent training as having an established evidence base for effective treatment. Emerging evidence suggested CBT and pharmacological treatments as effective treatment options. Discrepancies across diagnostic criteria, limited controlled studies, and the heterogeneity of IDD and mental health conditions limit the ability to identify evidence-based best practices for individuals diagnosed with IDD and presenting mental health symptomology. Totsika and colleagues purport that additional research to establish evidence-based best practices will require “substantial” resources (e.g., specialized staff, universal screening systems, and early intervention) (p.). Barriers including socioeconomic factors and stigma should be addressed as factors inherent in effective treatment. Universal preventive models to address mental health issues in individuals diagnosed with IDD are needed to identify and treat their emotional, behavioral, and mental health needs.

For persons with ASD specifically, Linden et al. (2022) discovered that various intervention strategies, such as pharmaceuticals, cognitive behavioral therapy (CBT), counseling, and mindfulness-based therapy showed signs of positive impact and opportunity. However, the analysis and findings of the study suggest that blanket therapies and policies are likely to be ineffective since each person with IDD/MH responds differently to the intervention strategies they are exposed to. In other words, what works for one individual with ASD and depression may not work for all persons with ASD and depression. Therefore, it is suggested that such strategies be catered and flexible to account for the individual needs of the person.

Comer-HaGans et al. (2020) noted that youth with IDD typically experience coexisting mental health and neurodevelopmental conditions, thus using more services than youth without IDD. Although research documents the prevalence of coexisting mental health and neurodevelopmental conditions and service use among individuals with IDD, little is known about these factors across developmental stages. This information is essential when considering assessment and treatment because it provides a more nuanced, developmentally appropriate approach to understanding the complexity of coexisting conditions in individuals with IDD. Further, knowledge about developmental stages can inform intervention needs at later stages, positioning interventionists to plan and adjust programs as youth mature.

In a survey conducted by Hawley (2017), respondents living in Texas indicated they had been protected from abuse, neglect, and exploitation by participating in community engagement and family support services designed to address their disability and personal needs. As Friedman (2021) noted, when faced with the option of integrated environments for people with dual diagnoses, people were 136 times more likely to live in integrated environments when they had individualized organizational support. Lambros et al. (2016) found that with the introduction of pre-crisis intervention strategies that catered to individual needs, parent-reported maladaptive behaviors decreased, adaptive and compliant behaviors increased, and students were achieving goals and felt satisfied within their academic endeavors. Therapists also reported that students were making positive progress. These results show that this program helped improve students' mental health, academic achievement, and school functioning (Lambros et al., 2016). Further, families of and individuals with IDD continue to benefit from respite programs because of the proactive policies that have been implemented (Hawley, 2017).

An analysis conducted by Brennaman et al. (2017) of related policies designed by the Agency for Health Care Administration (AHCA) found that it has a new requirement for general hospitals with psychiatric units designated as receiving facilities: They must have a special psychiatric emergency reception and triage area that minimizes individuals' exposure to undue and exacerbating stresses. This study determined that the AHCA should implement regulations that reduce waiting times for those who need involuntary mental health services by requiring all emergency department personnel to be adequately trained in mental health crisis response. It should be noted that more complete data about the reasons for excessive wait times in emergency rooms before transfer to a mental health treatment setting is needed. The findings further suggest that agencies responsible for the regulation of hospitals and mental health facilities should use this data and engage front-line caregivers to identify statutory remedies (Brennaman et al., 2017).

Telemedicine, as an option, allows patients to receive mental health care from facilities closer to home. By implementing statewide initiatives and online directories that display facility bed availability, wait times for mental health care could be shortened. Funding for not only in-patient facilities but also outpatient facilities could also be applied to avert psychiatric crises, avoid the need for emergency department visits, and improve access to emergency mental health services (Brennaman et al., 2017).

Crisis Intervention Experiences and Needs of Family Members & Self-Advocates

Researchers have attempted to survey families and caregivers of individuals with IDD to discover how the system works; what improvements family members can identify; and how cultural differences may affect the perception of individuals before, during, and after crises. The experiences of involuntary

psychiatric admissions require a systematic review of the individual in crisis, their family members, and support providers. Such research is needed to inform disability policy, illuminate the needs of families, and create new knowledge to inform families and service workers.

Shivers and Kozimor (2017) evaluated the Association of University Centers in Disabilities, a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities, in addition to a national database of businesses that support individuals with disabilities and their families. Parental report of their child having IDD or IDD/MH challenges was used as inclusion criteria. Their investigation included 40 families with children reportedly having IDD and nine families with individuals who reportedly had IDD and mental health challenges. Parents of children with IDD/MH reported significantly higher incidents of behavior problems. Siblings in the IDD/MH group reported significantly higher hostility, anxiety, and dysphoria levels. Parental perception toward their child with IDD and mental health issues was associated with a negative impact on the family. While additional study with a larger cohort is needed, Shivers and Kozimor (2017) support earlier anecdotal findings and hypotheses regarding negative feelings toward siblings diagnosed with IDD/MH and a need to study further the impact of individuals with dual diagnoses on families.

An investigation by the Indiana Resource Center for Autism (2022) found that 7.6% of individuals with ASD have been hospitalized due to crisis management interventions, with an average stay of 7.5 days. The reasons for hospitalizations ranged from aggression toward caregivers to psychiatric evaluation needs to severe mental health conditions (e.g., depression and anxiety). Further, 10% of family members who completed the Needs Assessment reported that their loved one with ASD has attempted or threatened suicide in the last 3 years. Those with ASD are three times more likely to commit suicide.

Comer-HaGans et al. (2020) found that youth with an intellectual disability have a greater likelihood of having coexisting mental health and neurodevelopmental conditions and of using services. Specifically, they are more likely to have certain coexisting conditions (e.g., autism, ADHD) and utilize certain services specific to their developmental stage. The authors suggest that clinicians must move toward precision intervention approaches to acknowledge the unique needs of youth at their developmental stage.

Shivers and Kozimor (2017) noted that parents of individuals with IDD and mental health issues have negative perceptions of the individual, which affects the family unit. The individuals are at more significant harm of suicide, self-harm, aggression, and non-compliance; behavioral issues frequently lead to more restrictive environments. Family members struggle with stress, financial anxieties, and long-term health and care needs. Shriver and Kozimor noted that many siblings of individuals with IDD/MH were not adequately studied, despite

siblings often being an individual's closest relationship. Research on the impact of siblings with IDD and mental health depends on the type of behaviors exhibited by the sibling with IDD/MH and the severity of the intellectual disability and mental health issues. Siblings not diagnosed with IDD or mental health conditions may struggle with diminished time with their parents due to the needs of their sibling. Their voices are often not heard.

Suicide and self-harm ideation are more common in persons with IDD and mental illness, and their family members are likely to experience high levels of stress and related mental health deterioration markers as a result of their roles as caregivers (Blumberg, 2019). Merrick et al. (2006) contested the long-standing assumption that impaired intellectual capacity protects persons with IDD from having suicidal thoughts. They found that expanding research to specifically address suicidal versus non-suicidal thoughts suggested a correlation among disability and non-disability suicidal tendencies, with little evidence that IDD diagnoses prevented self-harm ideation. Further, a national report published in the *American Journal of Preventative Medicine* found that a significantly large proportion of persons with IDD had confirmed suicidal ideation, thoughts, and attempts (Marlow et al., 2021).

Additionally, Lord et al. (2010) determined that adults with IDD often lack a voice in the public discourse and are excluded from taking part in their own personal health treatment and management plans. This segregation impairs their participation in social and economic life. These barriers to inclusion have profound social and economic effects on individuals with disabilities and their families or caretakers, prohibiting an opportunity for some level of independence and sustainable quality of life. A study conducted by Sugiura et al. (2020) emphasized this, finding that some adults with IDD felt abandoned when their families signed the admission documents. Those who felt suicidal or wanted to hand over control to medical professionals preferred to be admitted but felt they were not treated with care. Some felt that mental health systems did not work, while others wished they could be treated more like outpatients. As Friedman (2021) emphasized, people with dual diagnoses are more likely to live in integrated environments, interact with others, and participate in their community when they receive individualized organizational support.

Service Provider Perspectives

Although improvements have been made in assessing and treating individuals with dual diagnoses, developing training and support for the service provider professionals working with individuals with IDD/MH remains a priority focus for states and organizations. The development and implementation of evidence-based training and practices are required for professionals to have the ability to ensure effective assessment and treatment. Training and projects designed to effectively support people with a dual diagnosis will benefit from collaborations among families, mental and behavioral health clinicians, health professionals, service providers, and school systems. Without personnel specifically trained to assess and support individuals with dual diagnoses,

individuals with IDD will not have their mental health needs met, which can impact their mental and physical health and quality of life over time.

To gain the perspective of educators, Salm (2017) surveyed school personnel and trainees to assess pre-service training opportunities designed to support individuals with dual diagnoses in a Canadian urban high school. Salm interviewed 21 pre-service practicum students and in-service personnel who participated on a school-based team. Investigators included questions regarding learning opportunities for collaboration for students with dual diagnoses, how learning was applied to practice, barriers to pre-service learning, and the overarching vision of the team. Four competencies were assessed as essential support strategies: (a) role clarification, (b) student-centeredness, (c) communication, and (d) team functioning. Salm (2017) noted that the interprofessional competency model offered an exceptional professional development strategy but suggested a need for more culturally responsive practices and integration of inclusive educational stratagems.

In a study that evaluated provider views, Wormdahl et al. (2021), concluded that reducing referrals to involuntary admissions cannot be examined separately from the provision of other services. For example, when emergency services are busy, or general practitioners lack understanding of the individual, referrals to involuntary admissions are preferred over other options. Although mental health legislation requires that all options for voluntary engagement be exhausted, there is a possibility of unlawful referrals to involuntary admissions. This happens if services for this group are organized in such a way that the time-consuming nature of considering voluntary alternatives in an acute situation becomes the rationale for referral to involuntary admission. When professionals encounter situations where they must choose between an individual's right to autonomy and health care, a health care organization influences the decision. Professionals must then choose between involuntary admission and neglect, and the rationale and justification for the decision are potentially left unchallenged (Wormdahl et al., 2021).

Sugiura et al. (2020) noted that most providers tried to be empathetic and listen to their clients, but they felt coercion was necessary. They rationalized their decisions but welcomed the services that encouraged or allowed communication (e.g., Named Person role, advance directive, crisis plan, mental health review), and sometimes these services prevented involuntary admission. Professionals assessed patients using a medical model and felt the need to protect them was the most important thing. Professionals felt it was unnecessary to explain information to their clients because they would not understand it; however, they expressed a need for more coordination of their efforts for an effective admission process (Sugiura et al., 2020). As Man and Kangas (2019) noted, many psychologists treating people with intellectual disabilities do not believe their job includes mental health diagnosis. Although skilled in describing components of best practice, they do not report that their assessment practices reflect this. They often leave this to psychiatrists, with

some psychologists taking on more of a facilitative role. Interestingly, psychiatrists working with people with intellectual disabilities similarly report a lack of confidence in mental health assessment and diagnosis with the intellectual disability population (Man & Kangas, 2019).

Finally, when surveyed, many undergraduates support intellectual disability training, reinforcing the belief that education in intellectual disability benefits care in other areas of medicine, like working with patients with IDD. Having the capacity to work with patients with intellectual disability requires many skills, like being able to communicate effectively with the patient and using advanced communication skills, such as speaking in simple, concrete terms. In addition, taking a history from informants such as care providers and family members is often required. The advantages of having these skills are incredibly relevant to general psychiatry residents and were confirmed by 93% of respondents in a recent study (Burge et al., 2008).

Changes Needed to Improve Existing Systems

Depression in individuals with ASD is a common problem. Appleton et al. (2019) notes that anxiety in those with ASD and intellectual disability is unique and is not typically visible, so it is not always easy to identify. Without a reliable means of identifying and diagnosing those with ASD and an intellectual disability, individuals cannot receive the treatment and support they need. Care providers should be aware of this. In North America, one million people with ASD will experience a depressive disorder in their lifetime, and depression is often accompanied by other psychiatric comorbidities (Hudson et al., 2019). Regularly screening for comorbidities can facilitate access to treatments, such as talking to a school counselor or therapist, and mitigate the social and personal costs of these disorders.

Recent data show that involuntary commitments increased 64% from 2004 to 2015, partly due to misuse of the system (Monde'jar, 2018). Meanwhile, the elderly population—who suffer from dementia and act out as a symptom of the disease or other illnesses—are also often “Baker Acted.” While mental health advocates applauded the Baker Act in the 1970s, they now express concerns regarding the validity of research used to promote the status quo and subdue the call for more reforms of the current Baker Act system. Florida ranks 49th of the 50 states in terms of money spent on mental health care, and allocated funds are not enough to enact reforms because lawmakers passed them without providing the necessary funding.

Involuntary placement into a mental health treatment facility is an approach many Florida schools utilize to address safety concerns and an absence of other options in moments of behavioral crisis. The use of “Baker Acting” with school-aged children is increasing in Florida, often outside the legal scope of the Florida Mental Health Act (Southern Poverty Law Center (SPLC), 2021). The disproportionate use of the Baker Act toward students with disabilities contributes to inequities within educational settings and can also result in the

bypass of safeguards such as parental consent for restrictive procedures. Children with intellectual disabilities, with or without secondary mental health issues, are a vulnerable population requiring protection.

Reform is needed to ensure that there are consistent and reliable policies, practices and oversight structures employed in each instance of involuntary commitment. Such reforms could ensure that involuntary placements are not only essential in each situation but that the families are involved in the decision-making and that the intervention is the most appropriate and safe approach in caring for an individual in crisis.

Many opportunities exist to address concerns related to the overuse of the Baker Act. They include training school personnel, law enforcement professionals, mental health counselors, and families on IDD, mental illness, and trauma-informed approaches to crisis prevention and crisis management. Other options are integrating crisis teams with expertise in mental health, IDD, and risk assessment into school settings and adopting minimally invasive protective strategies during transportation to mental health facilities.

Although improvements have been made in assessing and treating individuals with dual diagnoses, developing personnel with competencies in evidence-based practices to support these individuals remains a priority. To effectively support individuals with IDD and mental health conditions requires collaboration among stakeholders, families, mental health coordinating staff, and school systems. Without personnel specifically trained to assess and support individuals with dual diagnoses, the needs of these students may not be recognized, and they will be at risk of becoming marginalized. Therefore, collaborative training opportunities that teach evidence-based best practices should be systematically explored. As Eaton et al. (2021) discussed, while behavioral indicators (in people with IDD) may not be considered “depressive equivalents” due to their limitations, they should alert clinicians to the possibility of underlying distress, which may be a depressive disorder. This is particularly relevant given that challenging behavior may not only indicate the presence of underlying depression but may also increase the risk of developing depression in the future.

Regarding law enforcement and the judicial system, Lemieux (2020) suggests that, at least in Florida, each police department be required to implement crisis intervention training and that the state establish a magistrate-certified mental health professional in every county. The state may also need to assign a public defender to hear only Baker Act cases to ensure continuity in the legal process. Further, the Legislature should amend the Baker Act to expand public defender access for juveniles.

Existing systems are more challenged in rural and other underserved regions. Technology facilitates relationship-building and expands access to care by allowing organizations to reach more people. Individuals living in poverty and rural areas are disproportionately impacted by a health care system that is

severely and pervasively fragmented and under-resourced. A subset of rural dwellers—those with a concurrent mental illness and developmental disability—face additional marginalization (Kreitzer et al., 2016). Technology also benefits agencies by offsetting workforce pressure and increasing the capacity for community-based organizations to expand their reach.

Poor communication represents another challenge within existing systems. Sugiura et al. (2020) notes that at involuntary psychiatric admission, clients were marginalized by a lack of communication and a power imbalance in the decision-making process. This sense of marginalization was exacerbated by professionals who rationalized coercion and by family members who relied heavily on hospital admission. Services and providers should respect an individual's autonomy. Clients need to speak and be informed. Families need to be informed and participate. For this to happen, professionals need to listen, explain, be aware of their power, be cognizant of their assumptions, and let go of feeling obliged to protect or provide solutions.

Many of these challenges will require government leadership and collaborative, interdisciplinary relationships to transcend structural and financial silos that exist in government-funded support systems. There are many examples of innovation in policies and practices that may provide guidance to state and local government in better supporting dually diagnosed individuals and their caregivers. Medicaid, for example, is an essential element in the development and success of innovative strategies. Policy must address changes in the way support services are funded, provide education and training to consumers and professionals, and provide criteria for administration of the state plan. Other efforts, such as those to improve and maintain the clinical capacity in the states, can also benefit from Medicaid through administrative dollars, including those potentially above the typical 50% match rate (NASDDDS, NADD, NASMHPD, 2019).

Part IV: Summary of Research Findings

Online Survey Questionnaire

A total of 244 individuals consented to participate in the study. Of these, 239 answered questions within the English survey questionnaire, five within the Spanish survey questionnaire, and none completed the Haitian-Creole survey questionnaire. Seventeen participants did not provide consent for the English version, two for the Spanish version, and none for the Haitian-Creole version.

The SurveyMonkey platform deployed all three surveys between May 6, 2022, and July 4, 2022. The questionnaires included both multiple-choice and open-ended questions. Each participant was screened-in through the SurveyMonkey site and digitally signed an adult consent form before they were able to continue with the questionnaire. The criteria required that individuals be at least 18 years of age; reside within the United States; were able to speak and

understand English, Spanish, or Haitian-Creole; and identify as a clinician, medical provider, first responder, law enforcement official, educator, case manager, family member, or direct support professional. Each subsequent questionnaire corresponded to the participant's affiliation designated as part of the screen-in process. Each question was voluntary, and each respondent provided answers to different amounts of questions, resulting in a completion rate of 58% for the English version and 29% for the Spanish version.

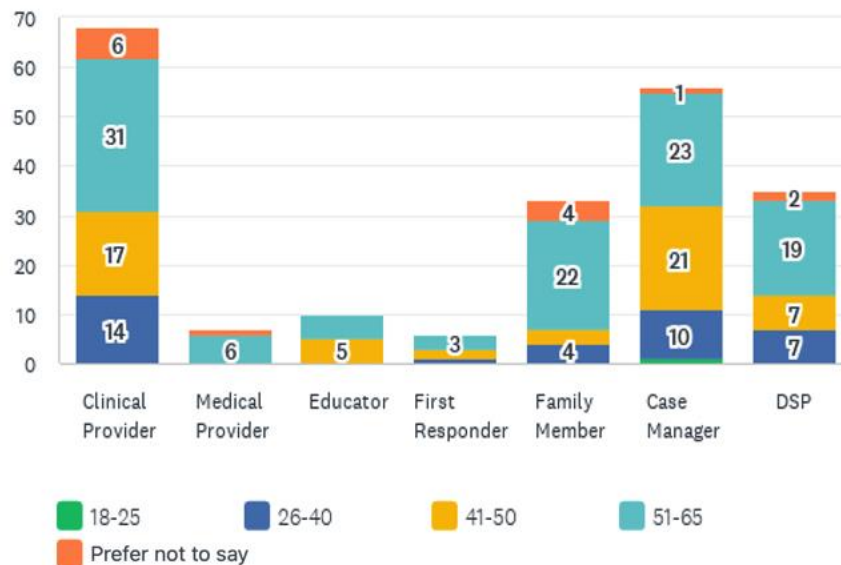
Participants were provided a contact email address for the NADD Research Team to use if they had questions or requested a copy of the digitally signed consent form. No compensation was offered or provided to any participant as part of this study.

Upon the surveys' closure, the data were downloaded and converted into a Microsoft Excel file and stored on NADD's encrypted Google Drive. They were organized by affiliation and assessed for information gaps, associations, and analyses performed within the IBM SPSS software. No identifying information, besides the unique automatic number assigned to each respondent by SurveyMonkey, was recorded or associated with any analyses or supporting material.

The open-ended responses for each participant were independently transcribed and coded using the NVivo software application. Thematic analysis was applied to determine parallels and variations within and between responses of the same affiliation, age range, gender, and geographic location. These data were consolidated with the multiple-choice responses (shown in **Figure 1**) and run through the IBM SPSS software application.

Figure 1

Affiliation by Age Range

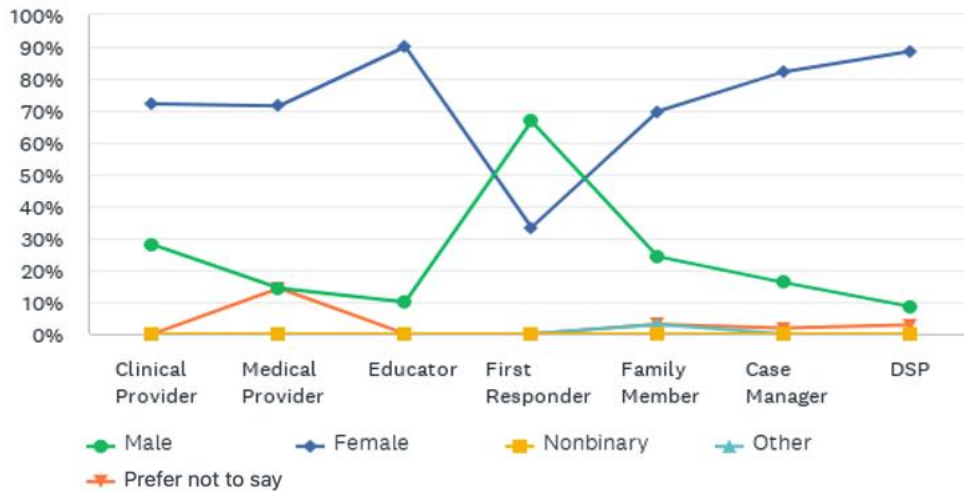


Note: Respondents aged 51-65 (51% of the population surveyed) were in each affiliation category. Subsequent age ranges of 41-50 and 26-40 comprised 26% and 17% of the total participant population, respectively. The remaining survey respondents (roughly 7%) were individuals who either preferred not to disclose their age or were 18-25 years old.

Further analysis was conducted regarding the composition of participants based on their affiliation and gender and is provided in **Figure 2**.

Figure 2

Gender by Affiliation

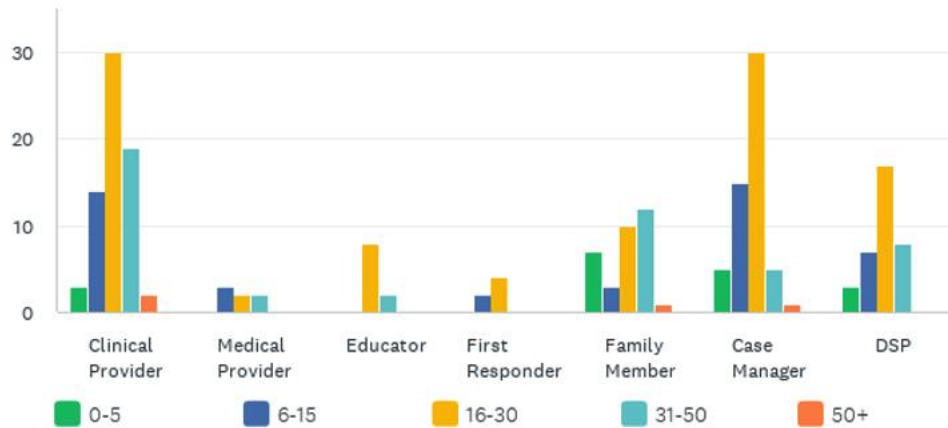


Note: Most respondents (77%) were female, especially if they identified as a clinical or medical provider, educator, family member, case manager, or direct support professional. Of the 45 male respondents who completed the survey questionnaire, 42% identified as a clinical provider, while less than 10% identified as any of the remaining affiliation categories.

Additional data were collected regarding the participant’s experience level with dual diagnosis, as shown in *Figure 3*.

Figure 3

Experience Level (Years) by Affiliation

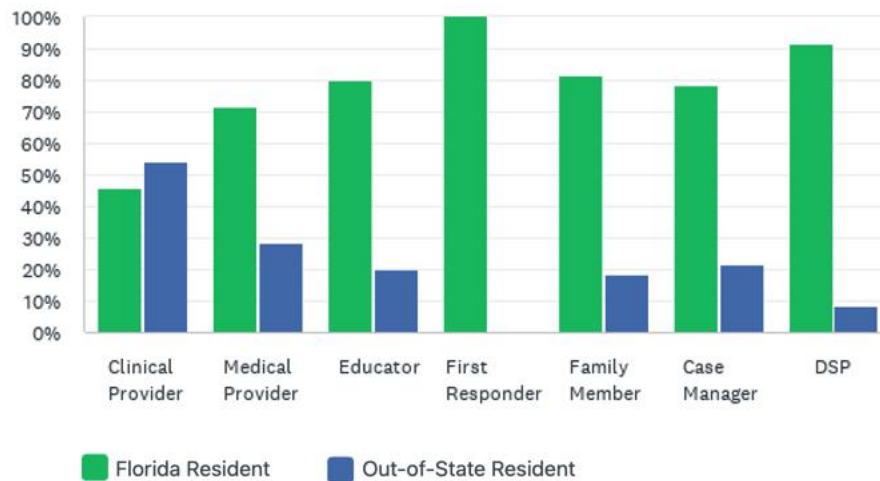


Note: The data analyzed shows that while most respondents (47%) noted that they had between 16-30 years of experience in their respective fields, much of this experience (76%) was attributed to persons who identified as clinical providers, case managers, or direct support professionals.

Finally, demographic data specific to residency was collected to differentiate participants who resided in Florida from those living in other states and is presented in *Figure 4*.

Figure 4

Florida Residencies by Affiliation



Note: Roughly 71% of the respondents disclosed that they resided in Florida. However, the counties in which they lived were spread out throughout the state, and not every county was represented.

Virtual Zoom Interviews

Nineteen pre-screening sessions were scheduled, with five no-shows. Nineteen interviews were scheduled, with one canceled by the participant, one canceled by the NADD Research Team due to lack of consent, and two rescheduled by the participants. All pre-screening sessions took place between June 27 and July 8, 2022, and all interviews were conducted between June 1 and July 20, 2022. The pre-screening sessions and interviews were presented in English and completed using the Zoom audio/video platform. The interview questions consisted of open-ended questions, and copies were provided to each participant via email before their scheduled interview date.

Each interview with a family member or self-advocate included the interviewer and the NADD Research Team’s Certified Trauma Informed Care representative. Individuals who identified as a multi-role individual were asked the interview questions for each of their respective affiliations. The interviews lasted an average of 30 to 60 minutes. No state-specific geographic questions were asked, though some participants chose to disclose that they resided in Florida, Maryland, Ohio, California, Tennessee, Idaho, Missouri, or Nevada.

All participants provided consent for the interviews to be audio recorded, and all recordings were downloaded and transcribed within 24 hours of completion of the interview. Transcriptions were coded by a member of the NADD Research Team, and all recordings, transcriptions, and database files containing the coding information have been and will continue to be stored on NADD's encrypted Google Drive. Upon project completion, all files related to the interviews will be downloaded to a password-enabled and encrypted external hard drive and stored in a locked filing cabinet for no less than 5 years.

Using homogenous sampling, 14 individuals were interviewed. Of the 14 participants, six were servicers, eight were family members, and five were self-advocates (some participants identified as multi-role), as shown in **Table 1**. Self-advocates and family members shared narratives that revealed some common themes that may be useful in an examination of existing systems of support.

Table 1

Interview Participant Demographics

	Affiliation	Residence	Gender	Ethnicity
BW.	Case Manager	Ohio	Male	Caucasian
IR.	Family Member, Case Manager	Florida	Female	Hispanic
IB.	Self-Advocate	Idaho	Male	Caucasian
LL.	Case Manager	Maryland	Male	Caucasian
MN.	Family Member	Florida	Female	African American
AG.	Self-Advocate	Nevada	Female	Caucasian
JK.	Family Member	Tennessee	Female	Caucasian
DC.	Self-Advocate	Unknown	Female	Caucasian
JW.	Family Member, First Responder	Missouri	Female	Caucasian
MC.	Family Member, First Responder	California	Male	Hispanic
KK.	Family Member	Nevada	Female	Caucasian
AL.	Family Member	Tennessee	Female	Caucasian
AK.	Case Manager, Family Member, Self-Advocate	Unknown	Female	Caucasian
AC.	Self-Advocate	Florida	Male	African American

Note: Although names were collected as part of the interview coordination process, each participant was assigned an acronym to protect their identity and keep their information confidential. Interviews were coded and analyzed by applying a thematic analysis to the respondents' answers.

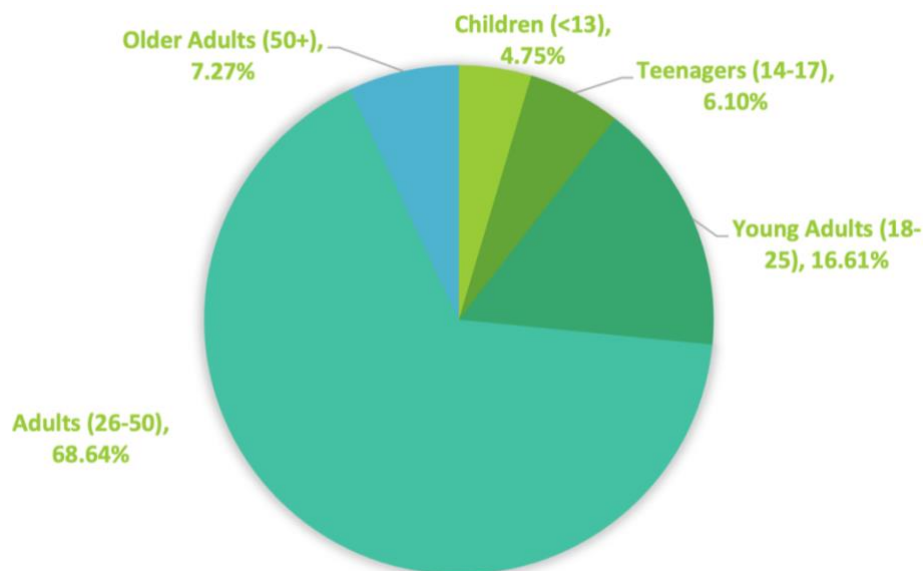
Part V: Discussion of Findings

The survey responses and interviews provide valuable information regarding effective support strategies, promising practices and policy considerations, and insights from personal experiences of being involved in crises.

Most of the participants noted that they primarily cared for, treated, or interacted with persons with IDD who were between the ages of 26 and 50, as noted in *Figure 5*.

Figure 5

Population Ratio by Age Range (Persons with IDD)



Note: A large proportion of the population identified (over 27%) were children, juveniles, young adults, and of college age. This suggests that proper diagnosis, treatment, and care is essential at an early age to support the needs of persons as they transition through developmental stages into adulthood.

Participants were asked to provide their perceptions of the existing processes, resources, and policies that have impacted them or the person they treat or care for directly. **Table 2** provides a high-level view of the responses of each affiliation category as a consolidation of the main themes derived from their grouped responses.

Table 2

Analyses by Affiliation

	Training	Collaboration	Resources & Services	Accessibility	Success Measures
Clinical Provider	Adequate	Adequate	Insufficient	Difficult	Non-job-related training Behavioral management techniques Trauma-focused lens to care
Medical Provider	Inadequate	Non-existent	Insufficient	None specifically identified	None specifically identified
Educator	Inadequate	None specifically identified	Insufficient	None specifically identified	Active engagement within school system
First Responder	Inadequate	Adequate	Sufficient	Unknown	Self-assessment training to reduce violence
Family Member	Inadequate	Unknown	Insufficient	Difficult	Responsive care that focused on the individual (not condition)
Case Manager	Adequate	Adequate	Insufficient	Difficult	Self-education helped in crisis situations
DSP	Inadequate	Inadequate	Insufficient	Difficult	Strong support system
Self-Advocate	Inadequate	Inadequate	Insufficient or Unknown	Difficult	Allowing primary providers to be involved Giving self-advocates a voice in the process

The data analyzed shows that successful intervention strategies and policies surrounding collaboration, self-advocate participation, expansive and individualized responsive care, and enhanced training beyond the standards currently in place positively impacted a crisis event. Incorporating some (or all) of these concepts into future procedures may reduce the risk of unnecessary intervention strategies for all involved.

Experiences of Family Members and Self-Advocates

The following sections provide details combining quantitative and qualitative data collected from the surveys and interviews with family members and persons who have been diagnosed with IDD (self-advocates).

Family Members and Caregivers

Thirty-three persons who identified as a family member or caregiver participated in this study (twenty-five took the survey, and eight were interviewed). **Table 3** shows the respondents' demographic markers representing the individuals they cared for.

Table 3

Demographics of Individuals Cared for by Family Members (% of the Population)

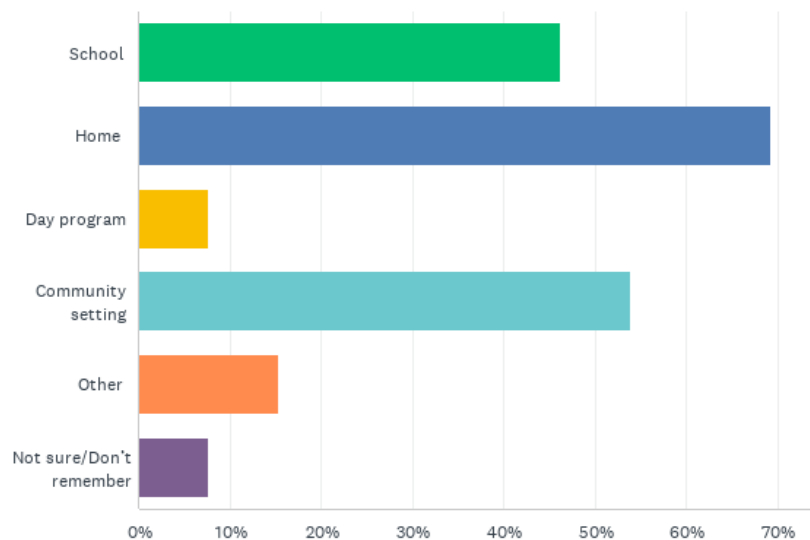
	Number of Respondents	Age Range	Gender	Ethnicity	Diagnosis(es)
Parent or Guardian	26	Adult (30%) Child (30%) Teenagers (30%) Young Adult (10%)	Male (60%) Female (40%)	Caucasian (65%) African American (15%) Prefer not to say (10%) Hispanic (5%) Asian/Pacific Islander (5%)	ID (60%) DD (50%) ASD (45%) IDD/MH (45%) Mental Illness (35%) Other (20%)
Adult Sibling	3	Teenagers (67%) Adult (33%)	Male (67%) Female (33%)	Caucasian (33%) Hispanic (33%) African American (33%)	Mental Illness (67%) DD (67%) ID (67%) Other (33%)
Significant Other	1	Prefer not to say (100%)	Male (100%)	Caucasian (100%)	Unsure (100%)
Prefer not to Say	3	Adult (67%) Older Adult (33%)	Male (67%) Female (33%)	Caucasian (67%) Prefer not to say (33%)	DD (67%) Unsure (33%) ASD (33%) ID (33%) Other (33%)

Although a majority of the family members surveyed or interviewed identified as a parent or guardian, it is evident that spousal and sibling caretakers also play a key role in the care of persons with IDD as they age. Further information about how lifelong caregiving is impacted by existing policies and resources may produce opportunities for long-term IDD treatment services.

Family members and guardians were asked about where crisis intervention events their loved ones experienced took place, with many noting that these incidents occurred in various locations. **Figure 6** shows the percentage representation of these events for each location identified.

Figure 6

Crisis Intervention Events by Location

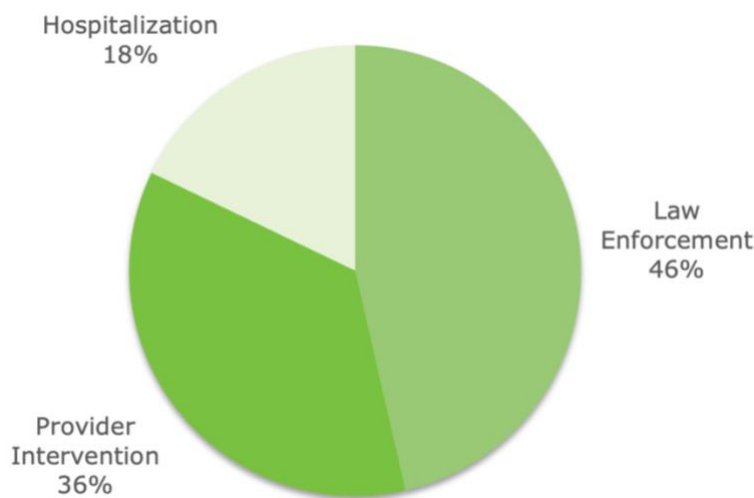


Note: This figure details the locations identified by 29 respondents who stated that their family members experienced a mental health crisis within the last 10 years, with 17 requiring crisis intervention procedures. Many of these crisis intervention events occurred at home or within a community setting, with others occurring at schools or day programs.

Figure 7 presents the percentage of these reported crisis events that involved third-party support (i.e., not family) to de-escalate or resolve the situation. Law enforcement and clinical or medical providers responded to most of the crisis events documented, reinforcing the need for these professionals to be properly trained, adequately educated, and sufficiently prepared to interact with individuals and their families during these incidents.

Figure 7

Intervention Rates by Third Party (Family-Reported)



Most respondents noted that the interactions with law enforcement tended to be more harmful than interactions with service providers or hospital staff. These participants mentioned that they felt that police were ill-equipped, poorly trained, and lacked the compassion or empathy required to handle the situation without resorting to aggressive tactics. However, participants also felt that some emergency rooms were overwhelmed, and that the intake process was arduous and cumbersome, especially given the situation’s emotional and behavioral circumstances. Approximately half of the participants did not feel their child’s or family member’s medical or clinical provider(s) were prepared enough to de-escalate the crisis before calling the police or referring the individual to the emergency room for treatment.

Several participants stated that their positive experiences related to successful de-escalation techniques. These techniques prioritized temperament moderation, rapport building, and cultural and linguistic accommodation, and included participants in the de-escalation and subsequent treatment process. Speaking in calming tones, utilizing providers who have a solid relationship with an individual, speaking in the primary languages of the families, and listening to those in distress had a tremendous impact on how the situation was resolved.

For example, one person interviewed mentioned that permitting them to have their dog with them during a crisis “helped tremendously with redirecting their anxiety,” ultimately de-escalating the situation before it required involuntary commitment or emergency services. Two individuals specifically acknowledged their appreciation for having someone who spoke Spanish fluently talk with them and their families to help address their concerns. They stated that this “made them feel as though they were being listened to,” and it helped calm them down and made them “feel more comfortable” than had they been forced to speak in English alone.

These resolutions often avoided unnecessary or prolonged hospitalization, reduced instances of self-harm (or threats of harm to others) and established a level of trust for both family members and those experiencing the crisis so the situation could reach a safe end.

Most participants felt prepared to manage and respond to their loved one’s mental health crisis. Roughly half reported that they felt comfortable and confident locating resources needed to support their child or family member’s mental and behavioral health. Knowledge of the various local, state, and federal laws and regulations surrounding the mental and behavioral health rights of their loved ones hovered around a 50% confidence level across all respondents. Finally, access to and familiarity with community programs and resources available to them to provide additional support options was split among participants. Several noted that they felt that what was available was insufficient and exclusive (i.e., race and socioeconomic bias play a role in the resources available within their communities).

Regardless of how the crisis events were resolved, the laws in place, or the resources available, most respondents (>80%) expressed concern for the health and well-being of their loved ones. Several respondents specifically talked about being “released without any direction” and how they felt emergency departments were “overwhelmed and unprepared” to help them.

Opportunities to enhance the services provided and promote positive outcomes from the family perspective include:

- Localized crisis prevention protocols for and involving people at risk, which include responsive, person-centered approaches designed to prevent escalation and address moments of crisis in a calm, non-reactive, and planned manner
- A model of collaborative engagement between the organizational, medical, and clinical treatment teams that intersect to support individuals with complex needs
- Cultural and linguistic competency when developing strategies

Self-Advocates

All respondents who identified as self-advocates stated that they experienced a mental health crisis requiring crisis intervention procedures within the last decade. Most of these intervention events took place at home or school. **Table 4** shows the respondents' demographic markers that represent how they identified under each category.

Table 4

Demographic Representation of Self-Advocates (% of the Population)

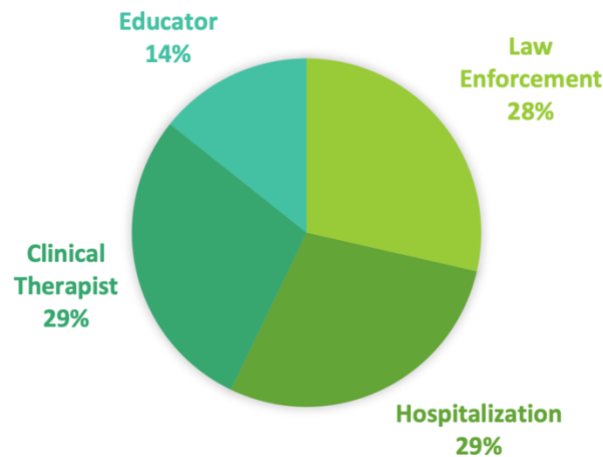
Number of Respondents	Age Range (Diagnosed)	Gender	Ethnicity	Diagnosis(es)
7	Young Adult (57%)	Female (57%)	Caucasian (86%)	DD (100%)
	Adult (29%)	Male (29%)	African American (14%)	ASD (57%)
	Child (14%)	Non-Binary (14%)		Mental Illness (57%) IDD/MH (57%)

Note: Seven persons who identified as self-advocates participated in this study (two took the survey, and five were interviewed).

Of these reported crisis intervention incidents, the self-advocates in this study identified four main third-party supporters, as shown in **Figure 8**.

Figure 8

Intervention Rates by Third Party (Self-Advocate Reported)



Note: This figure reiterates the prevalence of law enforcement’s involvement in crisis events, as well as the need for cross-collaboration among various participants in crisis intervention strategies, such as providers, educators, and hospital staff, to help de-escalate events effectively.

All the participants conveyed that they were confident in caring for their own medical and mental health needs. A few acknowledged the robust support systems that helped them cope and manage their symptoms. Specifically, one individual who disclosed previous suicidal ideation talked about their collaborative support network that comprised family, providers, and therapists who appeared to work together seamlessly. They noted that although they had thoughts of self-harm in the past, they had incorporated a diversified treatment and management team that addresses various aspects of their health and wellness, helping to teach them new ways to cope and de-escalate, as needed.

Many of the self-advocates stated that when they had a mental health crisis and their primary clinician was included, they felt calmer and more capable of coping with the situation. This was usually because their provider was well-informed and knowledgeable about their circumstances, feelings, and needs. The primary clinician performed various roles in the crisis, including speaking with them directly, listening to what they needed and how they expressed their needs, and conveying some of this information to the intervening officer, medical doctor, or whoever was present. Specifically, one respondent commented on how their provider “knew them well enough to change the subject.” Another respondent disclosed that their provider was able to calm their family members, which helped to “calm the nerves of everyone.”

Many participants felt appreciated and comforted by the support staff of the therapists and medical providers more than the providers themselves. Respondents who experienced a crisis intervention and did not have familiar support (such as family, a provider, or a primary care physician) present, commented that they felt uncomfortable, ignored at times, and unsafe.

The few participants who interacted with law enforcement during a crisis event felt the officers were too aggressive and intimidating. Specifically, when the officers would yell at them or have their hands on their firearms, they felt unsafe. One participant recalled that a law enforcement officer had told them they'd "end the situation using whatever means necessary," leading to an arrest and hospitalization.

Opportunities to enhance the services provided and promote positive outcomes from the perspective of people with lived experience include:

- Comprehensive training resources specifically relating to ASD and mental illness
- Training on culture, sexuality, and gender identity considerations when working with individuals with IDD
- Engaging the people receiving services and integrating their perspectives into treatment planning and support

Perspectives of Providers, Law Enforcement, Educators, Case Managers, and DSPs

The following data was collected from participants who completed the online survey only, and who identified as working within law enforcement, clinical or medical treatment, education, social services, or as a direct support professional.

Clinicians

There were 39 clinical providers that completed the online survey. These providers include psychologists, psychiatrists, therapists, and behavior analysts. **Table 5** summarizes the demographic population treated by these clinical providers.

Table 5

Demographic Information of Clinical Provider Patients

Avg. Clients per Month	Service Location(s)	Age Range of Clients	Clients' Diagnosis(es)
41 (online and in person)	16% - Private Practice (Home)	3% - Teenagers (ages 14-17)	73% - IDD
	26% - Telehealth (Phone)	8% - Children (up to age 13)	54% - IDD and Mental Illness
	32% - Other Intake Facility	18% - Young Adults (ages 18-25)	17% - IDD (undiagnosed mental illness)
	34% - Specialized Mental Health Intake Facility	72% - Adults (ages 26-50)	
	34% - Private Practice (Office)		
	47% - Telehealth (Video)		

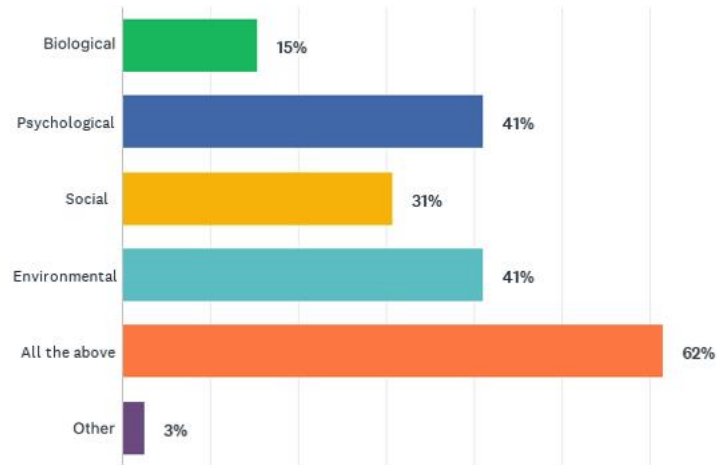
According to the respondents, approximately 68% of their clients showed indicators of self-harm or risk of harm to others. Of these, roughly 58% required a crisis intervention or referral to another person or agency who was able to provide the individual with more restrictive care. These referrals varied but typically included an in-patient psychiatric treatment center (38%), hospital emergency room (32%), an alternative community organization (15%), specialized outpatient mental health center (3%), or jail (<1%). Most respondents (68%) stated that referrals were typically completed within 72 hours, with some reporting timeframes anywhere from a week (3%) or longer (16%). A small percentage of the clinical providers noted that individuals with IDD were refused referrals due to their IDD status (5%).

Nearly 83% of the reported individuals who displayed signs of potential self-harm or risk of harm to others avoided involuntary intervention due to successful de-escalation procedures. Some of these procedures included isolation of the individual, implementation of dialectical behavioral therapy strategies, mobile crisis teams, crisis intervention-trained personnel, personalized emotional and behavioral support plans, and comprehensive follow-up management procedures.

Figure 9 identifies the components that significantly determine an individual’s diagnosis(es) of IDD/MH, as expressed by the clinical providers who shared their views on factors that contribute to involuntary intervention events escalating.

Figure 9

Involuntary Intervention Factors

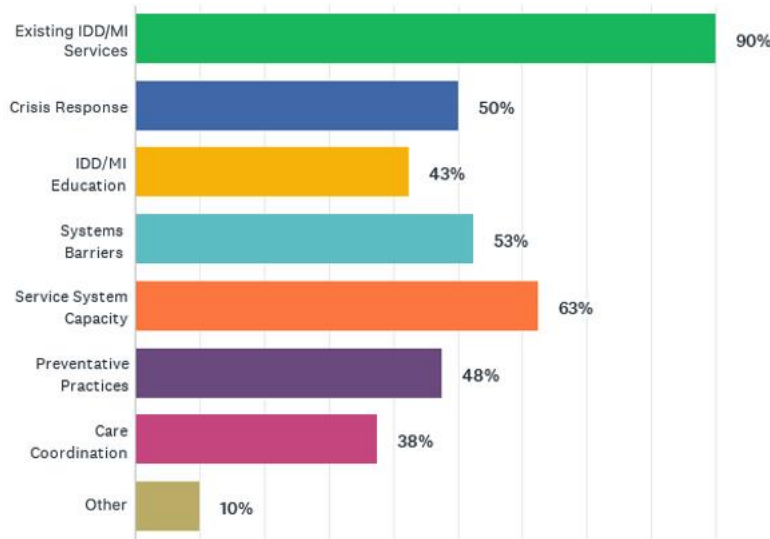


Note: The dominant factors that impact an individual’s IDD/MH diagnosis(es) include a combination of internal and external markers that comprise genetics, psychology, social aptitude, and environmental constraints.

In addition to these biological and behavioral factors, the clinical providers also suggested challenges to care that likely contribute to inadequate or insufficient services. **Figure 10** details the various barriers clinical providers discovered that negatively impact an individual’s ability to receive successful IDD/MH care.

Figure 10

Challenges to Proper Care



It is evident that existing systems play the most significant and impactful role in obtaining or prohibiting proper care for persons with IDD/MH. Taking into consideration the various other barriers noted, enhanced and improved policies and procedures that build upon the success measures currently in place may play an integral role creating promising practices in the future.

The following are current practices that clinicians noted have positive impact, promote very good service outcomes, and can be built upon across Florida:

- Trauma-focused responsive care to a crisis event
- Self-regulation and behavior management techniques provided to individuals as part of their standard care plan
- Access to regional and national certification and training programs or models, including CBT; rational emotive behavior therapy (REBT); applied behavior analysis (ABA); NADD dual diagnosis training and credentialing services; Systemic, Therapeutic, Assessment, Resources, and Treatment (START); relational frame therapy (RFT); and the Assessment, Intervention and Trauma Treatment Model (ACT)

Based on the data collected, opportunities to enhance services and promote positive outcomes include:

- Culturally relevant training focused on the needs of individuals with IDD and mental health conditions
- Specialized training designed to promote crisis prevention and management from a holistic approach
- Implementation of alternative crisis intervention tactics, including mobile crisis teams
- Crisis intervention training
- Expanded collaboration to incorporate cross-agency and cross-workforce training opportunities that apply real-world scenarios
- Inclusion of family and community support networks as part of treatment and management plans
- Definition of specific systems barriers and development of a plan to address those barriers
- Expanded training and education in IDD and mental health conditions in medical and mental health programs within schools

Medical Providers

Five individuals who identified as medical providers responded to the online survey. They included nurses, nurse practitioners, and primary care providers. The average years of professional experience were over 30 years each.

The respondents noted that they received limited training in treating individuals with IDD. One individual noted that they were currently a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) trainee. In contrast, three others stated they had participated in mandatory job-related training early in their careers. The respondents noted they had received limited training to work with individuals with a mental illness, with much of their job-related knowledge coming from self-exposure, self-learning, and school-related education before beginning their career. Training related to working with persons with a dual diagnosis was also limited; only one person disclosed that they had participated in an APD-required credentialing program.

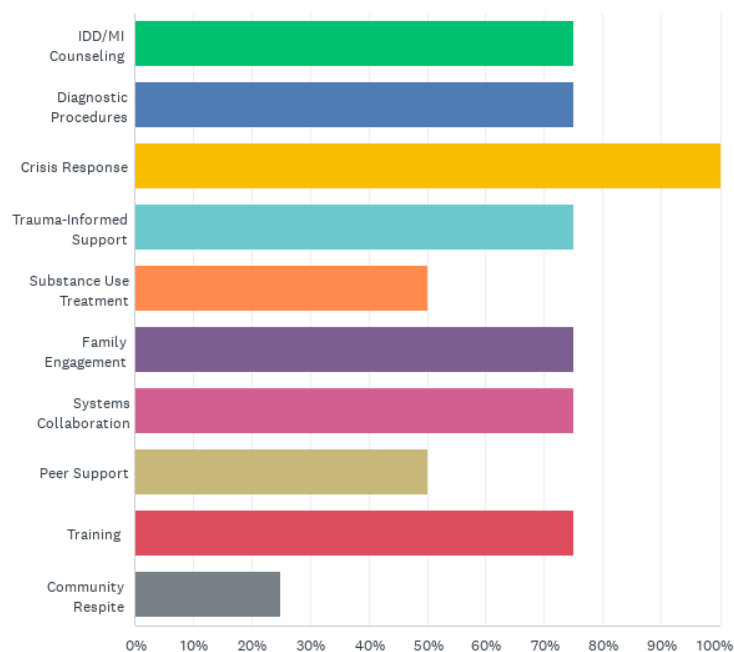
Though their training was limited, respondents stated they had personally been involved with an average of 54 incidents in which a client with IDD was experiencing a mental health crisis. During these events, their roles primarily centered around de-escalation supervision and providing medical treatment

due to injury. Most participants perceived the process in which the individual's treatment and care were transferred to another lead as efficient. However, they did not elect to, nor were they requested to, provide any follow-up with the transitioned individual or person experiencing the crisis.

Most medical providers who participated in this study agreed there are specific strategies that would foster successful outcomes for people receiving services, as shown in *Figure 11*.

Figure 11

Service Strategies Promoting Successful Outcomes



Note: The suggestions provided in this figure center around expanding or improving upon current systems and services already in place. The respondents noted that these strategies already exist but should be continually evaluated to enhance opportunities for successful treatment and care in the future.

Educators

Ten individuals identified as educators as part of this study. They consisted of teachers, administrative staff, an early interventionist, learning resource specialists, and district administrators, as shown in **Table 6**.

Table 6

Perceptions of Crisis Intervention Policies (% of the Population)

Policy Developer & Authority	Views of Policy Efficacy
60% - Principal	60% - Very Effective
40% - Regional or Local Education Authority	30% - Moderately Effective
30% - Teachers	10% - Nonexistent
20% - School Board	
20% - District Office	
10% - National Education Authority	
10% - Special Education Administrator	

Note: Roughly 80% of the participants worked for a public school, with the remainder acknowledging that they worked for a private school. All respondents said they worked in cities or towns with over 15,000 people. 90% of the respondents stated they worked in specialized settings, such as preschools, district offices, adult day facilities, or assigned program offices. Exceptional student education (ESE) or other specialized classes or programs were available at the districts, schools, facilities, or program offices where each participant worked.

Collectively, the educators who completed the survey noted that they felt that the existing policies and procedures surrounding crisis response and management tactics were effective and sufficient. Most of these policies and procedures have been developed by the principals or regional authorities but it isn't known if other faculty or staff at the schools or regional offices participated in the development process. **Table 7** provides the respondents' views on the training-related policies, procedures, and support systems they have directly utilized or been engaged with.

Table 7

Perceptions of Crisis Intervention Training and Resources (% of the Population)

IDD Training Available	Crisis Intervention Training Efficacy	Internal Crisis Support Systems Availability
90% - Yes 10% - No	60% - Very Effective 30% - Moderately Effective 10% - Nonexistent	70% - Specially trained teachers/aides 60% - Standardized crisis response training 50% - Crisis response team 30% - Psychiatric services 30% - Parental support services 20% - Collaborative procedures 10% - Not sure

Most educators (90%) noted that they have been involved with or provided mental health crisis intervention for students with IDD. Of these, 70% stated that they actively participated in the assessment or diagnosis of a mental health condition or IDD for students experiencing behavioral or emotional issues. Their roles varied from conducting behavioral assessment needs and Exceptional Student Education (ESE) evaluations to developing social and emotional development plans for students with IDD.

Based on this data, opportunities to enhance the services provided and promote positive outcomes from the educator perspective include:

- Expanded training for law enforcement, community mental health providers, family members, direct support staff, and crisis intervention team members
- Access to and utilization of effective diagnostic and assessment tools for people with a dual diagnosis

Law Enforcement

Five participants were identified as law enforcement for this study, with all stating they work in law enforcement as a police officer, sergeant, or lieutenant. **Table 8** details law enforcement’s level of knowledge regarding IDD and mental health resources, laws, and organizational roles and responsibilities.

Table 8

Law Enforcement's Knowledge of IDD and Mental Illness Influences

IDD and Mental Illness Familiarity	Availability of Community Resources	Knowledge of IDD and Mental Illness Laws	Organizational Responsibilities in IDD and Mental Illness Systems
80% - Moderately Comfortable 20% - Not Comfortable	60% - Moderately Aware 40% - Very Aware	60% - Moderate 40% - Excellent	60% - Moderately Familiar 20% - Not Familiar 20% - Very Familiar

The participants noted that they had received an average of 17 hours of training specific to IDD/MH crisis intervention in the last year. One stated that they felt the training was “excellent,” while the majority shared their training was “moderate to poor.” The key factor related to the positive perception of training centered on their ability to address the individual in crisis without using force. The main training issues were a lack of post-crisis management at the state level, assumptions of individuals as being all the same (with individual disabilities generalized), and a lack of continued training that evolved beyond the “entry-level” subject matter that was initially provided.

Most of the law enforcement officials felt that they personally, and law enforcement more broadly, were at least moderately prepared to support people with IDD/MH who are experiencing a crisis. All but one respondent stated that they were comfortable dealing with persons with IDD and mental illness during a crisis incident. Regarding crime, the participants reported arresting less than one person with IDD/MH per month over the last year.

However, this confidence may be impacted by assumptions and perceptions of an individual in crisis by responding officers. **Table 9** presents data collected related to likelihood of criminal activity and violence by persons in crisis as inferred by law enforcement.

Table 9

Impressions of IDD and Mental Illness-Causing Violence by Law Enforcement

IDD and Mental Illness vs. non-IDD and Mental Illness Aggression	Violent Crime Tendencies
60% - More Aggressive	40% - Less Likely
40% - As Aggressive	40% - The Same
	20% - More Likely

Based on the data collected, opportunities to enhance the services provided and promote positive outcomes from the first-responder perspective include:

- Introductory training on IDD, mental health, and dual diagnoses
- Advanced training on IDD, mental health, and dual diagnoses
- Training on non-aversive approaches to behavior management, including collaborative problem solving
- Standardized crisis intervention strategies

Case Managers

Thirty-five individuals identified as case managers for this study. Most (75%) reported that their clients are adults (ages 26-50); the rest are spread among children, teenagers, young adults, and the elderly. The participants anticipated an average of 41 persons they currently serve have IDD and mental illness (diagnosed or not).

Eighty percent reported receiving training focused on their work with persons with IDD/MH. One third believed the training was insufficient or ineffective. Approximately 83% of respondents disclosed being involved in a situation that required emergency responders or medical personnel because of a mental health crisis. Of these 929 incidents, all required the case manager to refer the individual to another case manager, facility, or agency for future treatment and care.

Many participants disclosed relying on law enforcement, self-education, mental health facilities, and a mental health crisis line to get assistance during an event when their client with IDD and mental illness was experiencing a crisis. More

than half of the case managers surveyed (66%) said they were not sure or confident about any available resources to use during a crisis.

Based on the data analyzed, opportunities to enhance the services provided and promote positive service outcomes from a case management perspective include:

- A comprehensive database of resources available to all professionals (clinicians, case managers, doctors, psychiatrists), individuals (people with IDD and their families), organizations (law enforcement, hospitals, providers), and systems (IDD, mental health, justice) involved in supporting individuals with IDD and their families
- Advanced on-the-job training
- Enhanced respite services
- Simplified and enhanced in-home support processes for families and individuals with IDD

Direct Support Professionals

Twenty-six individuals who identified as direct support professionals (DSPs) participated in this study. **Table 10** provides a breakdown of the general population served.

Table 10

Demographics of Clients Served by DSPs

Number of Clients Served	Age Range Served	Clients with IDD and Mental Illness
613 total (24 average per DSP)	69% - Adults 15% - Young Adults 12% - Older Adults 4% - Teenagers	290 total (11 average per DSP)

Half of the respondents stated they received some training designed to support an individual with IDD experiencing a behavioral or mental health crisis. The training types varied but mainly included NADD-DSP, behavioral support and analysis, and self-directed education.

Three quarters of the participants noted that they were involved in a situation with a client that required emergency responders or medical personnel. In such cases, 179 incidents resulted in the DSP referring the client to another provider or agency for further treatment and care.

More than 63% of DSPs surveyed stated they did not feel confident or were unaware of the resources available to assist them with dealing with individuals who experience a mental health crisis. Several DSPs stated they defer to family members, clinical providers, behavior analysts, medical providers, or law enforcement or call upon previous training to deal with challenging situations.

Sixty-three percent of the DSPs surveyed said they felt the individuals they support could benefit from expanded services, including additional community resources, better access to quality health and wellness care, additional and focused counseling, and expanded training for their families.

Based on the data collected, opportunities to enhance the services provided and promote positive service outcomes from a direct support professional perspective include:

- Dual diagnosis training for DSPs and family members
- A comprehensive database of community resources available to individuals with IDD and their families
- Increased collaboration with case workers and others who regularly interact while supporting the same people
- Diagnostic and assessment processes
- Community training to increase the education and understanding of people with IDD in their communities
- New or expanded community resources that welcome people with IDD

Overarching Changes Required

Nearly every respondent noted that improvements to existing training and access to additional resources were needed to ensure effective treatment and support for people with IDD/MH. Several respondents across different affiliation groups specifically addressed the opportunity for law enforcement professionals to become more educated about people who have intellectual and developmental disabilities and mental health conditions. They suggested that

collaboration and partnerships with IDD and mental health providers and other law enforcement as part of their existing training exercises will better support their work with individuals with IDD who have complex needs.

Many family members, self-advocates, and case managers supported processes that incorporate the direct engagement of the person receiving services in all service planning, including crisis prevention and intervention. Many participants noted that when they or their loved one was included in the process or had their needs addressed directly during a crisis, the crisis was resolved with limited to no hospitalization or further events recorded.

Respondents widely noted that an accessible and comprehensive directory of resources and information would be of immense benefit for families and all the different providers who support people with IDD. They stressed that currently it is a challenge to know what resources exist and how to find them.

Part VI: Conclusion

This study sought to assess promising practices related to supporting individuals with IDD and mental health conditions, obstacles to effective care, and the current state of the programs and policies that guide the intervention strategies used when a person diagnosed with IDD/MH experiences a mental health crisis. The data show not only systemic vulnerabilities but also a wealth of opportunities to promote the social and emotional wellness of people with IDD and mental health conditions.

The data and literature show strong practices are built on the following:

- 1) Leadership and commitment to collaboration, including building upon and enhancing partnerships; developing an intentional approach to build and maintain personal, effective working relationships; and ensuring cross-systems development and implementation of practices
- 2) Communication and mutual education, such as comprehensive evaluation of services and systems of care, assessment and clinical support, and capacity building through cross-training
- 3) Tenacity and creative solution identification, involving a collective willingness to try new strategies, like unique Medicaid structures, and continuing support over time with people who have complex needs
- 4) Expanded and collaborative education and training programs, tools, and resources in schools, including on-the-job training for caregivers and professionals who are fluent in current best practices for preventing and responding to mental health

crises for persons with and without IDD

This study produced many concrete recommendations regarding support strategies and policy initiatives that can be developed to promote the social and emotional wellness of individuals with IDD and mental health conditions. These can be broken into three categories—training, service innovation, and systems/policy considerations—which will be considered in turn in this report.

Training

- Develop distinct Dual Diagnosis Trainings on IDD, mental health conditions, and dual diagnoses for:
 - behavioral and mental health clinicians
 - case managers
 - direct support professionals
 - medical professionals
 - law enforcement professionals
 - school personnel
 - families
 - people with lived experience
- Adapt those trainings to meet the cultural and linguistic needs of the various groups that reside in Florida.
- Develop partnerships with law enforcement, school systems, and medical clinics/hospitals so they incorporate people with intellectual disabilities, their families, providers, case managers, etc., into their cultural inclusion or other training programs.
- Develop and provide training on non-aversive approaches to behavior management, including collaborative problem solving.
- Train professionals who provide diagnostic assessment to use the *Diagnostic Manual-Intellectual Disability* (DM-ID-2).
- Develop and provide community training to increase education about and understanding of people with IDD in their communities.
- Actively engage people receiving services and incorporate their perspectives into treatment planning and support.
- Identify, refine, and develop comprehensive training resources specifically relating to ASD and mental illness.
- Develop and provide training on culture, sexuality, and gender identity considerations when working with individuals with IDD.

- Create advanced dual diagnosis on-the-job training for case managers.
- Expand training and supports provided during in-home services for people who are dually diagnosed and living with families.

Service Innovation

- Define specific systems barriers to positive service outcomes and develop a plan to address those barriers.
- Simplify and enhance in-home support processes for families and individuals with IDD.
- Develop and deliver community training to increase the education and understanding of people with IDD in their communities.
- Identify and create new community resources that welcome people with IDD.
- Enhance respite services specializing in serving individuals with IDD and mental health conditions.
- Develop a Family Peer-Support Model or Program to address the care of individuals with complex needs.
- Create a comprehensive database of resources available to any professionals (clinicians, case managers, doctors, psychiatrists), individuals (people with IDD and their families), organizations (law enforcement, hospitals, providers), systems (IDD, mental health, justice), involved in supporting individuals with IDD and their families.
- Create a collaborative model of partnerships between intersecting systems that regularly engage independently (e.g., local police departments, providers, and medical personnel) to support individuals with complex care needs.
- Develop alternative crisis prevention, intervention, and post-crisis strategies that specifically address the needs of individuals with IDD/MH who are at risk of crisis and those around that person. Where possible, include the person in the planning before, during, and after the crisis.
- Establish localized crisis prevention protocols for people at risk that include responsive, person-centered approaches designed to prevent escalation and address moments of crisis in a calm, non-reactive, and intentional manner.

- Develop a local and regional service response team structure to assist providers and families who support people with complex needs to be deployed before a crisis.
- Standardize crisis intervention strategies for law enforcement.
- Develop trauma-informed crisis response strategies.
- Expand access to various regional and national certification and training programs or models, including CBT, REBT, ABA, NADD, START, RFT, and ACT.

Systems and Policy Considerations

The following systems and policy recommendations were developed through an analysis of the literature and data from the study, including support from an exploratory assessment conducted by NASDDDS in May 2022. This report is pending publication as of the conclusion of this project.

Policy Refinement—Many historic federal and state policies, particularly in the Medicaid program, have contributed to the exclusion of individuals with IDD from equitable access to mental health treatment. States making progress in these areas are undertaking policy and practice reviews to identify and eliminate these vestiges.

State System Collaboration—State systems supporting individuals with IDD and those supporting individuals with mental health support needs must collaborate to identify and remove systemic barriers to effective treatment and ongoing supports for individuals with IDD/MH support needs.

To build upon the work of this study, and work toward increased service capacity and enhanced life quality for individuals with IDD and mental health conditions, the FDDC may want to:

- 1) Initiate a cross-system workgroup to conduct a deep policy and practice review to identify specific policies and practices in Florida that limit the equitable access of mental health services for people with IDD.
- 2) Facilitate a collaborative process within the cross-system workgroup to create a strategic plan that addresses the identified policy and practice issues illuminated by the review of policy and practice.
- 3) Initiate a formal research study to learn about large systems changes made by other states to improve services, identifying what initiatives or approaches may be replicable in Florida.

- 4) Form a collaborative stakeholder committee to partner with the workgroup to identify options to affect systems change in Florida to better meet the needs of people with IDD/MH and to determine how to move those initiatives forward.

Part VII: Suggestions for Future Research

This study focused on collecting data to better understand the strengths and challenges related to supporting people with IDD and mental health conditions and examining existing programs, policies, and practices related to service approaches, including crisis prevention and intervention.

Although substantial insight and new information were obtained, future studies would benefit from the following considerations:

- 1) The low number of respondents within the medical, education, and first responder field requires that future studies focus on these fields specifically to learn more about their training, knowledge, and views on IDD/MH.
- 2) Future research may benefit from a strong emphasis on the inclusion of culturally and linguistically diverse groups within the research scope. It is likely that the low response rates of persons with limited English-speaking skills in our study relates to cultural and linguistic accessibility. Future studies should incorporate individuals who have direct ties within these communities and who could provide first-person perspective about any cultural barriers that may exist.
- 3) Future studies may be enhanced by a focus on semantics and linguistic identifiers to ensure terminology and categorical definitions have consistent meanings across groups studied.
- 4) Future studies should seek more objective data on results and outcomes of interventions designed to improve some of the areas of need presented in this study (e.g., training, education, and collaboration) as it relates to costs to private organizations, government, and families.
- 5) Future research may be improved with a focus on gender identity, race, and specific diagnosis (i.e., ASD) as a cross-section of the impact of resources, education, and training within IDD/MH care and crisis response. This intersectional assessment may further evaluate these potential factors as they relate to changes in policy, success measures, or inadvertent barriers to proper care.

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