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# National Crisis Intervention Research Study

An evaluation of best practices, barriers to service, and new insights to improve crisis response strategies and outcomes for school-aged youth living with a dual diagnosis in the United States.



NASMHPD

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## Executive Summary

The purpose of this study was to gain knowledge that would support improved crisis response strategies and outcomes for school-aged youth living with intellectual and developmental disabilities (IDD) and mental health issues (“dual diagnosis”) in the United States. This was accomplished through an extensive literature review and survey of current practices; the development and assessment of strategies that build capacity in the community; and the development of recommended strategies for improved crisis response.

Crisis response strategies for school-aged youth with dual diagnoses have historically included pharmacological interventions, hospitalization, or other approaches that exceeded or did not address the treatment need in the moment. We sought to identify current practices utilized to support individuals in the community (including homes, schools, and other locations) who experience behavioral and mental health crises, evidence-based best practices, and barriers to efficient crisis management.

The NADD research team assessed evidence-based practices that front-line personnel commonly used to support individuals and family members in home and community environments when crises occur, through the literature review and two surveys. The first survey was a preliminary assessment of current and best practices related to crisis response. The second follow-up survey assessed the feasibility of strategies and identification of resources needed should the strategies be implemented.

## Objectives

- (1) Identify strategies that build capacity in the community verified through a literature search and vetting of clinical practice of content experts.
  - Boolean search strategies were used to identify evidence-based practices. Search terms included: dual diagnosis, IDD, mental health, preventing hospitalization, crisis prevention, crisis intervention, intervention strategies, debriefing, de-escalation techniques, evidence-based practice, ethics, and culturally appropriate practice.
  - Analyses of the research to identify community-based crisis services associated with lower rates of hospitalization and recurrence of crises were conducted. Consumer characteristics associated with the risk of hospitalization were also identified.
- (2) Ask families, administrators, ER personnel (in states that utilize an ER-based behavioral hospitalization system), and first responders (in states that utilize a first-responder behavioral hospitalization system) about system issues.
  - Activities and questions were designed for quality improvement or evaluation of their program(s).

- (3) Conduct a follow-up survey of participants in the initial questionnaire to assess the resources needed to implement and sustain practices.

## Methods

This study was completed using a mixed-methods, quasi-experimental approach, with a focus on collecting both qualitative (open-ended) and quantitative (multiple choice) responses from family members, caregivers, providers, and professionals within the various culturally diverse dual diagnosis communities across the United States.

## Results

- The literature review identified the impact of trauma and crisis on the individual and family; alternatives to hospitalization; community-based interventions and elements necessary for the success of those interventions; disparities in service; school-based supports; and evidence-based practices. The data showed that effective crisis interventions require the incorporation of culturally informed best practices, a deep and sustained commitment to acquiring cultural knowledge, cultivating relationships with diverse communities, developing new evidence based training, practicing effective communication, and building sustainable processes for effective prevention and response.
- Survey results from approximately 856 individuals who participated in the first survey indicated that most mental health crises for youths with dual diagnoses involved mental health crises (80.4%) or behavioral incidents (77.74%). Other reasons for crises included harm to self or other(s) (68.37%) and aggression or threats (64.58%). Community providers and families indicated they are struggling to meet the needs of individuals in need of behavioral and mental health support.

## Conclusions

Several recommendations arose from this study that prioritized themes around improving the outcomes for persons with a dual diagnosis prior to, during, and following a crisis event, including:

- Improving communication strategies.
- Incorporating diversified information pathways, including embedding expanded technology opportunities to accommodate treatment and care preferences.
- Expanding and building upon existing training to include specializations for dual diagnosis providers.
- Providing clear options for referrals and alternative treatment services.

- Assessing the individual needs of each person with a dual diagnosis and their families in lieu of generalizing intervention and prevention services to a broadened audience.
- Prioritizing cultural, familial, and religious norms in crisis prevention and intervention efforts to ensure individual support/treatment plans address personal beliefs and traditions.



## Background and Literature Review

### The Crisis of Youth Mental Health

The past two decades have seen an alarming increase in mental health crises in children and youth. Nearly 20% of children and young people between the ages of 3 to 17 in the United States report a mental, emotional, developmental, or behavioral disorder, and suicidal behaviors among high school students increased by more than 40% in the decade before 2019. Mental health challenges were the leading cause of death and disability in this age group. These trends were exacerbated during the COVID-19 pandemic.

From 2009 to 2019, the proportion of high school students who reported persistent feelings of sadness or hopelessness increased from 26% to 37%. Suicidal behaviors among high school students also increased 44% during the decade preceding the COVID-19 public health emergency, with about 16% reporting having made a suicide plan in the prior year. Between 2007 and 2018, suicide rates among people ages 10 to 24 in the United States increased 57%, and early estimates show more than 6,600 suicide deaths among this age group in 2020.

The current mental health crises experienced by youth in the U.S. disproportionately affect young people with Intellectual and Developmental Disabilities (IDD) and their families. The prevalence of IDD with at least one co-occurring mental health condition ranges widely in the published literature, with estimates between 20 to 70% for children and adults (Kalb, Beasley, Klein & Charlot, 2016; Platt, Keyes, McLaughlin, & Kaufman, 2019; Stadnick et al., 2017). The chance of experiencing at least one behavioral or mental health crisis event is also correspondingly high for those affected, with risks persisting throughout their lives (Simonoff et al., 2013).

Seeking and receiving services is daunting for school-aged youth with dual diagnoses and presents caregivers and professionals with unique challenges and opportunities (Whittle et al., 2019). Many school-aged youth diagnosed with IDD have experiences that exacerbate mental health issues or trauma, further complicating accurate assessment and treatment. Cultural and familial barriers, including language differences, socioeconomic status, religious beliefs, and perspectives on mental health, also impact access to care. Addressing the wellness and mental health needs of school-aged youth diagnosed with IDD requires evidence-based approaches that are both culturally informed and responsive. The current state of the states regarding service provision for school-aged youth with dual diagnoses warrants evaluation and system change to meet the burgeoning needs of individuals diagnosed with IDD and their families (Guo, Biegel, Johnsen, & Dyches, 2001; Witwer & Walton et al., 2022).

A lack of collaboration between support agencies, high staff turnover, and burnout of providers adversely impacts the ability to provide effective treatment during critical periods, especially during behavioral or mental health crises. School-aged youth and

their caregivers often fall through the cracks when attempting to seek out mental health and wellness supports, and the disparities grow even wider when an individual has an IDD diagnosis. Some reasons for observed breakdowns in support include: (a) an inability to identify qualified service providers, (b) limited access to help in rural areas or overloaded urban areas, and (c) cultural barriers that contribute to fear or stigma involved in contacting established systems of support, including mental health providers, police, and other first responders (Vohra et al., 2014; Watson & El Sabawi, 2023). These factors impact the effectiveness of interventions and service providers' ability to build rapport and relationships to mitigate behavioral incidents and potential subsequent trauma. The identification of evidence-based practices will help guide research and policy and reduce systemic barriers that families of school-aged youth with dual diagnoses face when accessing mental health treatment.

The mental health needs of individuals with dual diagnoses (IDD and a psychiatric diagnosis) often go unrecognized and untreated due to a variety of factors. First, finding knowledgeable professionals with expertise in mental health and IDD who agree to provide services is a prominent concern (Adams & Young, 2021; Bishop; Fitzpatrick & Kind, 2017). Many professionals report feeling underqualified to support individuals with dual diagnoses of IDD and mental health challenges (Brookman-Frazee et al., 2012; Zerbo et al., 2015). One of the top concerns in a recent review of the literature on barriers to mental health supports was a lack of training on specific types of disabilities (e.g., ASD) within professional disciplines (Adams & Young, 2021). This perspective was reported by both individuals with an IDD diagnosis and family members.

A second issue that hampers access to mental health services relates to the availability of providers in locations where children with IDDs and their families reside. Access to care is often limited in rural areas but may also be problematic if people are placed on long waiting lists in urban areas (Adams & Young, 2021). Insurance coverage is another important consideration for families, especially when there is a lack of coverage and the costs for copays, specialists, lost time from work, and travel to appointments exceed what families can manage. In the wake of the COVID-19 pandemic, as many families grappled with threats to their health and livelihood, the gaps in service provision only widened. Providers struggled under higher caseloads, and many businesses shifted to a telehealth model of service delivery (Gibbs, Cai, Aldridge, & Wong, 2021; Stavropoulos, Heyman, Salinas, Baker, & Blacher, 2022). One positive outcome of the pandemic has been the increased attention to expanding access to care via telehealth and app-delivered mental health services to fill unmet needs.

A third critical issue involving mental health care for those with dual diagnoses involves disparities in care based on cultural variables. Reasons for disparities vary widely, including difficulties with access and communication with providers due to language barriers and family-specific issues, such as fear of contacting law enforcement and cultural and religious perspectives. A 2017 review on care for individuals diagnosed with IDD found stark differences in quality of care based on race

and ethnicity, with Latino and Black children experiencing lower-quality and less frequent care as well as less coordination with families (Bishop-Fitzpatrick & Kind, 2017). Other issues cited included having no primary care physician, less frequent referrals to specialists, and providers who demonstrated insensitivity to Black and Latino family culture and values compared to White families. Amid a behavioral or mental health crisis, a timely response is essential to promote stabilization. Many families who speak a primary language other than English report difficulties with communicating their needs effectively to first responders, thus hampering access to care (Haverkamp et al., 2020; Magaña et al., 2015; Magaña et al., 2016).

A further issue that warrants attention in health care for youth with IDD is the complex history of social injustice and systemic racism, which presents a barrier to many families reaching out for help. Access to quality mental health care, while already difficult, is rendered even more difficult for some families who may hesitate to seek assistance from first responders for a loved one experiencing behavioral or mental health crisis due to a history of unequal or abusive treatment by members of law enforcement. Research also indicates gaps in services for families of other cultures, including American Indian, Orthodox Jewish, and other minority families (Ni et al., 2017; Schnall et al., 2014). Other cultural variables include religious and cultural perceptions of IDD and mental health issues, which some families perceive as a stigma or punishment from a higher power.

The Mental Health Services Oversight and Accountability Commission, State of California (2016) reported on the process whereby Commission members surveyed youth, parents, consumers, policymakers, and advocates to gain a broad understanding of the real-world experiences of children and youth in crisis throughout California. The MHSOAC staff conducted an extensive review of published literature, training initiatives, and related material on children's crisis service models. The project also reviewed national guidelines and specific state models of successful system responses to children's mental health crisis services. This review provided a foundation for the development of specific, action-oriented policy and highlighted recommendations and opportunities for the rest of the nation to emulate for a holistic approach and strategic vision of mental health care for all.

The current approach to crisis intervention uses a “fail first” methodology. “Fail first” refers to an approach of rationing mental health services to those with the highest needs who are often identified following one or more major incidents such as hospitalization, school dropout, or incarceration. The “fail first” approach focuses on providing services following a crisis event rather than emphasizing prevention and early intervention.

The Commission summarized the essential flaws in the crisis response system as it exists today:

“Law enforcement and emergency rooms are ill-equipped to handle mental crises for children. Far too often, families and caregivers of children, some as young as 5 years

old, must turn to law enforcement and emergency departments that are ill-equipped to address mental health crises for children. The experience of waiting for hours or days in a noisy, chaotic, and frightening emergency department (“ED”) during what is already an extremely stressful and vulnerable time for children and their families can dramatically increase the mental and emotional trauma inherent in a crisis.”

## The Impact of Trauma

Recent research suggests that the effects of trauma are particularly harmful during childhood and adolescence. Children who experience trauma, especially repeated trauma, may display severe effects that may be interpreted as other psychiatric disorders. As a result, children and adolescents may be misdiagnosed and receive unnecessary and/or inappropriate treatment for psychiatric disorders they do not have (Rubin, 2009; Van Der Kolk, 2003). They may instead experience psychological, emotional, and even cognitive damage from repeated traumatic experiences.

Youth with IDD are at increased risk for various types of traumatic experiences. These experiences include physical and emotional neglect and physical and sexual abuse, as well as trauma secondary to restraints and seclusion and other interventions intended to de-escalate behavior that poses a danger to oneself or others. Youth with IDD are also more likely to experience changes in educational placements and school settings, out-of-home placements (at times accompanied by parental loss), and changes in residential placements. As a result, many youth are more likely to experience disruptions in social supports (Trauma and Intellectual/Developmental Disability Collaborative Group, 2020).

Children with IDD are at a heightened risk for teasing, bullying, rejection, and exploitation by peers and social media. This risk is further compounded for individuals vulnerable to discrimination due to race, ethnicity, language, and socioeconomic status. Youth with more severe IDD are likely to experience a higher number of health-related procedures, as they often have chronic or comorbid conditions that necessitate surgeries, other invasive procedures, and frequent healthcare appointments. Such disruptions may put youth with IDD at risk for medical trauma.

Nonetheless, trauma exposure and symptomatology are believed to be underreported for several reasons. As noted, some youth may be unable to communicate their experiences or distress to caregivers and professionals, who may themselves have limited understanding of trauma and trauma-related symptoms. Because of this, caregivers may attribute trauma-related behavior to the developmental condition alone. Such misattribution may delay or prevent needed services and contribute to or exacerbate a youth’s functional difficulties.

Children and youth with IDD experience high degrees of social isolation and abuse. Youth who experience ongoing abuse may experience extended periods of time in a state of fear and helplessness. Over time, this experience may result in learned

helplessness and a loss of self-efficacy, as they do not believe their actions make a difference in the outcomes of their lives (Schwartz, 2021). Individuals with IDD often experience significant treatment disparities and exposure to traumatic events (Houck & Dracobly, 2023). Identification of trauma in individuals with IDD may be challenging due to inherent communication difficulties.

## Families in Crisis

The development of family-based interventions and methods of effective treatment have largely been ignored. Monro (2009) suggested that family-based treatment methods for children and youth with IDD represent the most neglected area of professional training and development in the mental health professions. Yet, without the active participation of family members, well-developed, expensive, and sophisticated behavioral and psychiatric treatments may be rendered useless or fail. Stabilizing the family system benefits everyone and establishes a foundation from which to treat the child or teen with a dual diagnosis (Munro, 2016; Baker and Blumberg, 2016, p.187).

In times of emotional or behavioral crisis, families often have no alternative but to utilize hospital Emergency Department (ED) services (Weiss et al., 2011). Additional services may also be needed to stabilize individuals. Weiss and colleagues examined the demographics and features of crises associated with ED usage to develop a more proactive approach to mental health service provision.

When a family contacts law enforcement, they often lose control of the situation. Most law enforcement officers and other first responders serve to establish public safety and order, and they are not typically trained to recognize or effectively respond to a person with a dual diagnosis. After initial stabilization, the next course of action often involves transportation to a hospital emergency department. Frequently, the child does not need emergency room or mental care facility services; instead, they need other specialized services that are bypassed once law enforcement is called. Moreover, the costs of involving law enforcement, ambulance rides, and inpatient treatment facilities often become the responsibility of the family in need, adding financial stress to the already difficult situation.

Youth with IDD are at greater risk for suicide, self-harm, aggression, and non-compliance, and families bear the brunt of the burden of care. Family members struggle with stress, behavior, financial concerns, and long-term health and care needs. Shivers and Kozimor (2017) noted that parents of youth with IDD and mental health issues negatively impact parental perceptions of the individual, in turn affecting the family unit as a whole. A further finding was that many siblings of individuals with IDD and mental health issues are under-studied despite the important roles they play in the life of the affected individual. Research on the impact of siblings with IDD and mental health depends on the type of behaviors exhibited and the severity of the intellectual disability and mental health issues (Shivers & Kosimor, 2017). Siblings not

diagnosed with IDD or mental health issues may also struggle with diminished time with their parents due to the needs of their siblings, but their voices are often not heard.

For many families, a diagnosis of IDD or mental health disorder is a catastrophic event that alters their lives in immeasurable ways. The perceived stigma of disability and mental health issues is described by many parents and caregivers as isolating, while others reported resilience factors, especially based on cultural and religious variables (Mitter et al., 2019). A recent review on disability and stigma revealed different coping strategies used by families, with families from some Asian cultures hiding the disability from others out of a sense of shame or guilt, resulting in reported increases in stress and burden (Kang-Yi et al., 2018; Mitter et al., 2019). Some reviews of cultural experiences of disabilities in multicultural families reported benefits of support from their faith communities, including Latino, Black, and Muslim families (Cohen & Miguel; Rassool, 2015; Zuckerman et al., 2018).

Shivers and Kozimor (2017) surveyed the Association of University Centers in Disabilities and a national database of businesses that support individuals with disabilities and their families. The inclusion criteria included parental report of their child having IDD or IDD and mental health challenges. Investigators surveyed 40 families with children diagnosed with IDD and nine families of individuals who reportedly had IDD and mental health challenges. Adjusting for the disparate group sizes, statistical analysis indicated that parents of children with IDD and mental illness (MI) reported significantly higher levels of behavior problems. Siblings in the IDD plus MI grouping reported significantly higher levels of hostility, anxiety, and dysphoria. Parental perception toward the child with IDD and mental health issues was also associated with a negative impact on the family. While additional study with a larger cohort is needed, Shivers and Kozimor (2017) support earlier anecdotal and hypothesized negative feelings toward siblings diagnosed with IDD and mental illness and identify the need to study further the impact of individuals with dual diagnoses on families.

## Alternatives to Hospitalization and Involvement of Law Enforcement

### *Integrated and Community-Based Services*

Across the U.S., the urgent need for quality, community-based mental health care is well documented. A recent multi-state survey of individuals, caregivers, and professionals indicated that the majority struggled to access care during times of crisis (Farr et al., 2022). Few related positive experiences involving interwoven networks of support tailored to their diagnoses and unique needs. Two major outcomes of the survey by Farr and colleagues were the need for improved communication between teams on behalf of individuals with IDD and better training for respondents to behavioral or mental health needs.



Psychiatric hospitalization remains a controversial issue. First and foremost, concerns exist regarding possible negative outcomes during and after a psychiatric admission. A brief period of stabilization may lead to a revolving door with a return to the hospital without long-term planning. Loch (2014) summarized some of the most important negative outcomes after discharge from a psychiatric institution. These experiences were organized into two groups: those after a brief psychiatric hospitalization and those after a long-stay admission. Loch (2014) further suggested ways to minimize these adversities, emphasizing the need for increased awareness of the needs of youth with dual diagnoses who may experience behavioral or mental health crises.

Psychiatric hospitalizations of children with IDD are common; however, there is limited comparative information on the effectiveness of different psychiatric hospital treatment models. Co-occurring mental health issues (e.g., anxiety and depression) are more prevalent in individuals with IDD (Taylor et al., 2019). Specialized care that focuses on the individual's needs inherent in an intellectual disability (e.g., communication deficits) as well as existing mental health support is necessary. Unfortunately, psychiatric hospitals with personnel trained in the effective treatment of individuals with dual diagnoses are few and far between. Taylor and colleagues compared a specialized unit with staff who had expertise with both IDD and mental health to a "general" psychiatric hospital unit. While children in both centers showed marked reductions in aberrant behavior, school-aged children admitted to the specialized unit were less likely to have a subsequent ED visit and reportedly were better prepared to deal with behavioral incidents related to hospitalization. Key inpatient treatment components mirrored the findings of McGuire et al. (2015), who recommended an expanded admission interview, screening for medical issues underlying behavioral problems, assessment of comorbid diagnoses, behavior-based reinforcement systems, and communication supports. The development of treatment pathways for school-aged youth with dual diagnoses to inform treatment providers in hospitals and the community is critical.

Okafor and colleagues (2016) investigated integrated emergency medical and psychiatric care at an urban, low socioeconomic public hospital. The researchers identified quality improvement metrics to develop a more efficient system for processing individuals presenting with mental health crises. Previous surveys of physicians noted that the use of emergency departments for mental health services reduced the quality of care in hospitals. Minimal training of first responders further exacerbated the use of emergency departments as triage centers for mental health crises. Length of stay and reduced use of restraints were noted for a significant number of the 4,329 patients tracked. Integrated emergency care services were also associated with the overall load on hospital emergency rooms. Okafor et al. (2016) noted the need to develop community-based integrated behavioral health care to better serve the needs of individuals with behavioral health disorders.

Hall et al. (2006) examined the services provided to individuals who have IDD and comorbid mental health needs in England. Hall and colleagues compared a specialized psychiatric hospital setting to an outpatient "virtual" treatment model. The inpatient

unit included a treatment team trained on the needs of individuals with IDD and comorbid mental health issues. Members of the inpatient treatment team also worked with and coordinated community-based services with inpatient mental health services. The virtual team included community services and nursing support from inpatient nursing staff. The virtual team met on a regular basis and provided additional support during crisis, facilitating discharge from the hospital as well as ongoing post-hospitalization support in the community. Both groups showed improvements in outcomes, with the participants receiving inpatient services showing a non-statistical increase in placements compared to individuals in the community-based virtual team treatment grouping. It should be noted that individuals receiving inpatient services also reported increased use of polypharmacy—an increased use of medications to treat symptoms. The community-based treatment model was associated with individual reports of met needs above those reported by individuals treated via the inpatient model. Despite the success of community-based models, some individuals with IDD and mental health issues may require inpatient hospitalization; service models that integrate both inpatient and community-based practice can effectively diminish the need for crisis intervention.

Individuals with IDD often experience significant treatment disparities and exposure to traumatic events (Houck & Dracobly, 2023). Identification of trauma in individuals with IDD may be difficult due to inherent communication disparities. With adverse events a critical feature of trauma, assessment instruments must be modified to accommodate communication deficits and efficiently identify how trauma affects behavioral incidents and how behavioral incidents lead to subsequent trauma.

Traditional forms of counseling and psychotherapy have historically been unavailable to individuals with IDD, leading to discriminatory and reactive practices, including segregation and isolation. Houck and Dracobly (2023) contend that problematic behavior is exhibited by individuals who have experienced traumatic events, and overt recognition of the trauma is critical to prevent repetition of the traumatic event. The authors recommend that professional organizations include training on recognizing the signs of trauma and precursors that lead to repeated incidence. Furthermore, assessment tools are needed to accommodate communication issues and help families recognize the impact of distress. Policymakers and service providers should work collaboratively to identify best practices when it comes to the identification of traumatic events and their impact on the behavioral and mental health of individuals with IDD and dual diagnoses.

### *Use of Emergency Departments and First Responders*

Youth in crisis often present to emergency departments (EDs) but may not need or benefit from that level of care. Instead, data reflect improved clinical and financial outcomes when communities offer a continuum of crisis services. Sowar et al. (2018) presented care models from two communities—Ventura County, California, and the state of Connecticut—and reviewed program development, implementation, and



monitoring. Sowar and colleagues also highlighted principles for leaders to consider in developing these services.

Youths are using emergency departments for behavioral health services in record numbers, even though EDs are suboptimal settings for service delivery. Fendrich et al. (2019) evaluated a mobile crisis service intervention implemented in Connecticut and examined whether the intervention was associated with reduced behavioral health ED use among those in need of services. Using comparison groups, Fendrich and colleagues provided evidence suggesting that community-based mobile crisis services, such as Mobile Crisis, reduce ED use among youths with behavioral health service needs.

Kalb et al. (2012) examined the prevalence and characteristics of psychiatry-related ED visits among children with an autism spectrum disorder (ASD), including the specific reason for the visit, as well as the influence of insurance type. Thirteen percent of visits among children with ASD were due to a psychiatric problem, compared with 2% of all visits by youths without ASD. Results from the multivariate analyses revealed that the likelihood of a psychiatric ED visit was increased nine-fold among pediatric ASD visits compared with non-ASD visits. Children with ASD who were covered by private insurance, compared with those with medical assistance, were at even greater risk for a psychiatric ED. Visits among children with ASD were more likely to be due to externalizing and psychotic disorders compared with visits among non-ASD children. This study highlights the need for improving community-based psychiatric systems of care for youths with ASD to divert psychiatry-related ED visits, particularly for those children with private insurance.

Lunsky and colleagues (2014) described emergency service use, including EDs, paramedics, and police involvement, among adolescents and adults with ASD and examined predictors of using emergency services. According to parents, 13% of their children with ASD used at least one emergency service in a two-month period. Sedation or restraints were used 23% of the time. A combination of need and enabling variables predicted emergency service use with previous ED use in the last year, a history of hurting others, and having no structured daytime activities were the strongest multivariate predictors in the model. Lunsky et al. (2014) concluded that patients with ASD and their families are likely to engage with paramedics or police or visit the ED. Further education and support for families and emergency clinicians are needed to improve and, when possible, prevent such occurrences.

Weiss et al. (2011) noted that families required additional services during periods of crisis, including the use of EDs at local hospitals. Weiss and colleagues examined the demographics and features of crises associated with ED usage so a more proactive approach to mental health service provision could be developed. The importance of the family unit to facilitate services and diminish the likelihood of crisis hospitalization was emphasized. Several factors, such as interpersonal difficulties, environmental changes, and trauma, were associated with an increased likelihood of crisis, but not all factors led to the use of EDs as a conduit to crisis intervention. Use of

ED systems for mental health crises was higher for younger males who lacked structured daytime activities and had multiple mental health diagnoses. Individuals with moderate to severe levels of intellectual disabilities were less likely to use ED services than families who supported individuals with more mild intellectual disabilities.

Owen, Bowers, Heller, Hsieh, and Gould (2017) reported that community-based interdisciplinary support teams decreased the likelihood of hospitalization for individuals with IDD and behavioral challenges. As many states have moved to deinstitutionalize individuals with IDD to community environments, strategies to reduce hospitalizations, or at least the length of hospitalizations, are essential. Support service teams were used to build capacity and concurrently reduce the burden on EDs. The Olmstead Act of 1999 (Ginsburg, R. B. & Supreme Court of The United States, 1998) was an impetus for building proactive, community-based strategies for people with disabilities. Services provided by a team-based approach include observation-based assessments, service planning, technical assistance for individuals and families, linkage to available services, and individualized supports. When used in conjunction with other wellness and social services for people with IDD, crisis intervention services ensure they receive appropriate, timely, community-based care, reducing the likelihood of reactive and restrictive services.

## Disparities in Service

Latino and other immigrant groups utilize fewer mental health services than Whites and African Americans (Pumariega & Rothe, 2010); disparities in diagnosis and treatment exist. For example, there is an underdiagnosis of ADHD among Latino children and differential expression of anxiety symptoms in Latino youth. Pumariega and Rothe (2010) suggest that ethnic disparities contribute to the increased risk of psychopathology and referral to juvenile authorities among immigrant youth. Xu, Zeng, Wang, and Magaña (2022) conducted a scoping review of Latino immigrant families with children diagnosed with autism spectrum disorder (ASD). The effectiveness of parent education programs in reducing disparities was examined. It was suggested that future interventions should expand their focus to include diverse immigrant communities with children who have IDD.

Many of the studies had small sample sizes, except for one large randomized controlled trial (RCT), which showed positive outcomes in terms of increased service utilization. No large-scale translational studies were found. The characteristics of the intervention studies revealed some promising trends. First, interventions involving both parents and children were found to be effective in improving outcomes for the family and the child. Second, interventions that utilized lay health workers, who spoke the same language as the families, were shown to be a cost-effective and feasible approach to increase service accessibility for low-resourced families, such as Latino immigrant families. Last, these findings highlight the importance of future translational research to adapt interventions and address the disparities faced by diverse families with children who have IDD.

## Mental Health Supports in Schools

Lazarus et al. (2021) advocated for a culturally responsible dual-factor model in school psychology, which involves significant changes in practice. Proposed changes include: (a) greater focus on psychological well-being, (b) addressing racial disparities in school mental health practices, (c) prioritizing population-based mental health services, and (d) ensuring access to mental health services for all children. Two decades of research on children's psychological well-being supports the need for these changes. Despite the lack of representation in existing policies and practices, Lazarus et al. (2021) emphasized that the time has come for school psychology to transform its practice and take responsibility for meeting the mental health needs of children. The main challenge in implementing the culturally responsible dual-factor model is the shortage of school mental health professionals.

The recommended ratio is one school psychologist for every 500 students, but the actual national ratio is nearly double this. The shortage is more severe in rural and urban districts. To address this, the public education system would need to invest \$2.7 to \$4.9 billion annually. The proposed solution involves hiring more school psychologists and improving the pipeline of qualified professionals. Implementing the model requires reallocating existing resources and increasing resources. Strategies to address the shortage include increasing the number of school psychologists accepted into programs, securing federal grants for free tuition, expanding program access through online training, advocating for well-paying internships, and forming task forces to develop training programs.

## Improving Service Provision Through Evidence-Based Practice

McNally and McMurray (2015) provide several options for incorporating mental health services for individuals with intellectual disabilities: (a) additional training and an integrated supervision system, (b) investment from administration including allocation of resources, (c) monitoring staff for anxiety and trauma, and (d) follow-up with ancillary services (e.g., early intervention, autism services, and addiction services).

## *Community-Based Interventions*

Effective service to individuals with IDD, especially those with challenging behaviors, requires a multimodal approach to assessment and treatment in addition to a comprehensive, integrated system of care (Beasley, Klein, & Weigle, 2016). This section is an annotated bibliography on community-based interventions and is a review of current studies focused on the nature of crises in children and youth with IDD and other mental health challenges. The articles identify promising treatments to promote mental wellness and resilience and systemic alternatives to police involvement and hospitalization. The studies cited reflect an understanding that our current responses to mental health crises are not effective and often result in harmful consequences for youth and those who care for them.

Mandell et al. (2012) examined whether increased provision of community-based services is associated with decreased psychiatric hospitalizations among children with ASDs. In this study, the researchers found that among Medicaid-enrolled patients diagnosed as having ASD who were aged 5 to 21 years, 2.4% experienced at least one psychiatric hospitalization in 2004. After adjusting for many patient- and state-level characteristics, increased use of respite and home/community aide services was associated with a decrease in the risk of psychiatric hospitalizations for children, adolescents, and young adults with ASD. In many cases, hospitalization may result as much from the stress the child's behavior places on the family as from the behavior *per se*. Respite care and home- and community-based aides may considerably reduce stress on families, leading to reduced hospitalization rates (Mandall et al., 2012).

### ***START and I-START***

Higher rates of psychiatric disorders and referrals to emergency services are associated with IDD (Beasley et al., 2018). Beasley et al. (2016) provided an overview of the factors that contribute to challenging behavior for people with IDD. The START (Systemic, Therapeutic, Assessment, Resources, and Treatment) program uses a World Health Organization (WHO) public health prevention model to address this need. Evidence from the START program indicates that a skilled, integrated, and coordinated approach to service delivery can reduce the need for acute care and emergency services. The Iowa Systemic, Therapeutic, Assessment, Resources, and Treatment (I-START) program included mobile crisis stabilization, respite, future crisis prevention and intervention planning, outreach, and integrated community training of professionals (Rubin et al., 2007). Implementation of the START program has resulted in decreases in behaviors related to crisis, reduced need for hospitalization, and a decline in the number of psychiatric hospitalizations for individuals in rural Iowa. The I-START model focuses on mental health treatment by training support providers on strategies to detect and de-escalate impending crises. To date, the START service model is either in progress or has been implemented in 11 states (Beasley et al., 2018; Kalb et al., 2019; Kalb et al., 2021; Kalb et al., 2016). The START program offers a promising area of research on service delivery. The START program uses a three-tier approach to service provision: (a) build system capacity to assess and address the needs of individuals with dual diagnoses, (b) prevent escalation of crises, and (c) develop a tertiary intervention to stabilize an individual after a crisis.

Kalb et al. (2016) posit that inpatient hospitalization should be viewed as one (last) option in a continuum of treatment alternatives in behavioral health care, noting that the U.S. is over-reliant on hospital-based services because community-based services are not always available. Kalb and colleagues noted that families of school-aged youth may find inpatient hospitalization unpalatable; however, the need for services often overwhelms the capacity of the family. Unpalatable services may be chosen over no services.

### *In-Home Community-Based Services*

One of the purposes of this review was to examine the evidence on alternatives to inpatient mental healthcare for children and adolescents requiring intensive treatment for severe and complex mental health problems. Systematic reviews of intensive case management in adult mental healthcare conclude that intensive treatment models such as assertive community treatment and crisis resolution teams improve patient satisfaction and reduce hospital use in some circumstances (Lamb, 2009). The few studies on children suggest that intensive community-based services can be as effective as inpatient care for certain groups. However, the mental health needs of the young people involved in the studies, their social and family circumstances, and the context of local mental health provision varied greatly. Lamb (2009) found that recent studies support the use of alternatives to inpatient admission for groups of young people and suggest a need for a combination of complementary models of specialist intensive provision.

Shepherd et al. (2009) assessed the effectiveness, acceptability, and cost of mental health services that provide an alternative to inpatient care for children and young people and identified the range and prevalence of different models of service that seek to avoid inpatient care for children and young people. Young people receiving home-based mental health treatment services experienced improved functioning of externalizing symptoms and spent fewer days out of school and out-of-home placement. At short-term follow-up, the control group had a greater improvement in terms of adaptability and cohesion; this was not sustained at four months follow-up.

Evans et al. (2003) described one of the few studies to examine the comparative effectiveness of three alternative approaches to in-home crisis services for children and their families. Results suggest that children and adolescents can be treated successfully in their natural environment and that some gains for both child and family can be maintained six months post-discharge.

Crisis Resolution and Home Treatment Teams (CRHTTs) provide 24-hour, seven-day-per-week support for people in crisis. The COVID-19 pandemic has placed significant demand on urgent care and increased the need for brief interventions in CRHTT settings with flexible methods of delivery. Mulligan et al. (2022) examined client satisfaction with the “Crisis Toolbox” (CTB), a brief, skills-based intervention delivered by one CRHTT during COVID-19. All participants who received the CTB completed a satisfaction questionnaire. Descriptive statistics were calculated to quantify acceptability, and qualitative themes were generated using thematic analysis. Fifty-eight people participated, all of whom reported high levels of satisfaction with the CTB. Mulligan and colleagues (2022) found that the CTB appears to be a valued intervention. Further research is needed to assess its clinical impact and effect on operational indicators.

The family-based crisis intervention (FBCI) is an emergency psychiatry intervention designed to sufficiently stabilize suicidal adolescents within a single ED visit so that

they may return home safely with their families (Wharff, Ginnis, Ross, White, & White, 2019). The objective of this article is to report efficacy outcomes related to FBCI for suicidal adolescents and their families. Children of families receiving FCBI services were significantly more likely to be discharged to their homes with outpatient follow-up care, and families reported significantly higher levels of family empowerment and client satisfaction with care. Gains were maintained over the follow-up period. No completed suicides were reported during the study period in either condition. The authors conclude that family-based crisis intervention is a model of care for suicidal adolescents and may be a viable alternative to traditional ED care that involves inpatient psychiatric hospitalization.

### *Peer-Delivered Interventions*

Bowersox et al. (2021) conducted a scoping review to characterize the breadth of peer-delivered suicide prevention services and their outcomes to inform future service delivery and research. Many published studies were program descriptions or uncontrolled trials, with only three of 84 articles qualifying as randomized controlled trials. Despite a lack of methodological rigor in identified studies, peer support interventions for suicide prevention have been implemented that utilize a diverse range of peer provider types and functions. New and existing peer-delivered suicide prevention services should incorporate more rigorous evaluation methods regarding acceptability and effectiveness (Bowersox et al., 2021).

Lobban et al. (2020) sought to determine the clinical effectiveness and cost-effectiveness of an online supported self-management tool for relatives: the Relatives' Education And Coping Toolkit (REACT). This was a primarily online (United Kingdom), single-blind, randomized controlled trial, comparing REACT plus a resource directory and treatment as usual with the resource directory and treatment as usual by measuring user distress and other well-being measures at baseline, 12, and 24 weeks. A total of 800 relatives of people with severe mental health problems across the UK took part; relatives aged  $\geq 16$  years who were experiencing high levels of distress, had access to the internet, and were actively seeking help were recruited. An online self-management support toolkit with a moderated group forum is acceptable to relatives and, compared with face-to-face programs, offers inexpensive, safe delivery of National Institute for Health and Care Excellence-recommended support to engage relatives as peers in care delivery.

### *Follow-Up/Aftercare*

The one-year readmission rate for children and youths hospitalized for a psychiatric condition is estimated at 38% (Cheng et al., 2017). Studies suggest that these high readmission rates result from a lack of aftercare, but the evidence is mixed. Cheng and colleagues further explored the relationship between aftercare and readmission among children and youths ages 5 to 24 in Alberta, Canada, using the same study sample to identify predictors of both outcomes. Cheng et al. (2017) demonstrated a significant



effect of aftercare in reducing readmission risk, which indicates a need to improve these services.

### *Treatment of Substance Abuse*

Bond et al. (2005) examined the relation between adolescent depressive symptoms and risk and protective factors identified for substance use. A questionnaire developed to measure these factors in a young person's community, family, school, peer group, and individual characteristics for substance use was used to assess associations with self-reported depressive symptoms. Data was provided by a representative sample of 8,984 secondary school students in Victoria, Australia. The prevalence of depressive symptoms was 10.5 percent for males and 21.7 percent for females. Depressive symptoms were associated with factors in all domains, with the strongest associations in the family domain. Strong relationships were found between the number of elevated risk and protective factors and depressive symptoms maintained after adjusting for substance use. Patterns of associations were similar for users and non-substance users. The findings indicate that prevention programs targeting factors for substance use have the potential to impact the onset of depression and depression symptoms.

### *Mobile Crisis Services*

Mobile crisis services for children and youth have been available in Ontario since 2000, yet little descriptive information about such services exists (Braganza et al., 2019). In this evaluation, crisis workers gathered demographic information and details about the nature of the crisis from youth ages 12 to 17 and parents/guardians of children from birth to 17 during a crisis intervention. Approximately two weeks post-intervention, participants responded to a quantitative questionnaire administered via telephone that measured levels of upset, awareness, coping, and confidence. This paper adds to the literature by describing the types of calls received, characteristics of service users, and outcomes for youth and families. The findings suggest this type of service may be valuable in serving youth and that more rigorous examination is required by mobile crisis services for youth to demonstrate the true contribution.

Guo and colleagues (2001) evaluated the prevalence of hospitalizations following crisis for aged-matched cohorts. The quasi-experimental design included a community-based mobile crisis intervention cohort compared to a hospital-based treatment group. Individuals who received treatment from a mobile crisis team were less likely to be hospitalized. Mobile crisis-based interventions impacted individuals with mental health needs, their families, service providers, and the mental health system. Critical factors for crisis intervention include psychopharmacological interventions and the active participation of a psychiatrist. The overall goal of intervention should be to reduce unnecessary hospitalizations; however, some incidents will require hospitalization. The researchers found a correlation between community-based mobile crisis and lower incidence of hospitalization. Guo et al. (2001) established the importance of community integration, including employment, in reducing future hospitalization.

Although mobile crisis intervention is time-limited, it nonetheless has great utility for addressing the needs of youth with a preexisting disorder (Singer, 2005).

Vanderploeg et al. (2016) evaluated the Emergency Mobile Psychiatric Services (EMPS) mobile crisis service model. The EMPS model provides assessment and brief intervention services, community connections, and crisis stabilization in the family home, local schools, emergency departments, and community locations. A centralized call center triages referrals and provides data analytics for quality improvement and training purposes. Data usage indicated high service utilization, a rapid response time, and improved outcomes for school-aged youth. EMPS was seen as a critical component of a comprehensive continuum of crisis services (Vanderploeg et al., 2016). Service provision in the home and community reduces stigma and service demands in emergency departments and is associated with cost savings. Providing follow-up and community linkages helps families navigate the complicated and often fragmented service delivery systems. Community-based crisis intervention services ensure that school-aged youth with mental health needs receive effective crisis stabilization so they can remain in their homes and communities as much as possible. Mobile crisis outreach for youth brings services to families during times when their coping skills have been exhausted, and it provides immediate assessment, referral, and crisis stabilization (Singer, 2005).

### *Online and Web-Based Services*

Marshall et al. (2022) aimed to understand how caregivers experience supporting family members with psychosis or bipolar disorder who have also experienced suicidal behavior. A qualitative thematic analysis of online peer forum posts was carried out on the Relatives Education and Coping Toolkit (REACT) website, an online intervention for carers of people with psychosis and bipolar disorder. The analysis was based on 178 posts by 29 forum users. Posts were selected based on their relevance to suicidal behavior. Three themes were generated: “Suicide as the ultimate threat” highlights fears emerging from caregivers’ difficulties with understanding and managing suicidal behavior. “Bouncing from one crisis to another” reflects caregivers’ experiences of recurring crises and the challenges of relying on emergency healthcare support. “It definitely needs to be easier to get help” emphasizes caregivers’ desires to be acknowledged by healthcare professionals and included in the support offered to service users. Marshall and colleagues (2022) concluded that digital platforms, including online forums, brief interventions such as safety planning, and interagency crisis models, hold the potential to meet caregiver needs in this context. However, further research is required to investigate the effectiveness and implementation of these approaches.

### *Counseling and Psychotherapy*

Brown et al. (2013) conducted a longitudinal single-group pilot study that examined whether individuals with impaired intellectual functioning would show reductions in challenging behaviors (CBs) while receiving standard DBT individual therapy used in



conjunction with the Skills System (DBT-SS), a DBT emotion regulation skills curriculum adapted for individuals with cognitive impairment. Forty adults with developmental disabilities (most of whom also had intellectual disabilities) and CBs, including histories of aggression, self-injury, sexual offending, or other CBs, participated in this study. Changes in their behaviors were monitored over four years while in DBT-SS. Large reductions in CBs were observed during the four years. These findings suggest that modified DBT holds promise for effectively treating individuals with intellectual and developmental disabilities.

While evidence suggests that psychotherapy may function as an effective treatment option, barriers to effective implementation persist (Witwer et al., 2022). Additionally, proper assessment of underlying mental health conditions can be difficult due to inherent communication issues, stigma attached to diagnostics and labels, and a lack of practice and treatment guidelines. Bakken & Martinsen (2013) explored the recognition of anxiety symptoms and aimed to provide suggestions for assessing anxiety in individuals with autism and intellectual disability (ID). The differentiation of symptoms related to autism and psychiatric disorders demonstrated in the present thesis may contribute to a better conceptual understanding of the phenomena and reduce the difficulties related to identifying psychiatric disorders in individuals with autism and ID, facilitating increased awareness among professionals and improving the quality of the mental health care for this group. Clinicians need guidance in developing structured interviews and assessment tools for diagnosing co-occurring mental health issues exhibited by individuals with dual diagnosis (Witwer et al., 2022).

### *Self-Regulation*

Dishion and Connel (2006) focused on the concept of self-regulation as a measure of resilience in children and adolescents. The study collected measures of adolescent attention control from parents and youth and a measure of self-regulation from teachers. The measures of effortful attention correlated highly with teacher ratings of self-regulation. The composite measure of self-regulation (youth, parent, teacher report) was found to moderate the impact of peer deviance on adolescent antisocial behavior as well as the impact of stress on adolescent depression. These findings suggest that self-regulation is a promising index of adolescent resilience. The construct of self-regulation also provides an excellent target for strategies to improve child and adolescent adjustment in problematic environments and stressful circumstances.

### *Promoting Resiliency*

Resilience is a dynamic process of adaptation or recovery in the context of risk or in response to a threat. Resilience is negatively associated with depression, anxiety, and trauma in children and adolescents. Integration of this concept into methods of clinical treatment and approaches to crisis response is crucial as it enhances protective factors that decrease the risk of negative outcomes for youth and families (Mesman et al., 2021).

Children who exhibit elevated levels of conduct problems are at increased risk for developing co-occurring depression symptoms, especially during adolescence. Cutuli et al. (2006) tested the effectiveness of a manualized after-school intervention, the Penn Resiliency Program, for the prevention of depression symptoms among a subset of middle school-age students who exhibited elevated levels of conduct problems but not depression symptoms at the start of the study. Longitudinal analyses demonstrate that the program successfully prevented elevations in depression symptoms across early- to mid- adolescence compared with no-intervention control subjects.

Glaser et al. (2022) examined whether an online mentoring health intervention (OMHI) would strengthen characteristics that can prevent risky behaviors: resilience, perceived social support, psychological distress, and crisis concerns. OMHI participation was associated with improved resilience and social support and decreased psychological distress, making it an effective strategy in health promotion for at-risk youth. An online intervention program combining mentoring in physical activity and interpersonal connections may constitute an effective health promotion strategy for at-risk youth, especially in times of crisis.

Preventive interventions focus on reducing risk and promoting protective factors in the child as well as his or her cultural ecologies (family, classroom, school, peer groups, neighborhood, etc.). By improving competencies in both the child and their contexts, many of these interventions promote resilience. Although a substantial number of preventive interventions reduce problem behaviors and build competencies across childhood and adolescence, there has been little integration with recent findings in neuropsychology and neuroscience. Greenberg (2006) examined the integration of prevention research and neuroscience in the context of interventions that promote resilience by improving the executive functions (inhibitory control, planning, problem-solving skills, emotional regulation, and attentional capacities) of children and youth. Illustrations are drawn from recent randomized controlled trials of the Promoting Alternative Thinking Strategies (PATHS) curriculum. The discussion focuses on the next steps in transdisciplinary research in prevention and social neuroscience.

### *Counseling and Spiritual Interventions*

Rassool (2015) discussed the development and effectiveness of multicultural counseling competencies, specifically in relation to Muslim clients. This study highlights the benefits of using religious psychotherapy as an effective treatment for anxiety, depression, and bereavement in Muslim patients. The section also emphasizes the importance of incorporating Islamic beliefs and practices into counseling sessions, as many Muslim patients prefer counselors who understand their religion. Islamic counseling is presented as a contemporary therapeutic approach that integrates spirituality into the therapeutic process. The counselor's role is described as a combination of counselor and spiritual facilitator, requiring an understanding of the cultural, social, and political context of Muslim clients. The section also mentions the use of spiritual interventions, such as prayers, fasting, and recitation of the *Qur'an*, as part of the preferred treatment for Muslims. The concept of *ruqyah*, which involves the

recitation of the *Qur'an* for healing purposes, is discussed as a means of treating evil eye, jinn possession, and black magic. The importance of respecting cultural beliefs and involving an Imam in cases of jinn possession is highlighted.

Rassool (2015) highlighted the complex relationship between cultural and religious beliefs and conventional medicine, particularly in the context of mental health. The author emphasizes the importance of respecting religious and cultural considerations when treating mental health issues while also acknowledging the need for psychiatric methods. The involvement of Islamic institutions, such as collaborating with imams, is suggested to improve access to appropriate mental health services for minority Muslim communities. Ultimately, fostering communication and trust between Muslim religious leaders and mental health professionals is crucial for enhancing culturally appropriate psychiatric care.

### ***Function-Based Crisis Intervention***

A percentage of individuals with autism and other developmental disabilities engage in severe and dangerous challenging behaviors at higher levels than others without disabilities (Hill & Furnis, 2006). Two common approaches for intervening in these behaviors are function-based interventions (FBI), which have been effective at reducing such behaviors, and crisis intervention, which has been shown to increase staff skills for managing dangerous situations (Newcomb & Hagoian, 2018). These two methods have different theoretical foundations, and as such, the two approaches often recommend competing strategies for a given challenging behavior. Therefore, practitioners may feel they need to choose between the two approaches, selecting either FBI or crisis intervention.

For instance, a functional assessment of behavior may indicate the need to implement procedures such as extinction/planned ignoring for attention-maintained behavior, which might result in a dangerous escalation of problem behavior in the event of a crisis. Stevenson, Bradley, Wood, and Iannello (2019) examined a way to blend the strengths of two approaches into a synthesized model referred to as function-based crisis intervention (FBCI). This model incorporates aspects of function-based treatment during periods of calm and gradually modifying strategies to ensure safety if an individual exhibits an exacerbation of behavior, up to and including the use of physical management techniques if needed (e.g., response blocking or restraint). Using a delayed multiple-probe design, results showed that FBCI reduced the severely challenging behavior of three students diagnosed with ASD. Implications for a combined approach to respond effectively to a developing behavioral crisis in future research and practice are discussed.

### ***Culturally Informed Crisis Intervention Strategies***

Culture is the way of thinking, feeling, and behaving learned during socialization (Martorell, 2004). It influences every aspect of life—from the way people label the disease, identify symptoms, seek help, decide whether someone is "normal" or not to organizing expectations of providers and giving them personal meaning (Martorelli,

2004). In the context of crisis intervention for youth with dual diagnoses, this approach includes identifying the type of event perceived as a threat or traumatic, how the school-youth interpret the meaning of crisis, and how individuals and communities express and respond on equal terms to crisis intervention and mental health support (Silva & Klotz, 2006).

Due to persistent health disparities across diverse populations and dimensions far beyond racial or ethnic, such as disability status, gender, sexual orientation, age, religion, socioeconomic status, and geographic location, adoption of a culturally informed approach to crisis intervention is key. Culturally informed crisis intervention is an approach to healthcare delivery that recognizes and respects each patient's unique multicultural background. It recognizes the impact of culture on a person's beliefs, values, customs, and lifestyle. This approach is based on the belief that people have different ideas about what constitutes dignified health care, and they are best served when they can employ their own cultural traditions while seeking and receiving health care services (Uprise Health, 2023).

In the case of youth, schools are increasingly diverse multicultural scenarios (Guajardo Rodríguez, 2004; Silva & Klotz, 2006). Schools committed to being culturally competent in all aspects of school life are more likely to cope better with crisis situations (Silva & Klotz, 2006). The ability to prevent future crises requires culturally adapted awareness campaigns, a mechanism for early identification of the crises, and simulations of an appropriate response (Silva & Klotz, 2006). Interventions adapted to the social and cultural context of underserved populations as youth are more likely to increase effectiveness of behavioral interventions and to accelerate advances in minority health (Ezenkwele & Roodsari, 2013; Singer, 2005).

However, despite the consensus that cultural context and ethnicity are key components in behavioral health interventions and help reduce inequalities for underserved populations, there is an ongoing debate over how to design and identify the components of efficacious culturally sensitive health interventions. Hence, cultural competence (CC) was proposed as a concept and as a set of practices aimed at reducing unequal access to quality services as they are responsive to the needs of people (Whitley, 2012), and it is considered key to the delivery of optimal medical care (Ezenkwele & Roodsari, 2013; Singer, 2005).

## Characteristics of Effective Culturally Responsive Crisis Interventions

Cultural competence is more than speaking another language or recognizing the basic features of a cultural group. It also requires self-evaluation on the part of the provider or practitioner and patients (Singer, 2005; The University of Australia, 2023.) CC means recognizing that each of us, by virtue of our culture, has at least some ethnocentric/biased views provided by that culture and shaped by our interpretation of it (HHS 2003; The University of Australia, 2023.) People routinely generalize

(Ezenkwele & Roodsari, 2013) about cultures. For example, despite commonalities within Spanish-speaking cultures, an assumption of ethnic homogeneity among Latinos dismisses real cultural differences. The same situation applies to Muslim Americans (Ezenkwele & Roodsari, 2013).

Cultural competence requires providers to be aware of their own cultural values, their clients' worldviews, and culturally appropriate intervention strategies (HHS 2003; Sue et al., 1992; Singer, 2005; Silva & Klotz, 2006). While CC does not require that practitioners know everything about another culture, it requires service providers to be open to understanding about another culture (Dean, 2001; Singer, 2005). CC requires accurate translation of ideas as well as words (Singer, 2005). Even when professionals are bilingual, mental health concepts are often difficult to translate (e.g., the words *loca* or *nerviosa*.) For example, if a Puerto Rican mom reported that her school-aged daughter was nervous, one might assess an anxiety disorder. However, the word *nerviosa* in Spanish has a very different meaning from its English translation. The complexity of culture is apparent in the meaning of a single word, cultural variations in a concept, and differences in meanings attributed to behaviors and events (Singer, 2005).

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum (Goode et al., 2010). On an organizational level, cultural competence requires that organizations have a defined set of values and principles and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally. Organizations must have the capacity to value diversity, conduct self-assessment, manage the dynamics of difference, acquire and institutionalize cultural knowledge, and adapt to the diversity and cultural contexts of the individuals, families, and communities they serve. Culturally competent organizations incorporate these behaviors, policies, and structures in all aspects of policymaking, administration, and service delivery, systematically involving consumers, families, and communities (National Center for Cultural Competence, 2023).

### ***Integrating Cultural Variables in School Settings***

Hurles and Kong (2021) emphasized the importance of a strengths-based, holistic approach in a student's education plan, considering cultural factors that influence their self-concept, social growth, and family's understanding of disabilities. School counselors should openly discuss these aspects to give students and their families a voice in the Individualized Education Program (IEP) process, validating their cultural experiences. Cultural communication barriers should be understood, and counselors should provide sufficient time for processing information, asking questions, and giving suggestions during IEP meetings. Counselors can act as liaisons between educators and parents/students, championing parents' strengths and input, acknowledging their own biases, and working toward a compromise to meet the student's needs.

Moreover, it is important to consider cultural differences when setting educational or social/emotional goals, inviting families to participate, and incorporating strategies that are effective within their culture. This collaborative approach fosters a relationship of shared power rather than a rigid hierarchy (Hurles & Kong, 2021).

### *Culturally Competent Mental Health Services for Youth and Families*

Culturally competent services are crucial for effectively serving children, youth, and families from historically underrepresented groups. According to Pumariega and Rothe (2010), cultural competence involves provider characteristics such as awareness and acceptance of differences, understanding of one's cultural values, and the ability to adapt practices to the cultural context of the patient. System characteristics include valuing diversity, conducting a cultural self-assessment, and adapting policies and services to address diverse cultural needs. In mental health services, cultural competence can be operationalized in various ways.

During assessment, attention should be given to the cultural context of symptoms, youth and family acculturation, immigration history, and cultural strengths. Linguistic support through trained interpreters or clinicians fluent in the family's native language is crucial while using family members as interpreters should be avoided (Pumariega & Rothe, 2010)

Family involvement is critical, focusing on intergenerational conflicts, bridging the acculturation gap, and negotiating confidentiality. Psychotherapy should address traumas (including trauma associated with cultural identity), acculturation, and ethnic identity conflicts, utilizing culturally specific modalities or themes. Contextual supports should be built by promoting family strengths and community natural supports, avoiding institutionalization of youth, and utilizing ethnically specific programs if available. Pharmacotherapy, if used, should consider genetic and dietary factors, and involve effective education while respecting the autonomy of parents and elders. Overall, delivering culturally competent services requires both provider and system characteristics, and it involves attention to cultural context, linguistic support, family involvement, practical psychotherapy, contextual supports, and appropriate pharmacotherapy (Pumarieg & Rothe, 2010).

Sue et al. (2006) defined the conceptual framework of cultural competence in therapy and mental health services. The framework developed by Sue and colleagues included three areas: (a) cultural awareness and beliefs, (b) cultural knowledge, and (c) cultural skills. However, Sue (2006) indicates that the implementation of cultural competency has remained largely aspirational, with little attention given to measurement, conceptualization, implementation, and training. This has led to several questions, such as what characteristics constitute cultural competency, whether different competencies exist for different groups, and whether cultural competency is unidimensional or multidimensional. Sue et al. (2006) also highlighted the importance of considering cultural competency at different levels, including the provider level, agency level, and community level. To address the complexities and ambiguities of



cultural competency, it is necessary to view it as both a process and a substantive content area. Below, you will find descriptions of culturally based interventions.

Additionally, culturally based interventions using themes and practices from cultures of origin have been utilized. For example, *Cuento Therapy*, uses culturally based myths and stories, and Magical Realism is a cultural intervention for traumatized Latino children. Parenting interventions and mentoring programs have also been developed for Latino populations. And traditional cultural approaches, such as the *promotoras de salud* model and collaboration with cultural healers, have also been effective (Pumariega & Rothe, 2010).

### ***Cultural Competence in Psychotherapy***

Sue and colleagues (2006) discussed several important considerations when working with culturally diverse clients in psychotherapy. It emphasizes the need for therapists to assess clients' functioning using multiple measures, such as informant reports and job performance, to ensure accuracy. The concept of credibility is explored, with ascribed credibility being influenced by cultural values and achieved credibility being based on therapists' competence and helpfulness. To enhance achieved credibility, therapists can provide direct benefits or gifts to clients, especially those skeptical of Western psychotherapy.

Also, Sue et al. (2006) also emphasized the importance of therapists recognizing and addressing their own discomfort and resistance when working with culturally dissimilar clients. By examining these feelings, therapists can gain insight into cultural dynamics and improve their effectiveness. Understanding clients' perspectives is crucial, particularly their cultural conceptualizations of mental health problems, means for resolving problems, and treatment goals. Therapists should strive to learn about clients' cultures and develop tailored intervention plans accordingly.

### ***Cultural Competence Training: Current Service Providers***

Kaihlansen et al. (2019) explored healthcare professionals' perceptions of cultural competence training, which aims to enhance cross-cultural encounters by increasing nurses' awareness of their culture and biases. Participants initially expected quick-fix solutions or guidelines for interacting with patients from different cultures, but the training provided them with a different perspective. By increasing awareness of their own cultural and communicational features, participants were better able to recognize common pitfalls in cross-cultural communication and develop their communication skills. Kaihlansen et al. (2019) also found that participants appreciated the training provided by professionals outside the healthcare field and suggested involving members of different immigrant groups to share their views. Encouraging discussion and sharing experiences among healthcare professionals was seen as important, but there were challenges in effectively passing on the lessons learned. The study emphasizes the need for organizational-level cultural competency initiatives and cost-effective training methods like e-learning. Also, difficulties in scheduling and

attendance highlight the need for flexible learning opportunities that are not bound to specific times or places.

### *Cultural Competence Training: Future Service Providers*

Benuto and colleagues (2019) discussed the evolving process of training doctoral students to become culturally competent. The study reveals that the inclusion of diversity-related courses in doctoral programs has increased over time, from 41% in the late 1970s to 62% in 1990. Although the study surveyed individual psychologists instead of programs, it found that 85% of the sample reported taking a graduate school course in diversity, aligning with previous findings that most training programs offer such courses. The most used curricular methods for clinical training are didactic. Interestingly, despite the diversity in types of training programs attended by the participants, there were consistent training experiences, suggesting less variability across programs than previously documented.

Although participants expressed high satisfaction with their training, it is unknown whether this satisfaction translates into better outcomes with diverse clients. The relationship between cultural competency training satisfaction and skills development requires further exploration (Benuto et al., 2019). Supervision is identified as a crucial aspect of training, as it predicts satisfaction and provides an opportunity to teach clinical trainees how to work with diverse clients. Participants also expressed a desire for more concrete and technical training, indicating a need for skills-based training in cultural competency. Benuto et al. (2019) highlights the importance of active learning through practicum and supervision in psychology training programs. It also emphasizes the unique personal nature of clients and the need for training to address intersectionality and context-dependent factors in working with diverse populations.

### *Organization-Specific Cultural Adaptations*

Arundell et al. (2021) addressed the concept of cultural adaptations in the context of service design and delivery. Cultural adaptations at the organizational level involve changing the time, place, accessibility, and format of interventions to accommodate cultural factors better. Examples include: (a) modifying the length or location of the intervention, (b) implementing measures to improve access for specific communities, and (c) delivering treatments remotely or in group settings. For the authors, this typology of treatment-specific and organization-specific cultural adaptations serves as the basis for subsequent quantitative analyses.

Arundell et al. (2021) emphasize the importance of cultural adaptation in ensuring interventions are accessible and acceptable to diverse cultural needs. Organization-specific adaptations were found to be more efficacious, suggesting their value in improving outcomes for minority groups. The results also highlight the need for considering external environmental factors and the impact of organizational factors on intervention efficacy. For example, timely access to treatment and involving patients and community leaders in care provision were identified as important considerations. As reported by Benuto et al. (2019) cultural adaptations should be part of therapist



training programs, and future studies should consider organizational and service-level issues alongside therapy-related and content-related adaptations. (Arundell et al., 2021).

## Methodology

### Design and Rationale

The NADD Research Team applied a mixed-methods, quasi-experimental framework to this study to collect and analyze current practices, needs, and perceptions of dual diagnosis communities across the United States. This framework was used to evaluate the necessary changes to improve existing systems and policies that dictate crisis intervention strategies for school-aged youth with a dual diagnosis. With the goal of providing opportunities to create and explore best practices that can be applied to a diversified population, four main questions drove the development, deployment, collection, and analysis of information for this investigation:

- What crisis resources and services are available to families of diverse geographic, economic, and cultural backgrounds for school-aged youth with a dual diagnosis experiencing a crisis?
- In what ways do language and cultural norms (including beliefs, knowledge, and acceptance of dual diagnosis conditions) influence families of school-aged youth(s) seeking support or care for their child(ren) with a dual diagnosis during and following a crisis event?
- How do providers providing care for school-aged youth with dual diagnosis feel resources and support services should be amended to prioritize immediate needs versus long-term care options that include crisis management?
- How do families of school-aged youth with dual diagnosis see resources and care options for their child(ren) improving to better respond to—or even avoid—a crisis event?

### Recruitment, Selection, and Participation Logic

The NADD Research Team utilized existing relationships, listservs, and direct outreach to relevant national, state, and local agencies, organizations, and institutions directly involved in the dual diagnosis field to recruit eligible individuals to participate. All participants were required to be at least 18 years of age, care for (either as a caregiver/family member or provider/professional) a school-aged youth (or youths) with a dual diagnosis(es), live or work in the United States, and speak and understand English to participate. Participants for the follow-up survey were selected based on

their request to participate after completing the initial questionnaire, in which respondents provided their email addresses used for direct recruitment and outreach.

## Summary of Findings

### Survey 1: Preliminary Assessment of Current Practices and Best Practices

A key aim of this research was to establish the breadth and diversity of mental health services available to school-aged youth diagnosed with dual diagnosis, identify barriers and gaps to service delivery, and synthesize the literature and identify evidence-based practices. To achieve this, the NADD Research Team launched an initial survey to capture information and perspectives of family members/caregivers and providers/professionals relative to their lived experiences finding, obtaining, and utilizing resources for school-aged youth who have a dual diagnosis.

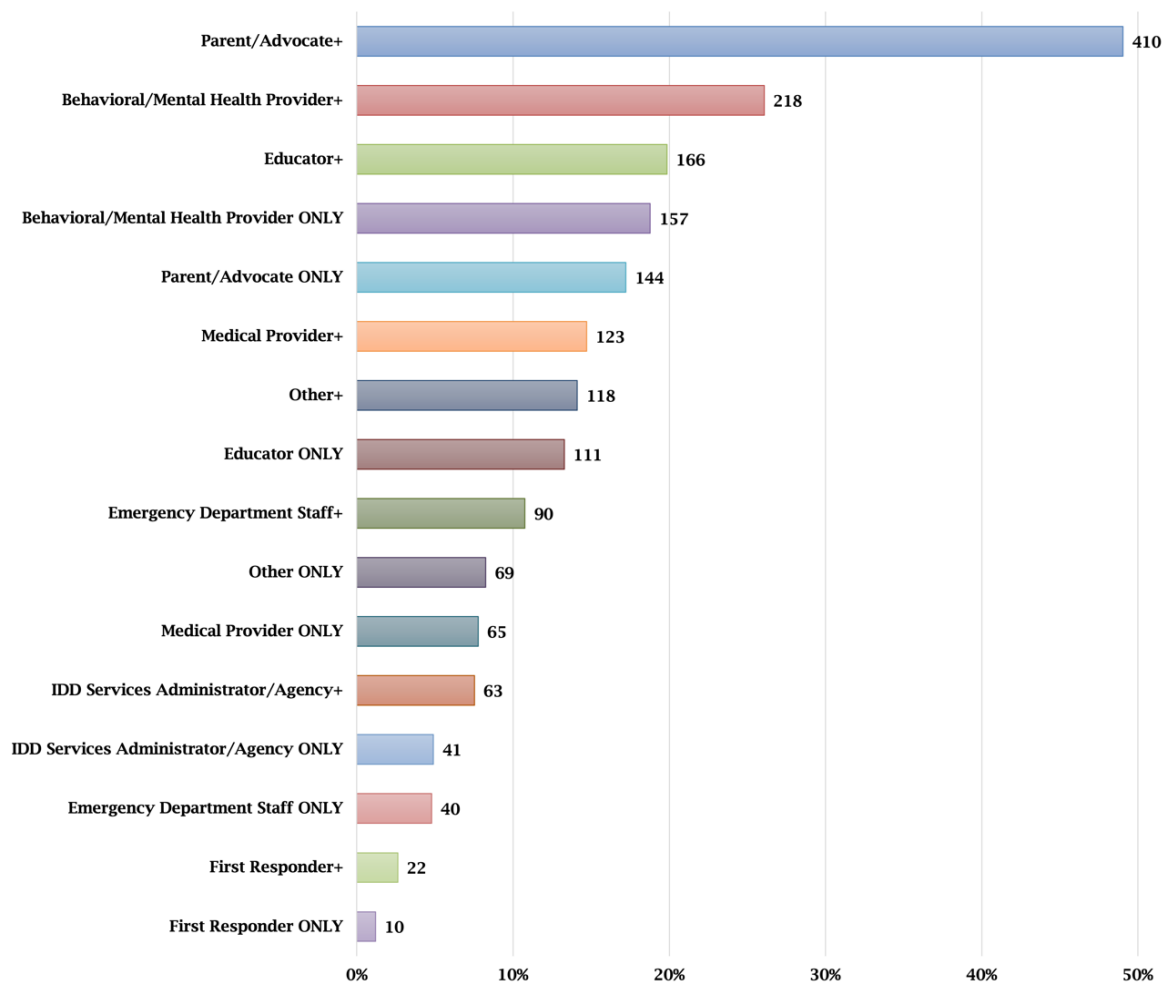
#### *Demographics*

One thousand two hundred and eighty-three (1,283) professional service providers, staff, agency personnel (including first responders, educators, direct support professionals, etc.), and family members initiated the survey. Of these, 836 participants representing over 45 states completed the survey.

As shown in **Figure 1**, most respondents denoted they were parents/advocates, with many indicating they served multiple roles, such as parent and provider/professional.

**Figure 1**

*Affiliation of Respondents within Dual Diagnosis Community*

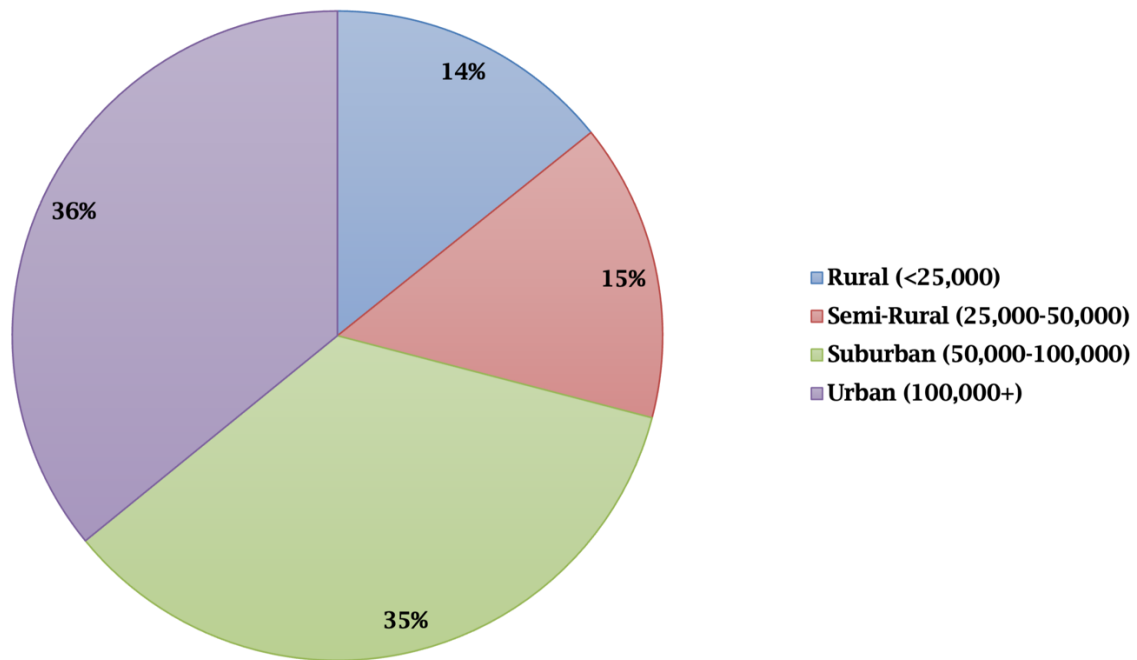


*Note:* Several respondents selected multiple roles, represented by “+” following the affiliation type. “Other ONLY” and “Other+” comprised of persons who identified as siblings, home care providers, advocates, supportive living staff, resource managers, and social workers.

Geographically, most respondents (over 70%) lived in urban or suburban areas comprised of populations of at least 50,000 residents, as shown in **Figure 2**.

**Figure 2**

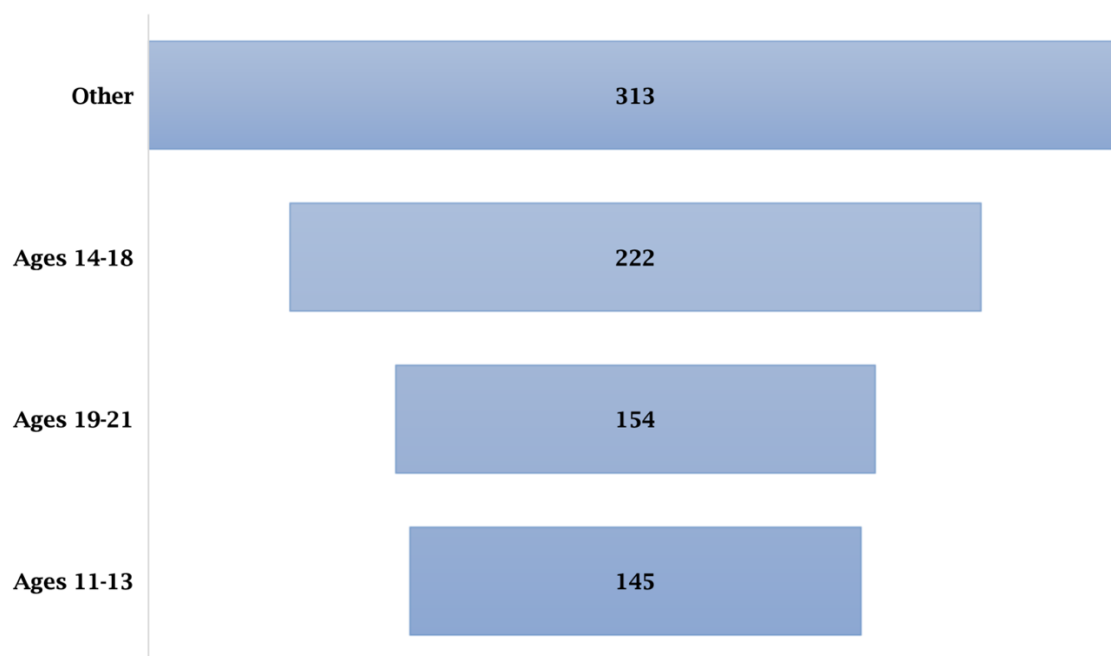
*Respondents' Geographic Location by Population Size*



**Figure 3** shows that most respondents noted that the age ranges of the school-aged youth with dual diagnosis that they cared for or treated were well blended among children (5-12), teenagers (12-17), and young adults (18-21).

**Figure 3**

*Age Ranges of School-Aged Youths with Dual Diagnosis*



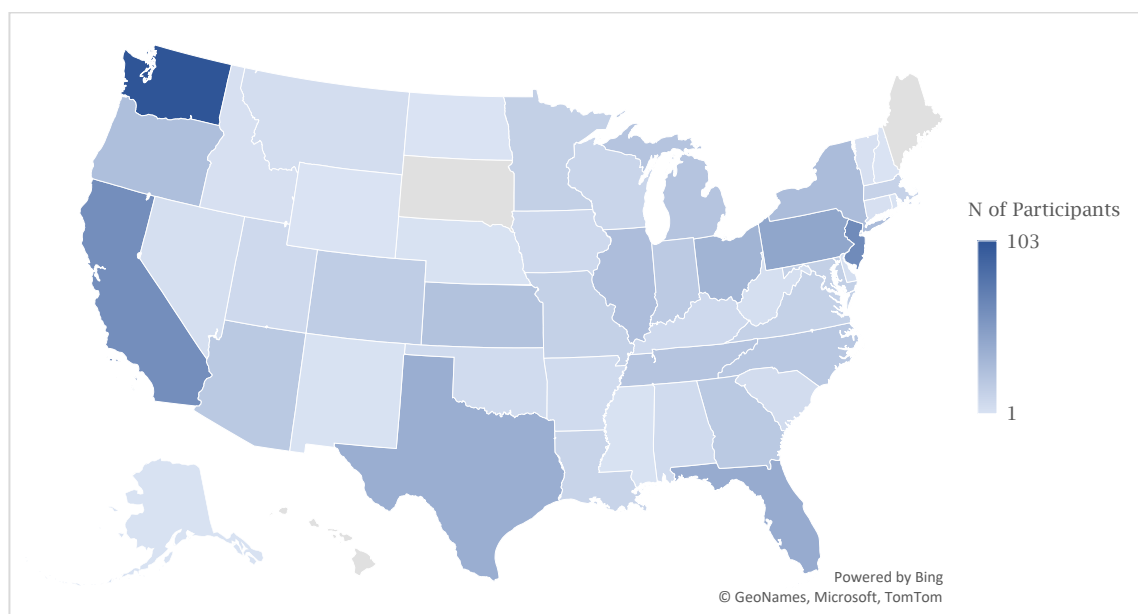
*Note:* Several participants who selected “Other” noted that they have or had provided services and support for all ages under 21 over their career’s lifespan or that the school-aged youth they care for falls within multiple age ranges as their child gets older.

Various states were identified as part of this project, with Washington (103), New Jersey (64), California (62), Pennsylvania (45), Florida (41), Texas (39), and Ohio (35) accounting for nearly half of all respondents (approximately 47%).

**Figure 4** provides a visual representation of the density represented by the participants based on the states they work/live in.

**Figure 4**

*Geographical Density by State by Primary Residence*



*Note:* Maine, South Dakota, and Hawaii had no respondents participating in this study. Additionally, there were outlier responses (<5) that resulted in multiple selections or that were undisclosed that were not included on this map.

The NADD Research Team did not collect any additional demographic information about respondents, including gender, ethnicity, languages spoken, or specific relationship associations to the person (or persons) they care for or provide services and support for as a part of the data collection and subsequent analyses of this study.

### ***Crisis Intervention Need and Availability***

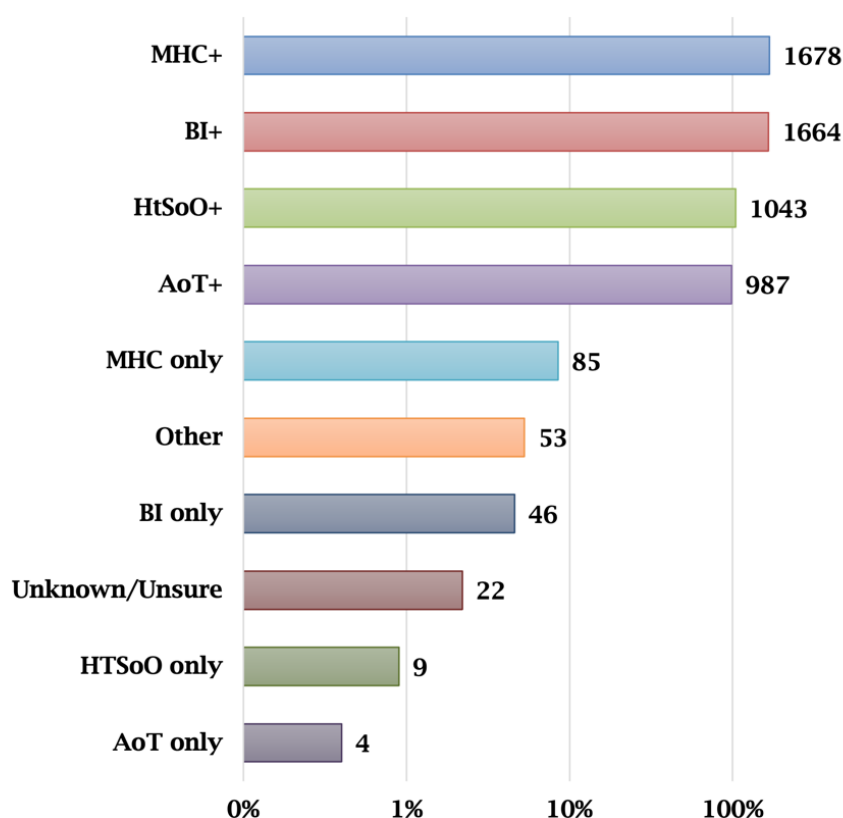
With 47 states represented by over 800 participants, the focus of this project was to collect information on what current services, resources, and support options are available, accessed/utilized, and missing from the perspectives of family members/caregivers and providers/professionals within the dual diagnosis

communities across the country. To address these questions, participants were first asked to identify what they perceived as circumstances that initiated a crisis event.

**Figure 5** shows that situations centered around mental health (MHC), behavior (BI), physical violence and self-harm (HtSoO), and aggression (AoT) were the highest triggers acknowledged. Participants noted that these events occurred independently of and concurrent to one another; however, the combinations of certain components with another varied by respondent, and many selected multiple options, accounting for a representative sample that exceeded the total number of respondents (i.e., >836).

**Figure 5**

*Circumstance(s) Leading to a Crisis Event*

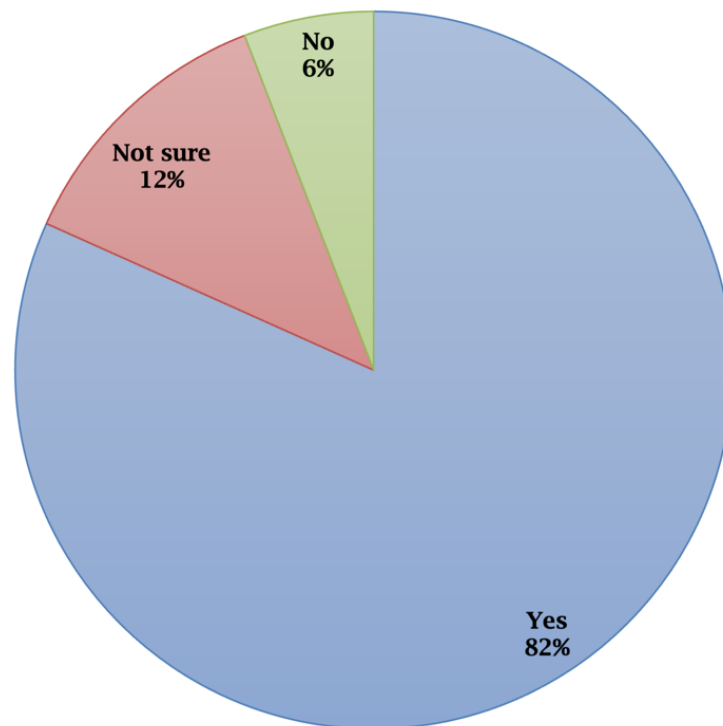


*Note:* For responses that selected “Other,” which accounted for approximately 6% of the answers, participants commented that substance use and abuse, displacement due to unforeseen circumstances or events (e.g., natural disasters, caretaker deaths), and external trauma and its related medical demands were also contributing factors to a crisis event they had experienced.

Both providers and families provided their views about whether they felt that there had been an increase in the need for crisis intervention services due to a corresponding increase in crisis events over the past several years, with more than two-thirds of participants selecting “Yes” (**Figure 6**).

**Figure 6**

*Perceptions of Increased Need in Crisis Intervention Resources*



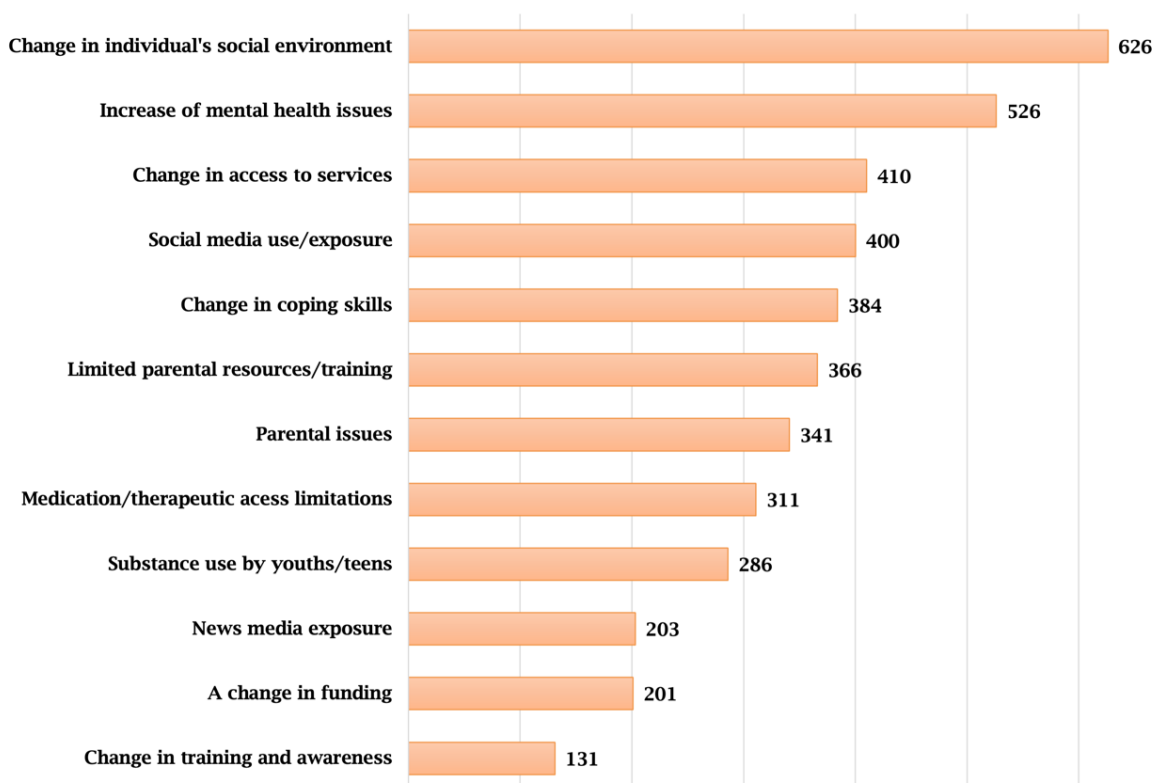
Of those who selected “yes,” most identified circumstances related to: (1) change in social environment, (2) increased mental health issues, (3) change in access to services, and (4) increased exposure to social media as the leading cause(s) of more frequent crisis events.



**Figure 7** further expands upon the reasons identified, with many respondents selecting multiple options, denoting that most crisis events were caused by compounding circumstances.

**Figure 7**

*Contributing Factors of Increased Crisis Events*

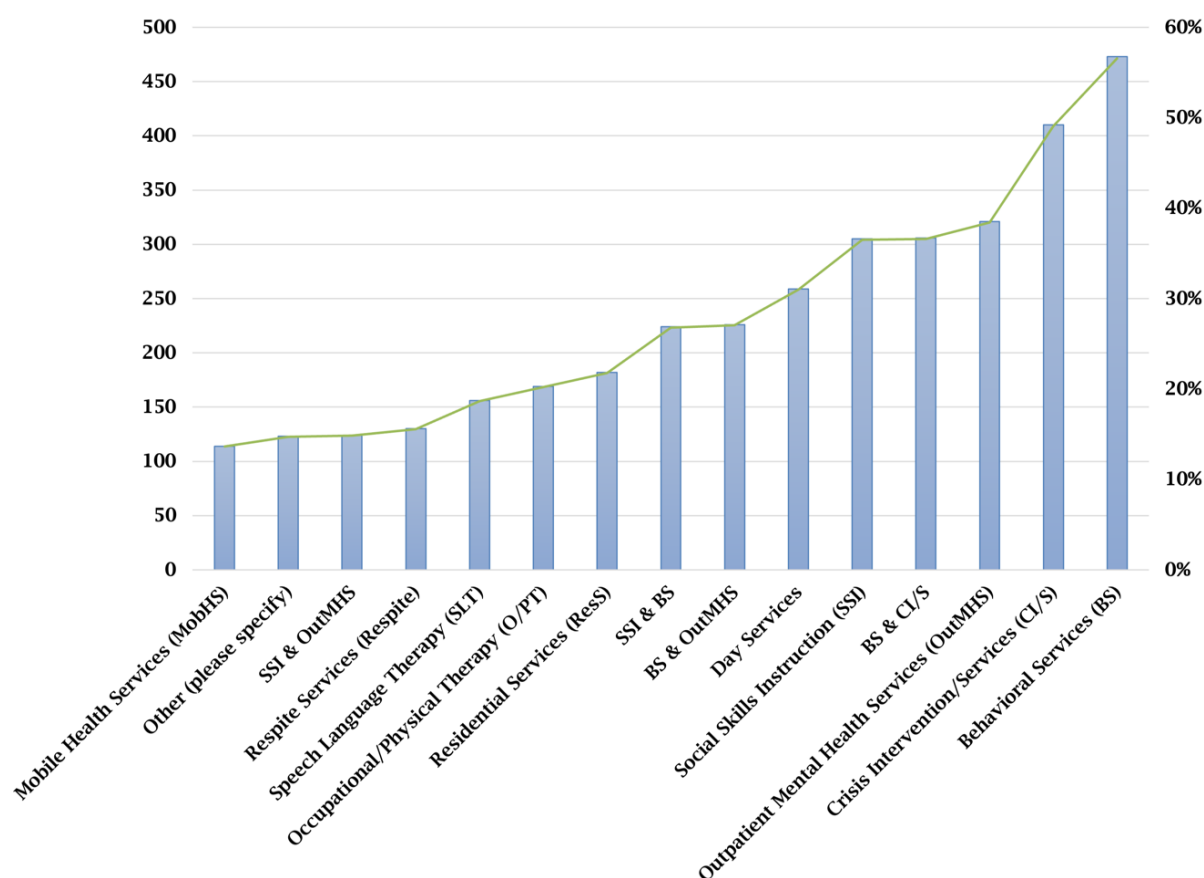


Finally, participants provided their knowledge of existing and available services within their local community or state-directed toward dual diagnosis conditions. A vast majority of these care options targeted behavior (BS), social skills (SSI), in-home care (ResS), and specialized therapies, such as occupational or physical (O/PT) and speech language (SLT). Further options were identified related to mobile health (MobHS) and respite services (Respite) as well as a combination of all these services, as denoted by the “+” following the acronym.

**Figure 8** provides a visual of these service availability options based on a percentage of the total amount of services identified by each respondent within their state.

**Figure 8**

*Services Currently Provided to Persons with DD*



### *Services Currently Used*

To better frame the current state of the crisis intervention strategies and resources across the United States, a process map was developed for this project based on the expansive literature review of existing research to show the steps taken during and following a crisis event to visualize where gaps may exist and where improvements can be made.

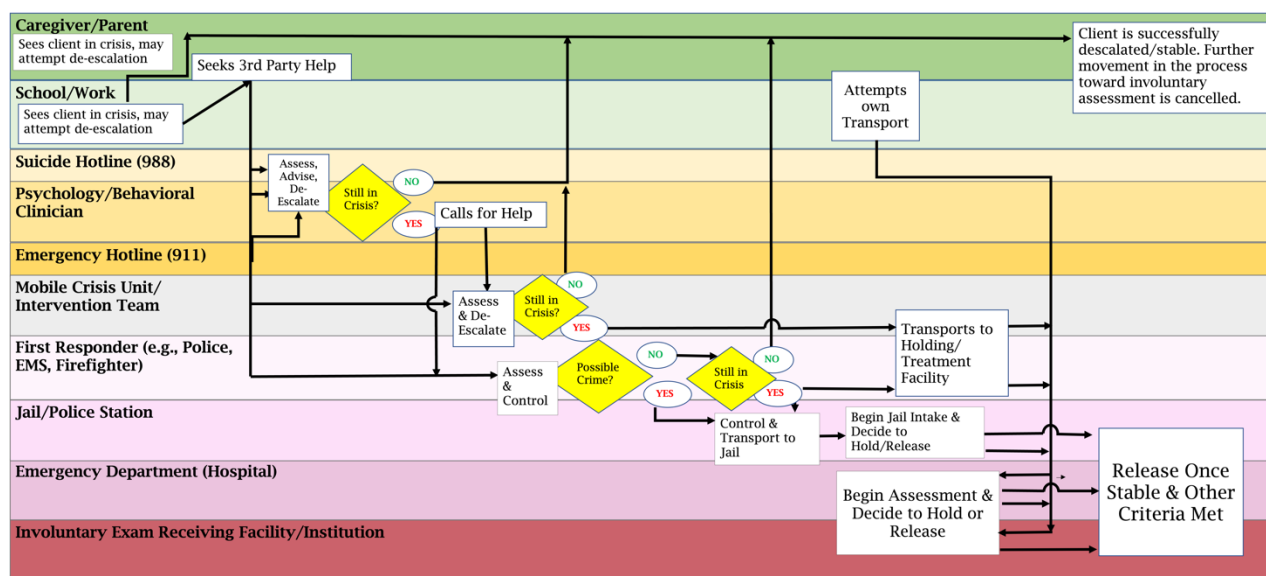
Process maps, also known as Rummler-Brache diagrams, visually depict the roles and responsibilities of different actors or groups involved in an organizational process (Rummler & Brache, 1990). To separate the steps or sub-processes performed by each actor or group, “swim lanes” are drawn between them, typically running from left to right throughout the diagram to show the flow of information or materials between them. Process maps help to clarify the interconnections and dependencies among the participants in a process, and identify potential sources of inefficiency, waste, or redundancy (Rummler & Brache, 2013).

Professionals in the field of Organizational Behavior Management (OBM), may develop and use process maps when consulting for organizations with large or complex processes that require more understanding. OBM is a subdiscipline of Applied Behavior Analysis (ABA), which is the scientific application of behavioral principles to change behavior in organizational settings (Wilder et al., 2022). OBM focuses on improving the performance and outcomes of individuals and groups in various domains, such as business, industry, government, and human services (Daniels & Bailey, 2014).

As depicted in the process map presented in **Figure 9**, current pathways that involve first responders, hospitals, and receiving facilities may create adverse situations that do not help to alleviate future crisis events from occurring.

**Figure 9**

*Process Map of Current Crisis Response Pathways*

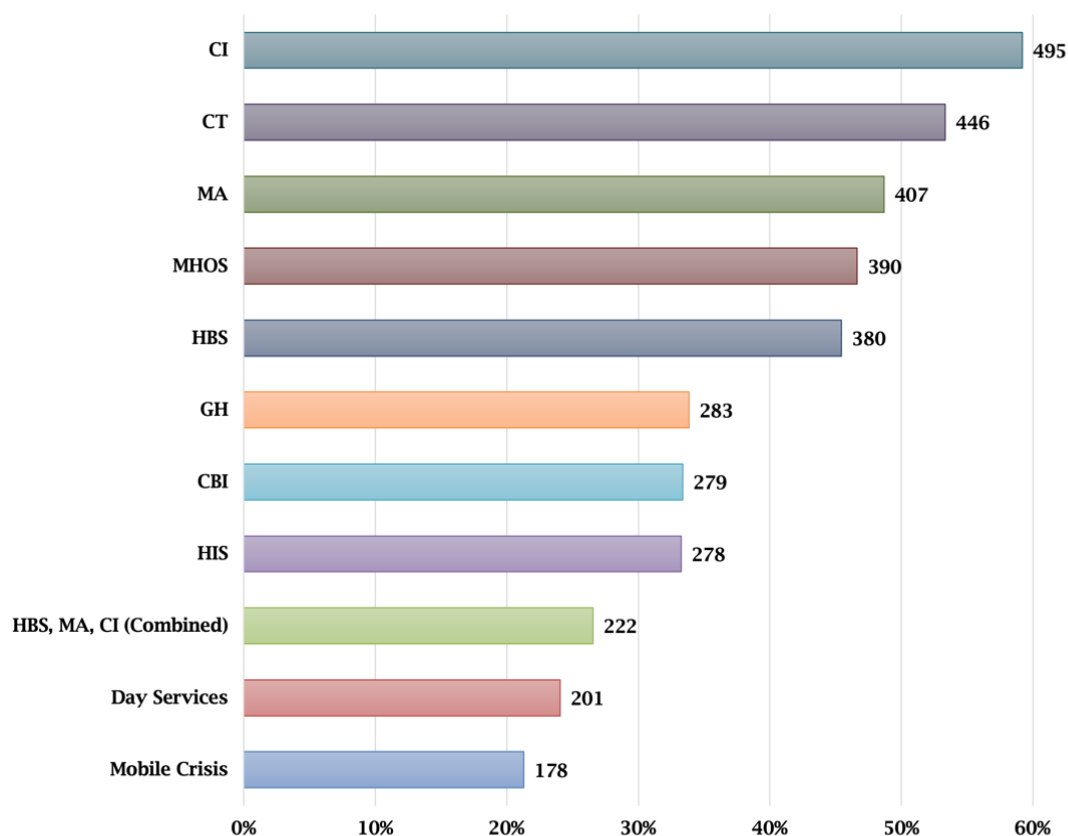


*Note:* Each service provider potentially involved in a crisis is labeled, from top to bottom, along the left edge of the figure above. Each service provider has their own horizontal band (a different color from top to bottom), and the major role(s) are stated within that band from left to right as events during a crisis unfold. The arrows show the direction of events and decisions that different providers will likely make during a crisis. For example, if caregivers fail to de-escalate a crisis, they may seek help through a phone call to a suicide hotline, 911, a mental/behavioral health clinician, a mobile crisis unit, or by directly contacting the police themselves. A caregiver may also skip calls for help and go straight to attempting their own transport to a facility (which may be more likely when caregivers have experienced long wait times for services in the past). For those already institutionalized or in a residential facility, the transport from one area of a building or campus would be shorter. However, the process map above should still generally apply.

Respondents who identified as providers or professionals within the dual diagnosis field noted that based on the standard crisis response pathways provided in the process map in **Figure 9**, several services were incorporated as part of the crisis response procedures they followed. As shown in **Figure 10**, most of these services centered on a pre-designed crisis intervention procedure complicated by siloed services related to counseling or therapy, adjustments to existing medication dosages, mental health services, and hospitalization focusing on behavioral services.

**Figure 10**

*Services Currently Utilized by Providers/Professionals during a Crisis*

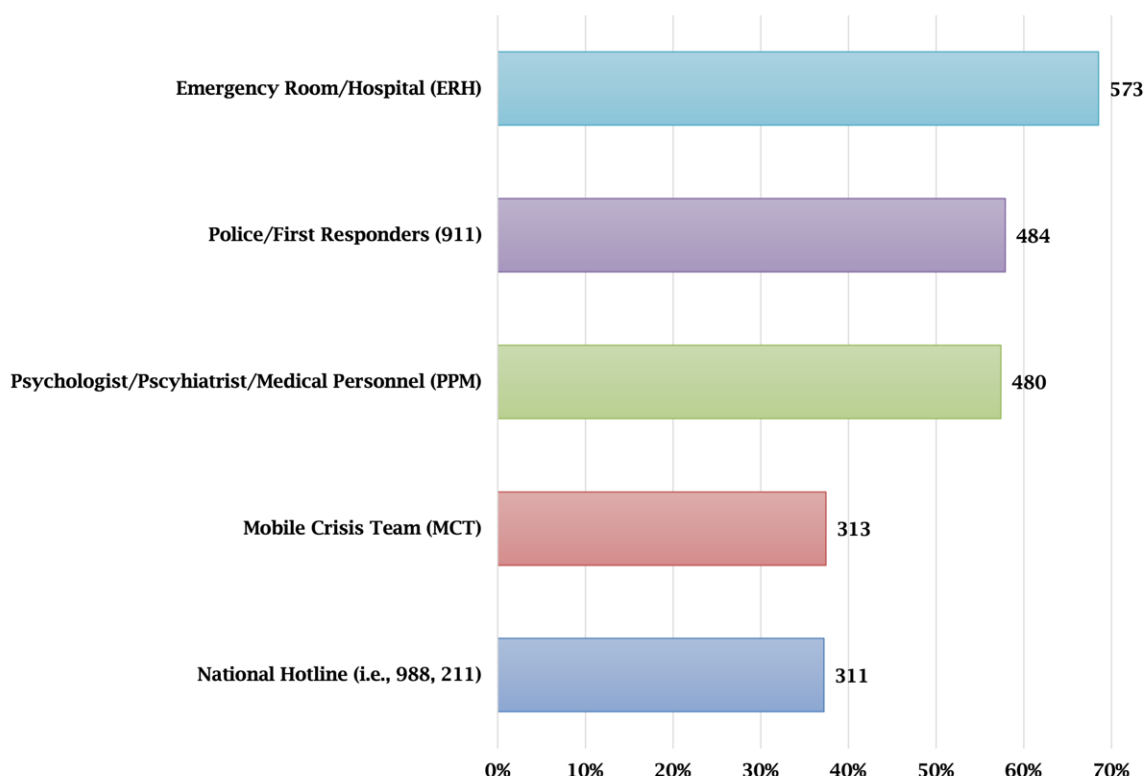


*Note:* Acronyms used are defined as follows: HBS – Hospitalization for Behavioral Services; MA – Medication Adjustments; CI – Crisis Intervention; IHS – Inpatient Hospitalization Services; CBI – Community-Based Interventions; GH – General Hospitalization; MHOS – Mental Health Outpatient Services; CT – Counseling or Therapy.

Families were also asked which services they utilized for help during a crisis event. As shown in **Figure 11**, most reached out to first responders and/or took their loved one experiencing the crisis to a hospital to get help or care. Many family members selected multiple options, suggesting they utilized multiple avenues of support during a crisis.

**Figure 11**

*Services Utilized by Families during a Crisis*

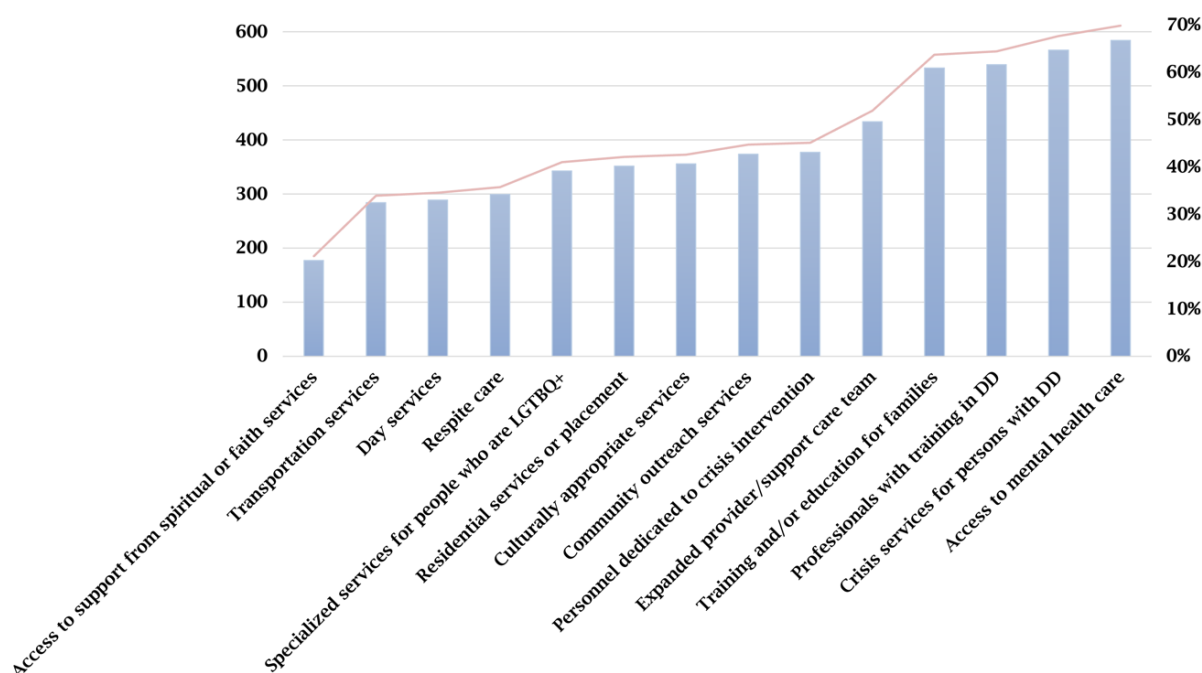


*Note:* Less than 8% (~60 respondents) noted that they did not access any of these services during a crisis, while approximately 4% (~33 respondents) weren't sure what they had used previously.

Furthermore, both providers and families were asked to identify crisis intervention services and resources they felt should be prioritized to improve crisis response in the future. As illustrated in **Figure 12**, many of those options suggested deal primarily with mental health care, individualized intervention services catered to the specific needs of persons with dual diagnosis(es), and inclusion of dual diagnosis-specialized training for providers and professionals in the field.

**Figure 12**

*Crisis Intervention Services That Should Be Prioritized*



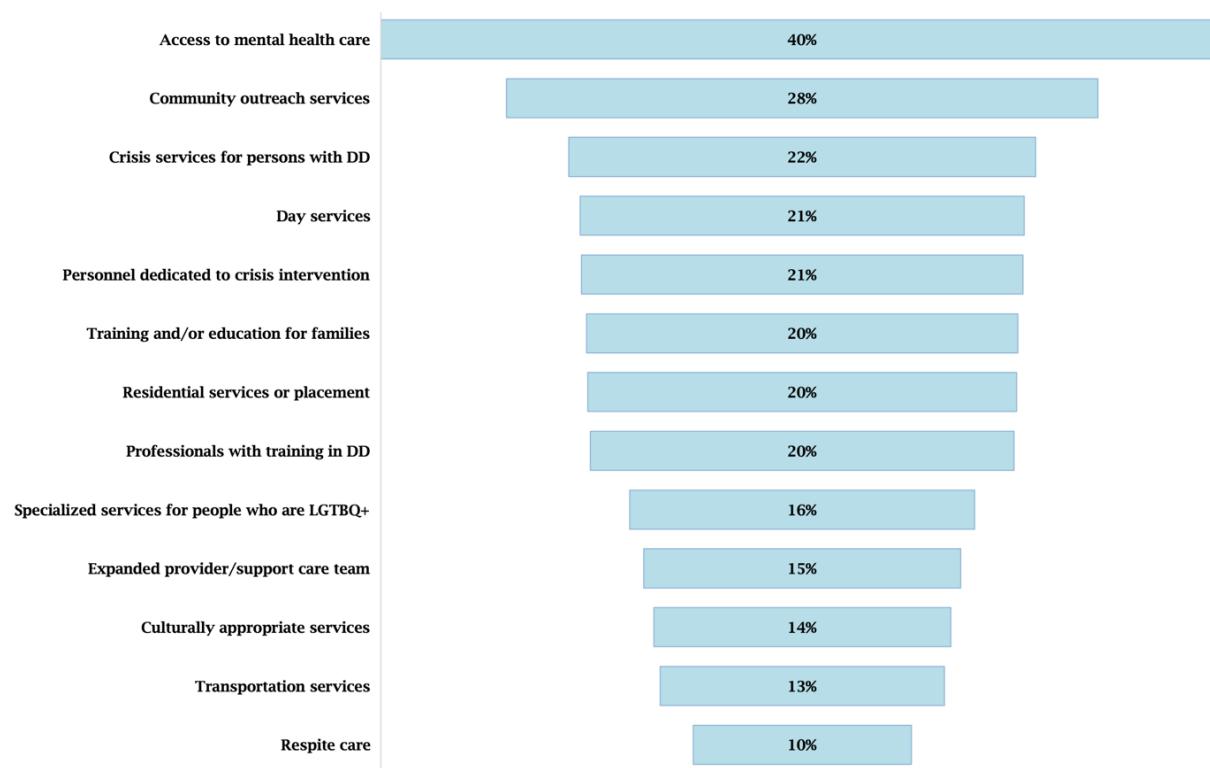
*Note:* All respondents selected multiple options, which coincides with the fact that crisis response and dual diagnosis service improvements require simultaneous avenues of resources and services from the perspectives of both providers and families.



Last, providers and families identified services and strategies that had been prioritized in recent years specific to crisis response prevention, management, and follow-up. Improved access to mental health care, increased community outreach services, and improved crisis intervention services that cater to the individual needs of persons with a dual diagnosis(es) topped the list (**Figure 13**). This suggests that what is most important to providers and family members to improve the crisis intervention strategies within their communities is to engage with agencies, and organizations responsible for delegating how crisis response measures are implemented.

**Figure 13**

*Crisis Intervention Services and Supports That Have Been Prioritized*



### ***Summary of Strategies that Build Capacities in the Community***

From the survey data collected, several key themes arose as opportunities to improve current systems for families and persons with a dual diagnosis experiencing a crisis. Because most of the crisis events were caused by mental health or behavioral disruptions, many of the supports currently utilized by families and providers directly involved behavioral services, crisis intervention services, outpatient mental health services, or a combination of one or more of these resources. From the provider perspective, these resources specifically included therapy or counseling, adjustments to prescriptions or dosages, or hospitalizations. For families, these resources primarily involved emergency room visits, calling 911, seeking psychiatric or medical help, calling a crisis hotline, or employing the use of a mobile crisis team. Collectively, both providers and parents admitted that their current course of action during a crisis event was either not effective or insufficient in managing the crisis at hand.

To counter these challenges, providers and families noted several alternative options that they felt should be prioritized within the process pathways of crisis response. These preferences include expanded access to mental health resources, crisis intervention training and support specifically designed for persons with a dual diagnosis. They also emphasized the importance of inclusive training for providers and families, and the need for a collaborative, dedicated provider network team that involves culturally competent training, respite care, day services, and community outreach services.

Using the response information collected from the preliminary survey, the NADD Team created a follow-up questionnaire that reflected the analyzed information to determine how the proposed strategies would work within a given dual diagnosis community.

## **Survey 2: An Assessment of the Strategies Developed from Survey 1 (A Follow-Up)**

### ***Demographics***

One hundred and three professional service providers, other providers, staff, or agency personnel (including first responders, educators, direct support professionals, etc.) from the first study started the survey. Twenty-six respondents did not complete the survey; a total of 77 responses were included in the data analysis. Forty family members from the first study started the follow-up survey. Five respondents did not complete the survey and were removed from analysis; a total of 35 responses were used for data analysis. In total, there were 112 participants in the follow-up survey.

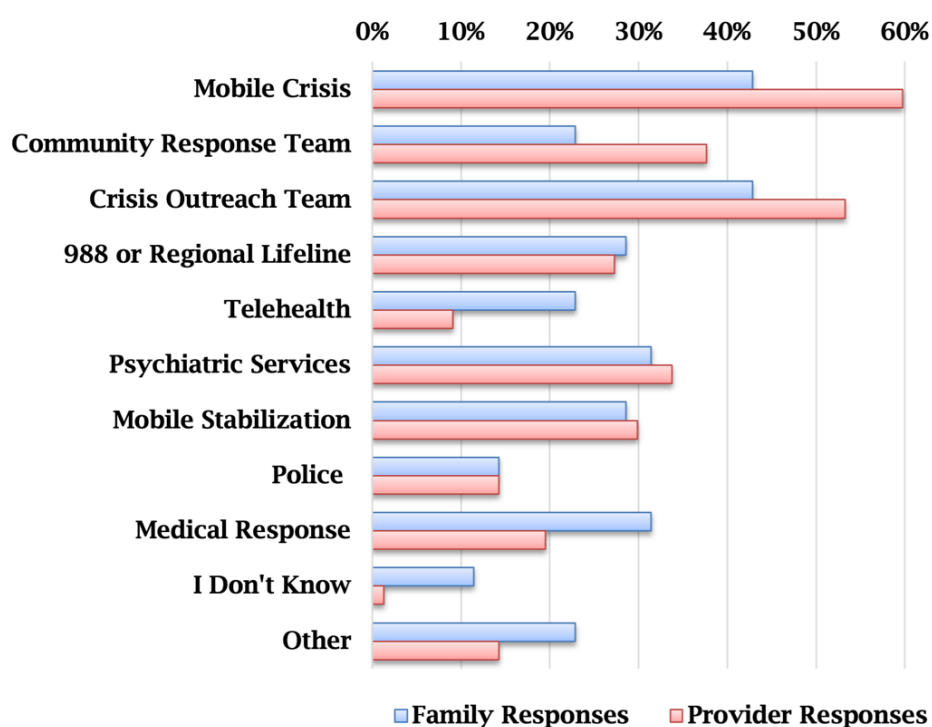
Four main themes emerged from the follow-up survey: (1) *top priorities* within the dual diagnosis field, (2) dominating factors that *trigger* a crisis event, (3) *gaps* and necessary changes to improve existing crisis intervention strategies, and (4) *effective strategies* to put in use that have a proven track record of success during a crisis.

### Top Priorities

Families and providers were mostly unified in their views of which processes and methods were the highest priority within their respective roles prior to, during, and after a crisis event. The top three priorities centered on: (1) protection of the individual and community members, (2) de-escalation of behavior, and (3) assessment of the situation and the individual. **Figure 14** provides a visual comparison of the consolidated responses by general theme and the percentage of responses corresponding to each.

**Figure 14**

*Top Critical Services Needed When Responding to a Crisis Event*



*Note:* Service providers added responses in the “Other” field including: (a) limited, if any, law enforcement involvement, (b) educated/qualified people assigned to respond to crisis situations, (c) a dedicated behavioral health crisis emergency room for evaluation and stabilization for up to 72 hours (about three days), (d) establishing trust and a safe environment for the client and community, (e) trauma-informed intervention and approach, (f) looking holistically at the person, not just their physical response, (g) all the above need to happen concurrently to ensure adequate treatment, (h) it is nice to have a plan if established, and (i) agreed-upon plans or cross-system agreements at point of service for first responders to use in interacting with the youth.

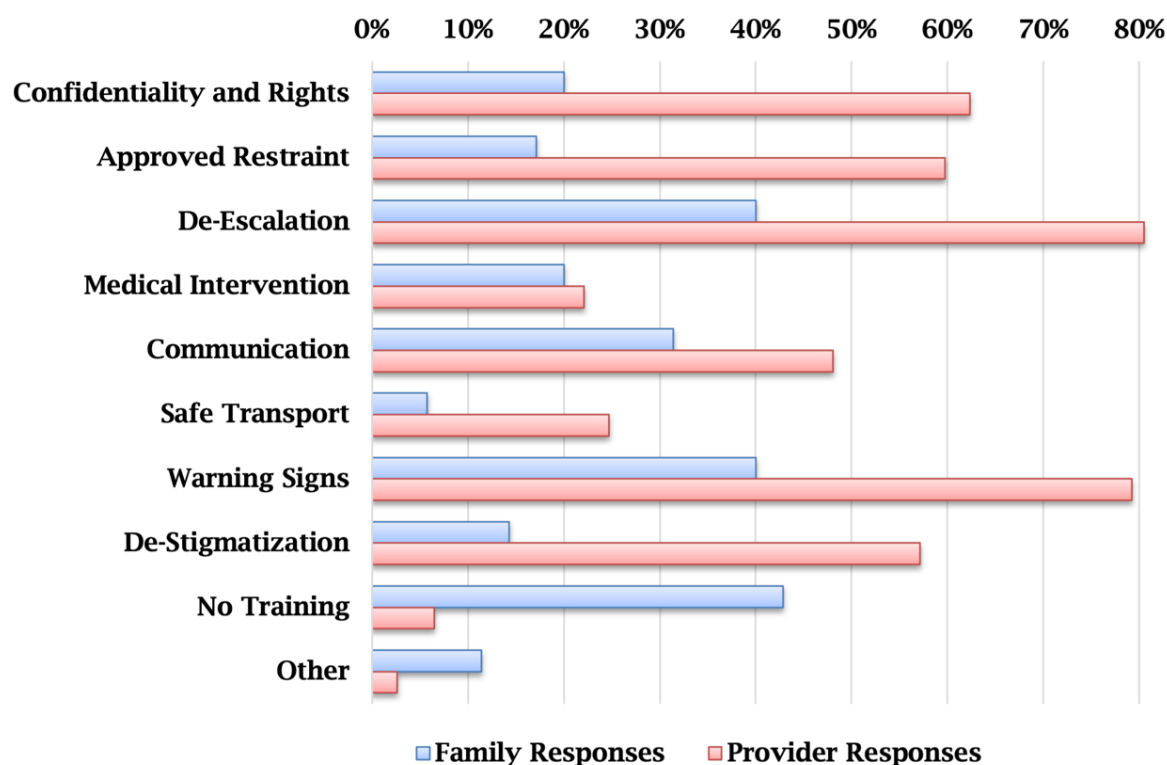
Based on their responses, respondents were then asked to identify specific ways the identified priorities could be achieved. Two main themes emerged: (1) increased training and (2) improved options for critical services.

Respondents were asked about the types of training provided regarding response(s) to crisis intervention for school-aged youth with dual diagnoses. They were instructed to select all the options provided that applied and allowed to type in an “Other” response to reflect any novel priorities. The “other” responses included interdisciplinary teams, minimizing waitlists, and proactive follow-up care. However, it’s clear from the answers that there is limited specialized training for families compared to providers.

**Figure 15** provides a visual breakdown of these training options based on the percentage of respondents from each affiliation category who selected them.

**Figure 15**

*Crisis Intervention Specialized Training Currently Provided*

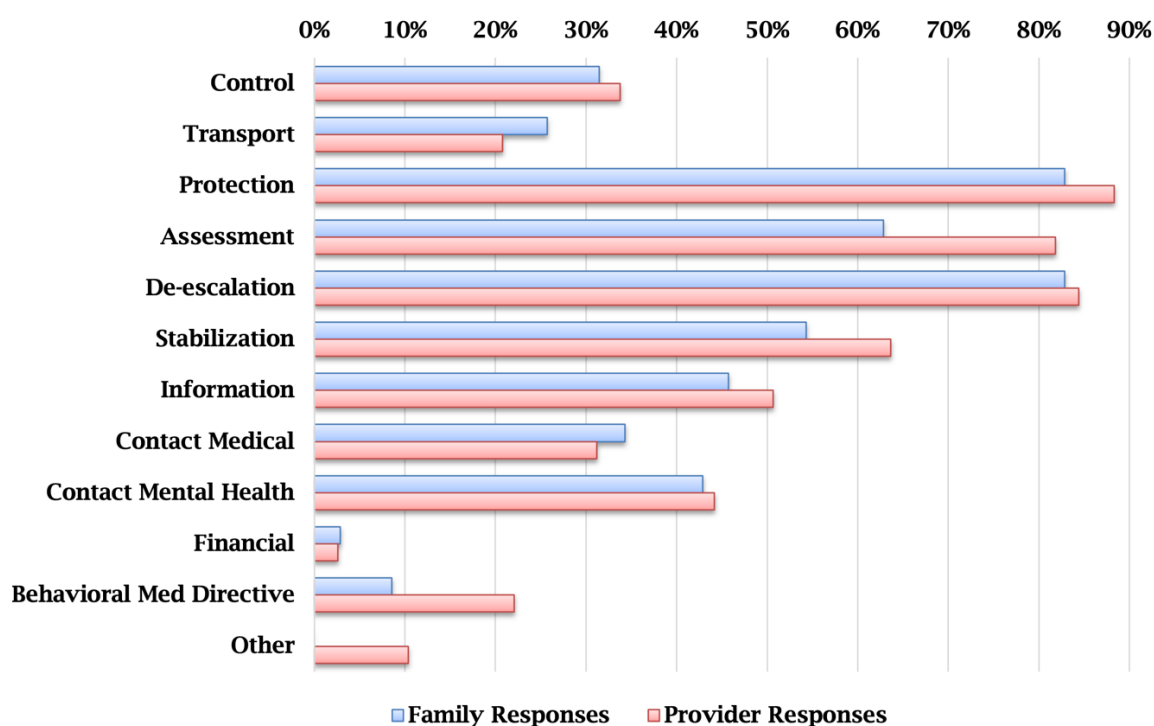


Additionally, respondents who selected “Other” added the following comments about funding priorities: (a) parent/family peer supports, (b) access to community-based services without service limits and regardless of geographical location, (c) service rural communities the same as big cities, (d) as a parent and professional, I have been developing some new strategies in collaboration with experts in these fields from some universities to help bridge the gaps of support that often happen in a school environment from grade to grade, (e) more intermediate and advanced training options for parents/families, (f) better/any integration between divisions (BH and IDD) to receive appropriate services that are integrated and actually person-centered, (g) de-escalation training and safe restraint training, (h) law enforcement education about IDD, (i) competent providers who can provide appropriate care to kids who have dual diagnosis, and (j) trained providers.

Based on their views of measures that could avoid crises and/or ways to minimize the negative impact of the aftermath that crisis procedures create, families and providers were probed to identify what they perceive to be the ideal measures after a crisis event. As shown in **Figure 16**, perspectives relating to transportation and contact with medical personnel were higher priorities for families than professionals, control and containment of the situation and contacting mental health personnel were higher for providers. Resources centered on preventive and reactive procedures (i.e., protection, assessment, de-escalation, and stabilization) were dominant themes identified by providers.

**Figure 16**

*Top Measures Related to Crisis Intervention / Prevention*



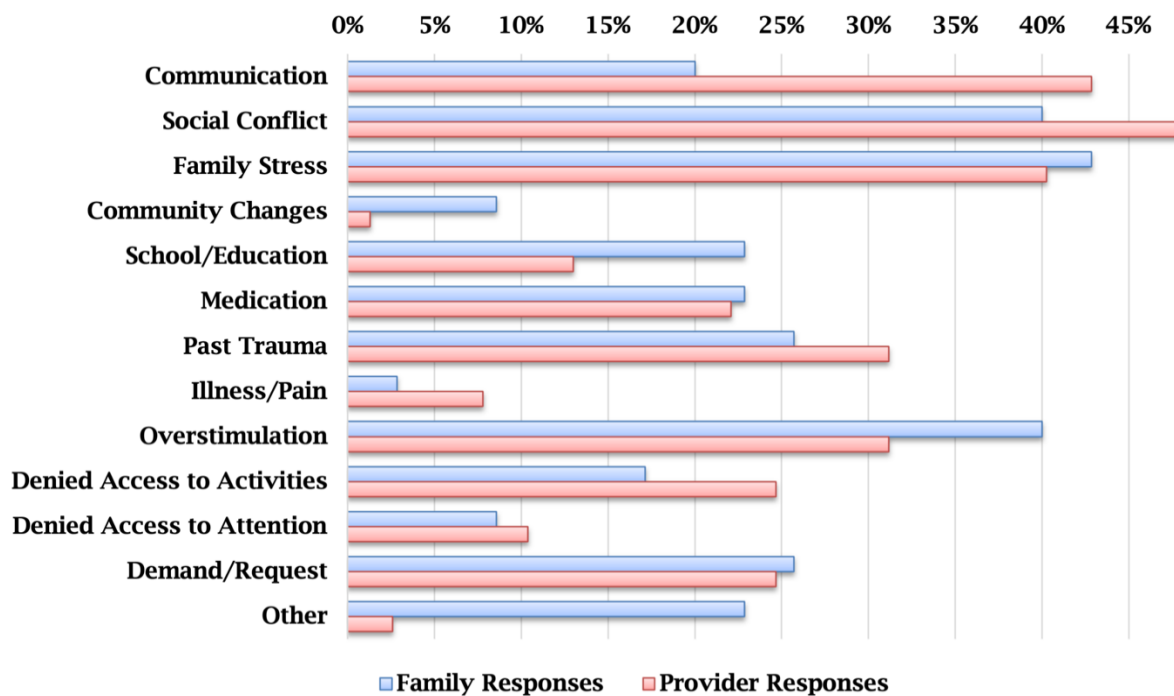
*Note:* For providers who selected “Other,” their responses consisted of more focused opportunities related to incorporating all these services within the scope of preferred languages and provider choices for families.

## Triggers

Many respondents across the provider and family groups noted they had experienced certain triggering events that caused or exacerbated a crisis event. The three most dominant circumstances for families were related to overstimulation, family stress, and social conflict. For providers, the three main causalities were communication, social conflict, and family stress. This clearly shows a level of intertwining within the perceptions that may trigger a crisis event from both the family and provider viewpoints (*Figure 17*).

**Figure 17**

### *Triggering Circumstances Leading to a Crisis Event*



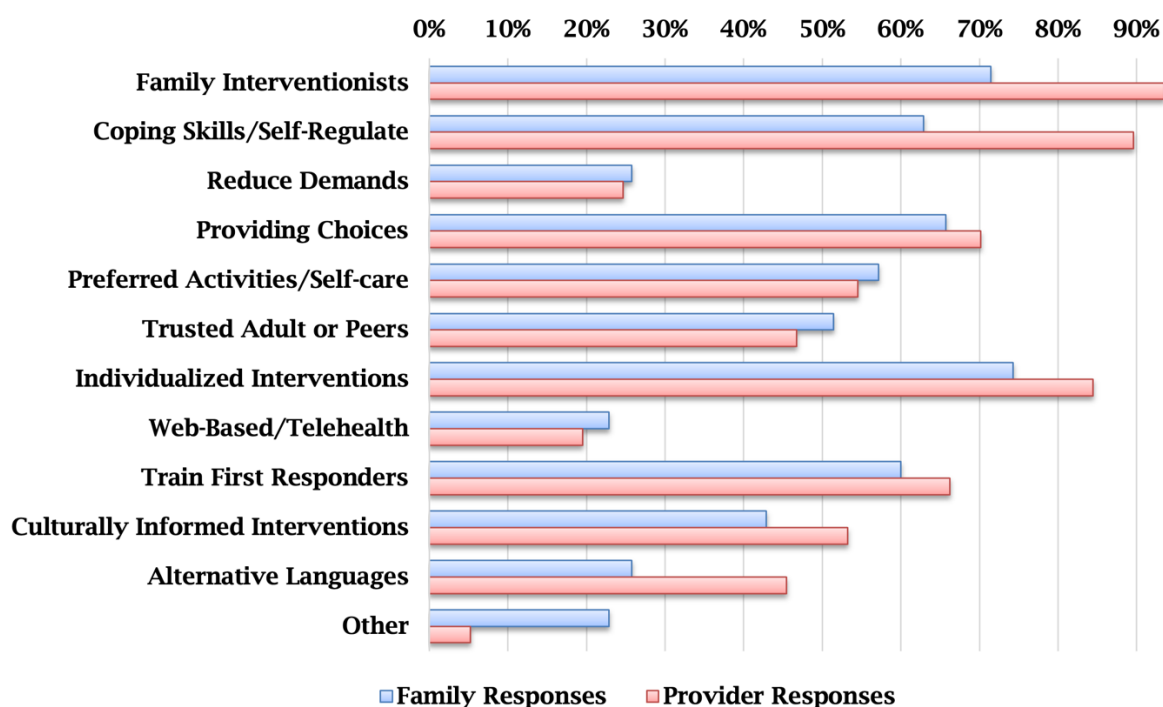
*Note:* Families provided additional suggestions within the “Other” category, which incorporated one or more of the above options. Providers, however, noted circumstances related to additional disabilities and limitations as well as conflicting provider care and referrals that were not flexible to the needs of the families or school-aged youths with dual diagnosis they cared for.



To counter these triggering events, respondents provided their suggestions for tools, resources, procedures, or actions that may help to de-escalate or prevent the crisis event. Of these recommendations, families encourage the use of family and individualized crisis intervention strategies coupled with expanded choices that create options for the person experiencing the crisis to self-regulate and calm down. Coincidentally, providers stated similar options, with more focus on introducing self-regulation techniques, as shown in **Figure 18**.

**Figure 18**

*De-Escalation and Improvement Strategies*



*Note:* Both providers and families suggested in “Other” that a multi-faceted approach would be beneficial to incorporate several components provided in this figure, further individualizing the care and response measures undertaken.

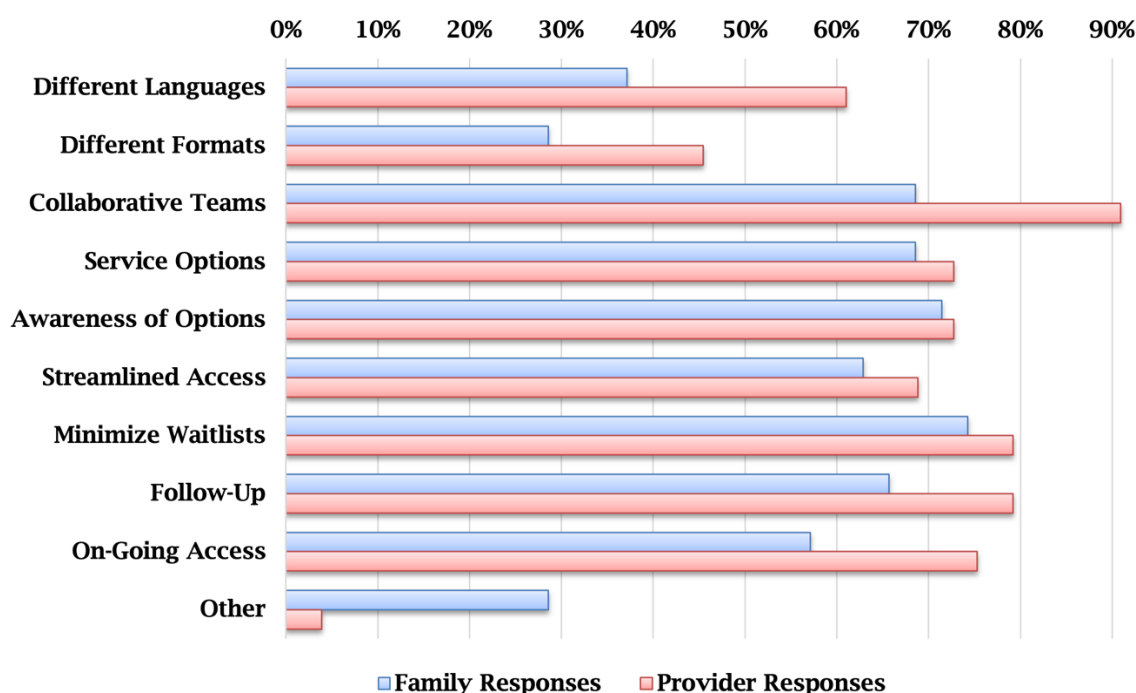
### Current Gaps

Respondents were asked about services they felt were critical, but lacking, for effective crisis response for school-aged youth with dual diagnoses. They were instructed to select the top three options that applied and were given the option to type in an “other” response to reflect any other services. Concepts surrounding collaborative teams, minimizing waitlists, and awareness of options dominated most responses.

**Figure 19** provides a visual breakdown of these training options based on the percentage of respondents who selected them.

**Figure 19**

*Crisis Services to Be Incorporated (Pending Funding)*

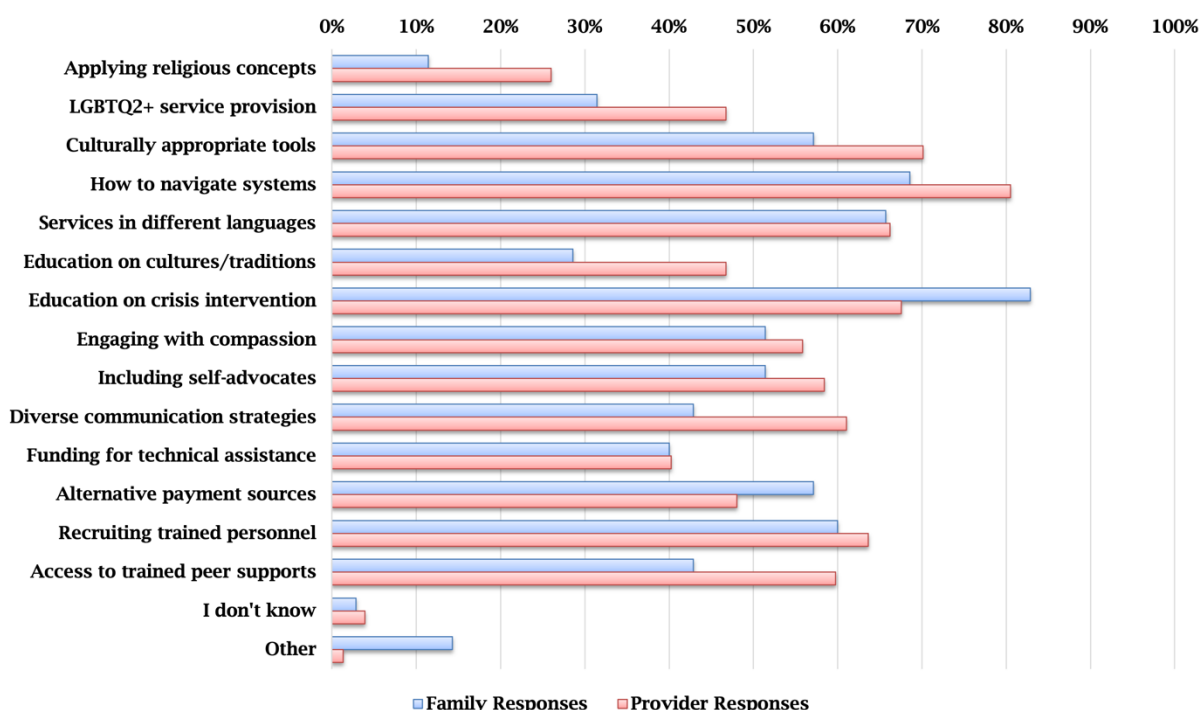


*Note:* Respondents who selected “other” added the following components: (a) hospital transport and (b) family/parent peer support workers. One respondent indicated they would not call the police or 911 for their child who identified as a person of a racial minority with a diagnosis of autism. Other responses included (c) trained school personnel and police to understand dual diagnosis, (d) crisis stabilization facilities for individuals with dual diagnoses and clarification of the designated funders to avoid long-term hospitalization, trauma, and neglect, (e) crisis planning and prevention, (g) a Community Response Team or Mobile Stabilization Units, and (h) the most important thing is prevention, including sufficient workers to provide care.

Service providers and family members were asked to identify what services would strengthen current crisis intervention services. Of the several options they selected, families and providers were aligned in their support for improving education about crisis intervention strategies, enhancing existing systems to make finding information easier and more streamlined, and incorporating culturally appropriate tools and languages that address potential language or knowledge barriers encountered by non-English populations. **Figure 20** provides more information about additional resources and services that could be incorporated to bolster current crisis response systems for school-aged youth.

**Figure 20**

*Opportunities to Strengthen Current Crisis Intervention Services*



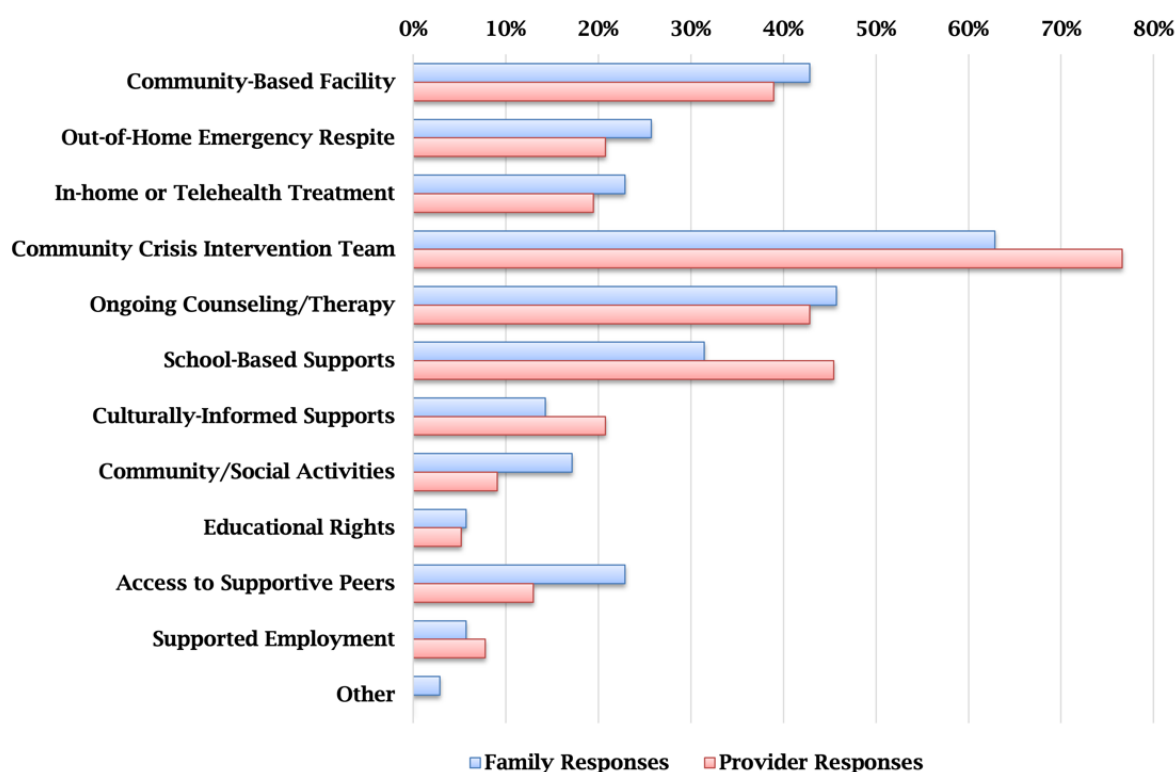
*Note:* Similar to the prevention measures identified to help de-escalate crisis situations, both families and providers emphasized the need for a multi-faceted and collaborative approach that encourages cross-collaborative professional care that is specifically designed for the individual circumstances required of each school-aged youth with dual diagnosis.

Expanding on earlier suggestions by all respondents that improved mental health supports were needed, participants were asked specifically about what they perceive to

be the best services or resources that could be established to help improve the current outcomes for mental health conditions for school-aged youth with a dual diagnosis. Both families and providers echoed one another in their recommendations to create a community crisis intervention team that would directly lead a crisis response event, which may include establishing a community-based facility (an alternative to an institution or involuntary facility). Further, embedding school-based support systems and ongoing counseling or therapy may foster a positive prevention and response pathway that could lead to better outcomes, according to the answers provided. **Figure 21** provides other outcome measures proposed that build upon these main components.

**Figure 21**

*Outcome Measures to Improve Mental Health Crises*



Family members added responses in the “Other” field including: (a) neurodivergent affirming care trainings, (b) stabilization, acute, subacute, and day treatment providers, (c) Providing crisis services with clinicians who have received training in dual diagnosis, and (d) Family stress management practices. One parent noted that professionals who can provide care in the community are needed to prevent crisis

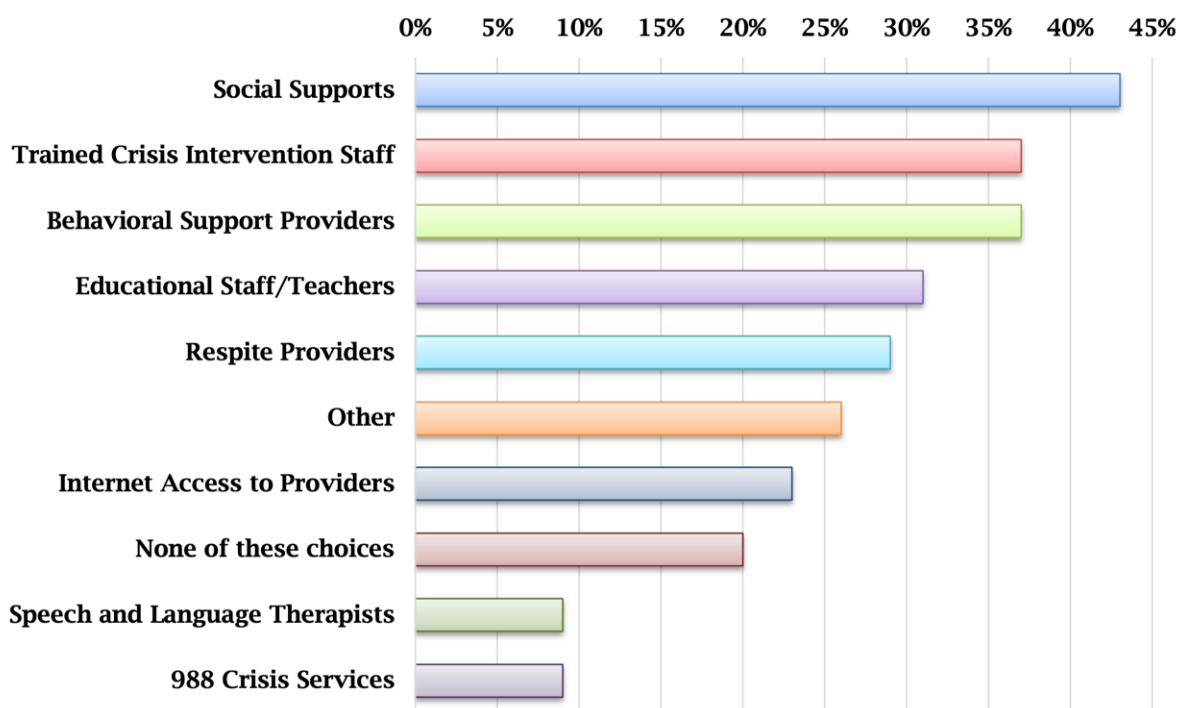
situations. If that doesn't happen, all the other strategies and interventions are meaningless.

### *Effective Strategies*

Family members were asked what effective home-based interventions [short-term, intensive services designed to avert psychiatric hospitalizations of children and youth] were available to prevent a crisis from occurring. They were instructed to select all the options provided that applied and given the opportunity to type in an “other” response. **Figure 22** provides a visual representation of their responses.

**Figure 22**

*Top Services Deemed Most Effective by Family Members*



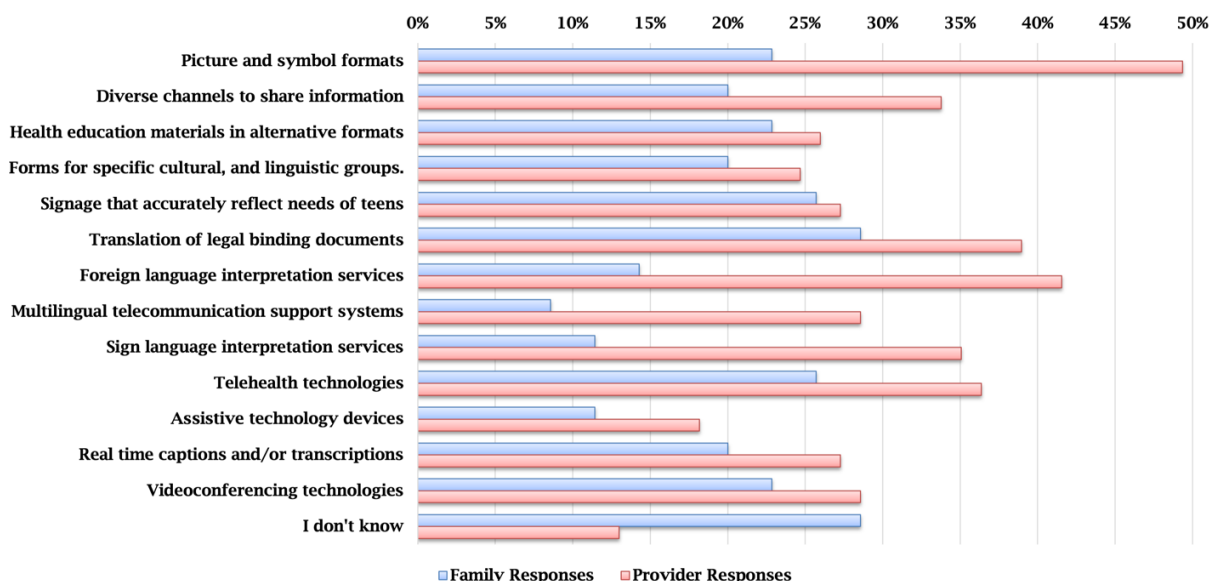
*Note:* Family members added responses in the “other” field including: (a) mental health therapists, (b) neurodiversity affirming supports, (c) Providers who LOOK like youth (people of color), especially intensive in-home behavioral services (d) CIT police officers, (e) consistent personal care providers, and (f) appropriate mental health services in the community. While all selections are technically available, limited resource capacity and waitlisting make them hard to use in a crisis.

One parent noted, “We need intensive home-based interventions long term. Short term is not sustainable. Intensive services involve peer mentors and skills trainers and access to psychiatrist 24/7. As soon as the child/adolescent starts to settle, they discharge and move them on, and the person then goes back into crisis. Some of these children/adolescents do not transition well and need the same structure/routines every day/week. Due to processing speeds, etc., they are not candidates for internet/tele-med services.”

Family members and service providers were asked to identify communication strategies used to bridge any perceived gaps in crisis intervention provision. Respondents were instructed to select all communication strategies they believed were effective, with families sharing that translation of materials, teen-oriented signage, and telehealth options were most successful. Providers, however, identified picture and symbol formats, non-English interpretation services, and alternative language formats as most helpful. **Figure 23** provides context relating to additional strategies that improved crisis response measures.

**Figure 23**

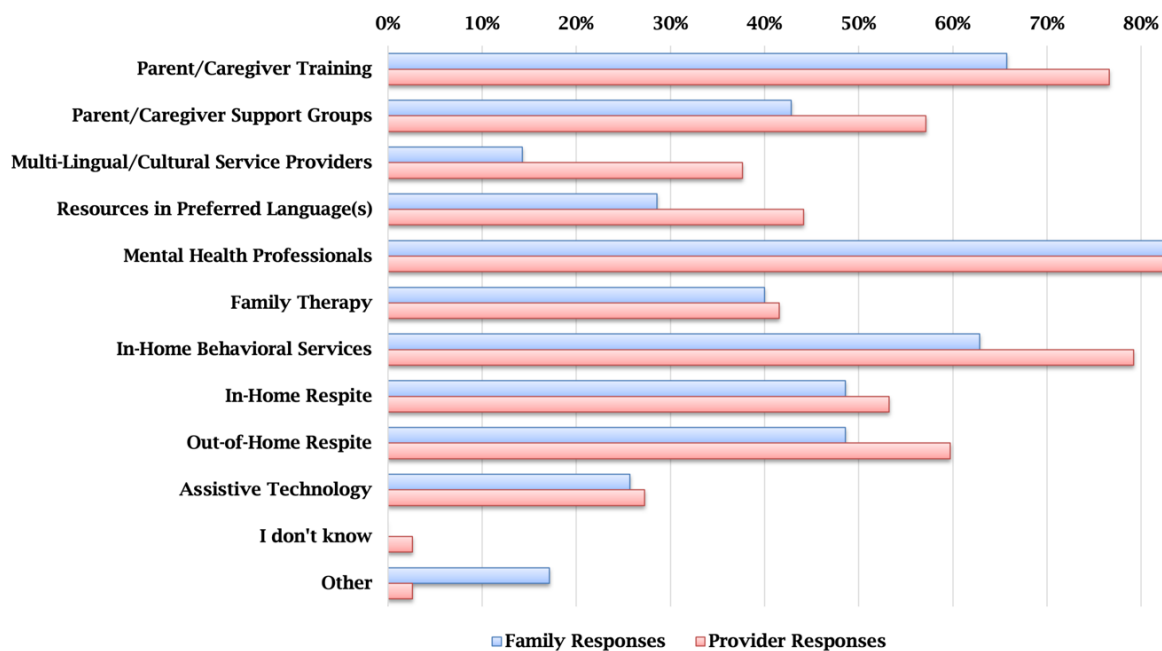
*Communication Strategies Bridging the Gap in Quality Crisis Response*



Moreover, both parents and providers provided insight regarding additional skills, resources, or services that could be implemented to help improve their ability to prevent a crisis from escalating. As shown in **Figure 24**, many of their answers embodied expanded training opportunities, in-home services, family-centered support, and culturally inclusive provider specializations.

**Figure 24**

*Additional Resources Necessary to Prevent Crisis Events*



*Note:* Care options and supports related to expanded options in rural settings and more virtual or flexible options for provider treatment to accommodate the individual needs of school-aged youth and their families were proposed by both families and providers alike.



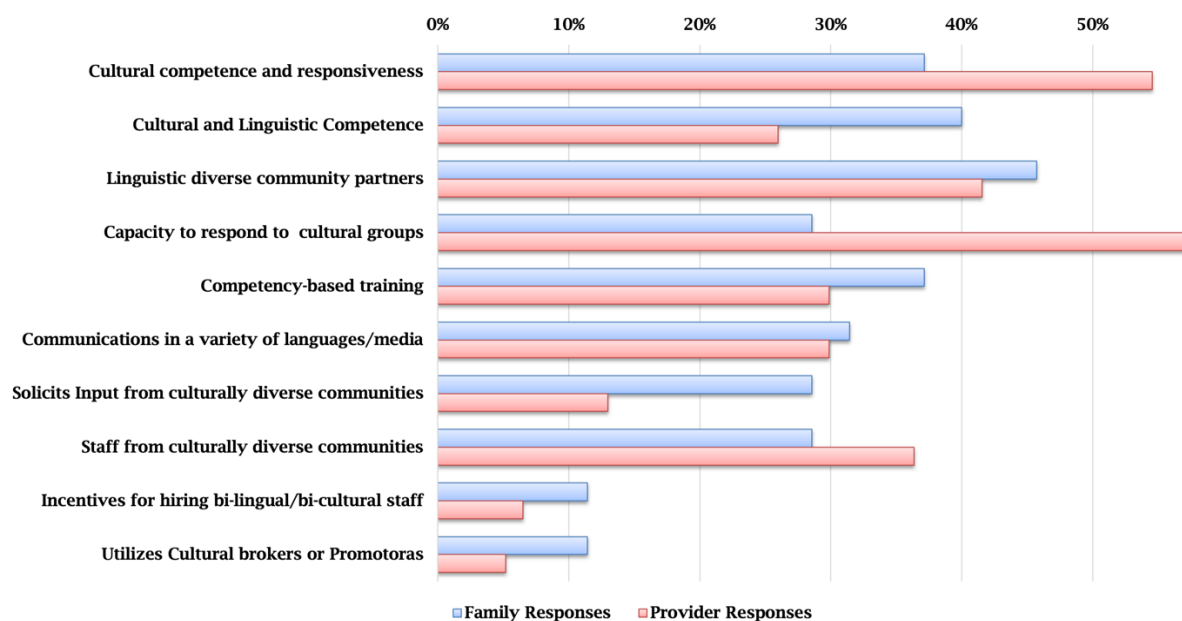
In response to the diverse populations that many providers working within the dual diagnosis field care for, service providers were asked if they felt they would benefit from culturally informed and cultural sensitivity training to assist school-aged youths with dual diagnoses in the community. Overwhelmingly, both families (~85%) providers (~91%) reported that training in cultural competency would be beneficial.

An open-ended question followed, asking providers to identify any culturally responsive training they felt should be provided, including training on neurodiversity, neurodiversity in the workplace, LGBTQ2+ issues, cultural humility, and system navigation (e.g., school systems and the IEP process). Service providers also suggested online training as well as making training available to individuals who are not service providers (e.g., contracted employees). Informational training, available in multiple formats, could also address topics such as physical disabilities, health impairments, and the use of AAC services/ devices. Coincidentally, when family members were asked the same question, they overwhelmingly stated yes (86%).

To further expand on the cultural components of providing proper care and support for school-aged youth with a dual diagnosis, all participants were asked to identify culturally informed practices that should be available in alternative languages or formats (e.g., Braille, ASL). As depicted in **Figure 25**, service providers suggested materials to help respond to the unique needs of cultural groups as a need (57%). Families suggested the integration of linguistic community partners (46%).

**Figure 25**

*Culturally Informed Practices Needed*

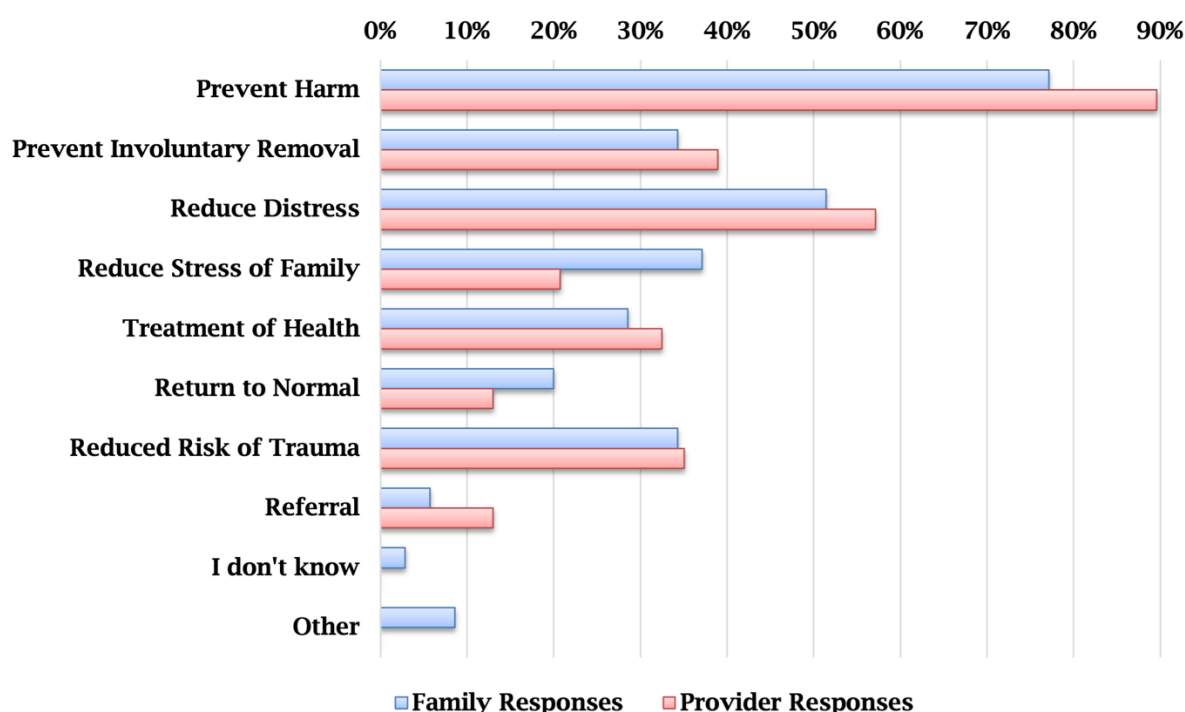


### *Summary of Services Needed to Sustain Effective Capacity Building in the Community*

There were slight variations between providers and families regarding which methods, resources, and supports they thought would best reduce or eliminate the impact of a crisis for someone with a dual diagnosis in their community. However, most of their answers aligned in the identification of what is missing, what is working, and where improvements are needed, with the idea of achieving specific goals that would emphasize protection, prevention, and treatment. **Figure 26** demonstrates that the most important outcomes from all participants centered on keeping school-aged youth safe while reducing the risk of trauma and stress to them and their families/caregivers.

**Figure 26**

*Top Goals for School-Aged Youth with a Dual Diagnosis in a Crisis*



To achieve these goals, providers and families highlighted the need for developing individualized procedures, such as reducing triggering factors and stressful events, by adopting crisis response procedures and policies (including training) that accentuated de-escalation, communication, and individualized care. These strategies may be achieved through various avenues, such as incorporating culturally informed practices, expanding individuals' treatment options, introducing self-regulation and self-coping processes, and providing individuals with dual diagnosis more involvement in their care options and choices (including any religious, linguistic, educational, or alternative

pathways they prefer or are more comfortable with). Pending the availability of additional funding and availability, many respondents felt these capacity-building opportunities could be achieved through the inclusion of more community-based facilities, expanded respite care options, ongoing counseling or therapy, inclusive school-based supports, amplified community outreach activities, and increased access to specialized employment, communication, and educational support systems that are accessibility-centered.

Across all responses, the key theme that arose from both families and providers was that current systems were shorthanded and lacking sufficient options and that to protect school-aged youth with dual diagnosis and provide them with a quality of life, specific goals needed to be met that corresponded with changes in policy, procedure, response, and after-care.

By focusing on improving existing systems to incorporate a more comprehensive yet interconnected care and support pathway, the strategies identified by both providers and families in this survey have the likelihood to achieve the major goals identified above.

## Discussion of Findings: Barriers and Recommendations

### Barriers

As this project has shown, crisis intervention needs to have some “flexibility” (McNally & McMurray, 2015). Service provision and post-crisis follow-up need to be adaptable in both the juxtaposition of appointments and the goodness-of-fit in terms of the capacity and family culture. As previous research has shown, effective service provision adapts to the unique needs of the youth, families, and cultural variations within service settings. While many respondents noted that a flexible continuum of services to support school-aged youth and their families is often associated with positive outcomes, issues surrounding service delivery variations led to discrepancies in clinical approaches, unclear eligibility criteria, and funding streams that at times seem to conflict. Though evaluation of crisis intervention service efficacy is difficult as outcomes, performance measures, and effectiveness measures differ by state, regional, and cultural community, it is crucial for developing effective delivery systems that are both available and accessed by families.

Successful alternatives that draw from existing research and recommended capacity-building opportunities suggest that the hurdles faced by families and providers of school-aged youth with a dual diagnosis center on the availability and usability of whatever services or supports are provided locally within their community. Although there have been significant advances in the use of technology and expanded trainings on crisis intervention within regions across the country, they do not cater to the individualized circumstances of the different families, communities, providers, and

circumstances each school-aged youth with a dual diagnosis goes through prior to, during, and following a crisis. As such, these circumstances make it difficult for families to obtain and use appropriate treatment and care supports, which leads to inadequate prevention, mitigation, and post-crisis support options.

### *Barriers to Service Availability*

Past research has shown that logistical issues related to crisis intervention continue to affect timely service provision. Mobile crisis, while more effective, requires practitioners to travel to the crisis. For individuals in more rural locations, wait times may be longer to access care. While these aspects may be difficult to diminish, web-based services may provide an alternative measure to utilize in minimizing escalation.

Many studies have shown that mental health care for individuals who have a dual diagnosis is often provided by separate systems, leading to fragmentation of care. This can result in disjointed treatment plans and limited coordination. Additionally, many regions report a shortage of specialized services or trained professionals to address the unique needs of youth with dual diagnoses. Transportation and accessibility continue to challenge service provider systems. As many families and providers noted, geographic and transportation barriers can make it difficult for families to access services, particularly if specialized treatment is located far from their homes.

As detailed in both the literature review and the survey responses, a lack of cultural competency can lead to an increased risk of unintentional bias and disparities in care. Research shows that school-aged youth with dual diagnosis(es) from minority or marginalized communities are more likely to receive suboptimal or inappropriate interventions due to a lack of understanding of their cultural backgrounds. This can perpetuate existing health disparities and lead to unequal outcomes. From both the provider and family members' viewpoint, integrating cultural competency can help bridge this gap, ensuring that all children, regardless of their cultural background, receive equitable crisis intervention services.

Also noted in existing reports, children who engage in suicidal thoughts or behavior or otherwise pose a risk to themselves or others in school, home, or the community are more likely to be admitted to inpatient hospitalization, psychiatric residential treatment facilities, or incarcerated (Vanderploeg et al., 2016). To counter this, many families and providers admitted leaning on emergency departments and juvenile justice systems, among the most costly and restrictive options in crisis response. Research shows us that these restrictive settings are most often associated with suboptimal outcomes (Vanderploeg et al., 2016). Dependency on first responders and emergency department personnel for the treatment of mental health issues and involuntary hospitalization presents several significant challenges.

Most family members surveyed admitted to relying heavily on emergency rooms and hospitals to cope with a crisis event. The literature tells us that emergency departments are often overcrowded and may not have the resources or capacity to provide appropriate care for individuals with mental health issues. This can lead to long wait times and inadequate treatment, further increasing the distress of those in crisis. In many cases, individuals who are involuntarily hospitalized for mental health reasons may not receive adequate follow-up care and support upon discharge. This can result in a revolving door scenario, where people cycle in and out of the emergency departments without addressing the underlying causes of their mental health issues.

Families and providers agree that expanding access to alternatives, such as crisis hotlines, mobile crisis teams, and mental health crisis centers, can help reduce dependency on emergency departments and first responder systems. Addressing the problem of dependency on first responders and emergency departments for mental health issues requires a comprehensive approach that involves diverting individuals to appropriate mental health services, improving training for first responders, reducing the stigma associated with mental illness, and investing in community-based mental health care. This approach can help ensure that individuals in crisis receive the care and support they need in a more compassionate and effective manner.

### ***Barriers to Service Utilization***

Barriers that hinder a family's ability to receive appropriate and effective care identified in the first survey parallel the findings of previous research, with stigma, lack of awareness of available resources, insurance, and funding issues as the leading causes of non-utilization in resources. The stigma of mental health and/or intellectual disabilities can prevent youth and their families from seeking help, as they may fear judgment or discrimination. Further, insurance coverage for mental health services can be complex and may not always cover the needed treatments.

Mental health issues in school-aged youth can manifest in various ways, including behavioral problems, academic difficulties, or social withdrawal. When services are siloed, as many families in the survey noted, these signs may go unnoticed or unaddressed until they become more severe, making it harder to intervene early, which is crucial for effective treatment. When services are not coordinated, as most providers commented, resources may be allocated inefficiently. This can result in duplication of efforts, wasted resources, or gaps in services, leaving some youth underserved while others receive overlapping or unnecessary care.

Additionally, both family and provider surveys echoed existing research that acknowledged that navigating multiple agencies and providers can be overwhelming and may deter individuals from seeking help altogether. In a siloed system, communication barriers can hinder the exchange of critical information and the development of integrated treatment plans. School-aged youth with dual diagnoses often require ongoing support and care. A siloed approach is less likely to support the continuity of care necessary for long-term well-being. A more effective approach is to

adopt an integrated and collaborative model of care. This involves breaking down the barriers between service providers, improving communication and coordination, and considering the whole person in the context of their family, school, and community.

As the literature has shown, the lack of uniformity in how systems assess and identify Intellectual and Developmental Disabilities (IDD), mental health issues, and co-occurring mental health issues across states, agencies, and regional providers is a significant challenge in healthcare and human services. This lack of uniformity can result in disparities in diagnosis, treatment, and support for individuals with dual diagnosis(es).

One of the reasons for the lack of uniformity is the variation in diagnostic criteria used across different states and agencies. For example, the criteria for diagnosing autism spectrum disorder (ASD) may vary from one state to another, leading to differences in prevalence rates and access to services. Additionally, states and service providers often use different screening and assessment tools to identify individuals with IDD and mental health conditions. This can lead to inconsistencies in diagnoses and the level of support provided. Differences in funding and resources allocated to IDD and mental health services can also vary greatly between states and regions. This impacts the availability and quality of services, leading to disparities in care. Each state and agency may have its own policies and regulations governing the identification and support of individuals with IDD and mental health issues. This results in a lack of consistency in service delivery. Discrepancies in how data on IDD and mental health issues are collected and reported can also contribute to the lack of uniformity. This can make it difficult to compare prevalence rates and service utilization across regions. Addressing these challenges and promoting uniformity in the identification and support of individuals with IDD and mental health issues requires collaboration among states, agencies, and providers, as well as standardization of diagnostic criteria and assessment tools.

Most respondents (both providers and family members) identified limitations surrounding media type and the formatting of media as a barrier to service utilization for individuals with dual diagnosis(es). Media type and format affect how information is communicated to and accessed by service providers and families. Some service providers and government agencies use complex language and jargon in their presentations and available materials. Jargon is especially difficult to translate into materials that are non-English-based. Medical terminology, legal terms, and technical language can create confusion and limit service utilization, which many families noted impacts communication and understanding within minority populations.

Further, providers surveyed noted that some media formats are not accessible or are extremely difficult to use for individuals who have health impairments (e.g., Braille needed for the blind), processing issues (e.g., video with audio may be difficult to process simultaneously), or cognitive impairments (e.g., easy-to-read fonts and clear navigation). The literature reviewed coincided with this view, noting that media may overwhelm individuals with a dual diagnosis, leading to frustration and



disengagement. While digital platforms are increasingly common for dissemination, not all individuals with dual diagnosis(es) have access to or are comfortable using technology. As the literature further asserts, some individuals prefer face-to-face interactions and perceive remote therapy as a less preferred temporary stopgap. In this instance, the digital divide can limit the ability to access and utilize services. Additionally, some media content perpetuates stigmas and negative stereotypes, exacerbating mental health issues rather than resolving them. Families and providers agree that utilizing media should be individualized to the comfort and preference of the families and their school-aged youth with a dual diagnosis to ensure efficacy and usability.

## Recommendations for Improved Crisis Support

The recommendations to support improved crisis response strategies and outcomes for school-aged youth living with a dual diagnosis fell into the following categories: cross-professional collaboration and coordination; effective communication; using different media formats; assessment of client, client needs and cultural fit; educating and debriefing first responders and service providers; and training that includes cultural fit.

### *Cross-Professional Collaboration and Coordination*

Cross-disciplinary collaboration and coordination are essential components of service delivery systems for individuals with dual diagnoses. Providing effective care for school-aged youth with IDD and co-occurring mental health issues requires a multidisciplinary approach involving professionals from divergent fields and philosophical approaches (e.g., psychiatry, psychology, social work, counseling, behavior analysis, and other medical fields). A holistic approach to treatment that addresses physical, mental, and behavioral health is needed to improve the quality of care. Each profession brings unique expertise, allowing for comprehensive assessment, treatment planning, and ongoing care that focuses on the individual's physical, psychological, and social needs. The Substance Abuse and Mental Health Services Administration (SAMHSA) proposes an integrated care model, emphasizing the need for collaboration between mental health and addiction treatment providers. A wraparound approach involves creating a customized care plan for everyone, with input from various professionals, caregivers, and the person with dual diagnosis. This multi-faceted approach aims to provide comprehensive support tailored to everyone's needs. To achieve this goal, professionals need ongoing training and education on dual diagnosis treatment, evidence-based practices, and interdisciplinary collaboration.

### *Effective Communication*

Effective communication is an essential component of providing high-quality care and effective crisis services for individuals with IDD and co-occurring mental health issues. School-aged children with dual diagnoses oftentimes face unique challenges that require a multi-faceted approach to care and support that involves multiple systems.



Sharing knowledge among professionals, caregivers, and support staff helps accurately assess and build a comprehensive understanding of the individual's needs, strengths, and challenges. A holistic perspective enables targeted and effective interventions that support physical, emotional, and social well-being. Clear communication helps prevent misunderstandings that can lead to behavioral and mental health issues. Sharing knowledge allows for the timely identification of warning signs and the implementation of appropriate interventions. Additionally, effective communication provides families and caregivers with the resources and information needed to provide the best possible care, integrating them into the treatment model. Effective communication is also associated with reduced caregiver stress and provider burnout. Gathering and sharing knowledge about the challenges faced by individuals with dual diagnoses can inform policy development and advocacy efforts, leading to improved services and support. It is hoped that the data gathered as part of this project can be shared with policymakers to identify areas of best practice that should be prioritized for funding. Ultimately, the goal is to enhance the quality of life for individuals with dual diagnoses. Knowledge sharing and effective communication are critical components to achieving this goal.

### *Different Media Formats*

When developing and disseminating information, it is essential to ensure materials are available in clear language so information can be used by individuals who need additional support. Availability is needed in multiple formats such as Braille, large print, and accessible digital formats (e.g., subtitles). Another recommendation is to avoid long blocks of text that can be difficult for individuals with dyslexia, provide transcripts as needed, and add infographics, images, or voice-over to visual content. Multimodal augmentative and alternative communication strategies may be employed to support the sharing of knowledge for people who cannot always rely on speech to convey their thoughts. Screen readers and assistive technology can read text and describe images for individuals with visual impairments. Practitioners should strive to use inclusive language that is also culturally informed. For more information, see Section 508 Standards or Web Content Accessibility Guidelines (WCAG). Providing off-line options such as printed media that can be mailed to stakeholders may be necessary to help bridge the digital divide. For many individuals, multi-media formats such as webchats and texting applications offer much-needed help for individuals. Addressing barriers related to communication in formats users can easily understand enhances the accessibility of services for individuals with dual diagnosis(es), thus ensuring access to the supports they need to lead fulfilling lives.

### *Assessment of Client, Client Needs, and Fit within Culture*

Therapists working with clients from diverse backgrounds must conduct early and ongoing evaluations to understand the needs of service recipients better. Some factors include the family's country of origin, family structure, immigration history, birth order, sex roles, social class, gender identity, and pronoun usage as important

variables to consider (Sue et al., 2006). Assessing cultural backgrounds by asking families about important values, beliefs, and traditions in their households is crucial. Learning about the effects of racism and discrimination experienced by families from diverse cultures may also alert practitioners to their own strengths and deficiencies.

Assessment of a dual diagnosis (i.e., I/DD and a mental health disorder) is essential to ensure effective, long-term treatment options. Fletcher and colleagues (2009) reported that at least one-third of children with a diagnosis of I/DD also showed symptoms of a psychiatric disorder. A recent survey of 6,256 adolescents with a diagnosis of I/DD found approximately two-thirds had a lifelong risk of having a mental disorder (Platt, Keyes, McLaughlin, & Kaufman, 2018). Symptoms of an underlying mental health disorder may be overlooked by many professionals, due to limited training or experience with individuals with I/DD. Another reason for missing a dual diagnosis relates to diagnostic overshadowing, whereby a clinician erroneously attributes symptoms of a mental disorder to characteristics of the intellectual disability (e.g., behavioral or mood disturbance, difficulty communicating, or deficits in social skills).

Clinical professionals who support individuals with I/DD should optimally pursue additional training to detect signs and symptoms indicative of a potential co-occurring mental health diagnosis. The Diagnostic Manual of Intellectual Disability (DM-ID; Fletcher, et al., 2009) offers a helpful guide to practitioners who seek to narrow the gaps in the diagnostic process. Fletcher and colleagues recommend using the DM-ID to accompany the Diagnostic and Statistical Manual of Mental Disorders to provide a thoroughgoing diagnosis (DSM-5; American Psychiatric Association, 2013; Fletcher, et al., 2009).

Pre-therapy interventions, such as client-orientation programs, can be beneficial for clients of diverse cultural backgrounds who may be unfamiliar with psychotherapy. Similarly, therapist-orientation programs can help therapists familiarize themselves with the needs of diverse clients while also embedding specialized training opportunities to ensure a more diversified and ongoing building process for the services and supports school-aged youths with dual diagnosis as they age.

### ***Educating and Debriefing First Responders and Service Providers***

Another area of needed training and support pertains to first responders and other professionals involved in crisis intervention for individuals with dual diagnosis. Many first responders report feeling underprepared to effectively manage and de-escalate individuals in the midst of a mental health crisis (Kuehl, Kim, & Every-Palmer, 2023). The difficulties faced by first responders are further complicated by the presence of an intellectual or developmental disability, particularly when communication and social deficits exist. Better pre-service and ongoing training for first responders should be provided to guide decision making and promote the use of effective strategies. One proposed strategy includes a team-based approach that incorporates mental health service providers on crisis intervention teams (Kuehl, Kim, & Every-Palmer, 2023).

Debriefing sessions allow responders to reflect on the incident, identify what went well, and discuss areas that need improvement. This feedback loop can inform training, policies, and procedures. First responders often face emotional and psychological challenges when dealing with mental health crises. Debriefing can normalize their feelings and experiences, reducing stigma and isolation. Through debriefing, responders can identify specific stressors or triggers that impacted them during the intervention. This can inform strategies for stress management and coping in the future.

Debriefing sessions can emphasize the importance of self-care and provide resources for responders to maintain their mental and emotional well-being. For responders working in teams, debriefing fosters camaraderie and mutual support. It reinforces the idea that they are not alone in facing the challenges of crisis intervention. Consider cultural differences and sensitivities when debriefing responders. Cultural competence is essential to understanding how different individuals may experience and cope with mental health crises. Debriefing should not be a one-time event but part of an ongoing process of learning and improvement. Service providers should regularly assess the effectiveness of debriefing practices and adjust as needed.

Debriefing is an essential practice in ensuring the well-being of both professionals managing a crisis and the person in distress. It also serves as a catalyst for professionals to learn from and improve future responses. Because of the knowledge gained through debriefing processes, professionals can be better educated and prepared to deal with crises in the future.

### *Training that Incorporates Cultural Competence*

The need for training arose as a frequent theme throughout this research. Families and providers were aligned in their support for improving education about crisis intervention strategies emphasized the need for crisis intervention training and support specifically designed for persons with a dual diagnosis and inclusive training for not only providers but also families. In the follow-up survey, respondents were asked to identify specific ways improved crisis response could be achieved.

Concerns regarding the lack of training available on specific types of disabilities within professional disciplines was noted throughout the literature review. The review also showed that family-based treatment methods for children and youth with IDD represent the most neglected area of professional training and development in the mental health professions. While crisis response training exists, as noted earlier in this report, it is clear that opportunities exist to develop additional focused training to meet the needs of youth who have a dual diagnosis and are at risk for crisis: training designed to support families, first responders, clinicians, and other service providers who support school-aged youth. Essential for the success of any training that is developed is a keen focus on culture.

Cultural competence requires providers to learn and adapt treatment practices from a culturally sensitive perspective and is identified as a best practice toward better social services and health care for people with co-occurring conditions (Shanahan & Fields, 2016; Washington State Department of Social and Health Services, 2022). Cultural competency practices may include informal support networks such as extended family, religious institutions, and neighborhood supports (Singer, 2005). Providers should identify specific culture-related needs of the community (e.g., access to interpreters, religious leaders, cultural brokers, and healers) (Silva & Klotz, 2006). A further recommendation is to include crisis responders and cultural brokers (e.g., community leaders) from affected minority groups before, during, and after a crisis (Silva & Klotz, 2006). When crisis intervention professionals demonstrate cultural competence, it may lead to increased engagement and compliance from children with dual diagnoses and their families.

Ultimately, cultural competence means appreciating and respecting diversity and the richness it brings to life in society. Cultural competence is key to decreasing disparities in behavioral health service delivery as it improves: (a) clientele engagement in services, (b) therapeutic relationships between clients and providers, (c) adherence to treatment, (d) better treatment outcomes, (e) improved quality of life, (f) patient satisfaction, and (g) improved service provider performance (Alizadeh, 2015; HHS, 2003). It is vital that multiple forms of communication with youth, families, and community members are translated into a variety of languages and employ a variety of media (e.g., organization web pages, social media, print media, public meetings, and individual contacts (e.g., text, phone contacts, etc.) (Goode, Trivedi, & Jones, 2010).

## Conclusion

The purpose of this study was to gain knowledge to support improved crisis response strategies and outcomes for school-aged youth living with a dual diagnosis in the United States. The study incorporated an extensive literature review and two surveys. The literature review sought to gather information on evidence-based practices regarding supporting youth in crisis as well as the barriers to effective crisis response. The first survey included an assessment of current practices and perceived best practices currently utilized in responding to crisis. The results of that survey and information gained from the literature review produced a set of potential strategies. The second survey produced an evaluation of the suggested strategies.

Findings of this project include the following recommendations:

- Promote culturally informed crisis response practices that enhance family engagement in mental health treatment.
- Work to develop culturally informed and evidence-based training for each group who manages crises experienced by school-aged youth with a dual diagnosis.

Different trainings would incorporate the specific needs of each group and the inherent complexities of their role in intervening in the crisis.

- Establish effective communication strategies and methods to allow for efficient communication between systems, organizations, and families.
- Create methods to facilitate the broad-scale application of best practices for community-based crisis intervention.
- Develop practices that equip crisis responders with effective prevention and intervention strategies, as well as debriefing procedures post-crisis for individuals involved in crisis and support professionals.

This research produced clear recommendations for improved crisis response, including cross-professional collaboration and coordination, improved communication strategies and pathways (including expanded training for families and providers), a more expanded assessment of need, the need for training, and multiple strategies relating to cultural competence.

This study demonstrated the need for additional research or work in multiple areas. We highlight three of those as potential future explorations building upon these themes and are dedicated to creating replicable practices to compassionately address the needs of youth with a dual diagnosis who are vulnerable to crisis.

- Using information gained in this research, develop a series of pilot trainings focused on crisis prevention, crisis response, and post-crisis support. The trainings would incorporate recommended strategies for first responders, providers, and families. A second phase would involve “testing” by representative groups of first responders, providers, and families in both urban and rural settings for refinement and finalization for use.
- Develop and pilot a set of strategies to be utilized by families supporting youth with dual diagnoses in home settings prior to, during, and after crises to avoid external involvement or involuntary interventions.
- Study more deeply the many cultural aspects of school-aged youth living with a dual diagnosis in the United States who are vulnerable to crises. The purpose of this research would be to apply that learning in developing culturally responsive supports honoring the cultural differences inherent in their lives.

This research demonstrated the challenges that youth experiencing a dual diagnosis face in getting their needs met, identified excellent examples of effective care approaches, and illuminated a way forward to more sensitively and holistically meet the needs of our shared community.

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