

Mental Health Needs of Individuals with ASD in Indiana

• Indiana Resource Center for Autism

Nearly 50 percent of all individuals in the United States will meet the criteria for a mental health condition at some point in their life (Kessler et al., 2005), and these conditions negatively impact educational, vocational, and health outcomes across the lifespan (Jaycox et al., 2009). These outcomes are especially significant for individuals with an autism spectrum disorder (ASD), that occurs in about 1 out of every 44 individuals ([Data & Statistics on Autism Spectrum Disorder | CDC](#)). The co-occurrence of ASD and mental health disorders such as bipolar disorder, anxiety disorders, and depressive disorders is much higher than in the general population. For example, 70 percent of individuals with ASD have one co-occurring disorder, and 41 percent have two or more co-occurring diagnoses (Simonoff et al., 2008).

These numbers highlight the need to address the mental health of individuals with ASD. While the research is clear from a national perspective, investigations on a state level are critical, as access to and the quality of mental health services can vary dramatically across states and even local communities. As outlined in the [Indiana Bicentennial Commission Report](#) in 2016, the state would greatly benefit from increased mental health services for all individuals. In Indiana, services are provided in schools by licensed social workers and/or counselors, and via community mental health centers (CMHC). While all receive some basic training in mental health, most do not receive training or support in addressing the needs for those with co-occurring mental health and ASD.

IRCA's 2021 Needs Assessment

In 2021, the Indiana Resource Center for Autism (IRCA) at the Indiana Institute on Disability and Community (IIDC) conducted a legislatively mandated Needs Assessment to determine Indiana's current state of services and supports for individuals with autism spectrum disorder (ASD) and their families, including the mental health needs of individuals with ASD across schools and community mental health centers. Results indicated that most of the individuals with ASD included in the survey had at least one co-occurring diagnosis (78.2%; N = 475). Of those with a co-occurring diagnosis, a mental health disorder was common, including diagnoses such as anxiety disorder, bipolar disorder, and obsessive-compulsive disorder. These findings are in line with current estimates of co-occurring ASD and mental health disorders, as Brookman-Frazer et al. (2018) reported a significant prevalence of mood disorder symptoms and behavioral challenges in the population of children with ASD.



1 out of every 44 individuals are diagnosed with an autism spectrum disorder



Majority of individuals with ASD (78.2%, N=475) have a co-occurring diagnosis



Mental health disorders such as ADHD, anxiety disorder, bipolar disorder, and obsessive-compulsive disorders are among the most common co-occurring diagnoses



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Areas for Improvement

The results of the IRCA Needs Assessment highlighted several areas in need of improvement in service provision. These include school-based mental health services, community mental health center services, and crisis management and suicide prevention needs.

School-Based Mental Health Services

Many students with ASD receive supports and services through their local school district. Commonly, an Individualized Education Program (IEP) is crafted with the input of families, school personnel, and other qualified individuals who interact with the child in the school setting. An IEP must outline the supports and services that the school can provide to ensure that the learning environment is accessible and appropriate for the student, including accommodations and modifications made to support the academic and behavioral growth of the students.

While IEPs should address adequate support to the behavioral and emotional health of students, oftentimes in Indiana a student's IEP lacks these supports. The IRCA Needs Assessment found that, for those individuals with ASD with an IEP, 14% reported receiving counseling or mental health therapy as part of their IEP, in contrast with 25% of family members who believed their family member with ASD needed counseling or mental health therapy as part of their IEP. Too often, schools are not equipped with trained staff, and students and families are not provided the support they need for their mental health in the school system, which impacts their ability to learn.

• Percentage of individuals with ASD who receive counseling or health therapy through their IEP

14%



• Percentage of families who believe their child would benefit from counseling or health therapy through their IEP

25%



When student's mental health needs go unaddressed, this can often lead to adverse outcomes for the students in the classroom. The IRCA Needs Assessment asked family members to report on suspension, expulsion, and the use of restraints in the classroom as a result of behavioral issues, as mental health conditions are often outwardly manifested as behaviors. 12% of youth with ASD had been suspended or expelled from school due to behavioral challenges (e.g., aggression, disruption to school routines, interfering behavior). An additional 28.4% of youth with ASD had been restrained or placed in seclusion due to such externalizing behaviors. This figure depicts a large group of students with ASD who are removed from the academic environment because school personnel are not equipped to adequately address their mental health/behavioral needs.

Community Mental Health Center Services

A community mental health center is a community-based facility or group of facilities providing prevention, treatment, and rehabilitation mental health services, sometimes organized as a practical alternative to the largely custodial care given in hospital settings ([American Psychological Association](#)). Services provided by a CMHC include

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evaluations, therapies, treatments, specialized clinical settings, aftercare, and educational programming. These services are intended to provide a range of supports to individuals with mental health disorders.

1 in 5 family members who completed the IRCA Needs Assessment contacted their Community Mental Health Center (CMHC) to help address the mental health needs of their family member with ASD. However, 38% of those who attempted to initiate services with a CMHC were unable to access any type of mental health services for their loved one with ASD. Common barriers to accessing mental health services included long waitlists, lack of trained specialists in rural areas, diagnosis of ASD, and insurance or billing issues.

Need for Crisis Management and Suicide Prevention

To assess the extent to which individuals with ASD are impacted by mental health struggles, the IRCA Needs assessment asked family members to report incidents of short-term crisis management intervention at a hospital. Results indicated that 7.6% of individuals with ASD have received short-term crisis management intervention at a hospital, with an average stay of 7.5 days. The reason for hospital interventions ranged from aggression toward caregivers to psychiatric evaluation needs to severe mental health conditions (e.g., depression and anxiety). 10% of family members who complete the IRCA Needs Assessment reported that their loved one with ASD has attempted or threatened suicide within the last three years. Those with ASD are 3 times more likely to commit suicide.

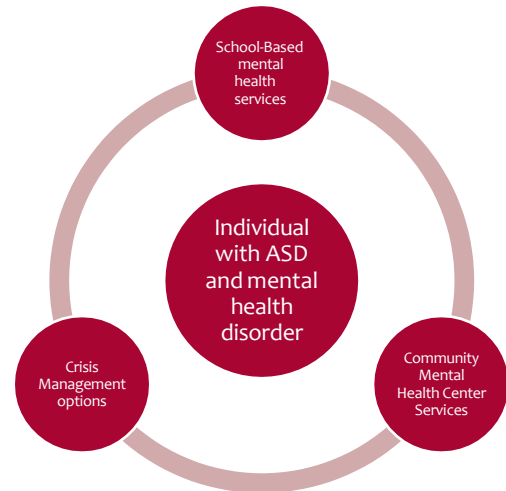
Recommendations

Given the increasing prevalence of ASD, Indiana must be positioned to support the mental health needs of this growing population. Without appropriately addressing these issues, costly and ineffective interventions will continue to produce suboptimal outcomes. Below are 5 recommendations of how Indiana can utilize this information to improve the community.

1. Increase access to evidence-based mental health services by enhancing community mental health center-school partnerships.

While schools and CMHCs are expected to create partnerships, many CMHCs are unable or unwilling to work with individuals with ASD and co-occurring mental health conditions. Stated barriers include staffing shortages due to financial constraints, in addition to a lack of education and training on working with individuals with ASD. While schools and CMHCs are attempting to provide adequate mental health support to this population, they continue to struggle to find avenues for collaboration. State policymakers should consider working with Division of Mental Health and Addictions (DMHA) and local CMHCs to determine appropriate remedies, including increased funding for

SYSTEM OF SUPPORTS



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staff, improving ongoing trainings (including trainings provided by the IRCA), and actively encouraging collaborations through incentives to improve programming options that address the growing needs of individuals with ASD across the Hoosier State.

2. State and local governments should consider allocating workforce development funds to increase the number of community mental health center (CMHC) professionals who are trained to support individuals with ASD.

Parents of children with ASD report a lack of access to mental health services because of a lack of professionals prepared to work with children with disabilities. These parental concerns are mirrored by psychologists who indicate that there are not enough opportunities to learn about working with co-occurring mental health conditions and developmental disabilities in graduate programs in the United States (Huff, 2021). Increasing the amount of CMHC professionals who are trained to work with individuals with ASD will shrink the long waitlists so many Hoosiers with ASD are experiencing across the state and fulfill the promises set out in the [Indiana Bicontinental Report](#) in 2016. Considerations for ongoing trainings or credentials at the state level could provide greater understanding of this population. The IRCA is willing and equipped to provide these trainings.

3. School district and mental health professionals need training, coaching, and support to address the ever-increasing behavioral needs of students.

Training professionals to meet the needs of children with ASD is not a standardized process, and many professionals are untrained in how to assess behaviors, develop behavior plans, and implement positive programming focused on teaching alternative behaviors. Statewide benchmarks are needed for professionals to appropriately address these needs, including expectations in undergraduate training and ongoing professional development.

4. Treatment options need to be more readily available across the state by increasing the number of qualified individuals who can address the mental health needs of individuals with ASD.

When an individual engages in significant problematic behavior in the home, family members often have two options: call the police or take their child to the emergency room. Neither are long term options. Families need other options, including access to CMHCs, short terms respite programming, and access to comprehensive medical oversight and management.

5. Those with ASD/IDD should be included in all state discussions around behavioral health and related topics (e.g., suicide).

While addressing the needs of those with mental illness is a growing concern in Indiana, those with ASD are often excluded from the conversation. A common refrain in the disability community is “nothing about us, without us”, and this needs to be considered in mental health conversations in Indiana. Individuals with ASD and their families should be included in all decision-making at the local and state levels.

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