



IACC Public Comments Response

On behalf of the Association of University Centers on Disabilities and the Autism Society of America, please accept our joint comments in response to the request for information about co-occurring conditions that present with Autism.

These comments were prepared by the Autism Society's Panel of Professionals, chaired by Marc Ellison, and the Association of University Centers on Disabilities.

Together, our organizations represent individuals with Autism, intellectual and developmental disabilities, their families, researchers, providers, and other professionals nationwide. This topic is critical to our organizations and the community we represent.

1. What are the most significant challenges caused by co-occurring physical health conditions in Autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)

Research demonstrates that individuals diagnosed with Autism experience frequent gastrointestinal symptoms, and those symptoms are associated with “an increase in self-injurious behaviors, somatic complaints, reduced sleep duration, and increased parasomnias (Restrepo, et. al, 2020). Initiating sleep and being able to maintain sleep are known challenges for Autistic children, as is sleeping for excessive periods of time and night sweats (Romeo, et al., 2021). Epilepsy prevalence is much higher in the Autistic population than in the general population, and experts believe there to be a connection between the two disorders (Besag, et al., 2017). GI problems, sleep disturbances, and sensory differences all correlate with anxiety.

Substance abuse and eating disorders have become more prevalent in the Autism community over the last few decades. While typically categorized as psychiatric disorders, these disorders clearly affect physical health and life quality when they co-occur with Autism.

2. What are the most significant challenges caused by co-occurring mental health conditions in Autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, aggressive or self-injurious behavior, suicidality)

For decades, mental health needs of individuals diagnosed with Autism have been misdiagnosed, ignored, and misunderstood. As our understanding of Autism evolves, our recognition of the mental

health needs of Autistic people improves. The National Autism Indicators Report: Mental Health (2021) shows that about three-quarters of children diagnosed with Autism meet criteria for one mental health condition, while one-half meet criteria for two. Well over one-half of those in the study experienced at least one adverse childhood experience (ACEs). The report finds that behavior and conduct problems, ADHD, anxiety, and depression are typically the most reported conditions.

Feeling one must blend into a neuro-normative society – called *camouflaging*, or *masking* – may create distress that leads to significant mental health conditions, including suicidality (Cleary, et al., 2023). Females diagnosed with Autism and Autistic members of the LGBTQ+ community have reported the distress they experience with masking. The distress of those who identify as LGBTQ+ is of particular concern as several studies have demonstrated an association between Autism and gender dysphoria. Emerging evidence suggests Autistic individuals may be represented in the LGBTQ+ community at a higher rate than the general public. Gender confusion and gender nonconformity are estimated to be around twice as high in the general population.

Suicidality is an emerging crisis in the Autism community. Several studies, including Cassidy et al. (2018) demonstrate that “*Autistic adults are at significantly increased risk of suicidality compared to the general population.*” So significant is this issue that Cassidy, et al. found that an Autism “*diagnosis and Autistic traits are independent risk markers for suicidality.*”

Co-occurring mental health conditions create additional – and significant – challenges for individuals diagnosed with Autism and can exacerbate challenges those individuals already experience in the areas of academics, social integration, social relationships, independent living, employment, and personal safety.

Bagget, et al., using data from the 2016–2018 National Surveys of Children’s Health dataset found that youth with Autism had higher odds of using ED services if they had unmet mental health care needs. Crisis services for those diagnosed with co-occurring disorders are sparse, and inconsistent across geographical regions. Emergency room professionals, who regularly see patients who are in medical or psychiatric crisis, are under-trained in how to identify and support the mental health needs of this population. People with Autism experiencing a mental health crisis deserve a mental health response. Some families must resort to calling law enforcement to help with a crisis. These situations too often lead to unnecessary incarceration, harm, or even death.

Psychological counseling is often inadequate; both therapists and clients in counseling rely on social and communication cues to develop a therapeutic relationship, and traditional counselor training programs do not train therapists in how to provide therapy to clients who are challenged in those areas.

Crisis beds for those experiencing a psychiatric emergency are limited in most areas, and not available in many areas of the country. Community-based living and training programs rely on funding from programs like Title XIX Medicaid Home and Community-Based Waiver programs to function; with limited funding (waiting lists), training, and support programs are not available to most diagnosed with Autism, including during times of crisis.

3. What are the most significant challenges caused by other conditions that co-occur with Autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?

Students with Autism who have also been diagnosed with a learning, developmental, or intellectual disability often require more support in the classroom due to their behavioral needs. Schools across the country are often not equipped with the tools or personnel to help a child who has Autism and a learning, developmental, or intellectual disability to manage their behaviors and emotions, and this results in a lack of access to an education with their peers without disabilities in the least restrictive environment.

When children reach a “transition period,” often in high school, their school programs set up experience-based learning experiences, like going to work at a local organization or grocery store. Children identified as having challenging behavior are often not included in these experience-based learning opportunities, as the businesses that contract with schools will not work with these students. Students with Autism and behavioral needs are therefore not given the same opportunity to learn about independent living skills or employment as their peers in their class.

Additionally, students with Autism and co-occurring conditions such as learning, developmental, or intellectual disability are often subjected to outdated discipline guidance, causing them to miss critical points in their education. Restraint, seclusion, and school dismissals are practiced around the country, and cause students to miss class time, thus falling behind in their education.

Sleep disorders, as mentioned in Question 1, can impact anyone's ability to get an education or maintain employment.

Individuals with Autism and co-occurring intellectual and mental health disabilities too often end up in the criminal legal system. Social and communication challenges present significant barriers to navigating legal proceedings as an Autistic person, and courts generally fail to consider Autism a mitigating factor in criminal proceedings. This is especially true for individuals with Autism that intersect with BIPOC communities.

4. What additional research is needed to help address co-occurring conditions for Autistic people?

- Psychotherapy, or counseling, is a fundamental treatment for individuals who experience mental health challenges or conditions. However, the service is not often available to Autistic clients, nor is it regularly effective when attempted. Counselors are traditionally taught to develop a therapeutic alliance through social cues, open-ended questioning, and reciprocal dialogue. Each of these may be a significant challenge for most clients diagnosed with Autism. Identifying effective psychotherapeutic techniques for this population is an important area of research to address the mental health needs of Autistic clients, as is counselor education about Autism and effective therapeutic strategies.

Much can be applied or adapted by special education strategies to benefit the support of those diagnosed with Autism and co-occurring conditions. Autistic clients often benefit from being told how something can be done or given options about how to do a task. Video modeling has also been shown to be effective by encouraging observation as a way to understand and solve problems. These and other techniques should make their way out of the classroom and into the practices of mental health therapists who support Autistic clients.

- Research into the topic of sexual and gender identity in the Autism community is integral to the overall mental health of Autistic individuals.
- It is imperative that the needs of females diagnosed with Autism are better identified and better understood.
- Employment-related research, such as how to make the workplace "Autism-friendly," is important to the overall mental and physical health of Autistic adults.
- While the transition to postsecondary training has been a topic of focus for decades, strategies for effective transitions into adulthood remain stagnant, especially in rural areas of the country. Research into using modern technology to better facilitate employment, housing, post-secondary education, etc. – especially technologies and strategies developed after the COVID-19 pandemic – should be a priority.

- A national task force of experienced clinicians should be assembled to develop a Gold Standard protocol for diagnosis.
- A new Autism intervention research network focused on communication needs (in particular, alternative augmentative communication or AAC) should be created. 25-30% of individuals with Autism are non-speaking or minimally-speaking. Individuals need access to communication assistants and/or devices at school and work. We need additional research to develop evidence-based alternative augmentative communication devices and methods.

5. What could be improved in Autism services and supports to help address co-occurring conditions for Autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)

Unintentional bias in the medical community – specifically the medical practitioner tendency to presume co-occurring physical and/or mental health issues are the result of Autism – is a well-known, long-standing issue in the Autism community. This presumption may occur inadequate medical and psychological training, inexperience of the physician, or even the communication challenges an Autistic person may encounter with contacting a doctor. As medical offices become more and more digital with communications and appointment scheduling, some of the missed diagnoses may be resolved.

Inequitable access to services often leads families to have to wait months to receive a diagnosis, and then sometimes years to receive services. A survey conducted by CMS showed that 60% of centers surveyed had over a 4-month waiting period, mostly due to workforce shortages (cms.gov). Additionally, the process of acquiring a diagnosis must be more affordable and accessible for Autistic people.

Another important service that must become consistent across the country is Autism-specific training to law enforcement and first responders. Individuals diagnosed with Autism have unique communication and behavior that may cause those professionals to be suspicious of their behavior. It is known that about 20% of all Autistic people have an interaction with police by age 21; for the safety of Autistic people and those first responders, training is a necessity. A few states, such as West Virginia, have this training codified into legislation. Other states must, too.

6. What lasting impact has COVID–19 infection and illness had on co-occurring physical and/or mental health conditions for Autistic people?

We need research into the impact of long COVID on this population as well as the general population.

With increased anxiety of many Autistics, the fear of contracting COVID and fear of death of oneself and for loved ones has left an impact on people diagnosed with Autism. Anecdotally, Autistics have expressed significant trauma related to being isolated during the pandemic.

7. What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for Autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

Anecdotally, numerous individuals diagnosed with Autism have experienced mental health benefits by being able to work remotely, as well as access health care via a telehealth option.

A significant negative impact would be the lack of social skills that young Autistic children were exposed to during the pandemic, and those children now struggle able to integrate into what we would consider a traditional school environment (i.e. lack of social distancing, hugging/handshakes, masks, etc.). Doing school from home allowed students diagnosed with Autism to learn in a more comfortable environment, and many students are struggling with the transition back to more in-person scheduling. More Autistic students and parents are continuing homeschooling, despite schools going back to in-person.

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