



February 12, 2024

Interagency Autism Coordinating Committee  
U.S. Department of Health and Human Services  
c/o National Institute of Mental Health (NIMH)  
6001 Executive Boulevard, Neuroscience Center (NSC)  
Rockville, MD 20852

To the Honorable Members of the Interagency Autism Coordinating Committee:

[Autism New Jersey](#) is the leading autism advocacy non-profit in New Jersey, dedicated to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Founded in 1965, Autism New Jersey shares its clinical expertise throughout New Jersey and serves as a collective voice for the autism community through public policy initiatives in collaboration with the New Jersey Legislature and Governor's administration.

Thank you for the opportunity to provide public comment regarding challenges related to co-occurring conditions for individuals with autism.

The impact of chronic health conditions is well documented. In children, it can result in developmental delays, social isolation, and adjustment disorders. In all patients, chronic health conditions are associated with a higher risk of depression and anxiety. Financial challenges can result, especially for those who are under or uninsured. Chronic health conditions are a leading cause of death and disability in the U.S. and one of the biggest drivers of healthcare costs.

In addition to the challenges faced and supports needed as a result of an autism diagnosis, the majority of individuals with autism must also grapple with co-occurring health conditions. People with autism are 1.6 times more likely to have eczema or skin allergies, 1.8 times more likely to have asthma and food allergies, 2.1 times more likely to have frequent ear infections, 2.2 times more likely to have severe headaches, 3.5 times more likely to have diarrhea or colitis, and 7 times more likely to report gastrointestinal (GI) problems (Isaken et al., 2013). Epilepsy, GI problems, and sleep disorders are the most common co-occurring health conditions. Up to 60% of children with autism have abnormal electroencephalograms (EEG), compared with 6%-7% in neurotypical children (Pacheva et al., 2019). GI problems are reported in as many as 84% of children with autism; the most common are chronic constipation, chronic diarrhea, gastroesophageal reflux and/or disease, nausea and/or vomiting, chronic flatulence, abdominal discomfort, ulcers, colitis, inflammatory bowel disease, food intolerance, and/or failure to thrive (Al-Beltagi, 2021). Relatedly, food allergies are more common in children with autism: up to 20%-25% compared to 5%-8% in the general pediatrics population (Xu et al., 2018). Finally, sleep disorders are reported in approximately 80% of individuals with autism (Al-Beltagi, 2021).

These conditions persist across the lifespan. In a study looking at health conditions of adults, it was found that there were significantly elevated rates of non-communicable conditions across all organ systems in autistic people, including gastrointestinal, neurological, endocrine, visual, ear/nose/throat, skin, liver and kidney, and hematological conditions (Ward et al., 2023)

### **1. What are the most significant challenges caused by co-occurring physical health conditions in autistic people? <sup>1</sup>**

This increased prevalence of co-occurring medical conditions is particularly concerning when viewed through the lens of the health disparity experienced by autistic patients. People with autism have complex healthcare needs but more unmet health needs. Some are unable to even find a provider to care for them; those who do access healthcare report lower satisfaction with provider interactions. Their healthcare costs are higher, and their health outcomes are poorer. The reasons for this health disparity are complex and multifaceted.

There are many challenges to diagnosing and treating medical conditions in autistic patients. First, most healthcare providers have no formal education and training in autism. Autism is a complex spectrum disorder, and without formal training, healthcare providers struggle to effectively provide even basic autism-friendly care, let alone diagnose and treat co-occurring conditions. Communication differences make it difficult for many individuals with autism to provide information vital to effective diagnosis and treatment. Some patients with autism may be completely unable to express internal states or pain to a caregiver or doctor, and other autistic patients able to use vocal speech may still be unable to use complex nuanced language to accurately describe their symptoms. Regarding visible symptoms, many caregivers report unusual symptoms. Their children often don't fit into the "norm," and some providers do not take them seriously or are not willing to investigate these non-typical presentations of medical conditions. Next, individuals with autism who are unable to express pain or discomfort verbally may do so behaviorally. For example, a child with GI issues may engage in self-injury related to discomfort or aggression toward others to escape or avoid eating foods that cause pain. It is common that caregivers, medical professionals, and other service providers overlook potential medical causes for these challenging behaviors.

Patients with autism may also receive substandard care because, despite having access to a provider willing to take the effort needed for effective and compassionate care, they are unable or unwilling to tolerate the needed procedures. How can someone with significant sensory sensitivities learn to allow an ultrasound tech to press on their stomach with a cold viscous fluid? How can someone who self-calms by pacing and hand flapping undergo an MRI? An autistic patient with sleep apnea may be completely unwilling to accept wearing a mask. The impact of these difficulties is clear: GI and neurological issues go undiagnosed and a sleep issue that has a negative impact on attention, behavior, and learning during the day persists.

The persistence of medical conditions that are undiagnosed or not fully treated has more negative impacts than physical deterioration. If pain is expressed as challenging behaviors, there may be a significant impact on educational, vocational, and living options for the individual with autism. A condition undiagnosed or untreated may overtime require more intensive and expensive

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<sup>1</sup> Autism New Jersey's electronic response to this question was truncated to comply with character limits set forth by the IACC.

treatment and for the autistic patient, more difficult and traumatic. If someone with autism struggles with a simple medical exam, how can they be expected to tolerate an invasive procedure and hospital stay?

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

Additional research into the cause of this increased prevalence is needed. A study using a large sample size of SPARK data found that 74% of individuals with ASD had at least one comorbidity and had a greater average number of comorbidities than their non-ASD siblings (Khachadourian et al., 2023) which would suggest that something specific to an individual's autism diagnosis is correlated with the presence of the co-occurring medical condition. Second, while many caregivers report atypical symptoms among their children, there is limited professional understanding of these idiosyncratic symptoms or their etiologies. Knowing more about the cause of and presentation of co-occurring medical conditions in individuals with autism can result directly in improved care and outcomes.

#### **5. What could be improved in autism services and supports to help address co-occurring conditions for autistic people?**

First, effective medical care for autistic patients can be improved by requiring formal education and training for healthcare providers on the complex presentation of autism in their patients and the most common co-occurring medical conditions. Healthcare providers who are well-versed in autism-friendly practices will provide better care resulting in better health outcomes.

Second, systemic changes in healthcare administration and third-party payor policies can result in improved care and outcomes. Providing adequate funding for hospitals and other medical providers to implement autism-friendly practices would incentivize healthcare organizations to take on these efforts. Changes to reimbursement rates and billing codes could allow for longer medical appointments for autistic patients, more case collaboration among professionals, and billing by behavior analysts in medical settings. When any of these things are piloted as quality improvement projects or via grant money, they show positive results (Boston Medical Center (n.d.) [Autism-friendly initiative](#)); the ability to expand and sustain these efforts can improve the health, safety, and quality of life for the autism community.