

ASHA's Response to Interagency Autism Coordinating Committee Request for Information

Note: 1500 character limit on each response to a question. These answers were entered into a form from the Interagency Autism Coordinating Committee (IACC) on February 14, 2024.

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)

- Sensory and motor challenges that impact feeding and safe swallowing.
- Challenges in conducting evaluations for AAC and other communication interventions, requiring additional time and observations to provide comprehensive and person-centered recommendations for individual needs.
- Hearing loss or other hearing-related challenges may impact the delivery of services. Equipment must be available, individualized, and tolerated due to sensory needs.
- If physical conditions impact overall health and ability to attend therapy sessions, progress may be interrupted or slowed.

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)

- Professionals are not consistently applying knowledge of how “masking” autistic behaviors impact the autistic person’s mental health.
- Anxiety impacts receptive and expressive communication, slows response time and could reduce the person’s ability to accurately and effectively communicate safety needs and/or sensory supports that would improve or reduce negative [feelings] experience.
- Impact of not having access to communication supports, AAC, or the ability to functionally communicate orally and be understood could exacerbate anxiety and contribute to other mental health conditions.
- Between masking and lack of familiar communication options, there is a cycle of impact that can be a constant stress or burden on the autistic individual. Speech-language pathologists and other professionals working with clients must be informed of best practices and apply that support consistently to address their autistic client’s needs.
- Time spent counseling families on how to support communication impacted by the mental health condition may reduce the time in direct service to the client with autism. (this supports the new CPT codes for parent/caregiver training)

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?

- Childhood apraxia of speech impacts reliable oral speech
- Ability to participate in treatment protocols not normed on persons with co-occurring intellectual and learning disabilities
- Fewer employment opportunities
- K-12 education and placement decisions
- Limited opportunities for higher education
- Independent living
- Independent participation in health care
- Impact of ADHD on learning and function
- Executive function difficulties impact problem solving and independence
- Literacy skills
- Timely and accurate diagnosis
- Limited funding options for interventions across the lifespan

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

Evidence-based comparative effectiveness research is needed to:

- determine which intervention(s) yield clinically significant improvements in speech, language, cognition (e.g., memory, attention, executive function), and social communication and address the unique challenges associated with the various comorbidities;
- understand which intervention approaches provide the most meaningful communication and social interaction outcomes for various age groups;
- identify which interventions are most beneficial for which sub-groups of individuals with specific co-occurring conditions including responsiveness to treatment at different times during the lifespan;
- examine the impact of changes in frequency, intensity, and duration of treatment;
- identify screening and assessment tools that are most effective at accurately diagnosing autistic individuals with co-occurring conditions, especially differential diagnoses.

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)

- Care coordination and health care access across the lifespan particularly during times of transition (new living situation, employment)
- AAC/assistive technology supporting communication and adequate time for direct instruction for the individual and communication partners

- Spectrum of need for autistic individuals is a barrier to equitable access. Providers implement prescriptive treatment protocols without adapting to the individual's needs and preferences
- Caregivers often become decision-makers without considering input of the individual with autism, specifically with choosing AAC vocabularies and devices that limit access to other options for communication. Some institutions provide only one type of communication support due to funding needs rather than individual needs
- Treatment should be individualized, considering all the areas of need, including communication and AAC for those who are non-speaking or part-time users.
- Treatment should address family and community knowledge and acceptance as part of service delivery and goal setting to decrease stigma.
- Improving models of interprofessional collaboration that includes time for training, information sharing, collaboration without the patient present. Billing pressures can disincentivize high quality care that teaming produces.
- Consider how social determinants of health impact autistic individuals over their lifespan. People with communication disorders have poorer health care outcomes than people without.

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

No response

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)

- Positive impacts include increased access to telehealth services, when appropriate, and increased acceptance of social media and alternative communication means (e.g., text, videoconferencing) improved assistive technologies like word prediction, voice banking, voice assistants, speech to text, and text to speech.
- A negative impact is delayed access to services resulting in language and learning loss post pandemic.