



SPAN Parent Advocacy Network & Family Voices-New Jersey comments to the National Institutes of Health on Co-Occurring Conditions in Autism

February 13, 2024

Thank you for the opportunity to comment to the Interagency Autism Coordinating Committee on co-occurring conditions in autism. The SPAN Parent Advocacy Network (SPAN) is NJ's federally designated Parent Training and Information Center, Family-to-Family Health Information Center, NJ State Affiliate Organization (SAO) of Family Voices, and the NJ affiliate of Parent-to-Parent USA. We also house a Military Family 360 Support program. Our staff has attended IACC meetings and made public comments. We have served on our Department of Education autism panel to review program quality indicators. We have also written articles on multiple publications on autism (Exceptional Parent Magazine, Autism Spectrum News, and Mental Health News). Our comments today are based on our years of work supporting families in advocacy on behalf of their children with special needs (including autism), as parents ourselves of children on the spectrum, as well as working in systems improvement activities across education, family support, and healthcare.

As far as *physical conditions*, the two most commonly cited are seizure disorder and gastrointestinal issues. In addition, health disparities and discrimination exist for people with developmental disabilitiesⁱ. We appreciate the NIH designation of people with disabilities as a population with health disparities. We participated and highly suggest IACC examine the Center for Dignity in Healthcare for People with Disabilities, now called [Think Equitable](#), recommendations on prenatal, mental health, transplant, and end-of-life care. Finally, we would add the risk to children/youth with autism and other developmental disabilities having limited access to good oral health providers.

Regarding *mental health*, there is comorbidity between developmental disability and mental illness. In addition, dual diagnosis of DD/MI is difficult to find treatment for, especially in crisis. There is a shortage of specialists, hospital beds, and wait lists. This was well documented in the [Family Crisis Handbook](#) which we ask the IACC to look at with their recommendations.

We also understand that there may be *other comorbid conditions* associated with autism such as LD, dyslexia, ADD/ADHD, etc. It is important for both educational and medical professionals to look at the necessity of additional interventions, although some developmental pediatricians may note there is nothing more that needs to be done medically based on if the child is already on medications etc.

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Research in autism continues to be essential due to increasing prevalence rates. We would suggest that more research be done on the comorbid conditions listed above. Note: Additional research should not take funds away from ensuring appropriate services and supports are available to people with autism and their families.

Services and supports are essential regarding comorbid conditions and autism. As stated previously, a secondary diagnosis may necessitate additional educational or medical interventions. In addition, not all states have ABA certification requirements. Some ABA practitioners use forceful manual guidance, restraints, and other aversive techniques. As members of the NAMI (National Alliance on Mental Illness) national restraints committee, we found that aversive interventions are ineffective as behavioral modification and experienced as trauma. Indeed, the U.S. Department of Education noted that these techniques are not evidence based best practicesⁱⁱ. There are alternatives to ABA such as DIR (Developmental, Individual-differences, Relationship-based) model which is child-led, otherwise known as FloorTime. In addition, many students with autism could benefit from sensory integration (by a specially certified occupational therapist) and social skills which are related services under IDEA (Individuals with Disabilities Education Act), but school districts may not readily offer and families may be unaware that these helpful therapies are available in addition to the usual PT/OT/speech (physical, occupational, and speech therapy).

The *effects of COVID* were two-pronged for people with autism. Physically, they were more at risk of COVID complicationsⁱⁱⁱ. Additionally, in some states there were actually injuries or even deaths due to health disparities, including for people with developmental disabilities, as healthcare was inappropriately rationed. Also, COVID exacerbated mental health conditions; some people who didn't have mental health issues do now, and some of those with pre-existing mental illness worsened. Many people with autism also had difficulty understanding the changes, hygiene, and social distancing associated with COVID, and some were unable to tolerate masking due to sensory issues. Long term effects of COVID (including Long COVID), both in terms of physical disparities and inequities as well as increased mental illness, remain.

In general, we would also highly recommend referencing [“Educating Children with Autism”](#) which has clinically researched interventions for effectiveness. We also highly recommend the NIH [National Center for Complementary and Integrative Health](#) as the NIH found almost 81% of families of children with autism used alternative medicine.^{iv} We would also suggest consulting with the [AAP \(American Academy of Pediatrics\) clinical guidelines and policy statements](#) as they relate to autism. For example, AAP cites the dangerousness of chelation for autism, or that gluten/casein-free diets do not cure autism but may be helpful in identifying food allergies only.

Thank you again for the opportunity to provide input on co-occurring conditions in autism.

Sincerely,



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To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.

ⁱ <https://www.healthaffairs.org/content/forefront/advancing-health-equity-people-intellectual-and-developmental-disabilities>

ⁱⁱ Pg. 10 <https://sites.ed.gov/idea/files/qa-addressing-the-needs-of-children-with-disabilities-and-idea-discipline-provisions.pdf>

ⁱⁱⁱ <https://pubmed.ncbi.nlm.nih.gov/36781428/>

^{iv} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4739350/>