Consortium for Citizens with Disabilities
Task Force on Developmental Disabilities, Autism and Family Supports
Comment on
2021-2022 IACC (Interagency Autism Coordinating Committee) Strategic Plan

November 30, 2021

Question 1: How Can I Recognize the Signs of ASD, and Why is Early Detection So Important?

Research shows that early diagnosis of and interventions for autism are more likely to have major long-term positive effects on symptoms and later skills. We also have some data (but not enough) to show that children of color, girls, and non-English speakers are frequently not identified, under-identified or mis-identified. Given what we know about the importance of early identification, this inequity leads to poorer outcomes for these children.

If we want to be a society fully accepting people with ASD, then we must increase our understanding and develop services and supports to address these inequities. Related to these gaps, we additionally need to identify the downstream effects of later or missed identification for these underserved populations.

[Question 2 skipped.]

Question 3: What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted?

We continue to need a better understanding of all the different types of ASD. Thanks to the work of the NIH (National Institutes of Health) research institutes, we have a better understanding that there is not just one autism. Rather, there are many causes to our neurological differences.

There is a research gap that focuses on the most challenging behaviors related to autism. We need to understand how best to support individuals with autism with support needs and behaviors that put them at risk of injury or avoidable institutionalization or justice system involvement. Identifying risk factors and support strategies that ensure the safety of ASD individuals so that we can better help them maintain their freedom and independence.

This needs to be better defined and articulated in the strategic plan, including what is meant by disabling aspects and why they need to be prevented. Particularly as it relates to the aspects of autism spectrum disorder that cause early or premature mortality, poor health outcomes, out of home placement, institutionalization, involvement in criminal justice systems and other poor lifecourse outcomes such as high school dropout, unemployment, etc.

Question 4: Which Treatments and Interventions Will Help?

There are significant gaps in the research around effective behavior interventions, interventions to assist people who are non-speaking or minimally verbal and treatments to help the core ASD challenges.

The community has significant needs to address safety concerns for individuals with significant support needs. This includes developing approaches that ensure autistic individuals remain safe and supported in the community. We need to deepen the evidence for all of the different behavioral health interventions. Significant historic investment has gone into establishing a supportive body of evidence for Applied Behavioral Analysis (ABA). ABA and ABA-derived interventions currently exist as the de facto standard for “evidence-based” autism interventions. We need to develop a broader evidence base for non-ABA and ABA-derived modalities; it is unacceptable for a population as diverse as the autistic population to only have one available modality which does not work for many autistic individuals. Similarly, we know that many autistic individuals have significant communications support needs, and that some types of support such as AAC (Alternative and Augmentative Communication) can be beneficial to nonspeaking or partially nonspeaking autistic individuals, but at the same time, the absence of a robust evidence base for communications supports has at times permitted unproven types of support to predominate. Therefore, we need more research to demonstrate effective, evidence-based interventions.

We need more evidence around the safety and efficacy of pharmaceutical therapies that may help individuals with autism. Risperidone (Risperdal) is the only drug approved by the FDA for children with autism spectrum disorder. It can be prescribed for children between 5 and 16 years old to help with irritability; nevertheless, this drug has significant side effects including increasing the risk of diabetes.

Some doctors will prescribe other drugs in certain cases, including selective serotonin reuptake inhibitors (SSRIs), anti-anxiety medications, or stimulants to address challenges some individuals with autism have in domains of socialization or executive function, but they are not FDA-approved for autism spectrum disorder specifically, nor is there an identified robust evidence base for some of these unapproved uses1. At the same time, care should be taken to distinguish between unapproved use of these drugs for managing behaviors associated with ASD, and the indicated use of the same drugs to manage common co-occurring disabilities such as Attention Deficit-Hyperactivity Disorder, Major Depressive Disorder, or anxiety disorders, all of which are common co-occurring conditions for autistic individuals. Co-occurring medical conditions are extremely common in autistic populations, and additional inquiry is needed into the most effective approaches -both pharmacological and non-pharmacological- for managing overlapping medical conditions like sleep disorders.

There are no drugs approved that help with the core ASD challenges: 1) social skills, 2) difficulty with expressive and receptive communication, and 3) the presence of restrictive and repetitive behaviors. More discussion is needed as to whether these domains are proper targets for direct pharmacological intervention and on the safety and efficacy of pharmacological intervention in autistic populations more broadly.

Question 5: What Kinds of Services and Supports are Needed to Maximize Quality of Life for People on the Autism Spectrum?

The Autism CARES Act authorized the development of evidence-based services and supports however the resources have not been provided to develop the services. Clinicians and medical doctors who serve people with autism are often not trained to use the standards. Doctors are not trained to serve children and adults with autism. We need more doctors and other interdisciplinary services providers trained to serve people with autism. Once people are diagnosed with autism, medical professionals often fail to screen for other co-occurring conditions. As noted above, most people with ASD have co-occurring mental health challenges.

Question 6: How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood?

There are huge research gaps on how to address access to housing and how we can serve more individuals in the community, especially how to serve people with significant needs on the continuum of services and supports, including those with multiple medical complexities and those with significant challenging behaviors.

There has been a lot of momentum and energy focused on employment, however that has not necessarily translated into an evidence base of employment strategies that work for people with ASD across the spectrum. More research needs to be done that demonstrates how effective practices can better serve people with severe ASD and how to rapidly scale those services across the country. For example, the Workforce Innovation and Opportunity Act established an Advisory Committee on Competitive Integrated Employment. The Committee developed bipartisan policy recommendations to address many of these barriers. The IACC could review and recommend that relevant agencies implement these proposals.

Furthermore, recommendations should be developed that address policy barriers that disincentivize work for people with ASD who rely on Social Security and Medicaid.

Address existing service gaps for underserved populations with ASD. Underserved populations often experience barriers in receiving supportive services such as Vocational Rehabilitation and HCBS. When they are connected to services at all these services are often less effective in supporting under-served populations.

Question 7: How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community?

The American Rescue Plan provided a temporary 10 percent increase for Medicaid home and community-based services and supports (HCBS). The Build Back Better Act proposes investing $150 billion (originally $400 billion) for HCBS. If passed by Congress, this will be a start to build the infrastructure of services and supports for individuals on the spectrum. However, given the decades of neglect, continued investments must be made. There must be a continuum of residential services available to all those on the spectrum

Supplemental Question 1: What are important issues for the IACC to consider with regard to the impact of the COVID-19 pandemic on the autism community?

People with IDD (Intellectual and Developmental Disabilities), including autism, were disproportionately impacted by the pandemic. A cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Individuals with intellectual disabilities are at significantly elevated risk of contracting Covid-19 and they will subsequently be admitted to ICUs and/or die in-hospital more often. Besides underlying conditions, individuals living or working in congregate settings are at much higher risk of contracting the virus and spreading the virus.

Supplemental Question 2: What are important issues for the IACC to consider with regard to the needs of underserved populations within the autism community, including racial and ethnic minorities, economically disadvantaged communities, and rural populations?

- Identify and address the downstream effects of late diagnosis for underserved populations, particularly racial and ethnic minorities, and socioeconomically disadvantaged populations whose late, under-, and misdiagnosis is further compounded by under-allocation of education and service resources.
- Identify and address overlapping risk factors and co-occurring disabilities driven by racial, social, and economic disadvantage: e.g., ASD children in low-quality housing have additional risk of lead poisoning from deteriorating lead-based paint.
- Rural services access, including HCBS and vocational rehabilitation, transportation barriers, etc.
- Address education and service barriers for English Language Learner/Low English Proficiency/Language Minorities with ASD.