



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

**Statement for the Interagency Autism Coordinating Committee (IACC), Sept. 27, 2018**

Thank you for the opportunity to provide comments today. My name is Annie Acosta and I am with The Arc of the United States. Today I am here on behalf of the undersigned Co-chairs of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support to share some of our top priorities regarding the health care needs of people with autism spectrum disorder:

**1) Mental Health Screening, Identification, and Intervention**

Children and adults with ASD have much higher rates of anxiety and depression which can interfere with their physical health and adherence to prescribed treatments. A 2015 study published in the British Journal of Psychiatry found that people with autism and no intellectual disability are nine times more likely than the general population to die young due to suicide, making it the leading cause of early death for that population. The rate of suicide among people with autism and intellectual disability is also considerable.

Despite increasing recognition of the interplay of mental and physical health, practical application in health care settings is often lacking. Health care professionals need appropriate training in identifying and managing mental health problems in this population. Lack of training results in difficulty for practitioners and patients alike. For instance, providers who are unable to help calm a person with ASD are more likely to rely on over sedation for relatively routine testing such as EEGs.

We also encourage the committee to prioritize training for health care professionals and research efforts that examine health outcomes of people with ASD that includes social determinants of health such as employment, education, and social connections.

**2) Reasonable Accommodations**

Going to the doctor can sometimes be a stressful experience for people with ASD and elevated stress levels may trigger challenging behaviors. There are, fortunately, a few practices that can help mitigate such events, such as giving patients with ASD the first or last appointment of the day to avoid long wait periods in crowded rooms.

However, the most needed accommodation is additional time for appointments. Health care providers should anticipate the need for flexibility in scheduling. We encourage the committee

to support research in efforts to improve public and private insurance reimbursement policies that allow for extended appointment times.

### **3) Transition from Pediatric to Adult Health Care**

Autism is more than a childhood condition, it is a lifelong condition that requires appropriate supports and treatments which change as people move through major life phases. This includes moving from the pediatric to the adult health care system. This transition is critical to ensuring appropriate treatment for adults. Youth and young adults with ASD and their families need assistance in transition preparation, transfer of care, and integration into adult-centered systems of care that are less coordinated than pediatric systems. We encourage the IACC to prioritize efforts under “Strategic Plan Question 5: Where Can I Turn for Services?” to implement the Six Core Elements of Health Care Transition 2.0 developed by the Center for Health Care Transition Improvement with support from the Health Resources and Services Administration.

### **4) Decision-making Options for Adults with ASD**

There are many incorrect assumptions made about the needs of adults with ASD for decision making support. For those who need support, guardianship is often treated as a default option for adults when a less restrictive one would suffice. Parents are often warned that, absent guardianship, they will be denied access to their adult children’s health information due to the Health Insurance Portability and Accountability Act (HIPAA). However, HIPAA allows the disclosure of protected information when a patient consents. However, parents will seek guardianship in order to go to appointments, schedule appointments, or access medical information.

There is a continuum of options that start with informal support. Other options include supported decision making, power of attorney and limited guardianship. We encourage the committee to promote health care practice guidelines that provide accurate information about the range of options for decision-making authority in health care settings.

Thank you for the opportunity to comment.

Annie Acosta

The Arc

Jill Kagan

National Respite Coalition

Erin Pranglely

National Association of Councils on Developmental Disabilities