Executive Summary
November 2018

2018 IACC Stakeholder Satisfaction Survey Report: Commentary on the Federal Response to the United States Autism Crisis

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Executive Summary

Autism, also known as Autism Spectrum Disorder (ASD), is a developmental disability that is characterized by a range of social, communication, and behavioral challenges. It is estimated to affect over three million Americans. The occurrence of autism in American children has risen over 120 percent since 2000, from 1 in 150 in 2000, to 1 in 59 in 2018. The majority of people with autism have co-occurring medical conditions, which affect their ability to live a healthy, independent, and full life. Research published in the journal *Autistica* has found that people with autism live on average 18 years less than their typical peers, mainly due to suicide, seizure disorders, and wandering behavior. The Federal Government's response, led by the Interagency Autism Coordinating Committee (IACC), has failed to address these urgent issues in 20 years.

Caregivers of people with autism also experience extraordinary difficulty. Research from the University of Wisconsin-Madison published in the *Journal of Autism and Developmental Disorders* shows that mothers of adolescents and adults with autism experience the same level of chronic stress as combat soldiers, based on cortisol levels. A University of Pennsylvania study published in the journal *Pediatrics* found that mothers of children with autism earned 56 percent less than mothers of children who had no health disorders.

In 2015, researchers at the University of California-Davis found that the estimated cost of caring for all people with autism in the United States is $261 billion per year. This includes the cost for ASD-related medical, nonmedical, and productivity losses. The researchers estimate that If autism prevalence continues to increase at similar rates, costs could reach $1 trillion by 2025. This is likely to occur given that there have been no causes of autism identified in the past 20 years, and no treatments found for the disabling features of the disorder, despite billions of taxpayer dollars spent.

In Summer 2018, four national autism nonprofit organizations, Autism Action Network, SafeMinds, The Autism Community in Action (TACA), and the Thinking Moms' Revolution (TMR), implemented an Internet-based survey to their constituencies to find out what autism community stakeholders thought about the effectiveness, inclusion, and accountability of the IACC. Over 1,400 survey respondents, including people with autism, family members of people with autism, caregivers of people with autism, and service providers, provided intriguing insights, including:

- Almost half of the survey respondents were unaware the IACC existed before completing the survey
- When asked if the IACC's work was improving the lives of people with autism and their families, over 56 percent responded, "no" and approximately 38 percent said they did not know.
- When asked if the IACC members represented their interests when it comes to addressing autism in the United States, nearly 60 percent of the 1,402 respondents answered "no." A full 33 percent of respondents said, "I don't know."

Autism has become a national crisis, and should be treated as such. The federal strategy thus far has been ineffective, exclusionary, unaccountable, and costly. Consequently, the United States now has more people with autism, and less resources with which to address their needs. We implore Congress to restructure the federal response as it considers reauthorization of the Autism CARES Act of 2014 in the following ways:

1) **Hold congressional hearings to discuss the effectiveness of the current federal response and suggestions for how to improve it; and to reassess resource allocation** given the significant increase in the number of people affected by this complex disorder. SafeMinds Board President Sallie Bernard has stated, "The IACC has failed to produce a response to the autism crisis commensurate with its scope and depth. Accordingly, our country now has many more Americans with autism, and less resources with which to address their needs."

2) **Replace the Interagency Autism Coordinating Committee (IACC) with a full-time Federal Autism Coordinator, who will lead an agency-neutral Office of National Autism Policy Coordination (ONAPC) in the Executive Office of the President.** The need for coordinating and assessing science-based policies and programs that are focused on addressing the many causes of and treatments for autism, and for providing services and supports for the autism community, has never been greater. These functions are supported by at least two U.S. General Accountability Office reports. The Office can be small, and staffed with detailees from those agencies now involved in addressing autism, including the Departments of Health and Human Services, Labor, Housing and Urban Development, Defense, Justice, Education, Homeland Security, and the Environmental Protection Agency.

3) **Establish an annual National Autism Strategy, coordinated by the new ONAPC, with measurable goals, objectives, and outcomes.** The new federal autism coordinator should lead a listening tour across the country, while ONAPC staff coordinate focus groups, to learn from subject matter experts and other community stakeholders and develop the National Autism Strategy. The Strategy should be data-driven, with a scientifically-sound autism "census" that quantifies the number of American children and adults living with autism. It should include science-based, multi-agency policies and programs. The Strategy should promote clinical outcomes that increase the health of people living with autism and co-occurring medical conditions, such as mental health challenges, seizures, wandering behavior, and gastrointestinal disease.

4) **Mandate the use of interactive technology to encourage and increase stakeholder participation in federal autism policy and research development, implementation, and evaluation.** The Federal Government should use interactive technology that allows stakeholders who are unable to attend meetings to give live feedback on ideas and discussions. Assistive technology should be available to those who are unable to communicate verbally.

5) **Monitor the effectiveness of Federally-funded programs and coordination among agencies that focus on autism.** These activities are critical for effective resource allocation management, program evaluation, and maximizing the American taxpayers' return on investment.