2018 IACC STAKEHOLDER SATISFACTION SURVEY

Summary Report: November 2018

Survey conducted by:

TACA
TALK ABOUT CURING AUTISM

safeMinds
resolving the autism epidemic

THE THINKING MOMS' REVOLUTION

2018 Interagency Autism Coordinating Committee (IACC) Stakeholder Satisfaction Survey

Executive Summary

About Autism

Autism, commonly referred to as Autism Spectrum Disorder (ASD), is a developmental disability that can cause a range of mild to severe social, communication, and behavioral challenges. Approximately 3.5 million people in the U.S. have autism. The U.S. Centers for Disease Control (CDC) has two databases that estimate autism prevalence. The Autism and Developmental Disabilities Monitoring Network's (ADDM) most recent *Community Report on Autism* stated that in 2014, one of every 59 eight year-olds in the United States has an autism diagnosis. In contrast, the National Center for Health Statistics' National Health Interview Survey found that 1 in 36 American children has autism.

Most people with ASD look like other people, but their behavior, social skills, and communication are markedly different than their "typical" peers. Further, people with ASD exhibit other deficits and symptoms which may affect their daily lives. Many of these outward symptoms and issues have underlying medical causes which, when treated, can be reduced in severity. By way of example, a toileting problem may be considered "a part of the child's autism," but may instead have such underlying causes as gastrointestinal inflammation, anxiety, stress, or another treatable problem. Each issue can and should be explored to find treatments. Unfortunately, such individualized clinical practices have not been developed in the United States.

Many commonly co-occurring conditions affect the safety of people with ASD. The journal *Autistica* published a study which found that people with autism live on average 18 years less than their typical peers, mainly due to suicide and epilepsy. Research from Penn State revealed that the percentage of children rated by their parents as sometimes to very often contemplating or attempting suicide was 28 times greater than that of typical children. The journal *Epilepsia* published a study which found that epilepsy occurs in up to 38 percent of people with autism. The journal *Pediatrics* published a study that found up to 49 percent of people with autism wander, similar to people with Alzheimer's.

Caregivers of people with autism are frequently under significant emotional and financial stress. The *Journal of Autism and Developmental Disorders* published a study which found that mothers of children with autism have similar stress levels as combat soldiers. The Kennedy Krieger Institute's Interactive Autism Network has issued a report on the findings that 56 percent of people with autism aggress against their caregivers. Caregivers have little to no support for respite or mental health.

In 2015, when the ADDM reported autism prevalence to be one in every 68 American children, health economists at the University of California-Davis estimated the total cost of caring for all people with autism in the United States. They postulated the cost for ASD-related medical, nonmedical, and productivity losses is $268 billion in 2015, and $461 billion for 2025. The researchers noted that these estimates are conservative, and if autism prevalence continues to increase at similar rates, costs could reach $1 billion by 2025.

About the IACC

The National Institute of Health houses the Interagency Autism Collaborating Committee (IACC). The IACC, as created by the Children's Health Act of 2000, is responsible for developing and annually updating a strategic plan with budgetary recommendations for autism research, and for monitoring ASD research across Federal agencies. The Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES) reauthorized the IACC, and expanded its role. The IACC is now also responsible for including a focus on supports and services in its annual strategic plan, and for increasing its research monitoring responsibilities to include services and support activities.

The IACC's activities have not realized the original intent of those who created it in 2000. By way of example, the IACC does not meet regularly, though it is supposed to meet at least twice a year, and it appears to operate with little to no oversight and accountability. The IACC website states that the current IACC members began meeting in November 2015, though the Autism CARES Act reauthorized the IACC in August 2014, and the new Federal fiscal year began in October 2014. Therefore**, the IACC failed to meet for over a year to fulfill its charge and mission, despite the autism community's complex needs and the skyrocketing costs of addressing autism to the American taxpayers. Further, as of mid-October 2018, the most recent IACC autism strategic plan for the organization available to the public is from 2016-2017, though the congressional requirement for the organization is for an annual plan.**

When the IACC was established by the Children's Health Act of 2000, the rate of autism prevalence in the United States was 1 in 150 children, according to the ADDM. Today, almost 20 years later, the rate of autism has risen to 1 in 59 American children. (See appendix 1). **The over 120 percent increase in autism prevalence in less than 20 years, with no new causes or treatments identified while the Federal government has spent at least $2 billion, is shocking, costly to the American taxpayers, and unacceptable.**

The IACC is comprised of representatives from many HHS sub-agencies, the departments of Education and Defense, the Environmental Protection Agency, advocacy group representatives, university professors, individuals with autism, and parents of children with autism. Notably, many of the parents of children with autism who are on the IACC are also HHS employees, which puts in question their impartiality. **The annual operating cost of the IACC is over $1.38 million.**

With each reauthorization since 2000, there has been very little turnover of IACC members, despite the bleak outcomes facing the autism community that have resulted from the organization's lack of accountability and effectiveness. Those who apply to be on the IACC are neither given a list of criteria by which they will be considered, nor notified why they were not chosen.

The IACC has been the subject of at least two critical U.S. Government Accounting Office (GAO) reports, “Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication” in 2013 (See Appendix 2); and “Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition-Age Youth in May 2017 (See Appendix 3).

The Autism CARES Act of 2014 authorizes the IACC until September 30, 2019, and many in the autism community have expressed their desire that Congress not fund it through that time. The IACC, among many of the disenfranchised and skeptical families who live with autism every day, has become a source of ridicule, frustration, and disappointment. (See Appendix 4).

Federal Autism Coordinator

The Autism CARES Act of 2014 required the Secretary of HHS to appoint a Federal Autism Coordinator, who would oversee and implement federal autism activities nationwide, and ensure that federal autism activities are not unnecessarily duplicative. **Though the Autism CARES Act passed in 2014, the Secretary of HHS waited almost a year and a half to designate Dr. Ann Wagner as the Federal autism coordinator.** This once again signaled HHS’ failure to act on the urgency of the autism crisis facing an increasing number of American families, and the costly nature of ignoring the problem to the American taxpayers.

Concerningly, the 2017 GAO report, “Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition-Age Youth” states that “the Autism Coordinator and other HHS officials told us (GAO) that the Coordinator would have limited capacity going forward to oversee ASD work across agencies and departments as required by the Act due to limited resources.” Considering the Federal autism coordinator’s lack of willingness to collaborate with the nonprofit sector as described below, this response is alarming.

In the Summer of 2018, the leadership of three national autism nonprofit organizations--SafeMinds, Talk About Curing Autism (TACA), and The Thinking Mom’s Revolution (TMR)—surveyed the autism community on its satisfaction with the IACC’s responsiveness, accountability, and effectiveness after they asked to speak with Dr. Ann Wagner, as the federal autism coordinator, about the 20 percent increase in autism prevalence in just two years, which the CDC announced in the Spring 2018. (See Appendix 5).

To explain why they were asking to meet with the Federal autism coordinator rather than the IACC, the nonprofit leaders’ letter wrote, “among many organizations and other members of the autism community, the IACC has a dubious reputation given its lack of transparency in vetting research studies and its own committee membership. The urgency of the autism crisis, measured in human suffering, increased mortality, lack of independence, and economic cost, requires a more comprehensive and timely response than the IACC is designed to give.”

A month after the groups sent their meeting request to Dr. Wagner, she rebuffed them, and suggested they participate in the three-to-five minute public comment segment of the October 2018 IACC meeting, which would be held six months after the groups sent their invitation to meet. (See Appendix 6).

Background on the 2018 IACC Stakeholder Satisfaction Survey

To clarify the problems that autism community stakeholders have with the IACC for the Federal autism coordinator, SafeMinds, TACA, and TMR designed and implemented a 15-question, multiple choice survey instrument, the "2018 IACC Stakeholder Satisfaction Survey." The survey also provided respondents the opportunity to provide text answers choices as an option.

Results of the IACC 2018 Stakeholder Satisfaction Survey were collected via SurveyMonkey from 1,405 respondents online, over a two-week period in the Summer of 2018. They elucidate how disenfranchised, frustrated, and dissatisfied a significant portion of the autism community feels about the IACC's operation, its narrow and repetitive policy and research foci, its failure to produce usable and relevant research, its lack of membership diversity, its lack of transparency, its failure to include and provide accommodations for those with severe autism, and its unwillingness to consider and act on the thoughts and feedback of its constituency.

"Seems to be more about preserving the status quo than the courageous work it will take to address autism in a meaningful way" (Survey responded self-identified as "family member")

Over 76 percent of the survey respondents described themselves as either a family member of a person with autism, or a caregiver of a person with autism. The remaining survey population is comprised of 17 percent "other," five percent "service provider to people with autism," and one percent as "person with autism." Those individuals in the "other" category identified themselves as friends of families who had a member with autism, teachers, health professionals, concerned citizens, and health advocates.

Survey Results (See Appendix 6)

- Almost half of the survey respondents in the autism community were unaware the IACC existed. Of those who were aware the IACC existed, the majority felt that the IACC had not addressed their issues.

- Respondents were concerned that the IACC has not coordinated or promoted research that would identify the causes of autism; how to appropriately prevent or treat autism; how to effectively ameliorate or eliminate commonly co-occurring conditions such as epilepsy and gastrointestinal issues, or how to help address the commonly co-occurring mental health issues such as anxiety, depression, and suicidality.

"I don't think the IACC is doing enough to uncover the causes of the explosion in autism cases since the mid-eighties." (Survey respondent who self-identified as "Retired school psychologist whose job included diagnosing children with autism.")

- Over 46 percent of 1,400 respondents reported that the work of the IACC has affected their life either "not at all" (24 percent) or "negatively" (22.21 percent) while 49.5 percent had not heard of the IACC until they completed the survey. Only 4.93 percent stated that the work of the IACC has affected their lives positively.

- Over 56 percent of 1,370 respondents said that the work of the IACC is not improving the lives of people with autism and their families, while 38.08 percent stated that they did not know if it was. Only 6.2 percent stated that it is improving the lives of these stakeholders.

"It (the IACC) hasn't done anything helpful yet. The numbers and costs grow while the government's actions aren't significantly different than 10 years ago." (Survey respondent self-identified as "family member of a person with autism.")

- When asked if they think the IACC is accountable to its autism community stakeholders, 56.51 percent of the 1,375 respondents reported that they did not. While 31.42 percent stated they didn't know if the IACC is accountable to its autism community stakeholders, only 12 percent answered in the affirmative.

- 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." While 33.38 percent of respondents said "I don't know," only seven percent stated "yes."

"The autism community is not being well represented by the IACC. If the IACC wants to make a positive difference in the lives of those suffering from autism and their family members, you must seek out and listen to organizations which represent that demographic." (Survey respondent self-identified as "service provider to people with autism.")

- Approximately 94 percent of 1,392 respondents have not taken the opportunity to provide public comment at an IACC meeting. Commonly-noted reasons for not providing feedback were:
    - Lack of ability to travel to Washington, DC given the responsibilities of caring for a person with autism, difficulty in finding appropriate child care, and the cost of traveling to Washington, DC from other locations
    - Lack of belief that the IACC members will take their comments seriously based on what they have seen while watching the meetings online, and that traveling to the meeting and taking the time to write and provide comment will have a low return on investment
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"My impression is that no amount of public comment will make a difference with them. They will do whatever they wish and the public comments are just a formality that means NOTHING." (Survey respondent self-identified as "caregiver of a person with autism.")

Notably, the IACC's meeting rules do not encourage participation by the public or provide an opportunity for discourse with the public and non-IACC members. Specifically, the IACC:

Restricts the number of people who can provide public comment at each of its meetings so the public comment segment lasts less than an hour;

Limits the amount of time for each commenter to three to five minutes

Restricts the number of times a person can give public comment to one time per year, regardless of whether or not a person represents a national organization; and

Does not provide an opportunity for an interactive discussion of the issues raised during the public comment section of its meeting.

Relevant Sections of the 2013 and 2018 GAO Reports

The May 2017 GAO report, "Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition-Age Youth" cites the IACC's "missed opportunities to collaborate regularly with agencies that provide services or financial funding to transition-age youth with ASD." Specifically, the report states that the IACC has neither included the Departments of Labor and Housing and Urban Development in its working groups tasked with updating the current IACC strategic plan, nor invited these agencies to join the IACC. This is particularly concerning given that the Autism CARES Act of 2014 calls for the IACC to include in its strategic plan, services for individuals with ASD. It is hoped that those responsible for holding HHS accountable for implementing the Autism CARES Act of 2014 will take note of these errors.

The November 2013 GAO report, "Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication" reported that the IACC and Federal agencies' efforts to coordinate and monitor Federal autism activities were limited. Specifically:

- IACC members provided mixed views on the usefulness of the IACC's meetings, strategic plan, and portfolio analysis in aiding coordination and monitoring activities;
- Only some agencies used the IACC's strategic plan and research funding analysis; and
- Shortcomings in the data the IACC used for its research funding analysis limited its ability to coordinate HHS autism activities and monitor Federal autism activities.

Notably, the GAO report found that collectively, these weaknesses limited the IACC's ability to monitor its progress.

Recommendations

The most significant result of the IACC's activities since 2000 has been the marked increase in the number of Americans diagnosed with ASD, from 1 in 150 to 1 in 59 (or 1 in 36) in less than 20 years. In an interview shortly after the 2018 autism prevalence data was released Dr. Walter Zahorodny, Ph.D., associate professor of pediatrics of the New Jersey Medical School at Rutgers University, and director of New Jersey ADDM Autism Study stated that, "Even though many people speak about better awareness of autism, when the ADDM network looked at the age of autism diagnosis, we saw that it didn't change in the last 14 years. It's been approximately 53 months throughout this period. and if autism prevalence was affected by greater awareness you would expect the age of first diagnosis to decrease, which it hasn't."

The autism crisis demands a more urgent, accountable, effective, and transparent response than what is currently provided. The crisis is characterized by a lack of supports, services, research-based medical treatments, environmental causation research, caregiver support, and clinical practices, among other insufficiencies. Looking forward, we suggest lawmakers consider the following:

- **Replace the IACC with a full-time Federal autism coordinator, who will lead an agency-neutral National Office of Autism Policy Coordination (NOAPC) in the Executive Office of the President.** The Federal government has provided staffing and funding for coordination of Alzheimer's and AIDS research, and similar efforts to address the autism crisis are in order now. The Office can be small, and staffed with detailees from the agencies 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. The need for coordinating research, policies, and programs related to addressing the causes and treatments for autism, and for providing services and supports for the autism community, has never been greater.

  Spending nearly $1,400,000 per year to operate an organization whose work does not affect Americans with autism living today is not an appropriate use of taxpayer funding.
  Relying on the same government structures to get a different result after two decades of costly research and staff support is therefore ill-advised.

- **Establish an annual National Autism Strategy, coordinated by the new NOAPC, with measurable goals, objectives, and outcomes.** The most striking responses revealed how few autism community stakeholders knew about the IACC's existence. It is clear the Federal government must endeavor to reach the autism community more frequently, and in locations closer to where people with autism and their caregivers live. The Federal autism coordinator should lead a listening tour across the country, and the NOAPC can coordinate focus groups in different U.S. locations as it formulates the National Autism Strategy. The Strategy should be data-driven, with a scientifically-sound autism "census" that quantifies the number of children and adults living with autism, and research-based policies and programs.

- **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 software the allows stakeholders who are not present to participate in meetings and give feedback on ideas and research. There should also be assistive technology available to those who do not communicate verbally.

- **Prioritize research that will affect clinical outcomes so that it becomes more relevant to people living with autism and their caregivers.** It seems likely that there will be increased engagement by stakeholders if the Federal government funds research that results in clinical protocols, policies, and programs that improve the lives of people with autism and their caregivers.

- **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 American taxpayers' return on investment.