



**Testimony before the  
Committee on Oversight and Government  
Reform  
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**Autism-related Issues**

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Good morning Chairman Issa, Ranking Member Cummings, and distinguished members of the Committee. Thank you for the opportunity to provide testimony today. My name is Dr. Alan Guttmacher, and I am a pediatrician and Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). I have been a member of the Interagency Autism Coordinating Committee (IACC) — created by the Children’s Health Act of 2000 (CHA), reestablished by the Combating Autism Act of 2006 and reauthorized by the Combating Autism Reauthorization Act of 2011 (CARA) — since my arrival at NICHD in 2009. I have been invited to testify on behalf of NIH and the IACC regarding the status of biomedical research, services programs, and interagency coordination of activities related to autism spectrum disorder (ASD).

The IACC appreciates Congress' continued support of research and services related to ASD. With the reauthorization of the Combating Autism Act, the Department of Health and Human Services (HHS) and Federal and private partners have continued — through the IACC — to engage with the public and work collaboratively on autism-related activities. These efforts have enabled remarkable advances in the field of autism research and helped us to identify and meet the service needs of all people affected by autism, individuals, and families alike.

ASD is a diverse collection of disorders that share common impairments in verbal and nonverbal communication skills and social interactions, as well as restricted, repetitive, and stereotyped patterns of behavior. The degree and specific combination of impairments can vary from one individual to the next, creating a heterogeneous disorder that can range in impact from mild to significantly disabling. Two decades ago, ASD was considered a rare disorder. Today, with the Centers for Disease Control and Prevention's (CDC's) March 2012 estimates of 1 in 88 children in the United States being identified with an ASD, this disorder has become an important national health priority, affecting virtually every community across the country. In 2006, Congress passed the Combating Autism Act to strengthen Federal coordination of issues related to ASD and to enhance public-private collaborations in order to

accelerate research to improve the lives of people with ASD and their families. Congress reauthorized the Combating Autism Act in 2011, allowing the continuation of these efforts, including the work of the IACC.

The IACC has played a pivotal role in helping Federal agencies, non-profit organizations, and members of the public work together to identify priorities and strategies to address key issues of importance to the autism community. I will briefly discuss the IACC's membership, its transparent process, its collaborative activities, the framework provided by the IACC's Strategic Plan, and its current activities. I also will share examples of efforts under way in various agencies within the Department, some recent advances in ASD research, and how the IACC's Strategic Plan with extensive input from the public has facilitated these advances.

Since its beginning in 2000, the IACC has provided both an important forum for public discussion of autism issues and a framework for research and services that incorporates the needs identified by affected individuals and families, advocates, providers, researchers, and other community members. The membership of the IACC includes both representatives of Federal agencies and public members, representing a diverse set of stakeholder groups within the autism community, creating a critically important public-private dialogue on issues related to autism. Currently, the IACC includes three people with ASD, several parents of children and adults with ASD, members of the advocacy, research, and service provider communities, and officials from the following Federal agencies and offices that are involved in ASD research or services provision: Department of Defense (DoD), Department of Education (ED), HHS's Administration on Intellectual and Developmental Disabilities (AIDD)/Administration for Community Living (ACL), Agency for Healthcare Research and Quality (AHRQ), CDC, Centers for Medicare & Medicaid Services (CMS), Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), five institutes of NIH, and the NIH Director. Major autism research and services organizations represented on the IACC include Autism Science Foundation, Autism Society, Autistic Self Advocacy Network, Autism Speaks, SafeMinds, Simons

Foundation, and Somali American Autism Foundation. The diversity of the IACC's membership serves to foster dialogue on a wide variety of issues of importance to the autism community.

In addition to the voices and perspectives added by its members, the IACC has served as a forum for public participation by having public comment periods at every full IACC meeting, regularly inviting written public comment, and conducting formal requests for information from the public and holding town hall meetings. The IACC has provided a high level of transparency for the public by actively disseminating information about its activities via e-mail, the IACC website, webcasts, and Twitter. By including both Federal and public members, and by fostering public engagement through a variety of means, the IACC ensures that a diversity of ideas and perspectives on ASD are brought to the table to inform the IACC's activities and recommendations. While the law requires the IACC to meet twice a year, the IACC and its subcommittees have met between 7 and 17 times a year since 2007, for a total of 67 times. This includes full committee and subcommittee meetings, planning groups, workshops, and town hall meetings.

Under the Combating Autism Act, enacted in December 2006, the IACC is charged with developing and annually updating the IACC's Strategic Plan for ASD research. In fulfilling these requirements, the IACC met many times and gathered extensive public input in 2007 and 2008 to shape its first comprehensive IACC Strategic Plan, released in January 2009; updates were issued in 2010 and 2011. The new IACC reauthorized under CARA is currently in the process of drafting a 2012 update of the IACC's Strategic Plan that reflects the latest advances and progress in the field of autism research, as well as remaining gap areas and emerging needs. The IACC developed its original 2009 IACC Strategic Plan with a great deal of participation from the public, including planning meetings, town hall meetings, and requests for information, and has continued gathering public input to inform subsequent updates.

The public's participation in IACC meetings and planning efforts, combined with the contributions of scientific and subject matter experts and all the major Federal agencies and private funders, resulted in a plan that provided a clear path to move autism research forward in targeted, innovative ways to help public and private agencies prioritize activities. The first IACC Strategic Plan was organized into six chapters that reflected the needs expressed by the community: early and accurate diagnosis, better understanding of how autism develops, enhanced ability to identify risk factors, development of new and more effective interventions and treatments, the need for more research to inform and enhance services, and the development of better approaches to meet the changing needs of people with ASD over their entire lifespans. In 2010, the IACC also added a chapter on the infrastructure needed to support a robust research effort. As you can tell, the IACC's Strategic Plan has a broad scope, in part because it was developed through the cooperation of both research- and services-focused agencies and private organizations. While the IACC's Strategic Plan focuses on research as the law requires, it encompasses a range of research that goes from fundamental biology of ASD to inform new diagnostics and therapies, to the actual development of necessary tools and approaches, and finally to research that can inform and enhance services programs to meet the needs of people with autism across the lifespan.

### Research Funding

Over the past decade, funding has grown significantly for research on the underlying biology and risk factors associated with ASD, as well as research that seek better treatments, earlier diagnoses and better, more effective services. The NIH leads Federal biomedical research efforts on ASD. The NIH invested \$169 million in ASD research in fiscal year (FY) 2011, more than 40 percent above FY 2008 levels. In FYs 2009-2010, \$122 million in funds made available through the American Recovery and Reinvestment Act (ARRA) were also invested across these areas, with the largest proportion of funding devoted to identifying genetic and environmental risk factors. The first IACC Strategic Plan was completed just as NIH received the significant additional funding from ARRA, so, with a strategic plan in place to guide priorities, NIH allocated

the additional funding between FY 2009 (\$64 million) and FY 2010 (\$58 million) to support a variety of projects addressing the most critical research needs highlighted by the IACC. Including these ARRA funds, the overall NIH investment in autism research was an unprecedented \$218 million in FY 2010, more than double the funding prior to the Combating Autism Act.

CDC leads surveillance research efforts and establishes United States prevalence for autism. Dr. Coleen Boyle will provide more details on CDC's surveillance work in her testimony.

### Research Advances

I'd like to share with you some of the exciting scientific advances we have seen in ASD research as a result of the increased investment in autism research. Since the passage of the Combating Autism Act, there has been a groundswell of activity on multiple fronts, from game-changing scientific discoveries reshaping the field of autism research to real-world applications that can help people with ASD and their families now.

### Diagnosis and Intervention

One of the main provisions of the Combating Autism Act was support for early diagnosis and intervention. CDC conducts surveillance and reports that the median age of earliest known ASD diagnosis documented in children's records varied by diagnostic subtype (Autism Disorder: 48 months; ASD/PDD: 53 months; Asperger Disorder: 75 months) and varied by sociodemographic group and geographic location. With recent advances, diagnosis by age 14 months is now a realistic possibility, and researchers are actively pushing the detection window to even younger ages. In April 2011, NIH-funded researchers demonstrated that a simple, low-cost, practical screening tool involving a checklist that takes only five minutes for a parent to complete in doctors' offices can be used to detect ASD during a child's one-year well-baby check-up. The checklist includes questions about the child's emotions, eye gaze, communication, gestures, and other behaviors.

More than 100 pediatricians in San Diego County, CA participated in a study using the tool to screen over 10,000 one-year-old children and found that the checklists accurately identified children with ASD and other developmental delays in 75 percent of cases. Impressively, all pediatricians who participated in the study decided to continue using the tool in their practices after the study ended because they recognized the tremendous potential benefit it could provide by identifying autism earlier, allowing them to direct families toward early interventions that can help support positive outcomes earlier in life. Another promising diagnostic tool in development is a simple, 1-minute test that detects eye gaze patterns specific to infants with autism. Researchers at University of California, San Diego who received funding from NIH found that this test, which assesses the infants' preference for looking at videos of moving geometric shapes versus social movement, identified infants as young as 14 months old who had autism with nearly 100 percent specificity based on their preference for staring at moving geometric shapes. These promising diagnostic tools, combined with CDC's health education campaign, "Learn the Signs. Act Early," can improve early identification and provide great potential for reducing the age of diagnosis, thus allowing children and their families to get the services and supports they need when those services and supports can help the most.

Of course, early diagnosis is only valuable if effective interventions are available. Recently published results from several successful trials of early interventions have validated approaches that are effective in young children, creating real promise of improved health outcomes and quality of life for children with ASD. In a recent NIH-funded study, children from 18-30 months old with autism who participated in an innovative, high intensity developmental behavioral intervention called the Early Start Denver Model (ESDM) showed normalized brain activity and greater improvements in autism symptoms, IQ, language development, and social behaviors, when compared to another group of ASD children that participated in a 2-year community intervention. In another groundbreaking study, a group of investigators jointly funded by HRSA and NIH reported that an intervention designed to enhance social engagement in toddlers improved social, language, and cognitive outcomes. Early interventionists have noted an

encouraging research challenge – the community is taking up new approaches that are being proven effective so quickly that it is difficult to find “control groups” for behavioral intervention trials. While this can complicate efforts to conduct randomized control trials, it is encouraging to know that parents and community practitioners are putting innovative strategies into practice quickly.

In addition to early interventions, progress is being made in developing interventions to help adults on the autism spectrum. A recent NIH-funded study showed that a computerized training program for adults with ASD who showed initial impairment in their ability to recognize faces, a disabling aspect of ASD for many on the spectrum, resulted in improved face recognition skills.

Many of these recent advances in early diagnosis and intervention were supported through NIH’s Autism Centers of Excellence (ACE) program, which was expanded under the Combating Autism Act. The ACE program was renewed in September 2012, and currently supports nine centers and networks at major research institutions across the country, with two additional ACE awards expected next year. The research conducted within the ACE program covers a variety of topics that are aligned with priorities identified in the IACC’s Strategic Plan, including nonverbal ASD, genetic and environmental risk factors, possible links between ASD and other genetic syndromes, potential treatments, and possible reasons why ASD is more common among boys than girls.

### Risk Factors and Prevalence

We do not know the causes of ASD, but very recent findings comparing identical and fraternal twins suggest the importance of focusing on both environmental and genetics factors. NIH and CDC are continuing to strengthen research investigations into possible environmental risk factors for autism, establishing large research networks with the capability to collect extensive sets of data on environmental exposures and health outcomes, and to conduct powerful analyses to determine which risk factors may contribute to the development of autism.



Population-based studies are the gold standard in epidemiology research. Large sample sizes and rigorous study designs allow researchers to examine many variables at once. Such networks, like NIH's Childhood Autism Risks from Genetics and the Environment (CHARGE) and Early Autism Risk Longitudinal Investigation (EARLI) are utilizing data from medical records, interviews, questionnaires, developmental assessments, and physical exams to explore a host of possible risk factors, focusing heavily on factors in the environment before, during, and after pregnancy. It will take a few more years for these research networks to mature fully, but already, published findings are contributing to the understanding of environmental and genetic factors that may increase the risk for autism. For example, the CHARGE study has identified a number of possible risk factors that may potentially contribute to the development of autism, including: air pollution; mitochondrial dysfunction; immune dysfunction; maternal metabolic conditions such as obesity, diabetes, and hypertension; and maternal influenza infections and fever. In addition to its findings on potential risk factors, CHARGE investigators have reported that use of prenatal vitamins may serve as a protective factor, reducing the risk of having children with autism. In another study, funded by CDC and Kaiser Permanente Northern California, researchers showed that widely-used antidepressant medications taken during pregnancy may also contribute to the risk of having children with autism. Further research on these and other potential risk and protective factors is warranted.

### Services

In addition to research to develop improved diagnostic tools and interventions, and to understand the causes of autism, interventions and supports are also available to help people with autism and their families today. HRSA is helping to pave the road from research to practice. Through funds provided by the Combating Autism Act Initiative (CAAI), HRSA has invested substantially in autism interventions to improve physical and behavioral health of people with ASD, practitioner training, and service provision models. HRSA-funded investigators are examining critical questions, such as the impact of co-occurring health conditions in autistic individuals and the effectiveness of parent-mediated and peer-mediated

behavioral interventions. HRSA's health professionals' training programs are designed to reduce barriers to screening and diagnosis by increasing professional capacity and raising awareness about ASD among providers in the community. Interdisciplinary training initiatives targeted health care providers (psychologists, pediatricians, speech language pathologists, social workers, nutritionists, nurses, physical therapists, occupational therapists, geneticists and genetic counselors, dentists, health administrators, and others), other professionals who work with children (special educators, child care providers and others), and families who have children with ASD/developmental disorders (DD).

In FY 2012, Congress appropriated approximately \$47 million to HRSA for activities associated with autism and other developmental disorders. This funding supports: 43 Leadership Education in Neurodevelopmental Disabilities (LEND) interdisciplinary training programs, providing services and training to 41 States, with many extensive training and services across multiple States, further extending the reach of the LEND training programs. The funding also supported 10 Developmental-Behavioral Pediatrics (DBP) training programs; three research networks and 14 autism intervention research projects examining areas of particular interest to families and addressing the needs of underserved populations; 13 State demonstration grants; two resource centers; and a national evaluation. All activities continue to be coordinated with the CDC's activities and with priorities of the IACC.

#### Highlights of HRSA Investments

Reducing Barriers: Reported increases in the number of children who received diagnostic evaluations over the course of the grant period provide an early indication of progress toward the goal of reducing barriers to ASD services. Including those who received diagnostic evaluations from a CAAI-supported LEND program in grant year 2008–2009, nearly 92,000 children were evaluated over the 3-year grant period.

Interdisciplinary Training: To address the shortage of health care professionals who are qualified to provide screening and diagnostic evaluation for ASD and other DDs, the LEND and DBP programs expanded their training resources and assisted local agencies and practices in building their capacity to provide community-based ASD services. During the 2009-2010 grant year, the LEND and DBP programs collectively trained close to 2,500 medium-term trainees (40-299 hours of training) and 1,400 long-term trainees (300 or more hours of training), with increases of 13 percent and 22 percent respectively during the 2010-2011 grant year.

Intervention Research: To improve the health and well-being of children with ASD, research grantees conducted studies addressing such topics as the efficacy of ASD interventions, early identification of ASD in minority populations, family well-being and transition to adult services, and developed consensus-based guidelines to support professionals in providing treatment for children with ASD. Together, research grantees developed eight medical guidelines, one comprehensive guideline report, 14 toolkits for providers and parents to use in monitoring and managing ASD symptoms, and seven new behavioral measures for assessing a child's progress.

### Public-Private Partnerships

In all of the autism research and services activities discussed, interagency coordination and public input facilitated by the IACC have played an important role. While I have described in brief some of the autism-related research and services activities undertaken by Federal agencies, it is important to recognize the critically-important role played by private organizations that fund research and provide services to the autism community, and that government, private organizations and the public need to work closely together to succeed in providing the biomedical innovations, evidence-based interventions, services, and supports needed by the autism community.

Examples of joint initiatives that are moving the field forward to enhance researchers' access to data include NIH's National Database for Autism Research (NDAR), which is federating with several other autism data repositories such as the Autism Speaks' Autism Genetic Resource Exchange (AGRE), and the public/private-funded Interactive Autism Network (IAN). In the community, programs like AGRE, IAN, and the Autism Treatment Network (ATN) that involve direct outreach to and collaboration with the patient community are bringing together hundreds of researchers and clinicians with tens of thousands of people nationwide affected by ASD, in the search for new and improved screening tools, enhanced understanding of the biology of ASD and ASD risk factors, effective interventions and services that will help people with ASD reach their fullest potential

Federal IACC member, the Administration on Intellectual and Developmental Disabilities (AIDD)/ACL, with the help of non-profit organizations, including the Arc of the United States, the Autistic Self Advocacy Network (ASAN), and the Autism Society, is supporting the AutismNOW Project, an innovative dissemination network to provide access to high-quality resources and information on community-based services and interventions for people with ASD and their families. AutismNOW offers a call center, web-based clearinghouse of resources, twice-weekly webinars on a variety of topics related to autism, and regional events for the community to connect in-person.

### Conclusion

Since the passage of the Combating Autism Act, we can see how the establishment of the IACC has brought a wide variety of research, services, and education expertise to a challenging area and has served to focus efforts across the Federal government, also fostering collaboration with private efforts. This remarkable effort continues to bring Federal agency representatives, parents, people with ASD, clinicians, scientists, and others together to work as an interactive team to address this critical issue. In doing so, it has produced the IACC's Strategic Plan that is updated annually to guide and focus Federal research efforts and catalyze public private

partnerships, while also providing a forum for public discussion and identification of additional needs from the community. With the reauthorization of the Combating Autism Act, the IACC has added new members to participate in the dialogue, in an effort to broaden the outreach of the IACC and infuse it with new perspectives.

On the research front, we have seen some remarkable progress in understanding the prevalence of ASD, developing screening methods and interventions with potential to be used to identify and treat ASD in very young children, and understanding the risk factors that may contribute to the development of ASD. This research is rapidly moving toward translation into practical tools that can be used in the clinic and community settings to change outcomes for people with ASD. In this time span, Federal agencies have also coordinated efforts to enhance critical services programs, identify best practices to support the education, health, and employment needs of people on the spectrum, and develop new mechanisms and strategies to enable broad access to healthcare, services, and supports.

The Combating Autism Act established the IACC to provide advice to the Secretary of HHS regarding matters related to ASD, to create a forum where the public could be actively involved in the process, and to develop a strategy to guide national research efforts. The enactment of CARA has supported the continuation of this work. While there has been unequivocal progress, much remains to be done to take gains that have been made and turn them into the foundation for future advances that will result in improvement in quality of life for people with ASD and their families.

Again, thank you for this opportunity to provide you with testimony on this very important topic.

## **Dr. Alan Guttmacher, Director, National Institute of Child Health and Human Development, NIH**

Alan E. Guttmacher, M.D., is the Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, part of the National Institutes of Health. In this role, he oversees the Institute's research activities in pediatric health and development, maternal health, reproductive health, intellectual and developmental disabilities, and rehabilitation medicine, among other areas. A pediatrician and medical geneticist, Dr. Guttmacher came to the NIH in 1999 to work at the National Human Genome Research Institute, where he served in a number of roles, including Deputy Director and Acting Director, thus overseeing the Institute's efforts to advance genome research, integrate that research into health care, and explore the ethical, legal, and social implications of human genomics. Among Dr. Guttmacher's areas of expertise is the development of new approaches for translating genomics into better ways of diagnosing, treating, and preventing disease. One of his major research interests is the disease hereditary hemorrhagic telangiectasia. A graduate of Harvard College and Harvard Medical School, Dr. Guttmacher completed an internship and residency in pediatrics and a fellowship in medical genetics at Harvard and Children's Hospital of Boston. He is a member of the Institute of Medicine.