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ON

*THE COMBATING AUSTIM ACT*

BEFORE THE

COMMITTEE ON ENERGY AND COMMERCE  
US HOUSE OF REPRESENTATIVES

Good morning Chairman Pitts, Ranking Member Pallone and members of the Committee. I am Tom Insel, Director of the National Institute of Mental Health (NIMH) at the National Institutes of Health (NIH). I have served as the Chair of the Interagency Autism Coordinating Committee (IACC), created by the Children's Health Act of 2000 and re-established by the Combating Autism Act of 2006 (CAA), since my arrival at NIMH in 2002.

First, let me express my sincere appreciation for the opportunity to give you some background on how the existing CAA has facilitated unprecedented collaboration between federal agencies and private organizations, enabling amazing progress in the field of autism research and serving to sharpen our focus on the need for better services for people with autism and their families. We at NIH are very grateful for the strong support that you in Congress have always shown for NIH and the thousands of researchers around the country that it funds. As chair of the IACC, I'd like to express the gratitude of all the federal agencies that are members for your continued interest and encouragement.

The CAA dealt with five general provisions: centers of excellence, surveillance, education for early detection and intervention, the IACC, and authorization of funding. The 11 Autism Centers of Excellence, surveillance efforts at the Centers for Disease Control and Prevention (CDC), programs for early detection and intervention, and funding for all of these programs is authorized to continue with or without reauthorization of the CAA. The one provision that requires reauthorization to continue is the IACC, which is scheduled to sunset on September 30, 2011. For this reason, I will focus my remarks today on the IACC, but I welcome your questions about other provisions of the CAA.

In order to give you the most comprehensive yet concise background, I'll briefly describe the IACC, its membership, its transparent process, its collaborative activities, the influential Strategic Plans that it has developed, and its various areas of intense interest. In short, this description will let you know that the IACC has fulfilled each and every requirement of the CAA. It has provided both an important forum for public discussion of autism issues and a framework for a research agenda that is optimized to take full advantage of scientific

opportunities. As time permits, I also hope to share some examples of the very recent research advances that are so exciting in this field, and how these advances have been facilitated by the existence of the Strategic Plans developed by the IACC with considerable public input. Finally, I'll discuss how the IACC has focused on the need to enhance services for people with autism.

Autism spectrum disorder (ASD) is a diverse collection of disorders that share in 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 CDC's latest prevalence estimates of 1 in 110 children in the U.S. being diagnosed with ASD, this disorder has become an urgent national health priority. In 2006, Congress passed the CAA to strengthen federal coordination around this issue and, to enhance public-private collaborations in order to accelerate research to improve the lives of people with ASD and their families.

The CAA outlines the membership of the IACC, which includes both representatives of federal agencies and public members representing a diverse set of stakeholder groups within the autism community. Currently, the IACC includes two 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 Education (ED), HHS's CDC, Centers for Medicare & Medicaid Services (CMS), Office on Disability (OD), Substance Abuse and Mental Health Services Administration (SAMHSA), Administration on Developmental Disabilities (ADD) in the Administration for Children and Families (ACF), 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, Autistic Self Advocacy Network, Autism Speaks, SafeMinds, Simons Foundation, Southwest Autism Research & Resource Center, and the U.C. Davis M.I.N.D Institute.

In addition to the voices and perspectives added by the members of the IACC, the IACC has fostered public participation by having public comment periods at every full IACC meeting, regularly inviting written public comment, conducting formal requests for information from the public and holding town hall meetings, and has provided a high level of transparency for the public by actively disseminating information about IACC activities via e-mail, the IACC website, webcasts and even Twitter. By including both federal and public members on the committee, 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. The IACC is a committed group—while the law only requires the committee to meet twice a year, since 2007, the committee has met around 16 times per year, including full committee and subcommittee meetings, workshops and town hall meetings.

Under the CAA, the IACC is charged with developing and annually updating a strategic plan for ASD research. In fulfilling these requirements, the committee produced its first strategic plan in January 2009 and has issued updates in 2010 and 2011. The IACC developed its Strategic Plan with a great deal of input from the public, gathered through planning meetings, town hall meetings, and requests for information. This tremendous public input, combined with that 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 as soon as it was released. The first IACC Strategic Plan was organized into six chapters that reflect the needs expressed by the community: early and accurate diagnosis, better understanding how autism develops, enhanced ability to identify risk factors, development of new and more effective interventions and treatments, more research needed to inform and enhance services, and the development of better approaches to meet the changing needs of people with ASD over the entire lifespan. In 2010, the committee also added a chapter on the infrastructure needed to support a robust research effort. As you can tell, our 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 Plan is a research plan, as the law directs, it encompasses a range of research that goes from fundamental biology of ASD to inform new diagnostics and

therapies, to the actual development of those needed 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.

Fortuitously, the first strategic plan was completed just as NIH received significant additional funding from the American Recovery and Reinvestment Act to help stimulate the economy through the support and advancement of scientific research. With a strategic plan in place to guide priorities, NIH allocated over \$122 million of additional funding between FY09 (\$64 million) and FY10 (\$58 million) to autism research, supporting a variety of projects addressing the most critical research needs highlighted by the IACC. This was in addition to NIH's investment of base annually appropriated funds for autism research, which was \$160 million in 2010. The overall NIH investment in autism research was an unprecedented \$218 million in 2010, more than double the funding prior to the CAA.

The IACC has also fulfilled the CAA requirements to produce an annual summary of advances in research and to monitor federal research activities. Since 2007, the IACC has issued four Summary of Advances documents, which describe what the committee felt were some of the most exciting advances in autism biomedical and services research each year. The IACC has also been actively monitoring not only federally-funded research, as the CAA requires, but has also tracked the research funded through private organizations, making for a much more complete picture of the research landscape across the U.S. All of the private organizations on the IACC that conduct research provided their data, and we have also collected data from all U.S. federal agencies and additional private groups. The result has been the IACC's annual "portfolio analysis." The first year, the data were presented at IACC meetings, but in subsequent years the IACC issued full reports on fiscal years 2008 and 2009 funding; the analysis of 2010 data is currently underway. These portfolio analysis reports have provided the first comprehensive look at autism research being conducted in the U.S. They also have facilitated a better understanding of how current research aligns with the IACC Strategic Plan. The committee has found both the summary of advances and portfolio analysis reports to be valuable tools for updating the Strategic Research Plan and determining the greatest areas of need for further action.

This year, the HHS/NIH office that supports the IACC, the Office of Autism Research Coordination (OARC), published a comprehensive Report to Congress, as required in the CAA, on federal activities that have taken place since the passage of the CAA. That report contains rich information about the programs and projects going on across HHS and the ED to meet the needs of people with autism. I urge you to take a look at this report because it provides the most comprehensive picture to date of how federal agencies are responding to the urgent needs of the autism community. The report contains details of the wide array of autism research, services and supports activities conducted by federal agencies, including biomedical and services research, public health activities, education initiatives, early screening, diagnosis and intervention services, provider training, healthcare delivery, social supports, and vocational training. We have copies of this and the other most recent reports mentioned with us and will be happy to give you copies.

Now I'd like to share with you some of the exciting advances we have seen in ASD research. Since the passage of the CAA in 2006, 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.

As I mentioned earlier, one of the main provisions of the CAA was support for early diagnosis and intervention. CDC reports that the median age for autism diagnosis is 4 and half years of age and varies widely 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 that takes only five minutes to administer can be implemented by doctors' offices to detect ASD around one year of age for many children. More than 100 pediatricians in San Diego County, CA participated and screened over 10,000 one year old children using the checklists. Impressively, all pediatricians who participated in the study are continuing to use the tool because they recognized the tremendous potential it provides to identify autism earlier and direct families toward interventions that can result in significant positive outcomes earlier in life. Another promising diagnostic tool is a

simple test that detects eye gaze patterns specific to infants with autism. A group of researchers at University of California, San Diego who have received funding from NIH to develop such a test recently reported that they could identify 1-3 year old children with autism with nearly 100 percent specificity. These promising diagnostic tools, combined with CDC's health education campaign, "Learn the Signs. Act Early.", to improve early identification, provide great potential for reducing the age of diagnosis and allowing children and their families to get the services and support they need when it 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 2010, NIH investigators reported that children with ASD who receive a high intensity behavioral intervention starting by age 18-30 months show improvements in IQ, language, and adaptive behavior, to the point where the autism diagnosis no longer applies to some children who receive treatment. Soon after that groundbreaking study, a group of investigators jointly funded by HRSA and NIH reported that an intervention designed to enhance social engagement in toddlers indeed improved social, language, and cognitive outcomes. Early interventionists have noted an encouraging "problem" – new approaches that are being proven effective are being taken up so quickly by the community that it is difficult to find "control groups" for behavioral intervention trials. While this can complicate efforts to conduct randomized control trials, the real story is that parents and community practitioners are putting innovative strategies into practice quickly. Many of these recent advances in early diagnosis and intervention can be credited to NIH's Autism Centers of Excellence (ACE), which were expanded under the CAA and now comprise 11 research centers at major research institutions across the country.

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 causes of autism, establishing expansive research networks with the capability to collect large sets of data

on environmental exposures and health outcomes, and to conduct powerful analyses to determine which risk factors may be contributing 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) and CDC's Study to Explore Early Development (SEED), will utilize 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 fully mature, but already, published findings are helping establish the evidence-base for ruling in and ruling out possible environmental triggers. In the first half of 2011 alone, the CHARGE study has implicated air pollution, mitochondrial dysfunction, and immune dysfunction as potential mechanisms for ASD. Just this month, CHARGE investigators reported that use of prenatal vitamins may reduce the risk of having children with autism. In the past week, another study, funded by CDC and a private group, showed that widely-used antidepressant medications taken during pregnancy can significantly raise the risk of having children with autism. In addition to their work on identifying risk factors for ASD, CDC also continues to provide the most comprehensive estimates to date of the prevalence of ASD in multiple areas of the U.S. through its Autism and Developmental Disabilities Monitoring (ADDM) Network. While great progress is being made for autism, CDC's prevalence estimates have documented significant increases in autism in the US, which highlights the need to continue research efforts and service advances being made with facilitation by the IACC activities.

With the pace of research moving so rapidly, I am confident that our continued investments in novel and innovative biomedical research in ASD will pay large dividends in the future. But there's a strong imperative to push the best of what we know now out into the community as rapidly as possible.

HHS's OD and the Assistant Secretary for Planning and Evaluation are creating the infrastructure to support and conduct patient centered research on health services and supports



for people with disabilities, including autism. Their new Center of Excellence, authorized under the American Recovery and Reinvestment Act, is part of a national strategy for quality improvement in health care and the expansion of health care delivery system research with a focus on person-centered outcomes research. Expanding on that effort, CMS is testing and implementing family-driven, person-centered and home and community-based service provision models for people with autism.

A common goal across many federal agencies is to support and empower people with autism to live more independently and enjoy an enhanced quality of life. Informed by the IACC Strategic Plan, NIH is making non-traditional investments in novel service and health delivery models, aided by the infusion of additional funds from the Recovery Act. Both the ED's Rehabilitation Services Administration (RSA) and HHS's SAMHSA "Supported Employment Toolkit" are helping people with autism secure and maintain jobs in the community. Medicaid continues to fund supported employment and habilitation services through States' home and community-based waiver programs, which pay for such services for many people with intellectual and developmental disabilities across the nation.

There are also interventions and supports that can 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) under the CAA, 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. HRSA's State Implementation Grants represent nearly \$2.7 million in funds to assist nine States with improving services for people with ASD. These grants promise to help identify best-practices at the individual, community, and policy level. When possible, partnerships between agencies are being formed – HRSA and CDC have joined to sponsor "Act

Early” Summits in all regions of the US and to facilitate the development of professional and community teams to improve the early identification of children with autism at a local level.

The coordination in the autism research community is unparalleled, and the IACC has played a critical role in fostering the growing list of promising public-private partnerships. Last fall, the mother of a child with autism spoke at an IACC meeting about the need to examine the high prevalence of autism in the Somali community in Minnesota reported in a state-funded study based on school data. Working collaboratively, several NIH Institutes, CDC, and Autism Speaks put together a research initiative to support investigation of the reported increase in ASD prevalence in the Minnesota Somali community and to identify the diverse service needs of these Somali-American children and their families.

As the Somali study illustrates, federal agencies recognize the autism challenge is not one we can tackle alone. There are a host of private organizations funding cutting-edge research, including four that hold a seat on the IACC – Autism Science Foundation, the Southwest Autism Research & Resources Center (SARRC) and the organizations identified by the recent IACC Portfolio Analysis as being the 2<sup>nd</sup> and 3<sup>rd</sup> largest private funders of research after NIH, Simons Foundation and Autism Speaks. Jointly, NIH, Autism Speaks, and Simons Foundation are driving several significant initiatives poised to accelerate the pace and quality of autism research. By developing the infrastructure and appropriate incentives, these public-private partnerships are encouraging data-sharing on an impressive scale, enabling scientists to do more with less. Additionally, NIH’s National Database for Autism Research (NDAR) 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) to enhance researchers’ access to data. And 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 a search for answers.

Federal IACC member, ADD, with the help of non-profit organizations, including the Arc of the United States, the Autistic Self Advocacy Network (ASAN), and the Autism Society, recently launched 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.

Looking back over the past five years since the passage of the CAA, we can see how the establishment of the IACC has served to focus efforts across the federal government, bringing federal agency representatives (research, services, and education), parents, people with ASD, scientists, clinicians and others together to work as a team to address the issues, and bringing a wide variety of expertise to a difficult area. In doing so, it has produced a strategic plan 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.

We have also seen some remarkable progress in the identification of how common ASD is within communities, how ASD develops, how we can detect it at increasingly earlier ages and what types of interventions are most effective, especially in young children. 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 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 – all leading toward improvement in quality of life for people with ASD and their families.

The CAA established the IACC, to provide advice to the Secretary 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. While there has been unequivocal progress, much work remains to be done. The reauthorization will be critical for continuing the

momentum and stability of the IACC over the next 3 years. It is crucial that members of the IACC—individuals, federal agencies and member private organizations—have stable support to continue their efforts to work together on autism issues.

I thank you for this opportunity to speak with you and look forward to addressing any questions that you may have.