



TESTIMONY OF DR. THOMAS INSEL  
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ON

*THE COMBATING AUSTIM ACT*

BEFORE THE

COMMITTEE ON ENERGY AND COMMERCE

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

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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

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 recommend

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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





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

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

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 clearinghou

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.