

Testimony before the
Committee on Oversight and Government
Reform

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

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,

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

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.

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

P r e v a l e n c e

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 Risks Early Environment the

behavioral interventions. HRSA's health professionals' training programs are designed to reduce barriers to screening and diagnosis by increasing professional capacity and raising awareness

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.

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.

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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.