

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
INTERAGENCY AUTISM COORDINATING COMMITTEE  
MINUTES  
November 30, 2007**

The inaugural meeting of the Interagency Autism Coordinating Committee (IACC) was convened on November 30, 2007, at 9:00 a.m. in the Rotunda Room at the Ronald Reagan Building and International Trade Center, 1300 Pennsylvania Avenue, NW, Washington, DC. In accordance with Public Law 92-463, the meeting was open to the public. Dr. Thomas R. Insel presided as Chair. The meeting was adjourned at 4:00 p.m.

Committee members present at the Meeting: **Thomas R. Insel**, M.D., National Institute of Mental Health (NIMH), *Chair*; **Ann Wagner**, Ph.D., NIMH, *Executive Secretary*; **Duane F. Alexander**, M.D., National Institute of Child Health and Human Development; **James F. Battey**, M.D., Ph.D., National Institute on Deafness and Other Communication Disorders; **Ellen W. Blackwell**, M.S.W., Centers for Medicare and Medicaid Services; **Margaret Giannini**, M.D., F.A.A.P., Office on Disability, U.S. Department of Health and Human Services; **Lee Grossman**, Autism Society of America; **Gail R. Houle**, Ph.D., U.S. Department of Education; **Larke N. Huang**, Ph.D., Substance Abuse and Mental Health Services Administration; **Yvette M. Janvier**, M.D., Children's Specialized Hospital; **Walter Koroshetz**, Ph.D., (representing Story Landis, Ph.D.) National Institute of Neurological Disorders and Stroke; **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences; **Christine M. McKee**, J.D.; **Patricia A. Morrissey**, Ph.D., Administration for Children and Families; **Lyn Redwood**, R.N., M.S.N., Coalition for SafeMinds; **Stephen M. Shore**, Ed.D., Autism Spectrum Consulting; **Alison Tepper Singer**, M.B.A., Autism Speaks; **Edwin Trevathan**, M.D., M.P.H., Centers for Disease Control and Prevention; **Peter van Dyck**, M.D., M.P.H., Health Resources and Services Administration; **Elias Zerhouni**, M.D., National Institutes of Health (NIH).

### **Call to Order and Opening Remarks**

Dr. Insel called the meeting to order and welcomed all in attendance to the first meeting of the newly formulated IACC. He then introduced Michael Leavitt, Secretary of Health and Human Services.

#### **Michael O. Leavitt**

Secretary Leavitt asked the members of the committee to introduce themselves, after which he spoke briefly about his experiences with autism. When Secretary Leavitt was Governor of Utah, a childhood friend who had a daughter with autism asked the Governor for help in starting a parents group in their hometown. Through his friend and through other people he met as Governor, Secretary Leavitt learned about the tremendous impact that autism has on families and society. While much about the cause and course of the condition remains unknown, there continues to be an increase in research investment and awareness of the condition.

Many Federal agencies sponsor research and deliver services associated with autism spectrum disorder (ASD), and the committee fulfills an important role of coordinating efforts between

parents, clinicians and researchers, the Secretary said. He told the committee that he looked forward to receiving its observations and recommendations.

**Elias Zerhouni, M.D.**

After being introduced by Dr. Insel, Elias Zerhouni, Director, National Institutes of Health, began by sharing with the committee a personal philosophy. When he was a child, his family used to discuss mathematical brainteasers, one of which was the following: if a vase is completely filled with large stones, pebbles, and sand and then emptied, what is the best strategy to refill the vase completely? It can be shown mathematically, Dr. Zerhouni said, that no strategy works better than filling the vase first with the large stones, second with the pebbles, and third with the sand. Committees need to make clear distinctions between stones, pebbles, and sand, said Dr. Zerhouni. Otherwise, it becomes very difficult to construct a clear strategy that contains all three elements.

In the 21st century, medicine has an opportunity to embrace a new paradigm, according to Dr. Zerhouni. Rather than waiting for something to go wrong and then intervening, medicine can intervene before symptoms appear and preserve normal function. This perspective is part of the NIH Roadmap for Medical Research, which embraces what Dr. Zerhouni called the “four-P” paradigm. The first P is that medicine will become more *predictive* as more is learned about the basis for disease. Better prediction and classification of disease will in turn lead to the *personalization* of health care. The ability to intervene in diseases before they strike will lead to the *preemption* of disease. Finally, diseases will be studied in their natural environments through the *participation* of patients and communities.

Dr. Zerhouni concluded by thanking the members of the committee for their willingness to spend so much time and effort coordinating autism research.

**Thomas R. Insel, M.D.**

Dr. Insel reviewed the task of the IACC as spelled out in the Combating Autism Act (CAA), which was signed by President Bush on December 19, 2006. The charge consists of five responsibilities.

1. Develop and annually update a summary of advances in ASD research.
2. Monitor Federal activities with respect to ASD.
3. Make recommendations to the Secretary regarding any appropriate changes to such activities and public participation in decisions relating to ASD.
4. Develop and annually update a strategic plan for the conduct of, and support for, ASD research, including proposed budgetary requirements.
5. Submit to the DHHS such strategic plan and updates to such plan.

Dr. Insel praised the work of the previous IACC, which met twice a year from 2001 until 2006. One highlight of the previous IACC’s work was the 2003 Autism Summit, which brought together representatives of stakeholders in ASD research and services for in-depth discussions of issues. Another was the construction of an Autism Research Matrix in 2003, which categorized the research activities being supported by the Federal government on ASD and a comparable analysis of ASD services. Dr. Insel noted that there has been rapid progress in many areas of

research on autism, including the growing recognition that we should recognize “autisms”, the many different types of disorders that meet criteria for an autism spectrum disorder.

Dr. Insel introduced the members of the NIMH Autism Team who will help staff the IACC. Joyce Chung, M.D. (Autism Coordinator), a psychiatrist with Georgetown University, is leading the team. Stephen Foote, Ph.D. (Senior Science Advisor), who has worked with autism research at NIMH, and Diane Buckley (Program Chief for Autism Reports and Evaluation), who has worked in the NIH Office of Science Policy, are focusing on development of the strategic plan and the other responsibilities laid out in the CAA. Dan Hall (manager of the National Database for Autism Research), a database management expert at the National Cancer Institute, is working to develop a system that will bring together results from many different autism-related research studies.

### **Strategic Plan for ASD Research: Proposed Planning Process and Discussion**

#### **Joyce Y. Chung, M.D.**

After the Federal members of the IACC briefly described their agencies’ involvement with ASD-related research, Dr. Chung presented to the committee a proposed process for the development of the strategic plan. After the NIMH Autism Team was assembled during the summer, it held a brainstorming meeting in August that brought together opinion leaders in the field. Four main conclusions emerged from that meeting. The first was that a diverse range of stakeholders needs to be involved in the development of the plan. Second, the plan needs to consider funding from both governmental and non-governmental organizations, with an eye toward developing synergy between these two funding sources. Third, the plan should be responsive to identified needs--for example, by incorporating cost estimates for needed research and through annual updates. Finally, the plan should set priorities, not just compile all possible research activities.

To help achieve these objectives, Dr. Chung asked the committee to approve the outlined process that would develop the strategic plan in a six-month timeframe. In addition, the IACC was asked to approve the formation of a Strategic Planning Workgroup whose members would be appointed by Dr. Insel. The workgroup, which would be advisory to the committee, would help oversee the initial steps of formulating the plan and would report back to the committee. The plan included a request for information (RFI) that would be issued to a broad group of stakeholders asking for input on research priorities prior to holding scientific workshops. The four workshops in the areas of treatment, diagnosis, risk factors, and biology, would then be asked to generate research initiatives that would be considered for inclusion in the final plan.

After the March 2008 meeting of the IACC, at which the committee would review the strategic plan process and finalize the research priorities included in the plan, a draft of the strategic plan would be written, which would then be submitted to the IACC in May for further revisions and ultimately for final approval. The plan could be delivered to DHHS by June 2008. The focus then would shift to implementation of the plan, with the possibility of forming a new workgroup focused on implementation.

When the committee was asked for input on the proposed process, Dr. Morrissey asked what kind of input the autism team expected for the workshops. She also suggested that the

descriptions of what each workshop will cover be expanded to provide a better context for the workshop discussions.

Ms. Singer emphasized the need to measure outcomes. Measurability became an issue with the previous IACC Autism Research Matrix because the items on the matrix were not expressed in such a way that outcomes could be readily assessed.

Mr. Grossman asked about the status of the Matrix, pointing out that the evaluation of the Matrix determined that it was deficient in the area of environmental exposures. He asked whether “treatment” includes psychosocial, educational, and behavioral research. He also asked whether the strategic plan was going to include short-term opportunities, such as treatments and interventions that are currently benefiting the ASD community.

Ms. Blackwell emphasized that many advocates and families are interested in services for children and adults, which did not seem to be emphasized in the proposed plan. She suggested thinking about “treatment” more as intervention rather than just medical or psychosocial treatments. Several committee members elaborated on this point, concluding that “treatment” needs to be better explained and defined.

Dr. Insel responded that the focus of the strategic plan is research. The IACC’s mandate therefore includes research on services, which he described as “services, supports, intervention, and treatments of autism spectrum disorder.” Issues of dissemination, access, healthcare disparities, and costs are all valid subjects of research.

Finally, Mr. Grossman worried that the six-month timeframe may be too short, emphasizing that it is important to secure input from all stakeholders and constituencies.

Following a break for lunch, the committee discussed details of how to move forward with the proposed process. First, the topics to be discussed at the workshops will undergo further refinement, in consultation with the IACC. The language of the CAA will be consulted and incorporated where appropriate. Second, widespread participation in the workshops will be emphasized, particularly of people on the autism spectrum. Third, the development of the strategic plan will include an emphasis on monitoring and evaluating progress. The committee then approved the process for developing the strategic plan with a show of hands.

## **Presentations on Non-Government Funding for ASD Research**

### **Gary Goldstein, M.D. – Autism Speaks**

Dr. Goldstein, President of the Kennedy Krieger Institute, described the work of Autism Speaks, for which he chairs the Scientific Advisory Committee. Autism Speaks was founded in 2005 by Bob and Suzanne Wright, the grandparents of a child with autism. It merged into a single organization four preexisting organizations: the Autism Coalition for Research and Education, the National Alliance for Autism Research, the Cure Autism Now Foundation, and the Autism Treatment Network.

Autism Speaks has had two major operational goals. The first is to raise awareness of the prevalence of autism and its effects on individuals, families, and society. The second is to fund scientific research. Autism Speaks tries to complement the portfolios of NIH and other funding organizations with an interdisciplinary approach to the causes, prevention, treatments, and cure for autism. In the year 2007, it distributed \$30 million in research funds, and it expects to distribute as much as \$40 million in 2008. Fellowships, bridge grants, beginning autism research awards, and other programs provide an array of funding mechanisms.

Autism Speaks sponsors workshops on specific areas of concern, such as the gastrointestinal disorders associated with autism, immunological factors, and environmental influences. It also supports large-scale initiatives such as the International Autism Genome Project, the Environmental Factors in Autism Initiative, the International Autism Epidemiology Network, the Baby Siblings Research Consortium, and the Early Treatment Research Network.

Dr. Goldstein discussed a particular project known as the Interactive Autism Network (IAN) Project. It provides an opportunity for families with children with autism to serve as research subjects in projects that need human participants. In 6 months, more than 20,000 individuals have joined IAN.

#### **Gerald Fischbach, M.D. – Simons Foundation**

Dr. Fischbach, Dean Emeritus of the College of Physicians and Surgeons of Columbia University, described the work of the Simons Foundation Autism Project, for which he is Scientific Director. The Simons Foundation was founded by Jim and Marilyn Simons, who became interested in autism and initiated the Simons Foundation Autism Research Initiative (SFARI). The broad mission is to improve the diagnosis, treatment, and prevention of ASD and related developmental disorders through the support of research.

SFARI works intensively with investigators and provides large awards--\$500,000 per individual award and up to \$1.5 million for consortia projects. It also holds conferences and supports informatics projects focused on autism. A particular focus is Simons Simplex Consortium (SSC), which is a consortium of universities that are studying families with one affected child, apparently unaffected biological parents, and at least one unaffected sibling. The goal is to look for differences in the affected child that point to the origins of the disorder.

Dr. Fischbach pointed out that autism can be studied on several different levels. The genetics of autism are very complex, but it is clear that genetic influences are important. At the same time, environmental factors can play a major role in autism, with the influence of these factors shaped by genetic variation. Autism also can be studied at the cellular, systems, cognitive, and behavioral levels, Dr. Fischbach observed, and all of these are being investigated through grants from the Simons Foundation.

A particular need that Dr. Fischbach noted is for clinicians trained to care for patients with ASD. A graduate or certificate program that would intensely train people who see, diagnose, inform, and treat children with autism would be extremely useful, he said.

### **James Gusella, Ph.D – Autism Consortium**

Dr. Gusella, Bullard Professor of Neurogenetics at Harvard Medical School and Director of the Center for Human Genetic Research at Massachusetts General Hospital, described the work of the Autism Consortium, for which he is Senior Science Advisor. Dr. Gusella said that his involvement with the consortium derives from his work, beginning in the 1980s, on discovering the gene responsible for Huntington's disease. Over the course of that research, he worked with clinicians, geneticists, neurobiologists, and drug developers. The experience made him realize that collaboration is essential in solving a problem.

The Autism Consortium represents clinicians, clinical researchers, and basic scientists from 13 institutions in the Boston area, with collaborators spread around the world and with support from multiple sources. Members of the consortium commit to several guiding principles. They agree to further the mission of the consortium, which is not just to do interesting science but to make progress on autism as quickly as possible. They agree to take a collaborative and interdisciplinary approach, with mutual trust to allow research to move forward without impediments. They support common research protocols so that data and results can be compared, and they commit to share data openly while respecting confidentiality, with joint publication ensuring that data are used to maximum advantage.

Research involving genetics, imaging, phenotyping, and other approaches can lead to hypotheses that can be tested in model systems, from cellular models to mouse systems. This research can in turn lead to improved treatment and interventions, whether pharmaceutical or behavioral. It may even be possible to predict problems before they occur through behavior or biochemistry. And these improved interventions in turn suggest new avenues for research so that all parts of the cycle interact with each other.

The Autism Consortium has helped develop family support networks within clinics to help families navigate the medical system. These networks help investigators learn what families find difficult in working with the system, which can be a way to encourage families to participate in research. Furthermore, the clinicians at different hospitals are discovering that treatment is more cost effective because of the new streamlined procedures.

### **Open Session for Public Comment**

Six members of the public joined the IACC at the table to share their views with the committee.

**Erin Lopes Bak, M.P.H.**, the mother of an 8-year-old son who has been diagnosed with epilepsy, autism, and a hearing impairment, said that she has become a leader of a local support group and a parent advisor for the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) and Early Autism Longitudinal Investigations (EARLI) networks. Ms. Bak applauded the diversity of the research approaches being taken by NIH. Autism has many different phenotypes, which means that different treatments will work for different children, and any one child can be different from anyone else. She also pointed to a looming challenge--educating children with autism in public schools. School systems are struggling to educate an increasing number of children with autism, and the tension between needs and resources can become an issue not just for the children but for families.

**Kristina Chew**, Ph.D., an assistant professor of classics at Saint Peter's College in Jersey City, New Jersey, and the mother of a 10-year-old boy with autism, writes a weblog about autism, Autism Vox, that attracts 4,000 visits a day from around the world. She pointed out that families affected by autism have a wide range of concerns, from the causes and treatments of autism to education, after-school care, integration of autistic children into all aspects of community life, and the development of independence. Research is needed on effective educational methods over the entire life span, how to train teachers and therapists, how to maintain autism programs over time, and how to prepare autistic children to get and keep jobs and live as independently as possible. She urged the Committee to focus on how to make the world a better place for autistic persons through education, jobs, and understanding and by listening to the full range of voices of people with autism.

**Nancy McPartlin Gardella**, a hospital administrator who also is the founder of a biomedical research group of parents, said that she has a child who has recovered from autism. Many physicians are helping children to recover from the disorder, but treatments can be very difficult to fund. Each child is unique, she said, which means that autism must be treated like cancer, which requires different treatments. By listening to parents and the providers of treatments, the committee could move the treatment of autism forward.

**Katy Neas**, Vice President of Government Relations for Easter Seals, said that Easter Seals is the leading nonprofit provider of services to people with autism, developmental disabilities, physical and mental disabilities, and other special needs. Easter Seals also works with universities and medical centers across the country on research to help find effective interventions and to broaden the choices of evidence-based interventions available to individuals with autism. She encouraged the committee to promote research on direct services for children and adults with autism. Many people need services now, and even more will need them in the future; so interventions need to be broadly applicable to meet the demand.

**Ari Ne'eman**, President of the Autistic Self-Advocacy Network, noted that he was on the autism spectrum and said that he was heartened to see increased attention and resources being directed toward the autistic spectrum. However, he said that this interest could be counterproductive without an equally strong commitment to autism acceptance. The name of the Combating Autism Act is not in the interest of people on the spectrum, he said. Instead, he praised the opening language of the proposed Expanding Promise for Individuals with Autism Act, which states, "Autism is a natural part of the human experience." While applauding the inclusion of one individual with ASD on the committee, he pointed to an overall underrepresentation of autistic representatives. He encouraged the committee to recognize that with the right services, education, and supportive environment, people with ASD can succeed as they are.

Finally, **John Erb** said that he has been working with autistic individuals for more than 20 years. Four years ago, while doing research on monosodium glutamate (MSG), he developed a hypothesis that the compound causes neurons to grow more rapidly than they would otherwise. Mr. Erb said that he is going to demand that the FDA remove MSG from the food supply, which he hopes will cause a drop in autism.

## **Closing Remarks**

Dr. Insel thanked the members of the IACC and the attendees at the meeting for their participation. The committee faces a huge and immensely important task, he said, a task that he is looking forward to undertaking.

## **ADJOURNMENT**

The meeting adjourned at 4:00 p.m. on November 30, 2007.

## **CERTIFICATION**

I hereby certify that the foregoing minutes are accurate and complete.

A handwritten signature in black ink, appearing to read "Thomas R. Insel". The signature is fluid and cursive, with a large initial "T" and "I".

Thomas R. Insel, MD  
Chair  
Interagency Autism Coordinating Committee