

**Department of Health and Human Services  
Interagency Autism Coordinating Committee  
Meeting Highlights  
May 11, 2004  
National Institute of Health  
Bethesda, Maryland**

*IACC Members in attendance:* Thomas Insel (Chair); Lester Crawford (represented by Kathy Carbone); James Battey (represented by Judith Cooper); Jose Cordero; Barry Gorden; Denise Dougherty; Sybil K. Goldman; Lee Grossman; Duane Alexander (represented by James Hanson); Elizabeth Duke (represented by Merle McPherson); Troy Justesen (represented by Gail Houle); Story Landis (represented by Audrey S. Penn); Patricia Morrissey (represented by Margaret Schaefer); Kenneth Olden (represented by Cindy Lawler); Jon Shestack; Thomas Scully (represented by Phillip Surine); Ann Wagner (Executive Secretary).

Member agencies not represented: Agency for Toxic Substances and Disease Registry

**Introductions, Overview & Highlights of Recent Activities**

Dr. Insel welcomed the IACC and asked the members to introduce themselves. He announced that the agenda was focused on implementation of the research matrix and hearing from specific centers on their programs to date, including updates from the subcommittees. He mentioned the International Meeting for Autism Research (IMFAR) meeting held this month in California, noting the remarkable attendance (604 attendees) and that this was a sign that the scientific community devoted to autism research was growing. Dr. Insel also noted that the UK recently completed a strategic plan for autism research, and passed around a report edited by Tony Charman and Pippa Clare. [Mapping autism research: Identifying the UK priorities for the future. Published by The National Autistic Society, 2004]. Finally, Dr. Insel mentioned that the NIMH has revised its pamphlet on autism spectrum disorders; they were available at the door and can be accessed from the NIMH web site <http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>.

**Implementation of the Research Matrix**

*Presented by Tom Insel, M.D., Director, National Institute of Mental Health (NIMH) and Chair of the IACC.*

Dr. Insel noted that the research matrix was discussed at the last IACC meeting, and that this meeting would focus on assessing where NIH and other relevant government agencies stand with regard to activities toward the matrix goals. The matrix has been submitted to Congress and can be found on the IACC web site (<http://www.nimh.nih.gov/autismiacc/CongApprCommRep.pdf>). He reminded the committee that Congress asked for this matrix in order to describe clear targets for the autism research community, and steps toward reaching those targets. This process will involve privately and publicly funded activities as well as public-private partnerships.

Dr. Insel also noted that Congress did not provide additional funding for the implementation of the matrix.

At this meeting, Dr. Insel proposed to review short-term goals of one to three years. He stated that the NIH Autism Coordinating Committee (NIH/ACC) revised and reissued a long-standing program announcement, “Research on Autism Spectrum Disorders” (<http://grants1.nih.gov/grants/guide/pa-files/PA-04-085.html>), to reflect the goals and priorities on the matrix.

The first goal discussed was “establishing resources for genotype/phenotype studies”. There has been growth in the Human Genetics Initiative largely, but not exclusively, through NIMH funding. In September, eight supplements were funded to add an additional set of families and trios into the genetics repository. There were also funds put into the Studies to Advance Autism Research and Treatment (STAART) Centers to provide resources for them to collect genetic samples.

Dr. Insel then discussed activities supporting three short-term goals related to the development of an Autism Phenome Project. This would be an effort to integrate existing and future databases on the major characteristics of autism. This process is beginning but has a long way to go. Specifically, there are difficulties in conducting such a project including reaching consensus on data sharing practices and consolidating findings in a way that allows for maximum public benefit.

Development of highly reliable and valid screening methods is an important part of the matrix, and there are developments in this area. Examples include funds toward further development of the Modified Checklist for Autism in Toddlers (M-CHAT) and the Social Communication Questionnaire (SCQ).

Two goals are related to establishing efficacy of treatments for symptoms associated with autism. Dr. Insel reported that five pharmacological trials and at least ten behavioral interventions trials are underway. Other treatment options being investigated include a diet-based intervention and an intervention to train individuals in face processing skills (reported by Dr. Fred Volkmar at the November 2003 IACC meeting).

A goal on the matrix is the establishment of infrastructure for neuropathological investigations. Funding has been provided for a National Autism Brain Bank at Harvard Brain Tissue Resource Center. The funding provides resources dedicated to autism as part of a larger brain banking effort.

Dr. Insel also talked about goals related to implementing interventions into community settings, and the need to expand the intervention to focus on older children, adolescents, and adults. The Department of Education supports a number of demonstration projects, outreach projects, and professional development centers.

Finally, Dr. Insel noted that although we have several prevalence studies, there are no incidence studies to date. We need to understand how prevalence is changing over time.

Although this appears as a mid-term goal on the matrix, it has been moved forward because of its importance. The CDC has funded several intensive, community-based prevalence studies that have built into them the opportunity to collect incidence data.

Dr. Insel stated that there were a number of other important activities to report. The first large-scale twin study is about to be funded in Wisconsin. Another important resource in need of further development is the Pediatric Neuroimaging contract. This large scale, multi-site project on normal brain development focuses on structural components, in particular using DTI to track white matter changes over the course of development. He emphasized that this study is going to be an important repository of data about what is different in the autism brain compared to the normal developing brain.

Dr. Insel next addressed areas of high priority for further development. There is an urgent need for peripheral biomarkers to further define the phenotype and facilitate early screening. Recent funding of Norwegian and Danish cohort studies will help address this need.

Randomized controlled trials of behavioral interventions are also needed, as well as outcome measures for behavioral and pharmacological treatment studies - and strategies for how those treatments can be implemented in to schools and community settings.

Another issue mentioned was communicating research findings to the public. There are a number of efforts to do this, including the CASA listserv (<http://www.onlinecasa.org/>) and the Autism Early Screening Awareness Campaign by CDC, which will be discussed later in this meeting.

Dr. Insel noted that the NIH budget devoted to autism research has gone from about \$26.8 million in 1998 to \$93.4 million in 2003. He noted that asking each Institute and center to report their autism expenditures derives these figures. There may be differences among the Institutes on how they determine that a project is related to autism. This “coding” issue is something NIH continuously grapples with. Some of the grants may have a broader focus than autism and include basic neurodevelopmental processes, such as the pediatric neuroimaging project described earlier.

*Discussion:*

Dr. Gordon asked whether there is a way of finding out what current projects correspond to specific items on the matrix. Dr. Insel responded that the members were given a list of currently funded grants that only have the title and abstracts so it may be difficult to understand the projects fully, particularly projects embedded within centers. Mr. Jon Shestack asked how much of the \$93.4 million is specifically going toward autism research. He noted that Congress asks the voluntary groups for their opinions on the numbers but they don't have the level of detail to speak with confidence about it. Dr. Insel replied that it is difficult to know how much to count our basic science as being relevant to a particular disease. Dr. Zerhouni, the Director of NIH, has made solving this issue a high priority – a cross-institute approach to coding. In the meantime, Dr. Insel

suggested that program staff can assist with breaking down a list of grants in terms of their content.

### **Intramural Research Activities at NIH**

Dr. Insel stated that 11% of the NIH budget is spent on intramural research. This is one of the largest clinical research centers in the world and is a place for highly innovative research. He announced that the John Porter Neuroscience Center would be opening in six weeks. This large new building on the NIH campus will house 12 Institutes that will be reorganized by theme rather than Institute of origin in an attempt to eliminate boundaries between Institutes.

Dr. Penn introduced the Bioepidemiology Branch of the NINDS Intramural Research Program, which is run by Dr. Karin Nelson. She explained that its focus is not primarily on autism but developmental neurobiology in general, which is relevant to autism. Dr. Nelson specifically focuses on neonatology and perinatology. Also relevant to autism is the neuroimaging program run by Dr. Alan Koretsky. Dr. Insel commented that Dr. Nelson found increases in particular neuropeptides in the umbilical cord blood of neonates who were later diagnosed with autism.

Dr. Hanson spoke about the intramural research program of NICHD. Dr. Phil Nelson studies mechanisms of neurodevelopment in healthy individuals, which is relevant to many different types of disorders. Dr. Bai Lu works on neurotrophic regulation and synapse development. Dr. Andres Buonanno has a program on the developmental regulation of neuronal and muscle plasticity. These three areas focus on normal human central nervous system development, but occasionally there are studies done that are more directly related to autism.

Dr. Swedo explained that NIMH has two investigative foci in the intramural program. One is neurodevelopment of the normal human system and the other is clinical investigation. Dr. Jay Geidd, whose work has been on normal development, is now collaborating with Dr. Alex Martin to look at structural morphometry of children with autism spectrum disorders. Dr. Swedo studies the autoimmune aspects of post-streptococcal and post-infectious symptomatology. She explained that they plan to expand their antibiotic prophylaxis trial to look at it in children with autistic spectrum disorders. They have also been working on characterization of obsessive-compulsive disorder (OCD) and are expanding that trial into characterization of children with autism spectrum disorders. These studies are in the early planning stages.

Dr. Judith Cooper stated that the National Institute on Deafness and Other Communication Disorders (NIDCD) has a small intramural program that includes investigations on auditory temporal processing. They are looking at familial trends with regard to auditory temporal processing, and include individuals with autism as one of the study's populations.

An audience member asked if NIH is developing animal models for autism. Dr. Insel answered that there is one primate study that has a group of monkeys who were raised

with social deprivation. Many of these animals demonstrated behaviors that might be thought of as similar to the phenotype of autism: disordered social behavior, a number of stereotypes, and bizarre vocal behavior.

Mr. Jon Shestack commented that while the intramural projects mentioned seem impressive, it does not seem like there is a huge monetary commitment to autism research given the large amount of money in the intramural budget. The intramural programs are ones in which the Institute directors have discretion and it is not necessary to ask Congress for increased commitment. Dr. Insel verified that this is not an area that needs appropriation, and agreed that the interest level and sense of urgency about autism need to be raised. He noted that there is a tradition of senior scientists having a lot of freedom to pursue their interests.

### **Data Coordination Needs in the Broad Autism Research Community**

*Presented by Dr. Sue Swedo, NIMH*

The autism research community is generating a large amount of clinical and laboratory data. This includes genetic data, phenotypic data, and neuroimaging data. An important question is where and how can the large amounts of data in individual databases be coordinated and organized in such a way that data can be shared. Dr. Swedo indicated that the Biomedical Informatics Research Network (BIRN; [www.nbirn.net](http://www.nbirn.net)) is an initiative of the National Center for Research Resources (NCRR) to provide information technology infrastructure to improve biomedical research. Their mission is specifically for large scale, multi-site trials, such as those we envision for autism. There are currently three “test bed” projects: the Function BIRN for schizophrenia, the Morphometry BIRN for depression and Alzheimer’s disease, and the Mouse BIRN for animal models. NCRR is looking for new projects and NIMH has initiated discussions with them to see whether autism could be a new project.

### **Updates on Centers’ Activities**

#### **Collaborative Programs of Excellence in Autism (CPEA)**

*Presented by Jim Hanson, M.D. and Alice Kau, Ph.D., National Institute of Child Health and Human Development (NICHD)*

Dr. Hanson reminded the committee that the Collaborative Programs of Excellence in Autism (CPEAs) are a group of ten institutions that have been in existence for eight years and have been quite productive. Collectively they have published about 700 to 750 manuscripts. They continue to have a strong organizational base with regular monthly conference calls and a variety of subcommittees such as genetics, data sharing, imaging and a committee on liaison with the STAART centers.

Dr. Hanson also announced that CPEA and STAART steering committees and investigators were to meet jointly for the first time in May 2004. The CPEAs were scheduled to present work from eight network projects. Topics to be presented include secretin, regression, cognitive profiles of preschool children, and several studies on genetic issues including the use of multiple sibling sets. Head circumference, functioning, and language functioning studies are also currently ongoing studies. He

announced that NICHD and the National Association For Autism Research (NAAR) recently formed a collaboration to look at children at high risk for autism, or “baby sibs” of autistic children. The NAAR collaboration will also include the STAART centers and a Canadian institution, developing a collaborative protocol for looking at head circumference growth.

Mr. Shestack commented about the data coordinating issue previously discussed by Dr. Swedo. He expressed frustration that it has not yet happened. He noted that if NCRR can perform that function, they should be encouraged to do so.

Dr. Swedo concurred and stated that she will follow up with BIRN and investigators in the field to make sure this happens. Dr. Insel told members that it is vital to remember most investment in autism is not through centers, but through individual grants and this is where this group can have the biggest impact. Integration of work across sites is key, but this change in policy that will have to be made clear to grantees – that there are expectations to share data. Dr. Insel noted that genetics and genomics are ahead of the curve, as we have repositories and someone who has never seen a child with autism could conceivably make the most important discovery in autism. This can only happen if the data are available, in a large set that is well annotated and that is in a repository.

Dr. McPherson pointed out that as we improve screening and early identification and the community pediatrician’s ability to identify those kids, providing services becomes a big issue. She wondered about the capacity for diagnosis and treatment in the centers of excellence. She has found that oftentimes the most expert clinicians have moved into research. Ideally, one would be able to direct families to the best facilities for a particular child, where they would get services as well as be available for research.

### **CDC Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)**

*Introduction by Jose Cordero, M.D., M.P.H., National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)*

*Presentation by Diana Schendel, Ph.D., National Center on Birth Defects and Developmental Disabilities, CDC*

Dr. Cordero introduced Dr. Diana Schendel, a Project Officer for the CADDRE sites. Dr. Schendel began by reminding the committee that the Children’s Health Act of 2000 led to the development at the CDC of the National Center on Birth Defects and Developmental Disabilities. It also mandated that the CDC establish autism surveillance and research programs, and specifically establish national autism and PDD surveillance programs and centers of excellence in autism. In response to this mandate, CDC used a model already in existence for surveillance in epidemiological studies of developmental disabilities, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

The primary goal of MADDSP was to conduct ongoing surveillance of select developmental disabilities in Atlanta including autism. Using this model, CDC established two programs: the Autism and Developmental Disabilities Monitoring (ADDM) Network, and the Centers for Autism and Developmental Disabilities Research

and Epidemiology (CADDRE) Network. Through both programs there are 16 sites and 18 states involved in autism surveillance.

CADDRE grantees include the California Department of Health Services, the Colorado Department of Public Health, Johns Hopkins University, the University of Pennsylvania, and the University of North Carolina at Chapel Hill. CDC participates as a sixth CADDRE site. The centers have a number of goals: conducting surveillance for autism and other developmental disabilities over time in their local area, participating in collaborative epidemiologic studies, and conducting site-specific, investigator-initiated research studies drawing on the expertise and interests at their individual site. The primary goal of the CADDRE and ADDM Network is to obtain as complete an account as possible of the number of children with autism in each site's area. They are currently examining children who were eight years old either in 2000 or 2002 as part of this effort.

The first collaborative multi-site study planned is the National CADDRE Study: Child Development and Autism. The study will examine the broader ASD phenotype, and will pursue studies in genetics and two potentially etiologic domains: infection and immune function, as well as reproductive and hormonal function. The protocol is a case-cohort study design using a population based ascertainment approach with 2,000 enrollees. Three separate groups of children will be enrolled: children with ASD, children with other neurodevelopment problems, and typically developing children. All sites will use uniform participant inclusion criteria and data collection, resulting in the largest epidemiological study of the causes of autism that has been planned to date. This project should address gaps that have been outlined in the research matrix.

Mr. Shestack stated that the CADDRE study is very impressive. He asked when the case control study will start, and what is the funding picture. Dr. Schendel answered that it could start this coming winter and that adequate funding to fully implement the study is not available yet. Since the CADDRE centers were funded, the sites have been involved in their surveillance activities and site-specific studies, while planning the case cohort study. Dr. Schendel noted that the protocol is complete and is in the process of getting through local and CDC Institutional Review Boards (IRB), but they do not have the resources for hiring study staff or enrolling participants. The Data Coordinating Center has been awarded. Dr. Insel suggested that it would be useful to have a secondary meeting to talk through some of the details on this project and be reassured that the CDC could get this project off the ground.

### **Children's Environmental Health Centers (NIEHS)**

*Cindy Lawler, Ph.D., Scientific Program Administrator, Organ and Systems Toxicology Branch, National Institute of Environmental Health Sciences (NIEHS)*

Dr. Lawler provided an update on progress within the Children's Environmental Health and Disease Prevention Research Program, funded by NIEHS and the Environmental Protection Agency (EPA). Two centers are specifically engaged in research relevant to autism: University of Medicine and Dentistry at New Jersey, and University of California at Davis.

The U.C.-Davis Center is comprised of inter-related research projects that examine the interaction of genetic susceptibility and environmental exposures in autism. A large case control epidemiology study, known as the CHARGE Study, is complemented by basic science projects to develop animal models of behavioral features of autism and a project to develop cellular and molecular mechanisms of neurodevelopment perturbation by toxicants. Plans are to enroll 700 children with autism and over 1,000 controls. The enrollment to date is over 150 children. A community advisory committee was established for this study and has been a key resource.

The UMDNJ Center is examining a large number of exposures in the home and community. Two community-based projects are performing clinical, behavioral, and biologic assessments. The study's clinical component plans to enroll up to 100 children. More than 30 children from four different states are currently enrolled. Environmental monitoring in homes is underway. In a few cases specific neurotoxicants have been identified at higher levels than the standards. Potential interventions have begun in three homes. Each center has evolved over the three years of funding so far. They have incorporated new investigators or new methodologies to follow up on questions that arose in the initial application. The web address for the Children's Center Program and the individual centers is <http://www.niehs.nih.gov/translat/children/children.htm>.

Dr. Insel asked if the Children's Centers are conducting research to try to understand what makes some children vulnerable and others resilient to toxicants in the environment. Dr. Lawler responded that the U.C. Davis center is collecting genetic samples and are developing focused micro arrays to identify relevant sites of genes that may be altered. They are also trying to find biomarkers for autism.

### **Studies to Advance Autism Research and Treatment (STAART)**

*Deborah Hirtz, M.D., National Institute of Neurological Disorders and Stroke (NINDS)*  
Dr. Hirtz began by giving basic information on the eight STAART Centers. The data-coordinating center is the DM-STAT group in Massachusetts, and their scientific collaboration is with Boston University. Dr. Hirtz noted that the upcoming CPEA-STAART steering committee meeting would include a number of symposia such as an animal model symposium, genetics symposium, intervention symposium, face processing symposium, and brain mechanisms symposium. Single site intervention studies include behavioral and neural plasticity in face perception at Yale, early characteristics and intervention at University of Washington, diet and behavior in young children with autism at University of Rochester, early detection and intervention at Kennedy Krieger, and peer-based intervention in autism at UCLA. Multi-Site intervention trials include Citalopram treatment in children with autism spectrum disorders and high levels of repetitive behavior and a potential project in developmental psychopharmacology of autism.

DM-STAT has been very busy helping the group to develop and decide upon core measures. They have created a website for both the STAART and CPEA networks. They have devoted a tremendous amount of work to get the Citalopram intervention trial



underway, including training study investigators, project coordinators and data managers. They have also been working on establishing a common database for all centers to use. A web site for the STAART Centers can be found at <http://www.nimh.nih.gov/autismiacc/staart.cfm>.

Dr. Hirtz presented slides describing a large NIH initiative for sharing genetic research resources. There were eight projects funded and over \$2 million in administrative supplements to existing projects to re-consent subjects and obtain blood and standardized phenotype data for deposit into the repository. This year, all of the STAART Centers' genetic studies, as well as the Citalopram trial and other studies, will contribute to the repository. By the end of the year, it is expected that there will be 1,600 families and trios and 2,400 samples from affected children in the repository.

### **Science Update from CPEA network**

#### **Disordered complex information processing in autism arising from functional under connectivity and abnormal specialization of neural systems**

*Introduction by Alice Kau, Ph.D., NICHD*

*Presenters: Nancy Minshew, M.D.; Marcel Just, Ph.D.; Jonathan Sweeney, Ph.D.; University of Pittsburgh CPEA Center*

Dr. Kau introduced Dr. Nancy Minshew from the University of Pittsburgh School of Medicine. She is a child neurologist who has been investigating the cognitive and neural bases of autism since 1987 and has received support from NIH during that time. She is the director of the CPEA site at the University of Pittsburgh, which includes collaborations with Carnegie Mellon University, and the University of Illinois at Chicago.

Dr. Minshew explained that over the past two decades, research has progressively defined the cognitive basis for many aspects of behavior in autism. This has greatly improved diagnosis and empowered intervention. Dr. Minshew described the research that her CPEA site has conducted over the past several years. They began with a study of the profile of neuropsychological functioning in autism, finding an unusual profile with areas of strength and areas of weakness. They noted that there were general problems with complex abilities and intact performance in simple abilities in the same domain. This was true in the motor domain as well as the cognitive domain. This means that what is wrong with the brain in autism is not confined to the three domains of social, communication, and problem solving upon which diagnosis is based but broadly involves the brain's mechanism for processing complex information. An fMRI study demonstrated an analogous pattern to this neuropsychological profile. When you look at fMRI studies, you see that normal individuals are using frontal circuitry for higher order or more complex tasks, whereas the autism group does not access the higher order circuitry. Instead the autism group relies on lower order circuitry related to more basic cognitive abilities. Understanding this profile is key to behavioral intervention with high functioning ASD individuals. Dr. Minshew also described a second line of research on concept formation. They found that concept identification (attribute identification and rule-learning) is intact in people with autism and normal IQ, but their ability to apply

concepts flexibly is impaired, as is their capacity to form concepts. Thus they have major difficulty with problem solving and changing strategies when the one they are using does not work, which leads to serious problems with adaptive behavior in life. As a result, autism is not just a problem with social behavior it is equally a problem with non-social problem behavior and adaptive function that has equally serious affects on function in life.

Dr. Kau introduced the next speaker, Dr. Marcel Just. Dr. Just is a professor of cognitive neuroscience at Carnegie Mellon where he holds the Hebb Chair. His work is in fMRI studies of high-level cognition, particularly language and problem solving, as well as computational modeling of cognition and brain activation.

Dr. Just presented underconnectivity theory, which can be called upon to explain the cognitive neural biological characteristics of autism. He started with the hypothesis that deficits in autism emerge when a high degree of integration or collaboration among brain regions is required and that autism is marked by anatomical and functional underconnectivity. Dr. Just described several studies completed by his lab that demonstrated deficits in complex comprehension in high functioning participants, and highlighted decreased (compared to normal) activation in relevant brain regions. Dr. Just also described how fMRI can demonstrate synchronized activity between two or more brain regions, and presented data showing less synchronization in participants with autism than in typically developing control subjects. He also presented data on white matter differences in the frontal lobe and corpus callosum of autistic individuals, and presented results showing a correlation between functional connectivity and size of the corpus callosum. Finally, Dr. Just presented a computational model of cognition called 4CAPS and how he is using the model to explain the disadvantage of individuals with autism on dual tasks.

Dr. John Sweeney was the next speaker for the CPEA network. He is a professor of psychiatry, neurology, and psychology at the University of Illinois at Chicago where he directs the Center for Cognitive Medicine. He is the co-director of the CPEA Center that Dr. Minshew directs. He began by emphasizing that the white matter findings have been an important discovery. Early on, during the first year of life, there is an overgrowth of white matter pathways in many individuals with autism leading to brain overgrowth and to an increased head circumference size. White matter pathways are important because they are the cabling that connect different areas in the brain to allow them to function. Animal models were developed to lay out very well defined neural circuits so their functional integrity in individuals with autism can be tested. He went on to describe animal models explicating the dorsolateral prefrontal cortex pathway, and the extra-striate pathway for processing visual motion information. Dr. Sweeney then described research conducted in his lab, in which they demonstrated similar deficits in functioning on tasks utilizing these pathways in individuals with high functioning autism. In effect, there seems to be a failure in the regulation of posterior brain systems by dorsolateral prefrontal cortex.

Dr. Sweeney described another line of research that involves the initiation of a pursuit response guided by sensory information. Individuals with autism have a selective deficit

in their ability to track visual motion when it moves into the right hemifield. His studies suggest that this is not a problem with perceiving visual motion, but rather in translating that basic sensory information to higher-order cortical areas for cognition and to guide action. This deficit appears on imaging as hypofunction in the left parietal cortex. Finally, Dr. Sweeney presented data suggesting that in autistic individuals, the prefrontal cortex is not specialized for higher cognitive operations as it is in typically developing individuals.

Dr. Sweeney summarized by stating that there may be a dysmaturational of functional connectivity in autism. Recent advances in imaging technology may allow for better explication of autism phenotypes, as well as developmental studies in much younger subjects. There is a possibility that this could lead to biomarkers for early detection.

### **Public Comment**

Reconvening after lunch, Dr. Insel announced that although public comments are taken at the end, Mr. Thomas Garvey of New Jersey would speak now because he must leave as soon as possible to get back to his family. Mr. Garvey began by thanking the committee for letting the public attend. He then introduced himself and talked about his son Patrick, who is two and a half years old and has autism. He spoke of the need to “fast track” services for providing early intervention. He described how expensive and time consuming it is for treatments such as ABA and Lovaas, costing \$8,000 per month for intensive treatment. He described how the financial and psychological burden of providing support falls on parents. Mr. Garvey thanked everyone for his or her efforts, and gave a special thanks to John. Dr. Insel thanked Mr. Garvey for his comments, and noted that this is a good introduction to the rest of our meeting.

### **Services Research Panel**

*Introduction and overview presented by Denise Juliano-Bult, MSW; Agnes Rupp, PhD; NIMH*

*Presenters: Joseph Morrissey, Ph.D., University of North Carolina Chapel Hill; David Mandell, Sc.D., University of Pennsylvania; Scott Grosse, Ph.D., CDC; Dr. Richards Roberts, Utah State University; Thomas Challman, M.D., Geisinger Medical Center*

Ms. Juliano-Bult began by explaining that the group presenting today was put together by the suggestions of members of the services subcommittee. She gave an overview of services research, noting that the task of services research is to determine what needs to be done to get optimal treatments and optimal services to the people who need them. Health services research integrates research, practice, and policy to improve treatments and services. The major components of services research are looking at the organization of services, the financing of services, quality of care, the outcomes of care, and access or barriers to access to services and treatments.

Agnes Rupp, Ph.D., introduced the first speaker, Dr. Joseph Morrissey. Dr. Morrissey is a sociologist from North Carolina who left NIMH in 1975 and established a productive services research career in academia.

Dr. Morrissey pointed out that the IACC matrix talks about the need to discover factors that moderate responses to interventions, create strategies to improve outcomes in schools and communities during transitions in development stages, and build our understanding of how needs change across the lifespan. A study that is currently being conducted in North Carolina examines the breadth and mixes of services that families access to deal with their autistic child, as well as their own needs. The study looks at generic services as well as autism specific services.

Dr. Morrissey then described the survey of 300 families in North Carolina with a child with autism, age 8 or younger. He was particularly interested in the transition from preschool to school. Focus groups with the families were conducted. Dr. Morrissey noted that the families were very motivated to do anything that they could to help understand the situation or develop some interventions.

Results of the survey revealed a diverse array of services that families are accessing. Many, but not all, are school based. The average number of services that each family reported using was about five: two in school and three outside of school. The most frequently used were speech and language therapy, and occupational therapy. Schools pay for a large proportion (42%) of services for children eight and younger. But a huge proportion (34%) is paid out of pocket by families and is not reimbursed by insurance. Dr. Morrissey described future plans for collaborating with the CDC's CADDRE project in Chapel Hill to obtain a prospective cohort, to verify diagnoses through the CADDRE project, and hopefully to gain access to school and Medicaid records. They would also be able to look at the transition from elementary school to middle school. They hope to learn which combinations of services are thought to be useful by families and how this might vary by different characteristics of the family, the different approaches to autism, the cost to the families, and who helps them pay for them.

Dr. Rupp introduced David Mandell, ScD. Dr. Mandell's research focuses on services for individuals with autism. Dr. Mandell described that, under the leadership of Estelle Richman, the Secretary of Public Welfare, the Commonwealth of Pennsylvania is reconfiguring the way services for people with autism are organized, financed and delivered. The Autism Task Force, which is composed of about 280 people, over half of whom are parents of individuals with autism, is a primary source for this change. To augment the work that has been done through the task force, Dr. Mandell was asked to conduct a statewide assessment of the needs of individuals with autism and their families. The needs assessment included an analysis of administrative data, focus groups with parents, and a statewide survey of families. Following the needs assessment, a daylong conference will be held in Philadelphia to report the findings of the needs assessment, describe changes being made to Pennsylvania's system, and to provide practical workshops to parents about negotiating Pennsylvania's system.

Dr. Mandell discussed the use of administrative data from schools and Medicaid databases to study autism. These large data sets are a good source of information for low prevalence conditions in children that qualify them for publicly funded services. Yet

when people turn twenty-one there is no further source of data since services are often not an entitlement for adults. Administrative data can provide basic data on treated prevalence and related costs and service use, but do not provide insight into why things are the way they are. For example, Dr. Mandell used Medicaid data from Philadelphia to find that children with autism are entering treatments at an average age of six years, but African American children enter treatment later than European Americans. These data do not tell us why this discrepancy exists. Chart review studies give richer data, but still do not provide the depth of information that allows us to design sensitive, responsive systems and services. He and his team use focus groups of parents to learn more about the processes that drive the data gleaned from administrative data and chart review.

Dr. Mandell described the next steps that will take place in Pennsylvania, which include taking their survey into the field, and taking steps toward developing consistent statewide decision rules for assessment, diagnosis and treatment, and developing a statewide system to train local providers.

Dr. Rupp introduced Dr. Scott Grosse. Dr. Grosse is a health economist and an intramural researcher at CDC. Dr. Grosse discussed work that he and his colleagues have been doing with the MarketScan database, a proprietary database on private claims that consists of almost six million individuals. They obtained a sample of over 2,500 individuals with a diagnosis of autism and related disorders from this database. Total health costs were found to be between \$5000 and \$6000 per year across age groups. Drug expenditures were surprisingly large. Healthcare expenditures were 6:1 for ASD:non-ASD. Costs rise rapidly with age as children move into adolescence. Future analyses will include a more detailed look at services including medication use, and analyses of trends. He ended by discussing the limitations of using this type of database.

Dr. Rupp introduced Dr. Richard Roberts from Utah State University. Dr. Roberts conducts research funded by the Department of Education. Dr. Roberts discussed implications for individuals with autism and their families of the Individual with Disabilities Education Act, the President's New Freedom Initiative, and Healthy People 2010. He presented a slide that illustrated the complexity of the service needs for individuals with autism and their families, and noted that all of these components must be considered when attempting to coordinate a system of care. Dr. Roberts described a study he is conducting, funded by the Department of Education, looking at outcomes for service integration models, including the actual cost of care coordination. Data collection and analyses are ongoing, but he was able to provide some preliminary results. The types of services children in early intervention typically receive are occupational therapy, physical therapy, speech therapy, and some type of playgroup or parent-to-parent network. The administrative system is complex and there is a tremendous administrative load on the service coordinators. Care coordinators usually have between 50 and 90 cases at one time, so they are unable to provide the quality services that families need to find what works for their child. The programs thus far have been moderately successful and cost between \$1400 and \$2800 a year per child. Dr. Roberts discussed the challenges of evaluating outcomes of early intervention services and future directions of his research.

Dr. Rupp introduced Dr. Thomas Challman. Dr. Challman is a full time pediatrician at the Geisinger Medical Center and has conducted some research supported by HRSA. Dr. Challman discussed the challenges of addressing gaps in care for children with autism, particularly in rural areas such as central Pennsylvania where Geisinger is located. He described the development of a screening instrument that will be linked with Geisinger's electronic medical records. Reliability and validity testing of this instrument are underway. The goal is to link outlying provider sites with the Geisinger hub to make screening and diagnosis fairly automatic, as well as provide clinicians and parents access to resources. Dr. Challman also described a process flow model they are using to increase the efficiency and standardization of clinical care in order to increase the patient care capacity. Included in this model is the development of kiosks where parents can enter historical information prior to a visit, and other online tools. Preliminary results suggest that implementing some of these changes does result in decreasing the time it takes to evaluate a patient as well as increasing the number of new slots. They are also developing guidelines for follow-up visits. Future efforts include the use of structured interviews with parents to gain more information about care coordination needs, and coordination with local intervention resources to develop a more formalized process of care.

Dr. Hanson asked whether there are any best practices guidelines for diagnosis and management of autism. Dr. Hirtz replied that about two years ago the American Academy of Neurology and the American Academy of Pediatrics published guidelines for screening in autism, based on data that had been published at the time. The question is whether there is new data that warrants updating these guidelines.

Mr. Grossman commented that the problem of service provision is daunting. The services subcommittee has been trying to tackle it, and he is excited to be part of that process. He is pleased that the IACC has elevated services to this level of priority. He stated that it is time to stop talking about the problem and start dealing with it.

### **Report from Services Subcommittee**

*Merle McPherson, M.D., Health Resources and Services Administration (HRSA)*

Dr. McPherson began by commenting that the services subcommittee's primary tasks are to identify the service needs of individuals with autism in families, describe the current Federal programs, identify the issues and challenges to provision of services, and make recommendations for actions. Individuals with autism and their families should have the same access to generic government programs as others; they should also have full access to disability services; and there are also unique needs and challenges that require targeted funding for autism. The services subcommittee proposes to utilize the model from the President's New Freedom Initiative. They are going to adopt the six core components from the New Freedom Initiative to develop a services matrix that would include goals for improving appropriate provision and coordination of autism services. The six components are: 1) families and individuals with ASD partnership/satisfaction; 2) access to all needed health, education and social services; 3) access to adequate insurance or other financing mechanism; 4) early and continuous developmental and medical

screenings; 5) organization of services for easy use by families; 6) youth transition to adult services, work, and independence. The subcommittee will embark on a process similar to the development of the autism research matrix, and will convene a group of experts with representation across the lifespan for a two-day meeting in September. They intend to have a report and presentation of a services roadmap at the November 2004 meeting. Dr. McPherson also noted that finding funds to staff and implement this activity has been an ongoing challenge.

### **Report from Screening Subcommittee**

*Deborah Hirtz, M.D., NINDS*

Dr. Hirtz reported on a meeting sponsored by the CDC in April in Atlanta. The meeting convened a group of experts who have been working on aspects of autism screening in terms of practice and research. Five general recommendations resulted from that meeting. The first is to examine current eligibility criteria for services in different states. Another is to analyze the data from the National Early Intervention Longitudinal Study (NEILS), sponsored by the Department of Education, to try to identify successful models and systems. Additional testing of screening models within the primary care settings is recommended. Additional evaluation of sensitivity and specificity of existing tools is needed, as well as development of guidelines for when to refer for further evaluation. Investigation into the possibility of developing a tool that could be incorporated into a general developmental screen was also suggested. Examining the role of families is needed. Finally, a strong recommendation was made for evaluating cost effectiveness, and incorporating economic and cost analyses into screening models.

### **Update on the Autism Awareness Campaign**

*Presented by Dr. Katherine Lyon-Daniel, CDC*

Dr. Lyon-Daniel reported on the status of the Autism Awareness Campaign. The CDC has conducted focus groups of healthcare providers and parents of children with autism and other developmental disorders, and with parents of children without identified developmental disorders. The final focus groups will be completed in the next few weeks. The key objectives of the campaign are to increase awareness among healthcare and childcare providers about the importance of early detection; to educate parents about key developmental milestones; and to increase early action. The campaign will attempt to add awareness of social/cognitive/language milestones to the more commonly known physical milestones. She showed examples of draft print ad executions and E-cards. They have sent out an article that can be used in newsletters of provider organizations. Eighteen professional organizations have agreed to publish it. They will also be setting up exhibits and talks at professional conferences. There are unique aspects to the consumer and parent outreach, including giveaways such as a keepsake book and growth charts with developmental milestones. After giving several more examples of activities, Dr. Lyon-Daniel invited people and organizations to join the campaign by sending an email to [angela.colson@porternovelli.com](mailto:angela.colson@porternovelli.com). Dr. Lyon-Daniel noted that they will be incorporating program evaluation tasks into their rollout, possibly through collaboration with the CADDRE centers. They hope to begin provider education in the summer, and public service announcements in the fall.

*Discussion:*

Several committee members noted the need for biomarkers, but also recognized that there would still be a need for continual tracking of development. An audience member introduced herself as Margaret Dunkle from the Department of Health Policy at the George Washington University. She informed the committee that in Los Angeles County a coalition is focusing on the development and acceptance of broad developmental screen for all children. They are trying to draft language that defines a high quality developmental screen that could be included in statutes or in regulation policy and guidance. She invited commentary on the language and partnerships with other communities.

**Public Comment**

Mr. Rich Martin from the New England Center for Children in Massachusetts commented that his center schools 225 children with autism. They have programs in early intervention, preschool, day school, and residential services and a small adult component. They are very interested in the IACC and want to know if they can contribute in any way. He noted that teasing out the good and most effective services are very important. Making effective intervention readily available to children and families is most important. He then talked about how applied behavior analysis is effective in modifying unwanted behavior in children with autism. He discussed the need for allocation of sufficient resources and teacher training to provide effective services for all children with autism.

**Closing Comments**

Dr. Insel thanked everyone for his or her participation and for his or her hard work. He closed by saying that there is a lot of work that still needs to be done and that the next meeting will be November 19, 2004.



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