Department of Health and Human Services
Interagency Autism Coordinating Committee
Meeting Highlights
November 19, 2004
National Institute of Health
Bethesda, Maryland

IACC Members in attendance: Tom Insel, M.D. (Chair), Susan Swedo, M.D., Ann Wagner, Ph.D. (Executive Secretary), Alice Kau, Ph.D., Duane Alexander, M.D. (represented by James Hanson, M.D.), Steve Moldin, Ph.D., Story Landis, Ph.D., Deborah Hirtz, M.D., Kenneth Olden (represented by Mary Gant, M.S), James Battey, M.D., Ph.D. (represented by Baldwin Wong), Barry Gordon, M.D., Ph.D., Denise Dougherty, Ph.D., Margaret Schaefer, M.A., Patricia Morrissey, Ph.D., Gail Houle, Ph.D., Jose Cordero, Ph.D., MPH, Jonathon Shestack, Merle McPherson, M.D., Sybil Goldman, M.S.W., Lee Grossman, Mary Duckett, M.S.W., Lester Crawford, D.V.M, Ph.D. (represented by Kathryn Carbone, M.D.)

Member agencies not represented: Agency for Toxic Substances and Disease Registry; Centers for Medicare and Medicaid Services

Introductions, Overview & Highlights of Recent Activities

Dr. Thomas Insel, Director of National Institute of Mental Health (NIMH) and chair of the Interagency Autism Coordinating Committee (IACC) called the meeting to order. He welcomed the IACC committee and asked the members to introduce themselves. Following introductions, he provided an overview on the state of autism research since the last meeting in May 2004, including information relating to several genetics, environment and imaging studies.

Dr. Insel described the Human Genome project, published in April 2003 that provided a consensus map for understanding the genome of the human species. However, the roadmap did not address individual variation within the genome, important for understanding the genetic basis of human disease. To address the issue of variation, a haplotype map is currently being constructed with completion expected by February 2005. The haplotype map allows for whole genome association studies, an approach which has recently proven useful for Crohn's Disease. NIMH has recently funded Dr. Aravinda Chakravarti, from Johns Hopkins University to conduct the first whole genome association study for people with autism. In addition, an ongoing study by Michael Wigler of Cold Spring Harbor Laboratory has been identifying changes in copy number of specific gene regions in children with autism.

Dr. Insel reported on some of the preliminary results from environmental and imaging research. Specifically, he discussed the results of a published paper by Mady Hornig and colleagues (Mol Psychiatry. 2004 Sep;9(9):833-45) that indicated that SJL, a autoimmune mouse strain, was especially sensitive to Thimerosal even at low doses. These results in mice suggest the importance of genetics in searching for environmental causes for neurodevelopmental disease. Dr. Insel also described the results of Martha Herbert and colleagues (Ann Neurol. 2004 Apr;55(4):530-40) from a study of the white matter changes in the brains of autistic children and

those with developmental language delay. The results of their investigation show that there is a significant increase in superficial radiate bundles in the prefrontal area of the brain for these children. While there is no clear answer as to what this means, these results are consistent with the hypothesis that the autistic brain has an increase in intra-hemispheric connectivity.

Matrix Update: Private/Public Partnerships

Genetics Request for Applications (RFA)

Presented by Steve Moldin, Ph.D.

Dr. Steve Moldin talked to the committee about initiatives relating to the genetics of autism. He gave an update discussing the 2004 resources for enhancing the sharing of genetic materials. An NIMH repository, the NIMH Center for Genetic Studies, houses clinical and DNA data from the STAART centers. Supplemental funding was provided to 5 of the STAART Centers (The University of North Carolina, University of California – Los Angeles, Boston University, Yale, and Mt. Sinai) to coordinate the consenting of subjects, drawing of blood, and standardization of the phenotype. The repository currently holds genetic material of over 400 families, 300 trios, and 200 unrelated individuals. The repository is open to all researchers.

Dr. Moldin also discussed how new research is beginning to identify candidate genes and mentioned the NAAR Autism Genome Project – a large scale collection of genetic information headed by Andy Shih, as one of the leading movements behind this research. In addition, Dr. Moldin reported on the public-private collaboration FY2005 between NIMH, NINDS, NICHD, NIDCD, NIEHS and the Canadian Institutes of Health Research, CAN, NAAR, Southwest Autism Research and resource center. There is a commitment of over $4 million per year, with a total cost of over $21 million towards this mission. The initiative will be implemented through RFAs.

Infant Sibling Consortium

Presented by Lonnie Zwaigenbaum, Ph.D.

Dr. Zwaigenbaum presented information about infant sibling consortium to the committee. This consortium is a private-public partnership between NIMH, NICHD, NAAR, and research groups associated with the Canadian Institutes of Health Research. It is a large-scale study that includes several of the STAART and CPEA centers that was designed to help with the early identification of autism. Dr. Zwaigenbaum discussed how many of the early markers of autism do not map with the DSM-IV, but rather there are behavioral and temperament differences with autistic children that have been noted in infancy. For example in retrospective parental reports infants were described as either fussier, docile, or had decreased facial recognition. However, Dr. Zwaigenbaum pointed out some of the methodological limitations of conducting retrospective studies through examination of home videos or case studies. Usually these examinations do not provide the context necessary for early identification and they often are riddled with bias. Therefore the goal of the infant sibling study is to examine high-risk infants with the aim of improving early detection within a prospective approach. There are several projects currently underway within the large consortium. One project is the study of head circumference and head growth. Other studies under development include: early predictors - examining genetic markers at ages 6-12mos and early diagnosis and establishment of diagnostic criteria, given that the DSM-IV was not developed for young children. Preliminary results from these studies indicate

that at 6 months only a few markers of ASD, decreased vocalization and passivity may be apparent. However, as children age towards 12 months there are several more indicators/ deficits present (e.g., poor visual tracking, quiet, lack of social babbling, decreased social behaviors, lack of imitation skills, and extreme reactivity).

Discussion:
Jonathan Shestack and Andy Shih, Ph.D. served as discussants regarding the private-public partnerships. Mr. Shestack commented that although a lot of promising research initiatives are on the forefront, it appears as though the autism matrix remains largely unfunded. For example, the matrix called for database management between the CPEA and STAART centers; however there does not seem to be any funding set aside for this endeavor. Mr. Shestack also questioned the committee about the availability of and commitment to intramural research on autism at NIH. He concluded his remarks by reminding the committee of the need for quicker dissemination of information and additional focus on the development of interventions for autistic children.

Dr. Shih echoed Mr. Shestack's sentiment about making sure to focus our joint efforts on the research and ultimately the treatment of autism. He discussed the importance of continuing to learn how to work together throughout these public-private relationships.

Dr. Swedo, in response to Mr. Shestack's comment about data sharing, updated the committee about NIH's progress in this area. She mentioned how in partnership with BIRN and CIT, NIH is committed to establishing a shared database for genetic and clinical information for autism. The plan is to have a more detailed plan to present at the next IACC meeting. She also addressed Mr. Shestack's point regarding NIH's commitment to intramural research by pointing out that while this area appears to be moving more slowly than extramural steps, that NIH intramural program is planning autism research activities. However, Dr. Swedo also mentioned that the importance of the intramural program is to conduct research that cannot be done better in the field.

In closing comments, Dr. Shih conveyed the importance of translational research in bringing basic science from bench to bedside and that perhaps these private/public partnerships could play a role in dissemination. Dr. Insel responded to this, by stating that in most cases it is the advocacy groups that provide the best arm of getting information out to the public when there is something to disseminate.

Center for Disease Control Update on Listening Sessions and Autism Awareness Campaign
Presented by Jose Cordero, M.D., Coleen Boyle, Ph.D., & Kate Galatas, M.P.H.
Dr. Cordero provided an introduction for Dr. Coleen Boyle who updated the committee on CDC's listening sessions on Autism. Thus far the CDC has conducted 4 of these sessions around the country. The process of these sessions begins with a presentation about the components of the IACC research agenda and then the floor is opened up for 2-4 hours of comments from those present at the meeting. Some of the major themes identified during these sessions include: research (treatment, best practices, genetics), vaccine-related concerns (re-evaluate the safety of current immunizations, repair distrust among parents and CDC), public awareness and education (educate teachers about signs and symptoms of autism, social skills training as part of curriculum for all, increase overall awareness of ASD), early detection, diagnosis, and intervention (need for

clear and consistent definition/diagnostic code to be used by all agencies, listening to parents more), and insurance and service provision (limited coverage and availability of services needs to be addressed, alternative services aren't covered by insurance, so many families are paying out of pocket).

From the listening sessions it was clear that parents and advocacy groups understand that there is strong link between autism and genetics, but many are also concerned about potential links between the environment and genetics and believe that more efforts should be focused here. As a result of these sessions, the CDC plans to use the comments and recommendations to produce their priorities when applicable. For comments that do not fall within the CDC's realm, they are being passed along to the heads of the appropriate agencies.

Discussion:
Lee Grossman commended the CDC for establishing the listening sessions and remarked on their importance for allowing the parents to feel that the federal government is truly involved and willing to interact with them. He also indicated that the response from parents about this outreach has been overall positive and he therefore urged the other agencies to embrace this type of outreach program.

A member of the audience briefly commented about concern regarding the association between the words "vaccine" and "autism" because it was not the vaccine in general where problems have been identified, but rather the thimerasol in the vaccines. If there continues to be an association between these two words then the lay public will continue to see these things as related, when there was only one aspect of a vaccine that was associated with autism. We should discuss the specific type of vaccine or component rather than classifying them all together.

Update on Awareness Campaign:
Dr. Cordero introduced Kate Galatas to the committee, as the discussant of the new awareness campaign scheduled to roll out in February 2005. He mentioned how important it is to have this campaign as a means of increasing early detection and awareness of autism.
Ms. Galatas described the "Learn the Signs. Act Early" awareness campaign. The goal of the campaign is to educate parents and healthcare providers about the importance of early intervention and diagnosis in order to increase better parent-provider dialogue, and increase early action. The target audiences of this campaign include parents of young children (4 and below), healthcare professionals (e.g., MDs, RNs), and childcare providers (e.g., head start workers, preschool teachers, childcare providers). As part of the rollout for this campaign e-cards were initially sent out and then resource kits (including fact sheets and informational cards) were provided in doctor's offices. A future direction of the campaign is to reach out to parents in the early part of 2005 through media exposure (e.g., TV, radio, and print PSAs). With respect to outreach to childcare providers, the CDC is looking to pair with national-level partners and work within larger federal agencies. Dr. Landis suggested contacting large medical resources such as Kaiser Permanente as another way of disseminating information.

Updates on Centers' Activities

Collaborative Programs of Excellence in Autism (CPEA)

Presented by Alice Kau, Ph.D. & Fred Volkmar, M.D.
Dr. Kau provided updates for the Collaborative Program of Excellence in Autism (CPEA) activities as well as introduced Dr. Volkmar. The CPEAs are currently working hard on individual and network projects. The newest network project involves "exploring the possibility of addressing gender issues in autism by combining existing data on girls/women from all CPEA centers". A new committee was established that focuses on research dissemination.

Dr. Volkmar presented highlights of the CPEA from 1996-2003. During this time span, the CPEA has collected data on over 2,000 children with autism, including diagnostic methods for toddlers and young children, symptoms identified in infants below one year, differential diagnosis, and validity of diagnosis over time. There has also been research on characterizing the phenotype and course in autism, with specific focus on aspects of the core social deficit. In addition, several studies have examined the broader phenotype of autism. For example, one of the CPEAs has been developing measures for defining the broader phenotype in parents and siblings. Initiatives are taking place to look at younger siblings and parents to discover the potential phenotypes including, face processing, ERP measures, and other kinds of measures. Studies are also being conducted that examine particular brain structures in parents of children with autism. Research in this area has focused on specific regions such as enlarged cerebral volume, abnormalities in CSF white and gray matter, abnormalities in the white matter of the corpus callosum, and other abnormalities, including the amygdala. Neuropsychological deficits have been identified, including prefrontal impairments in terms of working memory, attention shifting and response, and face processing. The CPEA network has been very active in this area, especially with regards to research on face processing deficits.

Etiologic studies have included the examination of specific chromosomes and the collection of over 250 multiplex (studies with more than one child with autism) families for lineage analyses. Intervention studies are also currently being conducted that demonstrate large effects on joint attention and symbolic play from a short-term intervention. In addition the role of parental behavior in promoting positive outcomes is being examined. Dr. Volkmar concluded his discussion by presenting a list of network projects that are being accomplished collaboratively with several CPEA sites.

Studies to Advance Autism Research and Treatment (STAART) Centers
Presented by Deborah Hirtz, M.D.
Dr. Deborah Hirtz gave an update of the Studies to Advance Autism Research and Treatment (STAART) network. She described the funding agencies (NIMH, NICHD, NIDCD, NIEHS, NINDS) as well as the eight funded centers. She reported on the joint CPEA and STAART meeting from May 2004, which included symposia on topics such as animal models, intervention, genetics, and face processing. Dr. Hirtz further reported on other recent and upcoming meetings, including the November 1, 2004 STAART steering committee meeting and the upcoming planning meeting for intervention studies, as well as the April 2005 STAART investigator scientific meeting.

Dr. Hirtz presented an update on the data coordinating center (DM-STAT) activities, which include website development and coordination of the ongoing multi-site pharmacological trial. She then summarized the STAART genetics studies, animal model studies, imaging projects,

early detection studies, neuropathology studies, and clinical intervention studies. Specifically, the STAART centers are currently conducting two early intervention studies, a study of peer interventions, a study of factors related to treatment outcomes, a study of parent-assisted friendship training, a study of a computerized face processing training, and a study to describe factors contributing to outcomes in casein-free and gluten-free diets. Finally, Dr. Hirtz reported on multi-site pharmacologic interventions, including the ongoing citalopram trial and the planned pilot fluoxetine trial.

Discussion:
Dr. Insel asked about enrollment to date, and Dr. Hirtz reported on good enrollment thus far for the citalopram trial. Mr. Shestack asked about the possibility of combining imaging data from the multiple STAART studies and Dr. Insel emphasized the importance of working towards that goal.

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

Presented by Jose Cordero, M.D.
Dr. Cordero summarized activities of the CADDRE effort. He stated that the case-control study has been planned and is expected to begin next year; however, the effort is awaiting funding for implementation. Mr. Shestack asked for further detail. Dr. Cordero reported that during the past 4 years of funding for the CADDRE centers they have been developing surveillance and conducting ongoing special projects in their perspective areas. Dr. Cordero further explained that in planning for the case-control study they recognized that it would require more resources than had been anticipated.

Science Updates

Investigating Developmental Delays Study (IDDES)

Presented by Craig Newschaffer, Ph.D.
Dr. Insel introduced Dr. Craig Newschaffer from Johns Hopkins University, who reported on a special project from one of the five funded CADDRE centers. He gave an overview of the center-specific studies and then described the Investigating Developmental Delays Study (IDDES). This case-cohort etiologic study is expected to recruit approximately 900 children across all of the sites. The intent of the IDDES study is to establish collaborations between Johns Hopkins School of Public Health and Kennedy Krieger Institute for population recruitment and assessment of participants. The goal of the study is to collect pilot data such as self-report ASD screeners, parental stress indices, and assessment/diagnosis history before launching the big case-cohort study as described earlier by Dr. Cordero. Over 1,000 parents have been contacted with a 27% return rate and of those screeners returned, 49 were positive. For children who screened positive as well as negative, behavioral assessments and biological samples were taken. In addition to the screening, a maternal interview was piloted, the medical records acquisition process was evaluated, and buccal cell sampling was tested. The Social Communication Questionnaire screener was also analyzed as a population-screener, including estimates of

sensitivity and specificity, with conclusion that the predictive ability of the SCQ is "good." A future step of the IDDES includes completing 50 clinical assessments.

Discussion:
Dr. Insel asked about the potential for the CADDRE studies to provide data for subtyping autism spectrum disorders and Drs. Newschaffer and Cordero described several of the special projects within the CADDRE centers that will address the phenotyping of autism. Dr. Hanson asked about processes for providing feedback and reporting adverse events when screeners are failed. Dr. Newschaffer responded by indicating that within the CADDRE protocol that post-identification monitoring would take place to help address this point.

Genetics in Autism
Presented by Bernie Devlin, Ph.D.
Dr. Insel introduced Dr. Bernie Devlin from University of Pittsburgh (and CPEA network), who gave an update of genetics research for autism. He opened with the statement indicating that we are poised to make great progress in the area of genetics, by being able to describe the complex behavioral phenotype that suggests a "spectrum." He described the importance of learning more about environmental influences, including developmental instability and gene-environment interactions. Dr. Devlin further described the strong familial nature of autism, and the hypothesis of an epigenetic model -- that is a model in which chromosomal material, but not the genetic code, is altered and affects gene expression. He described how liabilities should be heritable in these genetic models, and that this research question is currently being tested.

Dr. Devlin reported on nine linkage studies. From these results, several chromosomes have had several "hits". He discussed recent results from linkage analysis of the AGRE sample, which suggest chromosome 17 contains a gene affecting liability to autism in a sex-specific manner. He pointed out that there could be a connection between these linkage findings and the serotonin transporter, which lies in the linkage region on chromosome 17. He discussed another candidate region on chromosome 15 (15q PW/A) and how "imprinting", a form of epigenetic alteration, might be disrupted in this region. If so, then there could be genetic and behavioral connections to Prader-Willi (and possibly Angelman) Syndrome. Dr. Devlin then reported on data from the CPEA network on the serotonin transporter gene. Like other groups, the CPEA network has found association between variation at the serotonin transporter and autism. The association is not sex-specific, however, unlike the linkage findings reported from the AGRE sample. He described phenotypes under investigation (e.g., head size, serotonin levels), and under-investigated leads such as the 15qPW/A region and common chromosomal breaks. He concluded with summarizing several hypotheses, including the possibility of gene-gene interactions, and provided reasons for optimism.

Discussion:
Dr. Gordon asked about the subject size needed to adequately test the plausible hypotheses described. Dr. Devlin responded that there is a need for extended pedigrees, which he has not been able to acquire. Dr. Insel responded that if chromosomal instability is involved, it may not be high numbers that are needed, but that specific samples may be necessary to examine specific genes (rather than larger samples for linkage or association studies). Dr. Cordero highlighted the high numbers of children with autism, given the high prevalence rate. Dr. Carbone asked if

anyone is studying SSRI responders in genetics studies. Dr. Insel reported that this has been done in depression, and pharmacogenomics has only begun to help predict who may be responsive.

Report from Services Subcommittee: Development of the Autism Services Matrix

Presented by Merle McPherson, M.D., David Mandell, Sc.D., Cathy Pratt, Ph.D., & Stuart Spielman, Esq.

Dr. Merle McPherson provided the committee with the overview of the expert working group's roadmap for ASD services. She described the services subcommittee as being made up of consumers and the government agencies within HHS. She pointed out that the services for people with disabilities are complex given that they are comprised of both private and public agencies. Dr. McPherson also stated that the private-public cooperatives are extremely important to the implementation of services. She further pointed out that full inclusion is another important step to providing services for persons with autism. The President created the New Freedom Initiative that includes a plan for community-based systems for children and youth with special needs and their families. Due to this initiative there is now at least partial implementation throughout states.

Dr. Mandell, from the University of Pennsylvania Medical School, provided part of the update on the status of the roadmap for ASD services. Over a two-day meeting with parents and healthcare officials, the working group discussed questions and answers to some of the most pressing issues related to services for ASD. Dr. Mandell reported that autism is a growing public concern that has lead to a crisis in the need for better identification and implementation of services. The goal of the working group was to develop a plan that focuses on current systems and how to coordinate these systems better. There are six issues that outline the plan including (1) family/professional partnerships, (2) early and continuous screening, (3) access to health, mental health, education, and social services, (4) community-based coordinated services systems, (5) transition to adulthood, and (6) adequate public/private insurance and financing.

Dr. Pratt, from the Indiana Institute on Disability and Community, discussed the issue of accessibility to services for youth and families with ASD and provided goals for better attainment of these services. The first goal identified by the group is to ensure that all ASD individuals and their families have a well-established and trusting relationship with a healthcare professional who listens to their concerns. She further stressed the importance of listening to families because they are the ones with the expertise regarding what it is like to live with an individual with ASD. In examining the family/professional relationships some of the challenges that have been identified center on lack of time, knowledge, and training and the failure to integrate the multiple systems serving individuals with ASD. To address these challenges, suggestions were made by the group that include providing ongoing training and technical assistance, increase information about ASD and educational resources, integrate existing ASD initiatives to strengthen family support and involvement. The second goal revolves around providing early and continuous screening. Challenges in this area involve a lack of awareness, inadequate reimbursement, inadequate screening and diagnostic measures, and inadequate linkage to referral resources a service networks. The working group stressed the importance of supporting the current screening committee's efforts to increase public awareness, develop guidelines for ASD screening and diagnosis and then incorporate these guidelines into a

curriculum for residents and other healthcare professionals, and promote linkages between primary providers and resource networks. Another goal discussed was improving access to health, mental health, education and social services. Challenges involved with access consist of a lack of providers, inadequate time and resources, lack of education and training, and lack of services coordination. One of the problems with access is that several individuals with ASD also have comorbid psychopathology and often times it is difficult to find adequate services for these complex cases. Suggestions provided by the workgroup were to develop ASD practice guidelines for standards of care, provide incentives to ensure greater availability of well-trained providers, and develop an action plan for collaboration at all levels to address the service needs of persons with ASD. One of the questions raised by the group was whether there was the possibility of the states coming together and share information regarding what is working and what is not working well with respect to service provision. The fourth goal identified by the working group addresses community-based service systems, with challenges such as ineffective integration of ASD services into broader systems of care, lack of interagency coordination, and lack of access to information and resources. The workgroup stressed the importance of supporting family-driven initiatives, providing technical assistance to states and communities to implement more effective service delivery.

Mr. Spielman spoke to the committee about transition to adulthood issues of individuals with ASD. Some of the challenges within this area include lack of information about current services and experiences of adults with ASD (very little research has been done in this area), lack of appropriate education and training of families and health care professionals, ineffective transition planning and coordination of services, and few services tailored to adolescents and adults. In addition rarely is there a formalized plan developed for transitioning to adulthood. Suggestions made by the workgroup consist of collecting data about the life experiences and needs of adults with ASD, developing and supporting skill-building opportunities that provide self-determination in youth with ASD, formalize federal partnerships to ensure collaboration across service sectors, and establish a task force that will identify the needs of these individuals and how best to address them. Mr. Spielman also addressed the issue of inadequate public/private insurance and financing. Challenges involved with this are inadequate benefits in public and private insurance programs, lack of flexibility in publicly financed service programs, inconsistency across states and the lifespan in mechanisms that pay for services, and lack of assistance to families in providing for the financial needs of individuals with ASD. The workgroup suggested that health insurance benefits for ASD be expanded taking into account the need for a broad array of services, developing a model of financing for public/private insurance packages and Medicaid waivers, demonstrating the cost-effectiveness of early intervention, conduct a national study of the cost and insurance to determine policies and practices that affect the financing, eligibility, and service delivery. In summary the workgroup proposed the following: address urgent need for services across the lifespan, coordinate services across multiple systems servicing individuals with ASD, develop standards of care for screening, diagnosis, and treatment. The next steps for the group include convening the expert working group and representative agencies from the services subcommittee to develop a coordinated implementation plan and present the final ASD roadmap and implementation plan to the IACC at the May 2005 meeting.

Discussion:

Dr. Gordon asked if the natural disparities between services by communities and different states allow for the study of outcomes of these services. He explained that he was curious in knowing if it were possible to provide outcome data on which of these services are working well and which are not working well. Dr. Mandell responded to this question by stating that this question is not easily answered because it depends on the unit of analysis that is used. More specifically, he indicated that in order to have a careful account of the outcome of services that we should examine this question at the school district level; however a quicker response to this question could be provided at the state level. Dr. Mandell further reported that there are two papers coming out at the beginning of 2005. One highlights that the amount of money spent per pupil within the school districts is directly associated with the number of children with autism that they identify and the other states that the more pediatricians that there are per capita translates into more school-based mental health services and an increase in the identification of children with autism.

Dr. Insel reported that he is familiar with the question of cost-effectiveness since he has been taking part on the President's New Freedom Commission. He pointed out that one of the ways to address this issue is to examine what it cost to do things the way they are currently being done. He further suggested that if we continue to examine the trajectory of the cost associated with service provision, by the time individuals reach 18 years or older there will be a large economic challenge looming unless something is done in the short run to address this issue. Dr. Insel also asked the committee who should be responsible for creating and implementing the guidelines that the working group suggests needs to take place. Mr. Spielman suggested that the federal agencies could provide the organization and incentives for this to take place, but not necessarily fund the initiative. Dr. Grossman pointed out that the Autism Society of America could take the lead on developing and implementing the guidelines.

Dr. Geller made a suggestion to the group to think about the entire spectrum of autism when making their recommendations. She further stated that several individuals go on to have productive and independent lives, as adults and that part of the focus should be on examining moving an individual from dependence to independence.

Report from Screening Subcommittee

Presented by Deborah Hirtz, M.D.

Dr. Hirtz presented an update on the IACC Screening Subcommittee. She briefly discussed the subcommittee meeting that was held yesterday, which included consultants with experience in implementing successful screening programs. The group focused on developing a screening roadmap with an emphasis on implementation. One of the main goals of the roadmap is to promote early identification of ASDs and other developmental disorders and the committee plans to do this by working with the services committee. Another goal identified by the group is to have developmental screenings commence prior to age 3 and continue throughout childhood.

Dr. Hirtz outlined some of the critical components associated with an early identification initiative including, promoting awareness, establishing best practices for screening and early identification, and examining the resources and policies that are available. Therefore, the framework of the roadmap is to examine what is currently being done, what else could be done, and which agencies can take the lead in the organization and implementation of the plan. With

respect to awareness, Dr. Hirtz pointed out that there is a lot of work to be done to make sure that professionals and providers are listening to the concerns of the families, as they are the experts in living with an individual with ASD.
In terms of screening practices, the subcommittee suggested that the states and communities identify successful models of screening that could be applied to other states or specific communities in which these practices are inadequate. In addition, she mentioned that while more research is needed in the area of screening measurement, there are effective tools available today that can be used to implement screening. With regard to resources and policy issues, the group recommended addressing the cost-benefit of effectively conducting screening and referrals, as a means of affecting policy related change.

Discussion:
Dr. Cordero highlighted the point that even when we're talking about screening or services that essentially we are talking about a system. Essentially children need to be recognized early with autism and integrated into the appropriate services. He further stated that during yesterday's meeting he had the opportunity to see two models that work effectively in screening and service provision, one in Connecticut and another in North Carolina.

Dr. Insel asked if children could be identified earlier, are there services available to them.
Dr. Cordero responded by saying not at the moment, but that the kind of issues that would require services at an early age are smaller, because the deficits are not as severe at this point, so it would be more manageable to service this group than to service older children. Dr. Houle also responded to Dr. Insel's comment as she indicated that in many ways what might drive the appropriation of services is most likely ability to show need for them. Therefore she suggested that we should continue to identify the need regardless of whether services were available.

Dr. Insel also asked if there are instruments available with specificity and sensitivity to conduct early screening. Dr. Hirtz responded stating that there is a range of instruments that are now available, but that there is room for improvement. Dr. Cordero added that the real barrier in terms of screening is not the lack of adequate instruments, but really the lack of time or a measure that can be integrated into the current healthcare model.

Open Session for Public Comments
Dr. Bill Ahearn, Director of Research at the New England Center for Children, stated that he has been attending the IACC meetings since 2003 and has found them very informative. He continued by saying that the STAARTs and CPEAs have been productive and appreciates that weaknesses can be identified and discussed leading to greater education. He suggested that the current research initiatives by the IACC are not going to help the current ASD individuals and that at the last meeting they urged the group to accelerate the services intervention roadmap. The roadmap understates the problem in that there is a general shortage of professionals with supervised experience in working with ASD individuals. He recommended that what we need to do is increase the number of trained and informed professionals to work with persons with ASD. Dr. Ahearn also talked about the importance of measuring change now rather than later and that we need to have individualized curriculums to cater to children's needs and to develop better tools for measuring outcomes because current tools such as the ADOS are not sensitive enough

to do this. He concluded his statement by suggesting the need for further collaboration to provide effective services for individuals with ASD.

Ms. Margaret Dunkle, from George Washington University Center for Health Services Research and Policy, spoke about the early identification and intervention initiatives that are taking place in Los Angeles County. She asked if the committee to consider holding next year's meeting in Los Angeles County, with the idea of having a site visit there the day before.

Mr. Tom Garvey, a middle manager who has a 3-year-old son with autism, provided his opinion to the committee. He suggested that clarification must be made regarding the fact that it is not vaccinations in general that cause problems, but it may be just one component of the vaccine. He further stated that the vaccination program has an important role in society and that the answer would be for the agencies to educate the public about the information. He then discussed his personal experience concerning regulatory agencies and asked that the committee work harder to come up with solutions to some of the problems mentioned throughout the meeting irrespective of difficulties with funding.

Ms. Ruth Elaine Hane described herself as a person with autism who is verbal, with good memory, and appears somewhat normal, with only subtle differences. She reported that she is on the board of the Autism Society of America to speak on behalf of others, particularly those who are high functioning who suffer deficits in every day functioning, but yet do not qualify for services. For example, she talked of high-functioning individuals who hold advanced educational degrees such as Master's degrees and Ph.D.s., but are unable to function independently because they do not have the services available to them that could make this possible. Ms. Hane implored the committee to reach deeper and share and cooperate to move things forward.

Closing Comments and Future Agenda Items

Dr. Insel closed the meeting. He commented on the last speaker's point about the lack of presence of individuals with autism, and suggested that a step be taken to go back to the HHS officials to further explore the possibility of including persons with autism on the committee.