



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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**Department of Health and Human Services
Interagency Autism Coordinating Committee
Meeting Highlights
May 13, 2003
National Institutes of Health
Bethesda, Maryland**

IACC Members in attendance: Tom Insel (Chair); Ann Wagner (Executive Secretary); Audrey Penn; Duane Alexander; James Battey; Kenneth Olden (represented by Cindy Lawler); Jon Shestack; Lee Grossman; Lucille Zeph; Barry Gordon; Patricia Morrissey; Merle McPherson, José Cordero; Robert Pasternack (represented by Gail Houle); Mark McClellan (represented by Nancy Markowitz); Sybil Goldman; Marian James.

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

Introductions, Overview & Highlights of Recent Scientific Findings

Dr. Thomas Insel, Director of the National Institute of Mental Health (NIMH) and Chair of the Interagency Autism Coordinating Committee (IACC) called the meeting to order. He began by giving a preview of the upcoming announcement regarding the STAART Centers as well as the release of the California Department of Developmental Services report. Dr. Insel commented on science updates. He highlighted two recent findings: one finding regarding mutations of X-linked genes that encode neuroligins, and the other regarding difficulties with attentional processing of vowels in high functioning children with autism.

Dr. Insel summarized language from the FY 2003 NIH Appropriations Bill that asked the IACC to convene a panel of scientists to provide input for an IACC report to Congress, including a strategic plan for autism research that identifies roadblocks to progress and proposes initiatives to surmount them.

IACC Membership Policy

Facilitated by Ann Wagner, Ph.D., National Institute of Mental Health (NIMH) and Executive Secretary of the IACC

Dr. Wagner presented a summary of the language from the Children's Health Act regarding parent or legal guardian members to the IACC. The topic was raised because there have been public queries from individuals seeking to become members, and because two years have elapsed since the IACC appointed its parent members. The idea of staggering the terms of new parent members was raised. Dr. Wagner asked for ideas or comments on this issue. Mr. Grossman stated that it was difficult to comment on this before a strategic plan for the IACC was in place. Dr. Gordon seconded Mr. Grossman's

comment, and requested feedback regarding previous input from the IACC public members.

Comments also included the possibility of adding more parent members to subcommittees such as the services subcommittee, and the recommendation that advisory councils be used as a model, where a third of the members are public members. Dr. Zeph added the suggestion of having people with autism serve on this committee. Dr. Insel underscored that the decision regarding parent members is up to the Secretary of HHS.

The minutes from the November 22, 2002 meeting were unanimously approved without modification.

Updates on Centers' Activities

Collaborative Programs of Excellence in Autism (CPEA)

Presented by Duane Alexander, M.D., Director, National Institute of Child Health and Human Development

Dr. Alexander provided an overview of the CPEA network, now in its sixth year of funding. He gave a brief update about the composition of the network, which includes 10 centers, including the new addition of a site run by Dr. Katherine Loveland. He discussed the CPEA annual meeting, currently in progress in California, which includes a scientific advisory council that will serve both the CPEA and STAART networks. He also mentioned the soon-to-be funded data coordinating center, which will also be linked to the STAART network.

Discussion:

A bibliography of publications from the first six years of funding was requested, and Dr. Alexander stated that it would be made available.

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

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

Dr. Cordero introduced Andria Ratchford, MSPH, project coordinator for the Colorado Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE).

Presentation by Andria Ratchford, M.S.P.H., Colorado Department of Public Health and Environment

Ms. Ratchford gave a summary of the Colorado CADDRE center, which is conducting a surveillance study to determine the prevalence of autism spectrum disorders (ASD) in the Denver Metropolitan Area. In addition to the surveillance study, the CADDRE center is conducting a case-cohort study, which is investigating possible causes and risk factors associated with autism spectrum disorders. In particular, they are investigating infection and immune function, reproductive and hormonal factors, pre- and postnatal

environmental exposures, genetic factors and gastrointestinal and sleep disorders. The Colorado CADDRE has a specific study describing and comparing the gastrointestinal (GI) symptoms in children with autism, fragile X syndrome, non-specific developmental delay, and typically developing controls.

Discussion:

Dr. Gordon asked if there were preliminary data on the false negative rate for detecting autism and related developmental disorders in Denver, and it was noted that there have not been previous prevalence studies of autism in Colorado. The Colorado birth defects monitoring program that collects information on other developmental disabilities is a passive system, whereas the autism surveillance project will be conducted as an active surveillance system, making it difficult to estimate the false negative rate based on previous experience. Dr. Cordero expanded on the surveillance methodology of the Colorado CADDRE study, which includes an independent review of all of the information in the school record to cast a broad net for symptoms or findings that fall under the umbrella of autism spectrum disorders. Dr. Zeph raised a question about possible redundancy in the need to obtain memorandums of understanding with both the Department of Education of the State of Colorado and individual school districts, and it was indicated that they were both needed, since Colorado is a local control state. Dr. Insel asked if there is follow-up to the Atlanta epidemiological study that will examine incidence of autism as well as the prevalence, and it was indicated that there is an ongoing surveillance study in Atlanta.

NIEHS Centers

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

Dr. Lawler summarized activities of the NIEHS Centers for Children's Environmental Health and Disease Prevention Research. She discussed the development of the program, which originated from a 1997 executive order establishing children's environmental health as a priority. There are two centers that focus on autism. The University of California – Davis Center focuses on environmental factors in the etiology of autism and seeks to identify how the interaction of susceptibility genes and exposure to environmental agents may increase risk or severity of autism. The efforts include an epidemiological study. The second center focusing on autism is the Center for Childhood Neurotoxicology and Assessment at the University of Medicine and Dentistry of New Jersey. Researchers at this center seek to understand the interaction of autistic children with their environment and their unique susceptibilities to toxic environmental agents. Next steps for these centers were outlined, and may include a joint annual conference, sample sharing, and interaction with the STAART and CPEA networks.

Discussion:

Dr. Insel asked about other NIEHS investments in autism and environmental toxins. Dr. Lawler responded that, in addition to an ongoing effort to elicit applications in this area, NIEHS has contributed to the STAART network, as well as to a small grant examining the effects of ethyl mercury on neuronal functioning.

Dr. Gordon emphasized the need for data sharing and data coding coordination to ensure results are compatible across different centers. He also asked whether the NIEHS centers were initiated by neurotoxicologists, and it was noted that they were. Dr. Gordon also asked whether there are projects examining neurotoxicology in the STAART network, and the answer was that those types of opportunities would be discussed in the future.

A summary of the October, 2002 meeting at the New Jersey center was requested by Mr. Grossman, and Dr. Lawler responded that it was the first annual conference of autism genes and the environment, and afterwards a brainstorming session was held concerning the struggle to identify which particular environmental exposures may be relevant to autism. She also mentioned a separate program of environmental genome projects, which is aiming to identify susceptibility genes for a variety of problems and patterns of gene expression changes in response to a host of different environmental exposures.

Studies to Advance Autism Research and Treatment (STAART)

Presented by Deborah Hirtz, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

Dr. Hirtz presented an update of the STAART Centers, which included information about goals of the program, history of the program, and the announcement of awards made to six additional centers, creating a total of eight centers. She announced that, in addition to centers at University of North Carolina, Chapel Hill and Yale University, the 6 additional centers are based at University of Washington, University of Rochester, University of California at Los Angeles, Boston University, Mt. Sinai Medical School, and Kennedy Krieger Institute. She gave brief descriptions of center activities, including a focus on young children, studies of natural history, investigations of factors that influence the trajectory of symptoms as well as response to treatment, studies that utilize MRI and functional MRI techniques, and neuropathological studies. She also emphasized that collaborative psychopharmacologic trials are being planned.

Discussion:

Dr. Battey asked if the STAART Centers were cooperative agreements, and it was answered that they are, which means that there is more interaction with scientific and program staff at the Institutes and there is somewhat more flexibility in determining actual protocols and scientific conduct of the studies.

Dr. Insel asked if there is an effort to provide a uniform set of diagnostic criteria and uniform evaluations that allow data across centers and across the CPEA to be put together into one database. Dr. Hirtz answered that such a scenario is hoped for, and the data coordinating center will help facilitate this goal. Dr. Insel added that there are databases currently available that may be helpful to use in order to achieve this goal.

Dr. McPherson asked about what the centers will be doing with regard to services and training responsibilities, in thinking about how to translate research to practice. A response indicated that as one of the goals of the program, each center has at least one treatment project.

Dr. Gordon thanked the people who worked on the plans for the STAART centers.

Mr. Shestack stated that it is exciting to see the centers start with two collaborative programs.

Dr. Insel closed the discussion by commenting on the “good news” record time of getting the centers funded, and the “bad news” that there is still a lack of capacity to generate research broadly, and one of the hopes is that the network will help pull in people who are not currently working in autism.

Science Update from STAART Centers

Introduction by Deborah Hirtz, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

Dr. Hirtz introduced Dr. Joseph Piven, University of North Carolina, Chapel Hill.

Presentation by Dr. Joseph Piven:

Dr. Piven gave an overview of the STAART Center at the University of North Carolina, Chapel Hill, with collaborations at Duke University, The University of Iowa, The Institute of Psychiatry and the NIMH. He gave a summary of the context of the center, which included the long tradition of efforts in autism at UNC-Chapel Hill, such as with the TEACCH Program, and recent efforts in autism, such as the UNC Neurodevelopmental Disorders Research Center, which includes services research. He also emphasized efforts at UNC-Chapel Hill to conduct training in autism research and services. He discussed the STAART center’s focus on gene-brain behavior relationships, with a triangle of genes, brain and behavior. He outlined the five projects of the center: The neuro-imaging study aims to characterize the neural circuitry underlying social intentionality in autism, facial affect recognition in autism, ritualistic-repetitive behavior and executive functioning, and the development of frontal-striatal white matter tracts and their relationship to ritualistic-repetitive behavior. A second study aims to characterize the neuropsychological basis of autism and the broad autism phenotype and develop efficient and reliable measures of the broad autism phenotype. A third project involves novel approaches to finding genes in autism, and uses refined notions about the phenotype, narrows candidate regions through genetic linkage, and uses both bioinformatics and mutation screening. A fourth study involves gene dissection of autism-related behaviors in mice, and aims to identify clusters of genes whose expression profiles are predictive of the natural variation in social behavior and cognitive flexibility. A fifth study is a developmental psychopharmacological trial that will examine the influence of a pharmacologic agent on both proximal and distal effects of behavioral and cognitive development.

Discussion:

Dr. Insel asked a question concerning a possible “expertise” effect that children with autism may not be expert at looking at faces, simply because they spend less time engaging in that behavior. Dr. Piven responded that in the study of facial affect

recognition, the magnet will track where the children are looking, and tasks will be chosen that will not be too difficult for children with autism.

Science Update: Measles Virus Sequences in Children with Autism: A Replication Study

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

Dr. Cordero introduced Dr. Lipkin and Dr. Hornig to give a talk on the investigation of measles virus sequences in bowel biopsies.

Presentation by W. Ian Lipkin, M.D., & Mady Hornig, M.D., Columbia University
Dr. Lipkin began the talk by indicating that their research group investigates the role of gene-environment interactions in the development of neuropsychiatric diseases. The current study examines whether measles virus sequences are found at a higher rate in bowel biopsies of children with autism as compared with children with normal development. Dr. Hornig reviewed the background regarding the association of environmental factors, including infectious agents, with neurodevelopmental disorders such as autism, and explained the overall design of the current project. She described increasing concerns about potential contributions of environmental exposures to autism pathogenesis, with a wide range of agents implicated (e.g., toxins; vaccines; rubella and other infectious agents), and the importance of the interplay of genes with the timing of environmental insults. This study will include 25 children with autism and 25 children without developmental delay who are clinically referred for endoscopy, matched for age and other sociodemographic factors. Specific evaluation of features of autism and regression; gastrointestinal symptoms; medical history, including immunizations; and family history of autoimmune disorders will be performed. Dr. Lipkin discussed the molecular biologic methods and analytic approaches to be used in the study. He described the PCR procedure that will be used to ascertain even low level signals of the virus, including the strategy of extracting RNA from the clinical samples, application of synthetic measles virus standards, and RNA amplification protocols. Identical equipment, reagents, and methods will be used at each of three laboratory sites: Columbia University (New York), Centers for Disease Control and Prevention (Atlanta), and Coombe Women's Hospital (Dublin, Ireland).

Discussion:

Mr. Grossman asked about the timeline of the study, which would take approximately 6 months once it begins. Dr. Insel asked about interpretations of possible outcomes from the study; the response was that even if a higher viral burden is found in children with autism, this study is not designed to establish a causal relationship. Dr. Lipkin emphasized that the results of the present study will at best provide or fail to provide support for an association between the presence of measles virus sequences in bowel biopsy tissue and the combined diagnoses of autism and gastrointestinal disturbance. Another question was raised concerning how many children with autism are seen in

gastrointestinal clinics, for which the response was that there are enough children to conduct the study.

Update on Brain Banking Activities

Presentation by Steve Foote, Ph.D., National Institute of Mental Health

Dr. Foote gave a summary of brain banking activities at NIH. He stated that the motivation for emphasizing such resources is that increasingly sophisticated methodologies are available for investigating molecular aspects of brains, detecting anatomical correlates of disorders, and examining gene expression in the brain, all things we could not have imagined even a few years ago. The importance of brain banking was emphasized in the Children's Health Act, with its call for enhanced sharing of brain and genetic materials. Previously, there have been individual tissue banks, such as those sponsored by NICHD, the Harvard Brain Tissue Resource Center, the Autism Tissue Program, and investigator-specific support. There needs to be greater collaboration and coordination regarding these activities. In order to pursue these goals, an Autism Brain Banking Workshop was held at NIMH in March 2003. Scientists at the workshop generated a number of suggestions for optimizing brain banking efforts, and suggestions included the recommendation to centralize information and resources. The plan for the future of brain banking efforts in autism includes having a centralized brain bank, but will involve continuing decisions about where to put our resources (e.g. brain tissue vs. other tissue), to best enhance research activities in this area.

Sharing Research Resources for Genetic Studies on Autism

Presented by Steven Moldin, Ph.D., National Institute of Mental Health

Dr. Moldin discussed the history of data sharing in the NIMH Human Genetics Initiative and described three models of genetics data sharing. The first model is the community consortia model, in which members volunteer to share. Strengths of this model include self-selection and maximum investigator incentives; weaknesses include the long period of time that elapses before the broader scientific community gains access. A second model is a government-directed model, with strengths including broad sharing, minimal conflicts of interest and rapid availability, and weaknesses including its involuntary nature, lack of self-selection, and minimal investigator incentives. The third model, a mixed model, contains strengths such as self-selection, high quality data, voluntary and broad sharing, minimal conflicts of interest, and central distribution.

Currently, NIMH shares data through the NIMH Autism Genetics Initiative, which includes a samples collected under by Stanford University investigators, a Tufts University/University of North Carolina collaborative project, and the Autism Genetics Resource Exchange. Another NIH genetics initiative in autism soon will be launched to share data and materials from autistic subjects and pedigrees already collected and previously studied in NIH-supported research projects. This initiative will provide administrative supplements for researchers to engage in activities such as re-consenting subjects and redrawing blood, to enable sharing through NIMH's data management and cell line repository. It is hopeful that a year from now there will be over 1,000 families in

the repository. The criteria for success of this initiative will be the utilization and then ultimate discovery of genes that cause vulnerability to autism.

Discussion:

Mr. Shestack asked about the practicality of the initiative with respect to access for investigators with support from different Institutes, and it was responded that investigators funded by other Institutes may contribute to this repository and obtain DNA for free.

There was also a question about the monetary cost of the brain banking effort. The answer was that the concern is less with cost and more with interfacing with the various organizations that play a role in this effort.

Update on Screening Subcommittee

Presentation by Deborah Hirtz, M.D., National Institute on Neurological Disorders, and Stroke and José Cordero, M.D., M.P.H., Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)

Deborah Hirtz, M.D. introduced Katherine Lyon-Daniel, Ph.D., Associate Director for Health Education at the National Center for Birth Defects and Disabilities

Presentation by Katherine Lyon-Daniel, Ph.D.

Dr. Lyon-Daniel gave a summary of a proposed plan for the “Autism Awareness to Action” campaign. The campaign includes a promise by the CDC/HHS to raise awareness about autism and other developmental disorders, a promise to conduct research and a promise of each individual with autism to reach his/her potential. The vision of the project is that all children with developmental disabilities could reach their full potential through the earliest possible identification and appropriate intervention and follow-up. She briefed the committee on steps the CDC has taken to develop this campaign, including identifying and refining key messages for target audiences. Steps that need to be taken were outlined, and included partner outreach, identification of messages, audience research, and establishment of evaluation measures. Funds to conduct this campaign were discussed, as well as staffing and consulting expertise for the campaign.

Dr. Cordero reiterated that it is important to have the formative research to determine the messages, and then go to the dissemination piece. There is a barrier for information to parents and health care providers, and this campaign is a method of overcoming the barrier. Dr. Insel asked about role of advocacy groups in this campaign. Mr. Grossman responded by stating the difficulty of getting attention to this problem, and gave the backing of the Autism Society of America. Mr. Shestack discussed the need to partner with respect to financing the project. Dr. Hirtz reiterated the subcommittee’s enthusiasm for the campaign. She also added information about other discussions at the subcommittee meeting, which included a presentation by Jennifer Pinto-Martin, Ph.D. about a pilot study of the feasibility of carrying out the screening process. Issues such as time, feasibility and training were discussed, as well as other issues involved in

operationalizing the screening process. Dr. Cordero discussed the link from this screening to the need for services as well as education, including training of professionals.

Discussion:

Dr. Insel asked if the screening subcommittee has addressed the current availability of screening tools and their use. Dr. Hirtz replied that previous meetings have included discussion on this topic, but the recent meeting focused on a few tools being utilized by pilot studies. She mentioned ongoing research on improving the validity and reliability of screening instruments. Dr. Insel asked about the awareness campaign in light of the media coverage that autism has received, and Dr. Lyon-Daniel discussed the need to begin the campaign by conducting a communications audit. The nature of the workforce for the campaign was brought up, and Dr. Lyon-Daniel discussed the current CDC arrangement of contractors that works with their in-house health communications staff.

Update on Services Subcommittee

Presentation by Merle McPherson, M.D., Health Resources and Services Administration and Sybil Goldman, M.S.W., Senior Advisor on Children, Substance Abuse and Mental Health Services Administration

Dr. McPherson discussed the link between the services subcommittee and the screening subcommittee, and recognized the CDC for taking the initiative for the autism awareness campaign, in order to help improve recognition of children with autism. She also discussed the challenges of the services subcommittee, which is aiming to improve and expand basic service programs already out there, as well as simplify the service system. She also stressed the importance of family support programs for individuals with autism.

Ms. Goldman gave a presentation that summarized the report from the recent services subcommittee meeting. This report included the background of the subcommittee. Ms. Goldman explained that Dr. Richard Nakamura had asked the IACC to form the services subcommittee to address the services needs of individuals with autism. The subcommittee defined their mission to identify the service needs of individuals with autism and their families, describe the current federal efforts to meet those needs, identify issues and challenges, and make recommendations for action. An activity of the services subcommittee has been to determine each agency's activities with respect to autism services, and to determine service delivery issues. She discussed the need to reduce system fragmentation and funding complexities. She also discussed the importance of learning what the effective treatment and services approaches are, and utilizing knowledge from research into practice. She outlined a services paradigm in which children with autism should have access to all generic community services with appropriate accommodations, access to all disability community services and supports, and access to autism-specific services. She recommended that the IACC member agencies engage in reviewing and analyzing their programs and identify specific recommendations, and then connect with the President's New Freedom Initiative that is

charged with removing system barriers to full community participation for individuals with disabilities.

Discussion:

Dr. Insel stated that he discussed services issues with Dr. Robert Pasternack of the Department of Special Education, and Dr. Pasternack indicated that the cost of educating children with autism has increased astronomically in the last two or three years. Ms. Goldman concurred that these are genuine concerns. Mr. Grossman stated that the Autism Society of America has been working on this issue for the past several years, and estimates the cost of services for autism is now \$90 billion. Dr. McPherson stated that some of the costs are occurring because there is not an adequate model of care.

Dr. Houle stated that 17% of the costs of special education is paid for by the federal government, with state and local authorities paying for the rest. There is hope for greater early identification and intervention that would most likely reduce some of the cost later on, but there is no simple solution. Mr. Grossman stated that about 80% of the cost of treating autism is in the adult sector, and 80% of those in the autism spectrum currently are 18 and under. Dr. Cordero commented on a meeting he recently attending in the area of spina bifida, and recommended compiling what is known and not known from research in treatment and services, to figure out the gaps and how to translate them into action.

Dr. McPherson raised the issues of funds needed to put in place what we already know, as well as the possible creation of a health services research agenda. She inquired about the possibility of a committee staff member devoted to helping with implementing the recommendations from this subcommittee. A discussion ensued about the nature of the subcommittees, and role of the IACC, with questions arising about the IACC's function of either sharing information, or being fundamentally responsibility to define the problem and recommend that something needs to be done about it. Dr. Insel stated that part of the charge was to set up the STAART centers, but at the same time we are setting up research, we need to consider what the options are for services. The President's New Freedom Commission for Mental Health indicates that this is not an easy task.

Dr. Morrissey recalled the history that 10 years ago there was a push for ADHD, and dollars were earmarked by the Department of Education to package what was known, which resulted in several booklets. She also suggested that a needs assessment be conducted with respect to the services arena, and volunteered staff from the Centers of Excellence in Developmental Disabilities programs to have a conference call to list the services needs that families face, to put the gaps and success stories together. Mr. Grossman cited the connection of this discussion to IACC strategic planning.

Introduction and Orientation on Strategic Planning

Facilitated by Thomas Insel, M.D., Director, National Institute of Mental Health and Chair of the Interagency Autism Coordinating Committee (IACC)

Dr. Insel read language in the appropriations bill that Congress passed requesting that the IACC convene a panel of scientists to assess the field of autism research and identify

roadblocks hindering the process. This will help the IACC develop a matrix of items to address some of the roadblocks identified by the panel, which will be used to help guide future research at NIH and for the entire autism community. He explained that with the goal of completing this task in the current fiscal year, a meeting has been set up for July for two days to draft a matrix, which will be sent to the IACC committee members to work on electronically in order to have something to Congress by the end of the fiscal year.

Discussion:

Upon request, Dr. Insel announced the list of science panel members, and there was discussion about the composition of the group, considering the different topics that need to be covered (e.g. services). Dr. Gordon suggested that it would be useful to divide possible autism research into two parts: one related to discovering the cause or causes of the condition, and the other related to trying to benefit those who currently have the condition. Research on the cause or causes would be expected to ultimately lead to prevention and/or cures (if the condition could be attacked at an early enough stage). Research on treatments for those already with the condition is likely to take a very different form than that devoted to identifying cause; knowledge of the cause is not likely to strongly inform research into treatment. Allocation of funding for research between the two categories is a difficult balancing act, but one confronted in many other conditions such as cancer and heart disease. Dr. Insel clarified that the IACC should develop the matrix by the end of September. There was a discussion about the process (i.e. use of electronic distribution, conference call) and questions arose about the make-up of the committee, as well as the purpose. Ms. Goldman pointed out the need to include services research into this activity. A request was made to send around a list of science panel members with their affiliations and areas of expertise.

Dr. Insel raised the issue of the services agenda, and suggested that maybe we create a matrix for the services issues as well. Dr. Gordon agreed with that suggestion; what Dr. Gordon had earlier discussed as research into treatments for individuals with autism was clearly within the scope of what some would consider services. Dr. Gordon also suggested that we try to identify the most important issues for services/treatments, and that efforts on these top problems could be stimulated by Requests for Proposals from the relevant agencies. Dr. Insel raised the concern that the subcommittee should address the cost of not working on the services issue. A question was raised about whether there is clear evidence about which interventions are effective. Dr. Gordon discussed the recommendations from the National Academy of Sciences report, and their limitations, and suggested that we try to learn from services such as Head Start. Dr. McPherson stated that we discuss service delivery by discussing education, but there needs to be a linkage from identification to family support and social support as well as to education. She also suggested that maybe the services subcommittee is not ready to make a matrix, but first must move forth with recommendation one of the subcommittee -- conducting self-evaluation of services programs in the agencies involved in the IACC.

Dr. Foote gave a summary of the history of the IACC thus far, and commented on the enthusiasm and willingness of members to engage in jobs done up to this point. He

pointed out that as finances get tighter, it will be difficult for the committee to function, and pointed to the important accomplishments possible from the services subcommittee working on their recommendations and the possible positive impact of the matrix development. He suggested that the services subcommittee develop goals for itself along a continuum of difficulty. He suggested that the committee may need to move more slowly until we can get some of the resources to do the work.

The discussion of services issue continued. Dr. Zeph stated that it may be less expensive to work on helping individuals with autism access generic services. Ms. Goldman recommended the need for a staff person to work on the services subcommittee agenda. Dr. Insel accepted the recommendation for a staff person, and recommended that the subcommittee provide some of the data for costs and gaps. Mr. Shestack recommended contracting out, which may be more efficient.

Open Session for Public Comment

Jane Pickett from the Autism Tissue Program gave an update of the program. She discussed outreach, and the hope of having outreach carried out by research centers. She discussed the 30 projects that the program now supports, and issues such as genetic libraries and the Brain Atlas Project. She also discussed the program's relationship with organ procurement groups.

Sherri Chase spoke as a parent and advocate. She stated that a major roadblock is the number of roads to go down. She commented on Dr. Morrissey's suggestion of pooling resources regarding services, and suggested partnering with parents as well as individuals with autism. She also suggested there be a national resource for researchers to learn about therapies that work.

Dr. Insel closed the meeting by thanking the public attendees, as well as staff and members of the committee. He stated that he is looking forward to the next meeting on November 21, 2003.

The meeting was adjourned at 5:00 PM