Department of Health and Human Services

Interagency Autism Coordinating Committee

Meeting Highlights
November 21, 2003
National Institutes of Health
Bethesda, Maryland

IACC Members in attendance: Tom Insel (Chair); Ann Wagner (Executive Secretary); Story Landis; Duane Alexander; James Battey (represented by Donald Luecke); Kenneth Olden (represented by Mary Gant); Jonathan Shestack; Lee Grossman; Lucille Zeph; Barry Gordon; Patricia Morrissey (represented by Margaret Schaefer); Merle McPherson, José Cordero; Robert Pasternack; Mark McClellan (represented by Kathyrn Carbone and Robert Stasko); Sybil Goldman; Thomas Scully (represented by Phillip Surine).

Member agencies not represented: Agency for Toxic Substances and Disease Registry; Agency for Healthcare Research and Quality

Introductions

Dr. Insel welcomed the IACC, and noted the continuity of this meeting with the Autism Summit Conference that occurred on the prior two days. He commented on some of the highlights of the conference, including presentations by several members of Congress and administration officials. Committee members were introduced.

Autism Roadmap Matrix

Facilitated by Tom Insel, M.D., National Institute of Mental Health (NIMH) and Chair of the IACC; Presentations by Geraldine Dawson, Ph.D., University of Washington and Dan Geschwind, M.D., Ph.D., University of California, Los Angeles

Tom Insel discussed the matrix format, as well as the specific goals that have been proposed in the draft matrix. He described how the matrix is organized so that the x-axis indicates timeframe (1-3 years; 4-6 years & 7-10 years) while the y-axis defines level of risk. In this case, risk is defined as level of difficulty in attaining the goals, and the likelihood that the scientific endeavors would or would not be successful. He then introduced Geraldine Dawson, Ph.D., and Dan Geschwind, M.D., Ph.D., members of the science panel that worked on drafting the matrix. They were asked to speak about its development and content.

Dr. Dawson began her presentation by outlining the process under which the matrix items were suggested, identifying members of the science panel and describing the meeting in which the roadblocks and matrix goals and activities were discussed. The panel consisted of autism experts from various disciplines, including neurobiology, screening, brain function, genetics, epidemiology, environmental exposures, neurochemistry, diagnosis, early intervention, language and pharmacology. The group assessed the field of autism research, and identified roadblocks as well as specific goals and activities to surmount these roadblocks. She then described some matrix items, by focusing on screening, services and treatment. Intervention and treatment goals were outlined, including one- to three-year goals of improving outcome measures, carrying out randomized clinical trials of early interventions and establishing effective drug treatments for symptoms associated with autism. Four- to six-year intervention goals outlined included evaluating effective school and community interventions throughout the lifespan, identifying biomarkers for autism, developing effective interventions for toddlers and infants, and identifying individual characteristics of treatment response. Seven- to ten-year goals discussed included conducting longitudinal follow-up of early intervention studies, developing a treatment algorithm, the creation of intervention methods that allow 90% of individual with autism to develop meaningful speech, and prevention of 25% of cases of autism through early detection and intervention.

Mr. Surine asked why a percentage target for the early identification of autism was not included in the matrix. Dr. Dawson answered that this was a good point and should be considered, and the next step for implementation of successful screening is overcoming roadblocks to implementation of screening practices in the community. Dr. Gordon asked about using the word "prevention" in the item referring to preventing cases of autism. Dr. Dawson answered that it was not thought that one could prevent the biological vulnerability, but maybe it should be thought of as secondary prevention.

Dr. Geschwind continued by presenting other facets of the matrix development, outlining some roadblocks hindering the progress of research into autism causes and best treatment options. He then proceeded to link roadblocks to their accompanying goals. He discussed the specific goals that combine to constitute the autism phenome project, which will provide a comprehensive characterization of autism by activities such as establishing a twin registry, conducting twin and family studies, defining distinctions between the overlap of autism and other developmental problems, and executing a multi-site longitudinal study of high risk populations such as subsequent pregnancies and infant siblings of children with autism. The comprehensive and longitudinal nature of this effort is a necessary component to assure its success in setting a new foundation for biomedical research in autism. In the area of neuroscience, he discussed activities in the matrix designed to define the neuropathology and neurochemistry of autism. He also emphasized the goals of finding susceptibility genes and developing animal models of autism to further study the characteristics of autism and to find the genetic and non-genetic causes of autism and their interactions.

Discussion:

Dr. Insel opened the discussion, emphasizing that Congress requested that the current matrix focus on research, not on services. He highlighted the need for closure on this document, in order to send it to Congress soon. Dr. Cordero discussed "connecting the dots" between items, and used cancer as an example because it typifies a situation in which disease was identified early in its course and large populations of individuals with the disease were successfully enrolled in clinical trials. Dr. Insel agreed, highlighting this example as a situation where almost every patient in the community also serves as a research participant, and where the importance of collaboration with the advocacy community has become clear. Dr. Gordon inquired about the distinction between services and research, particularly because the research in the matrix should influence service. Dr. Insel responded that services research is crucial, and questions about dissemination and implementation could be raised in the future, but the science panel may not have represented this topic in the matrix at this point because it was felt that it was not the right time. Dr. Gordon also asked if difficulty with obtaining brains for use as controls in research was a barrier. Dr. Geschwind acknowledged the importance of this issue, and indicated that there are some brain banks with brains of typically developing individuals that have been utilized, but it is a challenge for research into many types of disorders to obtain such brains.

Dr. Pasternack discussed the importance of conducting research on specific factors related to developing a comprehensive array of services (i.e., types, intensity, duration). He also asked about inclusion in the matrix of issues facing older individuals with autism. Dr. Insel responded by pointing out the matrix items that include collaboration with the Department of Education, and Dr. Volkmar and Dr. Dawson responded by highlighting the science panel's emphasize on transitions (i.e. from high school to adulthood) as targets for intervention and the importance of investigating school-based interventions. Dr. Pasternack added that collaboration between NIH and the Department of Education should be extended to other agencies, such as the Department of Labor and the Centers for Medicare and Medicaid Services.

Mr. Grossman reported that the services subcommittee has decided to take on the task of creating a separate services matrix. He also asked about the possibility of including implementation of interventions earlier than the 7-10 year timeframe on the matrix. Dr. Dawson responded that the key word in the matrix regarding interventions was innovation, and the services matrix could focus on implementing what we do know now. She discussed differentiating implementation of currently available interventions and new, innovative interventions.

Dr. Hirtz recommended additions to the matrix related to research for developing screening methods and implementing screening into practice. Dr. Dawson responded that the matrix goal includes expanding screening downward in age from toddlers to infants, but the goal of validating screening tools now under development could be added. She also discussed adding infrastructure for screening research to the first few years. Dr. Cordero commented that wording on the prevention of diagnosed cases could refer to functional impairments/limitations.

Mr. Shestack discussed the importance of integrating patient and physician education (mandated by the Children's Health Act of 2000) into the matrix. He also asked about the evaluation method for the IACC to determine progress on implementing the matrix. Dr. Gordon suggested that the IACC, as well as scientific review panels who evaluate grants, will be best able to determine actual progress on the matrix. Dr. Insel suggested using part of this IACC meeting (on a yearly basis) as a forum to review and determine progress. Dr. Insel also noted the importance of making this review of the matrix an iterative process, as the matrix is a living document and should be modified as progress is made.

Dr. Zeph noted how broad and inclusive the school and community intervention section of the matrix is. She referred to Dr. Pasternack's point that inclusion in the matrix of targets for implementing "what we know" now is important, and suggested an attempt be made to make the matrix reflect the non-linear way in which current interventions are implemented, future interventions are created and evaluated, and interventions are integrated into practice using various methods. She also described her view of the roadblock that interventions and services requires exploratory research, particularly in aiming to benefit current generations of individuals with autism. Dr. Houle volunteered to craft language that would integrate the involvement of the Department of Education with respect to continually evaluating and implementing existing as well as innovative interventions.

Mr. Grossman asked about how much implementation of the matrix would cost. Dr. Landis compared this effort to the ongoing efforts in Parkinson's Disease, and she suggested that it is very difficult to try to create numbers to go along with a matrix such as this. She suggested that such an effort should be thought out extremely well. Dr. Carbone agreed that it is important to have a clear record in terms of translating research into practice, particularly as markers are developed, in order to translate them into medical, genetic and other therapies.

Dr. Insel gave a summary of issues including capacity for screening, inclusion of brains used as controls, more collaboration with other agencies, and examining interventions in order to include implementation of current practices. Dr. Insel suggested adding a face sheet to the matrix that defines risk, and points out that it is a living document. He described a plan and timeline for making suggested modifications to the matrix for its submission to Congress. Mr. Shestack asked about how this document will be used in the public, particularly by NIH staff and grant reviewers. Dr. Insel suggested that the matrix would go on a website, and that different institutes might use it in different ways. Dr. Wagner added that goals of the matrix will be included in reissuing the NIH Program Announcement in autism: Research on Autism and Autism Spectrum Disorders. Dr. Landis emphasized that the overlap in matrix items with goals of the STAART and CPEA networks provides a jumpstart for implementation.

Updates on Centers' Activities

Collaborative Programs of Excellence in Autism (CPEA)

Presented by Alice Kau, Ph.D., National Institute of Child Health and Human Development

Alice Kau presented an update of the CPEA network, noting that the network is in the second year of its second round of funding, and the network is very active, with working subcommittees on various topics. She discussed the planned collaboration with the STAART network, including a joint annual meeting of the networks. She also highlighted the involvement of the data coordinating center, which serves both the CPEA and STAART networks.

Scientific Advisory Committee Report of the CPEA Network

Presented by Steve Warren, Ph.D., University of Kansas, Chair of CPEA/STAART Scientific Advisory Committee (SAC)

Dr. Warren updated the IACC on activities of the STAART/CPEA SAC, including its presence at the CPEA annual meeting in May 2003 and its production of a report following this meeting. He provided a summary of the scope of this committee, as they will serve as advisors to the networks' steering committees and provide individual feedback, in their individual roles representing various disciplines. They will advise on ongoing and proposed cross-site projects conducted by the networks, and scientific advisors will review documents relevant to the network studies and give advice on aspects such as the soundness of protocol implementation and data collection, the need for protocol modifications, the appropriateness of add-on studies and the general quality of the implementation of the studies. Examples of feedback already provided include suggestions for improving recruitment as well as retention of participants in longitudinal studies. Suggestions were given for approaches to finding behavioral and neurobiological subtypes of autism. Recommendations were also given regarding the parameters of the development of data systems. Suggestions were also made concerning identification of non-genetic risk factors, identification of meaningful moderators and mediators of the development of autism, and investigation of individual differences. Finally, the committee emphasized the need to hasten the dissemination of research findings to the public.

Discussion:

Dr. Cordero asked about the role of non-genetic risk factors, and Dr. Warren responded that these types of risks factors are very important to study, and that it will be important to examine the interaction of genetic and environmental risk factors.

Studies to Advance Autism Research and Treatment (STAART)

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

Dr. Hirtz updated the committee on recent activities of the STAART network. She reviewed the names and locations of each of the eight STAART centers, reported on the creation of a website for this network (http://www.nimh.nih.gov/autismiacc/staart.cfm), emphasized the importance of the involvement of the data coordinating center, discussed oversight committees including the Scientific Advisory Committee and Data Safety and Monitoring Board, and she highlighted the activities of several of the working subcommittees. A number of recent advances were mentioned, including progress towards establishing processes and criteria for genetic repository contributions from each of the STAART centers, and near complete finalization of the common measures protocol for the network.

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

Catherine Rice, Ph.D., National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)

Dr. Rice presented briefly on the CADDRE network, indicating that the protocol is currently being finalized and will be submitted to Institutional Review Boards in January with expectation of beginning data collection in the fall of 2004. She also mentioned the Autism and Developmental Disabilities Monitoring Network (ADDM), which consists of 16 sites in 18 states, investigating the prevalence of autism through tracking. Additional prevalence data from the metropolitan Atlanta area should be available next year. She also mentioned that there currently is a Request for Proposals (RFP) out for a data coordinating center for the CADDRE network.

Discussion:
Mr. Grossman asked about combining data from the NIEHS centers with data from these other networks, and Dr. Hirtz replied that coordination with groups such as this is a goal, and these networks will follow NIH rules about data sharing to make such data accessible to other researchers.

Dr. Landis suggested an item for the next meeting could be to map activities of these networks onto the research matrix, and Dr. Insel suggested putting this on the agenda for the next meeting.

Dr. Insel asked if there have been impediments to data sharing among the centers. Dr. Hirtz responded that members network has been very willing to share, although the task of identifying common measures for the network has required extensive negotiation and coordination.

Science Update from STAART Centers

Introduction by Deborah Hirtz, M.D., National Institute of Neurological Disorders and Stroke (NINDS)
Dr. Hirtz introduced Fred Volkmar, M.D. Yale Child Study Center.

Dr. Volkmar began his presentation by broadly discussing theories of social impairment, none of which quite capture the totality of the social domain, so that new approaches will be essential. A theory that has been developed that focuses on processes that underlie social dysfunction in autism is based on the observation that individuals with autism may become experts on objects because they do not come into the world with a predisposition to become experts on people. He presented several experimental paradigms that exemplify difficulties individuals with autism have in recognizing and interpreting the saliency of situations with social attributes. Examples included reduced attribution of social meaning to interpretations of ambiguous visual stimuli. Dr. Volkmar also highlighted the specific brain structure known as the fusiform gyrus that has been implicated in face recognition processes, and he described the difficulties children with autism have with recognizing faces. He presented an fMRI study which indicated reduced activity of the fusiform gyrus in high functioning individuals with autism when engaged in a face recognition task.

Dr. Volkmar outlined the reasons for conducting eye-tracking research, which included the importance of investigating how individuals with autism interpret complex social situations. Eye tracking research provides a mechanism for gaining insight into how individuals with autism view the social world. Examples of such research were described. For instance, research that includes eye tracking while individuals view digitized videotape clips of a complex social situation demonstrated reduced attention to direction of gaze and to facial expression by individuals with autism. He described such research in older individuals as well as younger children and toddlers. He ended by discussing potential translation of this research into both screening and treatment practices. He described a treatment study currently underway that is piloting a newly developed computerized treatment game that is a manualized treatment protocol.

Discussion:
Dr. Insel asked if there is reduced activity in the fusiform gyrus of individuals with autism because they do not look at faces, or because they don't process the information. Dr. Volkmar responded that if you simplify the task in question, you can get fusiform gyrus activation. He also described a theory that the fusiform area is more of an "interest/expertise" area than specifically a face area.

A public participant asked if it would be more likely for the fusiform gyrus to be activated when viewing a familiar face, and if there is a difference when viewing static versus faces motion, and Dr. Volkmar responded that these experiments have not yet been attempted. There was also a question about how these findings may differ when using animated characters, such as Thomas the Tank Engine. There was a question about whether or not individuals with autism, if they focus more on mouths than on eyes, might possibly be lip reading. Dr. Pasternack commented that some of the research Dr. Volkmar described used a single-subject design, and asked about support for such research in addition to randomized clinical trial designs.

Closing the Gap in Autism Treatment

Presented by Margaret Bauman, M.D., Massachusetts General Hospital, Harvard Medical School & Richard Fade, Northwest Autism Foundation

Richard Fade spoke about the state of field with respect to treatment for individuals with autism, focusing on the broader health issues that frequently accompany autism. He reported that there are only weak insights into the overall health issues of individuals with autism, and there is no vehicle for collaboration, no data collection for obtaining information on biomarkers, no uniform set of clinical measures, and no nationally accepted treatment protocol. He reported on the isolation and desperation of parents and families, who are often treated by overloaded autism professionals and not community providers, and do not feel they have benefited from research thus far. He pointed out that the research matrix goal of a comprehensive treatment plan is not until year seven, necessitated collaboration now on the best available treatment for autism. He outlined the call to action for the Autism Treatment Network, a newly formed organization that plans to create a comprehensive treatment approach, examine the broader health issues and physiology of individuals with autism, and accelerate the establishment of infrastructure to more effectively treat autism. This effort would be a complement to existing interventions, and not a substitute. A goal would be to create systematic clinical records for individuals with autism, in order to assist in detecting patterns. There is a need to engage existing institutions, and create a "virtuous cycle" feedback loop to collaborate and evaluate treatment approaches. The Autism Treatment Network's vision is to "establish and support a community of engaged physicians, clinicians and researchers who will collaborate and create, and evolve effective treatments for individuals with autism; and make that treatment broadly available." Efforts in research and treatment of other disorders, such as cystic fibrosis, will serve as examples of such collaboration.

Dr. Bauman outlined a clinic she runs as an example of a service provider that includes elements of the Autism Treatment Network's vision. This clinic is LADDERS: "Learning and Developmental Disabilities Evaluation and Rehabilitation Services." She described the multidisciplinary clinic staff and the clinic's roles (e.g. examinations, recommending interventions, assisting in locating services, monitoring progress, empowering parents, advocating for children). She described several red flags indicating an individual with autism requires further medical evaluation. She also reported on several research projects the clinic is engaged in.

Discussion:
Barry Gordon commented on the large size of the undertaking the Autism Treatment Network is tackling.

Update on Brain Banking Activities

Steve Foote, Ph.D., National Institute of Mental Health
Steve Foote reported on advances in autism-related brain banking that have occurred in the past year. He first described a workshop held in March 2003 to explore the brain banking needs of the autism field and how they might best be met. In September 2003, the National Autism Brain Bank was established, with NIH and voluntary organization funding, at the Harvard Brain Tissue Resource Center directed by Francine Benes, M.D., Ph.D. It is hoped that the creation of this national resource will speed up the process of centralizing information, data and distribution decisions. Outreach activities for the Brain Bank, conducted by the Autism Tissue Program, were funded by an NIH-voluntary agencies partnership, in order to enhance collection of brains of those with autism as well as others that will provide comparisons.

Screening Subcommittee Report

Report given by Deborah Hirtz, M.D., NINDS and José Cordero, M.D., MPH, Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)
Dr. Hirtz reported on the activities of the screening subcommittee of the IACC, including a meeting held earlier in the morning. She outlined four obstacles to accomplishing goals in screening: 1) time it takes to screen, translating into money and personnel; 2) inadequate training for both pediatricians and other professionals; 3) screening for developmental disabilities needs to be integrated with such autism-specific screening; 4) the difficulty of referrals for appropriate services. Next steps for the committee include 1)

proceeding with the CDC/ASA Awareness Campaign, including acquiring the funds to continue this; 2) the CDC would like to evaluate existing programs to identify models for implementing screening into community practices; 3) multi-agency public and private collaborations to determine the best method for implementing screening. These advances would also help achieve the research matrix activities and goals for screening. Dr. Cordero added that it will be important to use existing small model programs to help implement the broader screening effort of incorporating the best screening methods into the healthcare and educational systems

Discussion:
Dr. Insel asked about the progress of the Awareness Campaign, and Mr. Shestack commented that there have not been sufficient resources to carry this forward. Mr. Grossman added that the question of carrying out the physician education mandate of the Children's Health Act has been raised before. Dr. Pasternack highlighted the Federal Interagency Coordinating Council (FICC) as an interagency committee wherein some of this type of work could be carried out, due to its role of focusing on care of young children with disabilities.

Sharing Research Resources for Genetic Studies on Autism

Steven Moldin, Ph.D., National Institute of Mental Health
Steve Moldin reported on progress with the NIMH Autism Genetics Initiative. He emphasized the importance of genetic research, as well as some of the difficulties that must be surmounted to achieve progress. For example, large data sets are necessary because there are most likely multiple genes involved in autism, each contributing a small effect. He described the advantages of sharing genetic data, including the increased power to detect genes and the avoidance of duplicative work. He described the purpose of the NIMH Autism Genetics Initiative which is to create a national resource of data and DNA, to speed up the process of finding genes that lead to vulnerability for autism. He described the data flow involved in the genetics initiative, and outlined the types of data included. He reported on the recent NIH supplements program, which was recently funded and allows eight projects to re-consent previously enrolled research participants to collect DNA for the genetics initiative. He also discussed efforts of the STAART network to contribute samples of individuals affected with autism, as well as family members.

Robert Stasko from the FDA commented on the emerging field of pharmacogenetics. He also recommended that parents track as closely as possible the side effects and reactions children have to medications they are taking.

Services Subcommittee Report

Dr. McPherson presented activities of the IACC services subcommittee, commenting that the Autism Summit Conference was helpful, and she thanked the Department of Education for their role in organizing the services panel, and she acknowledged the fruitful ongoing collaboration with HRSA and the IACC. She suggested that this subcommittee should take on the charge of developing a services roadmap. She commented that as a result of the information gathered at the Summit, the subcommittee has decided to change its short-term strategy, and first develop a services roadmap to inform its original goal of beginning to analyze the availability of programs at the federal level. Rather than begin with gathering information about federal programs and working toward a definition of access and gaps, a better strategy is to build a roadmap beginning with the service needs across the life span and across service sectors. Then, the committee can identify what agencies are responsible for or could contribute to attaining each goal. Another lesson she said was derived from the Autism Summit was that we need to build on existing programs, and that the federal agencies need to enhance their collaboration. Good programs need to be supported, expanded, and linked together. She also discussed the need for services research in this area to inform service systems. She noted that the leadership for service provision is not necessarily going to come from the federal level as it does with research. It is important to incorporate the state level.

Mr. Grossman then introduced two speakers who gave their personal perspectives on services for individuals with autism. First, he introduced Mr. Stephen Shore, who gave his perspective as a person with an autism spectrum disorder. Mr. Shore is on the board of directors of the Autism Society of America, and serves on the boards and is founder of numerous support groups in New England. He has a masters degree in music and will soon complete his Ph.D. in special education.

Mr. Shore thanked the group for their work. He emphasized the importance of early intervention, noting that he is thankful every day that he received appropriate early intervention. He suggested that there should be adults with autism spectrum disorder involved with this committee. He also noted that while early intervention is important, most people spend 75 to 80% of their lives as adults, and we need to work on helping adults with autism. Many just need a little bit of help to be fully functional in the community and lead fulfilling and productive lives. He called attention to the way we articulate our focus, emphasizing that we do need to help people that are on the autism spectrum when they are having difficulty interacting successfully with the environment, while preserving the personality and diversity that these individuals represent.

Mr. Grossman then introduced Anna Hundley. Ms. Hundley is the executive director of the Autism Treatment Center of Texas. She was a founding member of the Autism Task Force in Texas. She is president of a relatively newly formed organization called National Association of Residential Providers for Adults with Autism (NARPAA). Ms. Hundley noted that Dr. Ruth Sullivan, in July 2001, initiated a meeting of providers of adult services. One of the issues they have decided to work on is the training of direct care staff working with adults in residential settings. They have given themselves a year to come up with standard for treatment for residential care for adults with autism, which would then inform training of staff. They also plan to establish staff competencies and quality indicators for service providers.

Dr. Insel thanked the subcommittee and speakers. He opened the floor for public comment, noting that people who had signed up to speak would be called by name to give their comments first.

Open Session for Public Comment

Ms. Dina Gastner noted that she was prepared to tell her life story but given the time constraints she would be brief. She told the committee that she has an MSW degree, is trained as an interdisciplinary diagnostician, is a writer and a national presenter. At age 38 she was diagnosed with autism and has relatives with autism. She discussed the difficulty that her 14 year-old son with autism has had with school-related stress and anxiety. He is now in a private school and is doing wonderfully. She is pleased by this, but anguished about the years he spent being unhappy in school. Ms. Gastner noted that she is not handicapped by her autism, but by the lack of services in her community. She noted that she is gifted and talented in many ways, but also disabled in some ways. This dichotomy prevents many adults with autism from getting services. She agreed with Mr. Shore that it would be important to include an individual with autism on the Committee, and also urged that it be clear that the research goal is to ameliorate the complex challenges of autism, but not to invalidate the personality of the individual with autism. She emphasized the loss of personal and family time she suffered from misdiagnosis and inappropriate treatment, and urged the group to address problems like this in the mental health system. Ms. Gastner made the point that parents will be most motivated to participate and have their children participate in research when it helps them attain services immediately. She asked the committee to place a greater emphasis on support services.

Ms. Ilene Simon asked the committee to consider the possibility that clamping of the umbilical cord immediately at birth might be an environmental contributor to autism. She noted that the widespread adoption of this practice seems to correlate with the apparent increase in prevalence. She noted that research on oxygen insufficiency in newborn monkeys might be relevant, as the sites of brain abnormalities resulting from the asphyxia is similar to those that have been talked about in connection with autism. She distributed a summary paper of her ideas to the committee members.

Barbara Cutler introduced herself as an educational consultant, a parent of a child with autism, and a member of the Autism National Committee. She read comments from people with autism who are concerned that there is an over-emphasis on behavioral and genetic aspects of the disorder, neglecting sensory and motor issues, as well as anxiety. The commentaries included one from Ann Carpenter commenting on motor differences; Kathy Grant commenting on sensory problems such as auditory processing deficits; Barbara Moran emphasizing the distress caused by sensory processing differences; David Goodman describing the difficulty caused by auditory processing difficulties; Chammi Rajapatiranna describing the experience of being unable to talk while others are talking about you; Robert Cutler also emphasizing a need to focus on movement and sensory issues; and Sandra Radisch advocating for assistance rather than eugenics.

Cheryl Trepagnier introduced herself as a member of the Research Faculty at Catholic University and the National Rehab Hospital. She is the mother of a 27 year old man with autism. She advocated for including an understanding of the early developmental course of autism in the research roadmap, including when and where it diverges from typical development. She reiterated the importance of screening, early identification, and early intervention. She also asked for more of a focus on adults. She also emphasized the importance for electronic medical records to support both services and research.

Diane Kennedy spoke about her book, The ADHD-Autism Connection. She also said that her son has Asperger's Syndrome. She said that research suggests a genetic relationship between the disorders, and noted that some children like her son are hindered unnecessarily by being misdiagnosed with ADHD instead of an autism spectrum disorder.

Tom Challman is a neurodevelopmental pediatrician at Geisinger Health System, where they are embarking on several lines of research under the guidance of HRSA, including screening and patient services. He would like to see more emphasis in future conferences and meetings on services, including service delivery and the science behind service delivery. He also challenged the committee and others to look beyond traditional research institutions for scientific input, research, and ideas.

Valerie Hu introduced herself and stated that she has a 16 year-old son with Asperger's Syndrome or PDD-NOS. He was diagnosed early and had good early intervention but she felt that the school system "dropped the ball" when he moved out of the autism program into classrooms where they said he would have better social role models. She said that high functioning children can fall through the cracks and are being underserved.

Dr. Insel concluded the meeting by pointing out that the next meeting will be May 11, 2004.