Minutes of the Interagency Autism Coordinating Committee Full Committee Meeting

January 17, 2018

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a meeting on Wednesday, January 17, 2018, from 9:01 a.m. to 4:36 p.m. at the Bethesda Marriott Hotel on 5151 Pooks Hill Road in Bethesda, Maryland.

In accordance with Public Law 92-463, the meeting was open to the public. Joshua A. Gordon, M.D., Ph.D., Director, National Institute of Mental Health (NIMH) chaired the meeting.

Participants:

Joshua Gordon, M.D., Ph.D., *Chair*, IACC, Director, National Institute of Mental Health (NIMH); **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), (NIMH); **David Amaral**, Ph.D., University of California, Davis (UC Davis) MIND Institute; **James Ball,** Ed.D., B.C.B.A.-D., President and CEO, JB Autism Consulting; **James Battey,** M.D., Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD); **Diana Bianchi**, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (representing James Battey M.D., Ph.D.); **Samantha Crane**, J.D., Legal Director and Director of Public Policy, Autistic Self Advocacy Network; ; **Geraldine Dawson**, Ph.D., Director, Duke Center for Autism and Brain Development, Duke University School of Medicine (attended by phone); **Ruth Etzel**, M.D., Ph.D., Director, Office of Children's Health Protection, Environmental Protection Agency (EPA); **Jennifer Johnson**, Ed.D., Administration for Community Living (attended by phone); Laura Kavanagh, M.P.P., Health Resources and Services Administration (HRSA); **Alice Kau**, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Development (NICHD) (representing Diana Bianchi, M.D.); **Cindy Lawler**, National Institute of Environmental Health Sciences (NIEHS) (representing Linda Birnbaum, Ph.D.) (attended by phone); **Laura Mamounas**, Ph.D., Program Director, Neurogenetics, National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.);

David Mandell, Sc.D., Director, Center for Mental Health Policy and Services Research; **Robert H. Ring**, Ph.D., Vencerx Therapeutics (attended by phone); **John Elder Robison**, Neurodiversity Scholar in Residence, College of William and Mary; **Marcella Ronyak,** Ph.D., LCSW, CDP**,** Deputy Director, Division of Behavioral Health, Indian Health Service (IHS) Headquarters; **Nina Schor**, M.D., Ph.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.); **Robyn Schulhof**, M.A., Senior Public Health Analyst, Maternal and Child Health Bureau, Health Resources and Services Administration (representing Laura Kavanagh, MPP); **Stuart K. Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC); **Alison Tepper Singer**, M.B.A., Autism Science Foundation;; **Julie Lounds Taylor**, Ph.D., Vanderbilt University (attended by phone); **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., Congressionally Directed Medical Research Programs, U.S. Department of Defense (DoD); **Carrie D. Wolinetz**, Ph.D., Associate Director for Science Policy, Director, Office of Science Policy, National Institutes of Health (representing Francis S. Collins, M.D., Ph.D.)

Call to Order, Roll Call, and Welcome

Joshua Gordon, M.D., Ph.D., Director, NIMH, and Chair, IACC
Susan Daniels, Ph.D., Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC

Dr. Gordon called the meeting to order at 9:01 a.m., and Dr. Susan Daniels took roll call.

Welcome and Introductions

Dr. Gordon welcomed the Committee and introduced Nina Schor, who is the new Deputy Director at the National Institute of Neurological Disorders and Stroke. The minutes from the last meeting were approved without comment.

Advancing Behavioral Health in the Indian Health System

Marcella Ronyak, Ph.D., Deputy Director, Division of Behavioral Health, Indian Health Service (IHS) Headquarters, HHS

Dr. Ronyak introduced the IHS by explaining that there are a lot of differences within the IHS in terms of types of service delivery that are specific to location, and that it is important to understand these differences. Specifically, location differences can affect behavioral health services. As Dr. Ronyak serves as the Deputy Director of the IHS Division of Behavioral Health, she has seen significant differences across service and location, as well as from the different lenses of both consumer and provider. Dr. Ronyak said that she would also talk about telehealth services and advances in outreach within the IHS.

Dr. Ronyak spoke about the mission of the IHS, which is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives. She spoke about how it is important that the services provided to these populations are comprehensive, culturally acceptable, and evidence-based. Populations within tribal communities are diverse, and it is important to adapt treatment specific to culture. Dr. Ronyak talked about how the IHS looks at unique options that can target the individual, the family, and the community.

The IHS was put into place by legislation, which upholds the federal government's obligation to tribal sovereignty. This sovereignty is a government-to-government relationship, in which the federal government has a relationship with all 567 federally recognized tribes. There are differences between federally recognized tribes and state tribes, which Dr. Ronyak said she would discuss later.

Dr. Ronyak reviewed the four main pillars of the IHS: People, Partnerships, Quality, and Resources. The IHS serves 2.2 million American Indians and Alaska Natives. The IHS is broken into 12 areas, and each area operates their direct services or service units, covering the different community needs. There are 567 federally recognized tribes, which are recognized by both blood quantum and that their reservation is on federal land. The difference between federally recognized tribes and state tribes is that state tribes might not have a reservation and the blood quantum requirement is different. Blood quantum is the percentage of blood required to be federally recognized. People may have more than one blood quantum, but still must choose one tribe.

Dr. Ronyak reviewed the different types of health services. The IHS has 26 hospitals run by federal funds, and 22 tribal hospitals run by the tribes. A tribe can show that they can provide services rather than having the IHS run the facility, and the tribe may then pull shares or monies from the IHS budget. There are 53 IHS health centers and 289 tribal health centers. There are 150 Alaska Village Clinics (which are tribal) and 34 IHS Urban Health Centers. The are 30 IHS Health Stations, and 73 Tribal Health Stations. These health stations are small and mostly serve as a checkpoint for referral to a larger health center. There are school health centers, which are services for students that are in place through federal partnerships, such as the Bureau of Indian Education. There are 4 IHS School Health and 15 Tribal Health Stations. These are beneficial because the student can access health services without leaving campus.

Dr. Ronyak talked about the IHS budget. The IHS has a $4.9 billion discretionary budget, and a special diabetes program for Indians that is $147 million. When there is a medical diagnosis, there is often a mental health component involved, and so it is important to know the impact of that for funding. The 2017 budget was $5.1 billion, which Dr. Ronyak broke down across mental health and substance use. The budget for alcohol and substance use was $218 million, and $64 million for mental health—in total $312 million. Dr. Ronyak suggested that this is actually a small number set aside for mental health. The mental health budget is split between the IHS and the tribes, where the tribes receive about 20 percent of the budget for mental health.

There are approximately 2,000 IHS, tribal, and urban Indian mental health and alcohol/substance abuse personnel. There are 500 mental health and alcohol/substance abuse programs across the American Indian and Alaska Native communities. There are 12 youth regional treatment centers. Dr. Ronyak suggested that this seems like a lot of providers, but reminded the Committee that there are 2.2 million people in the population and there can be waiting lists and challenges in accessing services. The Division of Behavioral Health, where Dr. Ronyak is Deputy Director and Dr. Beverly Cotton is the Director, has 29 employees and focuses on policy development, budget formulation, support and resources, and grant funding. Each of the 12 IHS areas has a behavioral health consultant, who is the go-between for IHS headquarters and the direct services in each area. Dr. Ronyak pointed out at one person is taking care of the entire area. This one behavioral health consultant will know their area and the available services very well, and these consultants are invaluable partners.

The IHS has taken a stance that there is intergenerational and historical trauma that affects American Indians and Alaska Native populations. The IHS is looking to address trauma informed care, and there are two special initiatives: Family Spirit and Pediatrics Integrated Care Collaborative. There are special initiatives with youth focus: Generation Indigenous (Gen-I), Children & Mental Health Services in Schools, and Boys & Girls Clubs of America – Native Services. Dr. Ronyak talked about how these programs have been very well received.

Dr. Ronyak talked about the behavioral health grants that the Division of Behavioral Health at the IHS has provided to the tribes. These funds support substance abuse, suicide prevention, and domestic violence prevention. Some of the specific initiatives supported include the Behavioral Health Integration (BH21), the Zero Suicide Initiative, the Urban Indian Health Education and Outreach, Preventing Alcohol-Related Deaths, and the Youth Regional Treatment Center Aftercare.

Dr. Ronyak talked more in depth about the Substance Abuse and Suicide Prevention Initiative, which was established in 2009 and has moved from a pilot project to an actual initiative that has program evaluation and outcome reporting. The program has four purpose areas:

- Community and Organizational Needs Assessment and Strategic Planning
- Suicide Prevention, Intervention, and Postvention
- Substance Abuse Prevention, Treatment, and Aftercare
- Generation Indigenous Initiative (Gen-I) Support

The Domestic Violence Prevention Initiative was established a year later, in 2010. It now has 83 projects with a $11.2 million budget. This initiative has two specific areas:

- Domestic and Sexual Violence Prevention, Advocacy, and Coordinated Community Responses
- Forensic Healthcare Services

The Forensic Healthcare Services is the process of ensuring that evidence related to a sexual assault is available to law enforcement. We have found that if there is an event that occurs in a rural area, the individual has to travel many miles to get services. This program supports moving forensic services closer to the individual.

The Behavioral Health Integrations Initiative began in September 2017 and has $6 million that funded 12 awards to focus on integrating behavioral health into primary care.

The Zero Suicide Initiative is to reduce the risk of suicide across all individuals, and is focused on a community response. It began in 2015 with ten pilot sites. OF those ten, eight sites implemented the Zero Suicide model.

The Behavioral Health Grant program includes Urban Indian Health Education & Outreach, Preventing Alcohol Related Deaths, and Youth Regional Treatment Center Aftercare. The Preventing Alcohol Related Deaths program came about because there were no detox programs and people were dying in the streets from alcohol poisoning. This program provides social detoxification services for alcohol. The Youth Regional Treatment Center Aftercare program will get a total of $1.6 million for two awards—the IHS Youth Regional Treatment Center (which is federal) and the Tribal Youth Regional Treatment Center. Dr. Ronyak spoke about how they would lose track of youth who were in treatment centers. They would move back home and there wasn't case management to follow the. The aftercare program is a pilot to follow them and to evaluate outcomes after treatment.

Dr. Ronyak talked about how the IHS has taken all of these funds and funneled them through the Telebehavioral Health Center of Excellence (TBHCE). This program provides tele-education and tele-heath technical assistance to all 12 IHS areas. There are Telebehavioral Health services in 9 IHS areas, and intra-area agreements that allow for telebehavioral health with 8 IHS areas. There are telebehavioral health sites located across the nation. In 2017, the program provided services for more than 8,000 patients, and this represents services for people who would not otherwise be seen. Of those, most of the services are provided to children. The children coming in represents about twice that of the adult services, which is very exciting. The 2017 Telebehavioral Health program has provided 118 educational webinars, covering almost 9,000 training hours, many of which were continuing education. This has been a tremendous benefit, especially to providers who are remote.

Dr. Ronyak reviewed the Indian Children's Program (ICP) provides education, training and consultation for American Indian and Alaska Native youth including services for autism, fetal alcohol spectrum disorders, and ICP pediatric neuropsychology consultation. If people are not able to travel to access autism diagnosis and services, this program can reach them. This helps ensure that diagnosis is provided without years of delay. There are six series webinars on autism for providers. Providers can get autism-specific training, and then request a consultation for services. Within that consultation, the provider can help not only the individual but also the family in terms of stigma and extra stress. The Pediatric Consultation is a free provider-to-provider clinic for issues such as autism spectrum disorder, fetal alcohol syndrome, and attention deficit hyperactivity disorder.

Dr. Ronyak talked about how the IHS takes a holistic approach to their mission, and is focused on transitional living. They look across schools, detention centers, tribal police and courts, recreations centers, outpatient facilities, and youth regional treatment centers to identify resources, to find out where services are needed, and find the opportunities to be more successful. The IHS looks at the person, the family, and the community as a whole, and takes a holistic and culturally appropriate approach.

Committee Discussion
Dr. Diana Bianchi asked how accessible mobile phones and computers are to people in rural areas and tribal communities. Dr. Ronyak answered that most youth have a smart phone, more often so than they have access to a computer. Some tribes have very limited access to internet. Tribes are now applying for Federal grants for IT infrastructure. When it comes to telehealth, there haven't been issues getting into the areas, but the challenge is having enough providers.

Ms. Laura Kavanagh asked if there were waiting lists for telehealth consultations and if the consultations are interdisciplinary. Dr. Ronyak answered that there is a waiting list because the services are provided on the second and fourth Fridays. She said that if a provider doesn't have an answer to an individual's issue, they will request consultation with other providers.

Mr. John Robison asked about resilience and self-esteem for young people and specifically if there had been research about the role of autism in this culture, with a view for building self-esteem through understanding. Dr. Ronyak answered that the IHS doesn't conduct research and that Mr. Robison is correct in that the health system needs improvement in identifying the autistic population in this population.

Dr. Bianchi asked if the blood quorum was conducted via commercial DNA testing. Dr. Ronyak said that the blood test for blood quantum is a little difficult because each tribe does things a little differently. She said that the blood test does ensure that the parents are indeed biological. This is important because you need to be 25% or more blood quantum. There was a large fire many years ago, where a lot of historical information was lost. In response, people were asked to provide their blood quantum to reproduce the records. The blood quantum is held by the tribe and that identification is put on your ID card. Dr. Bianchi asked about the latest DNA testing and what happens to people who discover that they have Native American blood. Dr. Ronyak talked about how people can work with the enrollment department of each of the tribes.

Mr. Robison talked about how the IHS uses their budget for services and for not funding research for specific issues for IH services. Dr. Ronyak said that there is a research department, but that it is data mining function for electronic health records, not so much specific research activities. She said that the IHS partners with the CDC and other agencies to talk about what research needs to be done. Dr. Gordon talked about the NIMH conducting research specific to Native American populations and so does the other offices.

Ms. Samantha Crane asked about how the tribes work together to provide services, for instance if different family members are enrolled in different tribes. Dr. Ronyak answered that they do work together. This is also the case for the tribal court services. The tribes do work together, and the IHS also works with the tribes to provide coordinated care.

Dr. Nina Schor asked about cultural or stigma-related barriers to those who seek IHS services. Dr. Ronyak answered that there are always barriers—sometimes lack of providers, but also barriers related to stigma. There is sometimes a fear that in a small tribal community that everyone will know everyone's business. It's complicated, and so it's important for providers to build trust and set boundaries. This can help the youth get past stigma.

Dr. Gordon thanked Dr. Ronyak for her presentation.

Summary of Advances Discussion

Susan Daniels, Ph.D., Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC

Joshua Gordon, M.D., Ph.D., Director, NIMH, and Chair, IACC

Dr. Gordon introduced the Summary of Advances discussion. Dr. Daniels referred to the Summary of Advances nominations, and the latest nominations that will be discussed at this meeting. The Summary of Advances is a requirement under the Autism CARES Act, and provides information about recent scientific advances in autism. A booklet of lay-friendly summaries of the top 20 scientific advances is published each year. The process of vetting these advances is that people nominate articles and the Committee discusses and vets them for inclusion. The nominated articles that are not selected are referred to in the publication. The final publication will be presented during Autism Awareness Month.

Question 1: Screening and Diagnosis

Mr. Robison raised a concern about the nomination about the article on race influencing parental report of concerns. Mr. Robison agreed that the study is important, and that it shows disparities in services. The report shows that black parents had significantly fewer concerns about their children with autism than white parents. While this is a responsible hypothesis, Mr. Robison is concerned that there is not a companion study looking at autistic versus non-autistic families. For instance, his lack of concern about an autistic diagnosis in his son does not necessarily represent a lack of accessing services. Dr. Gordon responded that there is a control built into the study where it also showed a lack of concern by black parents for non-mental health issues in the same children. Dr. Gordon suggested that disparity health research shows a lot of evidence, but not exactly why these disparities exist or what to do about it. Mr. Robison said that he believes that the community does not adequately recognize the co-existing issues. Ms. Crane added that she believes this study should be included in the Summary of Advances, and added that if a culture does not seem particularly concerned about a behavior, it may mean that there should be services targeted to the behaviors that they are concerned about.

Dr. Geraldine Dawson talked about the study on adaptive behavior scales. She suggested that this study may not belong in this category. She said that one of the biggest challenges in novel treatment is the ability to measure outcomes. One measure of promise is the Vineland Adaptive Behavior Scale. The challenge is that there is development that can occur within the trial, changes that are just part of development that needs to be accounted for. This study looked at the natural course to determine the minimal change needed to show that this treatment is effective. Many clinicians are using this metric, and so this study has been very helpful, but it should perhaps go into the treatment category. Dr. Laura Pincock agreed that the article should be moved to the treatment category.

Dr. Gordon asked about the study on prediction of risk in children, as measured by cerebrospinal fluid. Dr. David Amaral responded that the study did show that increase extra-axial fluid at 6 months was association with a diagnosis at 24 months. The importance is that brain changes at 6 months predicts those who develop autism. It also turns out that children who had more severe autism had increased amount of extra-axial CSF, suggesting that there may be a causal relationship.

Mr. Robison talked about another study looking at parent-reported strengths in children with autism, where parents recognized autism as exclusively behavioral or cognitive differences in their children. There is powerful evidence of health problems later in life and it is reasonable to ask if early recognition and intervention could be helpful. Mr. Robison said that this study suggests ignorance of the broad range of health problems, and this should be addressed with more research. Dr. Gordon agreed that would be an interesting study.

Ms. Kavanagh reviewed the studies that she had nominated in the screening and diagnosis section.

Question 2: Biology

Dr. Gordon highlighted the postmortem study of 32 brains on underlying biology and asked Dr. Amaral if this is the largest such study. Dr. Amaral confirmed that it is.

Dr. Julie Taylor talked about the Duvekot study about the bi-directional effects between core ASD symptoms and anxiety. Dr. Gordon suggested that he would like to review the study to see if there is a predictive component. Dr. Taylor said that the anxiety symptoms significantly affected the ASD symptoms, specifically in social impairment. Dr. Taylor suggested that it was also surprising that the repetitive behaviors could be distinguished as being related to anxiety.

Question 3: Risk Factors

Dr. Cindy Lawler reminded the Committee that the lead author, Dani Fallin presented the first study from Question 3 at the 2017 IACC meeting. Dr. Lawler said she was excited about this study because it helped to understand the underlying biology of ASD. The research group brought together data from peripheral and core blood, published methylation data, and compared these data with a list of ASD risk genes from GWAS studies. Dr. Lawler said that looking at this overlap helps the understanding about the genome targets. This study is illustrating bringing together datasets to help address challenging issues such as gene expression in the brain. Dr. Gordon asked if this could also be a way to look at the interaction of environmental effects and epigenetic data. Dr. Lawler agreed that this would be an exciting path for research.

Dr. Amaral highlighted the paper on folic acid supplementation. He was impressed that the study showed the use of folic acid could reduce the risk of autism. He said that this finding was in a sense is good news, but it may not have trickled down into common practice. Dr. Amaral suggested that highlighting this finding would be a benefit to the community. Dr. Gordon talked about a different study on folic acid, reviewing that in this study, mothers showed initial low levels of folate in their system, but that there may also be a risk of high levels where folate supplementation may increase risk. Dr. Amaral suggested that there should be more research to determine the level of risk for certain. Ms. Kavanagh suggested that these were significant findings that need to be watched carefully from a public health approach. Dr. Gordon asked if the meta-analysis showed that folic acid is not just about reducing neural tube defects, and that it could be beneficial for more than that. Ms. Kavanagh said that her reading of the study suggested that it looked more at suboptimal status and a high-risk population. Dr. Schor said that it is interesting that there is a history of a relationship of serum folate and fever.

Ms. Alison Singer talked about the study on subcategorizing and segregating by genotypes. There were two things that came out of this study—there was a subgroup that had a number of variations at a known autism loci, in addition to the SHANK3 deletion, and that there were five girls in the study who had SHANK3 deletion but did not show clinical symptoms. Ms. Singer suggested this showed there may be a gender protection. Dr. James Battey concurred that this was an important paper.

Question 4: Treatments and Interventions

Dr. Gordon commented that reviews could be included only if there was a significant contribution. Dr. Amaral talked about the review on the changes in the definition of autism in the DSM. He suggested there is very little published data on this topic. Dr. Amaral said that the review shows close to null results in sensory challenges in ASD children and this could support a call to action.

Ms. Kavanagh talked about the school-based intervention study. The pilot study showed very early findings and it may not have the same impact as others. She suggested that the school-based study is more definitive, and Dr. Gordon agreed.

Dr. Mandell asked about the metformin studies, specifically if the randomized controlled trial trumped the other two studies. Ms. Kavanagh agreed that it did. Dr. Gordon asked about the number of participants in the randomized controlled trial. Dr. Jennifer Johnson said that it included 61 children and adolescents. Dr. Gordon asked about the clinical significance of the weight loss. Dr. Johnson said that there was lower BMI and secondary body composition measures, and that the participants were able to maintain the weight loss, but did not expressing further weight loss.

Question 5: Services

Ms. Crane talked about the Kuhlthau study on health-related characteristics, and that it was an extremely important subject. Dr. Gordon concurred that the issue is well-addressed in this study, in that it addressed lifespan. Mr. Robison said that lifespan does deserve mention in the Summary of Advances, but that it may take a number of years to change the course in research. Dr. Gordon said that it is an interesting suggestion, and that the issue is raised several times in this issue of the Summary of Advances. Mr. Robison and Dr. Gordon agreed to include an assertion that there is movement towards more lifespan research. Ms. Crane suggested to also confirm that the lifespan issues are critical to quality of life. Dr. Gordon suggest to also highlight the issue of co-occurring conditions and their impact to quality of life.

Question 6: Lifespan Issues

Dr. Julie Taylor asked the clinicians in the Committee for their opinion on the Mandy article about assessing autism in adults. She said that the sensitivity and specificity of the study were very good, and the study looked very promising. Ms. Crane suggested that any study on diagnosing autism in adults is going to be helpful, and that she did find it interesting that people with intellectual disabilities were not included because that group is also difficult to diagnose. Ms. Crane suggested it would be interesting to see the differences across race and gender. Dr. Gordon agreed that it would be interesting to identify autism in adults, but that the study may not be definitive enough to include within the Summary of Advances. Dr. Taylor agreed that the sample sizes were small, and that as a result the study may not be definitive enough to include.

Ms. Crane talked about the Sasson article that suggested that disclosing a diagnosis of autism improved other people's perceptions. Dr. Mandell reviewed the results of the study and how the findings impact stigma. He said that it can be difficult to address stigma in research, but that this study addressed it and offered some promising evidence that disclosure could be useful. Ms. Crane asked if the participants actually were diagnosed with autism or if they were fictional. Ms. Singer talked about another study of first impressions of non-disabled students, actual people and not images, to see if disclosure of autism had improved reception by peers, and it did. Dr. Gordon liked that the paper is actionable and wondered if disclosure of a disability that may not be evident can help understanding and knowledge of situations such as social interactions. Dr. Gordon wondered how strong the evidence is, and if it is strong enough to suggest putting it into practice. Mr. Robison agreed that this is likely a correct finding, and discussed historical recognition within the community of, for instance, writers in fine art programs that disclosure of vulnerability makes the them more likable and be treated with more compassion. Dr. Amaral said he would review the study to determine its rigor and novelty and bring that back to the Committee. Dr. Gordon said that anytime there is an actionable finding that the Committee has two responsibilities: one, to ensure that the finding has strong evidence, and two that the finding is disseminated if so. Ms. Crane asked about the breakdown of different types of perception. She suggested that one person might get dinged on perceptions of competence, but might not dinged on friendliness, and that someone who is thinking about self-disclosure would want to know that. Dr. Kevin Pelphrey talked about a more implicit assessment of stigma and how people react—what they believe versus how they actually act. Dr. Pelphrey said that it may depend on what people think of you before disclosure, and that it is such a complicated factor that it could be hard to determine if this study is truly actionable. Ms. Crane suggested that if the study does break down different perceptions, it could help people make a decision about disclosure.

Dr. Gordon encouraged all Committee members to review the full text articles, and to contact the IACC if the full text is needed before voting. Dr. Gordon also asked the Committee to review all the nominations in the packet before they receive their ballot. He also asked the Committee to look at all seven areas to determine the quality and impact of the nominated studies.

Question 7: Infrastructure

There were no nominations to review under this question.

Committee Business

Susan Daniels, Ph.D., Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC
Joshua Gordon, M.D., Ph.D., Director, NIMH, and Chair, IACC

Dr. Daniels thanked the OARC staff for their hard work to make this meeting and all the other products possible. The team is currently collecting data for the 2016 ASD Research Portfolio Analysis report. The OARC and the NIMH will be working with Autistica in the UK and the Canadian government on the first International Autism Research Portfolio Analysis. Dr. Daniels said that it will be interesting to learn what these other countries are working on and that she hopes they will present preliminary results at the INSAR meeting in Rotterdam in 2018.

The Autism CARES Act is the second required report to Congress that is due in September 2018. The first required report to Congress was the report on Young Adults and Transitioning Youth with Autism Spectrum Disorder. The OARC staff is collecting data from all relevant agencies for the Autism CARES Act report.

Dr. Daniels talked about the request from the Social Security Administration for information on strategies to improve adult outcomes for youth receiving SSI. Public comments are due by February 2.

Dr. Daniels reviewed the three new IACC working groups. The first is the Improving Health Outcomes for Individuals on the Autism Spectrum Working Group, which is starting now and is led by Dr. Amaral and Dr. Taylor. The other two working groups will focus on housing and safety.

Ms. Singer suggested adding self-injurious behaviors to the scope of the Health Outcomes Working Group. Mr. Robison asked if the issue should be broadened to violent behavior in general. Ms. Crane did not think that aggression towards others would fit will under the focus of the Health Outcomes Working Group, although self-injurious behavior does. Ms. Singer said that aggression towards others can lead to hospitalization and that there are reports of there not being enough capacity to serve this. Dr. Daniels added that aggressive behaviors from an intervention angle can be relevant, but that the subject is also relevant to the Safety working group. Ms. Crane said if there are topics included in more than one working group, that this be coordinated to ensure that there is no overlap. Dr. Daniels said that the outcomes of this first working group will be completed before the Safety working groups starts, and so that they will know the outcome. Dr. Amaral talked about including these kind of outcomes in the white papers that are developed and disseminated.

Mr. Robison asked if drowning should be included in the Health Outcomes Working Group scope. Dr. Daniels said that it could be addressed under premature mortality. Ms. Crane suggested also adding maternal health care and medical decision-making. Dr. Ball suggested including the premature mortality rate, and especially long-term medication use.

Dr. Daniels reviewed the planned activities for the Health Outcomes Working Group, which included phone meetings, a written document (which could be used towards the preparation of the 2018 IACC Strategic Plan), and the potential for a panel discussion at the April 2018 IACC meeting. Issues that are determined to be high priority could be addressed at the panel meeting, and presenters could help contribute to their knowledge of these issues. Dr. Amaral suggested that it may take several meetings to identify such priorities, and that April may be too soon for a panel. He suggested that June would be a better time. Ms. Singer suggested there be a panel discussion both in April and in June because there are so many important topics to cover.

Dr. Larry Wexler asked about the white paper from the working groups and if there could be a series of infographics that could be disseminated. He suggested this could help better represent data to a broader audience. Dr. Daniels agreed and said that Drexel University does such infographics, as does other agencies. She said that once they have content, they could work on developing infographics.

Mr. Robison added that all the studies are focused on evaluating and remediating deficits. He asked if it is within the scope of NIH to fund studies on employers to capitalize on these outcomes? Dr. Gordon agreed that this could be under the purview of the NIH. Mr. Robison talked about Autism at Work, and talked about two people present from Northrup Grumman who believe there is an advantage to employing autistic people. Dr. Daniels talked about an upcoming panel on employment and that representatives from Northup Grumman can be invited. Dr. Amaral talked about programs that go out of their way to employ people with autism—not to be inclusive, but because these individuals could add something valuable. He suggested that there are issues to be address, such as high turnover. Dr. Amaral said that this may not be on topic for the Health Outcomes Working Group discussion. Mr. Robison said that more employed people equals better health outcomes.

Dr. Amaral encouraged all members of the IACC to participate in this conversation about the Health Outcomes Working Group, and to let Dr. Daniels know if they want to contribute. Dr.

Daniels asked if she should send out an invitation to the entire Committee. Mr. Robison agreed that it should be sent to everyone.

Dr. Daniels said that Wednesday, January 24 is the deadline for nominations for the Health Outcomes Working Group, and that there will be the first conference call in February 2018. Dr. Bianchi added that including maternal health could complete the lifespan cycle, and that their PregSource website offered an opportunity to share experiences. Dr. Daniels suggested that if anyone had resources of knew that of specific events coming up that they let the Committee know to include in the newsletter.

Dr. Daniels requested that the Committee email her with suggestions for future meetings. They have changed the next IACC meeting to Thursday, April 19, 2018.

Summary of Oral Public Comments

Dr. Daniels introduced the three individuals presenting Oral Public Comments.

Dr. Lee Wachtel, a child psychiatrist at the Kennedy Krieger Institute, spoke on behalf of her patients and families, many of whom stayed at the Institute from childhood to adulthood. Many of their patients require treatment for very severe and challenging behaviors. There is frequently a waitlist at the hospital and it is difficult for her to tell a parent that a bed is not available for their child. Dr. Wachtel talked about parents making comments suggesting that they would not choose autism for their child. She understands that this is not necessarily the prevailing perception of autism by the greater community.

Dr. Wachtel suggested that the DSM-5 does not accurately describe autism, and this hinders science and the development of effective treatment. Many of these people will require ongoing support from the autism community, and there is a concern that their unique needs will not be met. Dr. Wachtel suggest that the IACC should consider prioritizing research for self-injurious and aggressive behaviors, promoting a choice-based approach for services, and more seats on the IACC for parents of severely affected autistic children who cannot represent themselves.

Ms. Crane spoke about a misconception that people may think that the people represented by the neurodiversity community are not those that would be clients of Kennedy Krieger. She suggested that on a bad day, people like herself may also need those services. Ms. Singer suggested that Dr. Wachtel brought up a very important topic that should be addressed and that could be a good complement to the employment panel.

Dr. Mandell said that he believes that self-injury and aggression may vary by individual, but they are still a part of the spectrum. He also suggests there is a need for better understanding of the more severely impaired, and the lack of or failure of services for these individuals. He said that there is also the issue that when those services are needed, there are so few available and that they need to be thinking about evidence-based care within the restricted settings as well as the community setting. Ms. Crane talked about the self-advocacy community, explaining that if you are high-functioning, you are seen as a person but not disabled, and if you are lower-functioning, you are seen as disabled but not a person. There are times when a person can be both, and within the same day. Ms. Crane suggested that no one who is a self-advocate does not also think they are not disabled. She said that many of the members of the self-advocacy community have been hospitalized, and there is not much to help them not stay at the hospital. Mr. Robison said that this topic shows a vast gulf in opportunity and strategies for life that will work for higher and lower cognitive abilities in general. He suggested that people who are high and lower functioning are not from different tribes, and he is strongly in favor of supporting people along all points.

Dr. Amaral thanked Dr. Wachtel and suggested that many people who have family members with serious problems feel underrepresented. He believes the Committee needs to go beyond fragmenting to address different issues, but that it's important to hear from all sides to include some of the more severe problems. Mr. Robison said that he is not opposed to this idea, but pointed out that there always has been parent advocacy and only recently have there been self-advocates.

Dr. Wachtel spoke about the many different needs across outpatient and inpatient services. She said that where she works, she tends to see those with very serious issues and that may require hospitalization, such as a detached retina that requires surgery. Ms. Crane talked about members of her advocacy group who have detached a retina and required the same surgery, but who are also considered too high functioning to be included in this kind of discussion. Dr. Wachtel reiterated that she is trying to advocate for those that cannot advocate for themselves, or even those who don't want to be heard because of what their issues represent. Ms. Crane said that people who are functioning on a lower level as Dr. Wachtel described are also members of her self-advocacy group., and that some have spent decades in inpatient settings and have moved on to self-advocacy.

Dr. Daniels clarified that IACC membership is open to those who have more severe disabilities, and there are resources available for them. However, she said that there has never been a nomination from someone with severe disabilities, but that they would be welcomed.

Dr. Gordon introduced Lucina Clarke for the next oral presentation. Mrs. Clarke spoke about her organization called My Time Inc. With over 25 years of teaching, she has learned that self-care is so important when raising someone with a disability. She talked about how My Time Inc supports the parents, shows them how they can take care of themselves, and provides the resources they need. Mrs. Clarke talked about how, when she came to the United States, she learned about autism and then recognized the lack of support for the parents. She talked about the very high divorce rate for these families. She talked about how they see a difference from parents who have learned to do conduct self-care versus those who don't. My Time Inc. aims to find the resources and conduct outreach to the parents who is raising a child with a disability. Parents can feel all alone and depressed, but by bringing together the community can give them a sense of wholeness. The ability to receive a service like recreational programs or emotional wellness can support the parent, who are then able to better support their children. Mrs. Clarke suggested that research be conducted for understanding the parents' needs and the services they may help. One goal My Time Inc. had this year was to provide a parent retreat. Many parents forget to date or go out, they can lose the essence of their life, and they need to find programs to help them find life again.

Mr. Robison thanked Mrs. Clarke for her presentation and how she has embraced the sense of community she brings. Dr. Amaral suggested that the program sounds wonderful and asked how the children are cared for while the parent participates. Mrs. Clarke talked about connecting parents with respite providers and how there is also reimbursement for those services. Mrs. Clarke talked about receiving a small amount of funding from the government.

Dr. Gordon introduced Shari Chase. Ms. Chase introduced herself as a Maryland state health leader and a parent of a 21-year-old who has autism. She talked about being a parent of a child with autism as a most difficult job, and how agencies and schools are not equipped to support those with autism. She suggested that there is a need for partnerships and vocational programs that are customized to those who work with pictures. She said there should be national awards for the development of advancements that support autism, grants that support mentor programs for those with autism, and alternatives to verbal messages. Ms. Chase suggested there be a lobbying effort to employ those with autism. There are already vocational programs that are requiring that a percentage of their workforce be individuals with autism. She said that there needs to be education for the public on how to work with individuals with autism.

Dr. Gordon said that the NIMH is very interested in helping small businesses develop the tools that Ms. Chase described. Mr. Robison talked about tax credits to employ people with disabilities and how Social Security will give a disabled person $25,000-30,000 a year in housing support to live, but gives an employer only $2,300 to employ a person with disability. He suggested that there needs to be a more serious tax benefit for employing individuals with disabilities. Dr. Pelphrey talked about his program at George Washington University and the development of a transition program from high school into adulthood. They use neuroimaging techniques to find what the kids may be best at. The post-high school program provides safe "failure" situations for them to learn. Dr. Pelphrey said that they are interested in partnering and collaborating with technology companies.

Joshua Gordon, M.D., Ph.D., Director, NIMH, and Chair, IACC

Dr. Gordon introduced the Oral Public Comments presentations.

Summary of Written Public Comments

Julianna Rava, M.P.H., Health Science Policy Analyst, Office of Autism Research Coordination, NIMH

Ms. Rava summarized the Written Public Comments received from nine people, which were organized under six broad topics: the role of the IACC, transition to adulthood and services, medical practices, the IACC Strategic Plan and research priorities, resources and support, and vaccines and autism.

IACC Committee Member Discussion of Public Comments

Mr. Robison talked about comment about housing, suggesting that the subject is complicated, but the end goal seems to be having a group of autistic people being able to live in a home together. Mr. Robison said that, on one hand, there is debate about people being subject to abuse or who are vulnerable, but on the other hand freedom of choice is also important. He also talked about the comments regarding the IACC research focus and suggested that though the end goal from both commenters is quality of life, there may be opposing views on how that is done. Mr. Robison said that more diversity on the IACC would be helpful, and he would support the addition of those with more severe disabilities.

Dr. Gordon talked about the working group for housing that will be coming up, and the Committee recognizes the complexities and will be addressing the issue. Ms. Singer commented on the overall tenor of the public comments and that felt that the Committee is hearing more about parents who are very severely affected who are feeling left behind. She talked about how parents used to dominate the conversation, but the pendulum may have swung and now parents feels left out of the conversation. Ms. Singer suggested that there is a need for balance, and the Committee needs to ensure that there is not an overrepresentation of one groups needs over another.

Ms. Crane talked about Ms. Rosa's comment and how her concerns with housing are regarding choice, specifically with regards to integration. Ms. Crane suggested that housing policy should be as flexible as possible so that people can say "this is where I want to live" and services can be brought in to accommodate that request. Ms. Crane also talked about the comment suggesting that she provide medical records of her autism. She spoke about how she serves on the Committee not just as an autistic person, but also as an autism advocate and a member of the Autistic Self Advocacy Network (ASAN). Ms. Crane felt that requests for people with autism to provide documentation of their qualifications as a Committee member is a silencing technique. Dr. Daniels clarified that there is a lot of diversity on the Committee, that several members are also a parent of someone with autism, and that the Committee respects them all.

Ms. Singer addressed the comment about housing suggesting that sometimes the waiting lists can be years long and that the problem isn't that places can't be filled, but that there are no available places. Ms. Crane said that the issue isn't that these housing spots cannot be filled, but that there is no other choice than the housing with a waitlist.

Mr. Robison suggested that even with the current level of diversity on the Committee, there is still an absence of people with very different views and opinions. He had met a person who had challenged both his and Ms. Crane's position on the Committee, but that there was still a lot to learn from this person. Mr. Robison believes that people with those differing opinions can be valuable, but that it may be hard for them to participate in the Committee with the current format. It can be very difficult, for instance, to follow the proceedings of the meeting without closed captioning. Dr. Gordon suggested that they can look into live closed captioning, but that the cost may be very high. Dr. Gordon said that the archived video is closed captioned. A member of the audience commented that, as an autistic person with auditory processing issues, live captioning would be helpful to her. Dr. Daniels said that those watching the proceedings on a computer can get live captioning. Dr. Gordon said that they will look into the capability and report back to the Committee.

Dr. Amaral commented on the issue of transition services and wondered if there was a need for specific transition approaches for autism or if there were models for transition services from other disabilities. Dr. Daniels talked about being in touch with Federal Partners in Transition, and that they may come to speak the Committee about this topic. Dr. Amaral said that he hoped it would not just be to address transition but also other related issues. Ms. Crane agreed that housing and related issues, such as being expelled because of challenging behaviors, would be helpful to discuss. Dr. Gordon said a good start to this topic that will be the housing working group.

Autism Screening Panel Presentation

Introduction to the ASD PEDS Network
Denise Pintello, Ph.D., M.S.W.
Chief, Child and Adolescent Research Program, NIMH
Acting Chief, Dissemination and Implementation Research Program, NIMH

Dr. Pintello introduced the ASD Pediatric Early Detection Engagement and Services Network (ASD PEDS Network), which is five different studies that was funded by the NIMH towards early detection and treatment for autism in very young children. The 2013 IACC Strategic Plan and the specific research question, "When Should I Be Concerned" was the impetus for the development of this Network.

Dr. Pintello talked about how the focus of this funding opportunity was on the underserved population of very young children. The top five proposals were selected to conduct research that span nine states and 16 different locations across the nation. One funded study is in San Diego and Phoenix and aims to test a three-stage early detection and intervention system. The second study is in Washington state to look at four different rural settings and a Screen-Refer-Treat model. The other three studies, to be presented at this meeting, are located on the East Coast and aim to test a number of approaches for screening and interventions. Collectively, these five studies would screen about 70,000 children, which may result in an estimated 1,000 diagnoses. Dr. Pintello talked about how they looked at ways to harness these efforts to form a network and to embed common measures within their study to improve statistical power.

These studies were awarded in 2014 and since then they have developed a website to share tools and publications, conducted cross-training, and presented at conferences. There was a United States Preventive Service Task Force (USPSTF) recommendation that found that there was insufficient evidence to support early screening in young children when there was no indication of parental concern. In response to this finding, the Journal of the American Medical Association (JAMA) responded with an editorial acknowledging the ASD PED Network and the that it was addressing the research gaps raised by the USPSTF.

The researchers of these five studies have started the fourth year of their five-year project, and they will be completed by fall of the 2019. They hope that these studies will be disseminated to begin utilization of these strategies. Dr. Pintello introduced the leads of the five studies.

Mobilizing Community Systems to Engage Families in Early Autism Detection & Services

Amy Wetherby, Ph.D., C.C.C.-S.L.P.

Distinguished Research Professor, Department of Clinical Sciences, Florida State University
Director, Autism Institute, Florida State University

Dr. Wetherby talked about the lifetime societal cost of autism, which can be from $1.4 to $2.4 million—most of which can be incurred in adulthood. If diagnosis and treatment can come earlier, then this could save money later. The American Academy of Pediatrics recommends developmental surveillance at well-child visits between the ages of 9 to 30 months and autism screening of children between ages 18 and 24 months. Dr. Wetherby discussed the limitations of current screening measures and strategies, and there tends to be a selection bias within published research on autism screening that can inflate the sensitivity and specificity of those studies. She also talked about the possibility of missing children who should be diagnosed, and that studies have shown that screening tools may miss diagnoses by as many as 10 children per 1,000. There are more promising approaches to screening for autism, but this problem is not limited to autism. There are also problems detecting early identification for developmental disorders. Only screening in the early intervention system may mean missing an autism diagnosis in as many as 80% of children.

Dr. Wetherby talked about one problem being about where to draw the line, and that the second percentile cutoff is too low to detect. Another problem is the developmental milestones used in screening, where for instance, being afraid of strangers or being shy or nervous can be milestones at different ages – how can hitting those milestones be distinguished from behaviors that are something else? Parental concern is less accurate when their children are very young. Very few parents report concerns specific to autism, but they are very accurate about what their child can and cannot do. To reach children under the age of 24 months, one cannot rely on parent concern.

Dr. Wetherby talked about their work to improve screening. Smart ESAC (Early Screening for Autism and Communication Disorders) is a new screening tool to streamline screening for young children. The parent gets ten questions, followed by 20 more if there is a positive screen. The Smart ESAC has shown to be a promising universal screening tool for children between 12 and 36 months.

Dr. Wetherby talked about how to build the capacity of communities to screen and provide services early. Their team is rolling out a set of online tools and courses targeted to community providers, primary care medical homes, social services systems, and other programs. In the first phase of the study, they conducted focus groups with families and found that the families do not feel comfortable identifying ASD in very young children. The parents are not familiar with some developmental milestones or the subtleties in the spectrum of autism, and feel powerless, especially when their physician tells the parent to wait and see. Parents are also concerned about accessing services.

In the Implementation phase of the study, they scaled up. To date, they have recruited 396 CSPs in four states from primary care and other service systems and screened over 5,000 toddlers. AutismNavigator.com is a collection of tools and resources for early intervention providers. The courses have been translated into Spanish and will be translated into other languages. They add new content regularly and also respond to feedback, such as that courses are too long. They have also built a portal for providers and parents, which includes the First Words Project—parents don't tend to look for autism but they do think about language, 16by16 – a lookbook that illustrates different gestures by children, and a Social Communication Growth Chart – with video clips across milestones and a charting function to track milestones. The last strategy is a new button on the FirstWords website, which is called Screen My Child for an online screening.

Dr. Wetherby invited the Committee to follow them on Facebook.

Ms. Singer spoke about being more likely to get a screening and diagnosis if the child is not first born, or if the child has a lot of interaction with grandparents, which speaks to parent experience. She asked if these programs should be targeted to new parents, such as at the OB/GYN office. Dr. Wetherby answered that during the OB stage and shortly after birth, parents may not be thinking about much besides sleeping and eating. There may be some very early signs, but observable signs do not evolved until 9 to 18 months. Their developmental guides starts at six months. Dr. Wetherby talked about having tried different outreach approaches, some that were successful and some that were not. They are working with different agencies that touch the pediatric population.

Ms. Crane talked about seeing a pattern of adult diagnoses after their child is diagnosed. The parent may be completely unconcerned because their child is acting a particular way and the grandparent is saying that the parent acted that way too.

Dr. Stuart Shapira thanked Dr. Wetherby for her presentation and talked about the Learn the Signs, Act Early project, which is not autism specific, but looks for delays that could be indicative on many issues.

Multi-stage screening in Part C early intervention to address health disparities in age of ASD diagnosis and service receipt

Alice Carter, Ph.D.
Professor, College of Liberal Arts, University of Massachusetts, Boston

Dr. Carter talked about a multi-stage screening protocol, which is an implementation program in partner with Part C Early Intervention agencies. This effort supports clinical knowledge as one part of the screening, diagnosis, and intervention cycle. There can be very long delays between parental concern and diagnosis, which is unfortunate given the early intervention window. This project is about shifting the diagnosis to a younger age and closing the intervention gap. There is a social health disparity in terms of differences in the access to and types of available services, and a variety of contributing factors to this disparity. These factors include external family-level factors such as language and insurance status, internal family factors such as trust in providers and fear of diagnosis, external clinic and provider level factors such as hours of operation and cost and untested screening, and internal clinic and provider level factors such as negative perceptions and families not following through.

Dr. Carter discussed how their broader project uses a health beliefs framework to address parental concerns. For instance, if parents don't see the child as having a problem, they will not seek help. Or parents are thinking about seeking help, but not necessarily seeking it. This approach looks at the different determinants across the help-seeking thoughts and behaviors that parents experience.

Through the ABCD Early Screening Project at the University of Massachusetts Boston, they are also looking at evaluating systems of care to monitor fidelity, costs, and simulation models for testing hypothesis for screening. Their goal is targeted, universal screening for all early intervention agencies. Dr. Carter talked about their phased approach, where Phase 1 is the screening process across three stages (initial screening, observational screening, and diagnostic assessment). They are targeting three agencies in Boston within the Circle of Promise, which are characterized by under-resourced families. They have trained 160 early intervention providers and 32 early intervention programs, and 94 of those providers have come to diagnostic assessments. One thing they have learned is that these providers need a lot of support; they are not as well trained in talking to parents as they are in working with children.

Dr. Carter's team developed a lot of resources to support communication with parents, which helps the providers open the conversation and reflect on the child's behavior together. They and their partners have also screened nearly 3,000 children, 35-40 percent of whom screen positive. As compared to other screening approaches, the rate of diagnosis is about 10 percent in this novel approach as compared to only about 2.4 percent using other approaches.

Dr. Carter talked about the high rate of racial minorities in their sample and how they are addressed health disparities such as race, language, and income in those populations. If English is a concern, for instance, the family may be coming in later and the child is diagnosed later. Risk factors are cumulative, which means that kids with multiple risk factors are less likely to make it into high-intensity services. However, Dr. Carter's team has moved the time gap from concern to diagnosis from about 1.7 years to about 2 to 3 months, which is improvement but still not enough. Dr. Carter talked about this research being conducted in Boston, which may not translate to different states because Massachusetts has a high rate of early intervention.

Dr. Mandell thanked Dr. Carter for the presentation and asked if different strategies were needed to address different risk factors. Dr. Carter answered that some of the strategies are the same, but that there is a major problem in linguistic competence. They desperately need Spanish providers, but those providers tend to have heavier caseloads.

Leveraging Urban Primary Care Systems to Improve Early Identification of Low-Income Children with Autism Spectrum Disorder

Emily Feinberg, Sc.D. C.P.N.P.

Associate Professor, Department of Community Health Sciences, Boston University School of Public Health
Associate Professor of Pediatrics, Division of General Pediatrics, Boston University School of Medicine

Dr. Feinberg talked about their project, Project EARLY, being focused on the continuum from screening to diagnostic assessment to intervention services. The project is a primary-care systems-based approach that is tailored to low-income, racial, and ethnic minorities. The program is ground in the chronic care model and aligned with the USPS Task Force analytic framework.

Dr. Feinberg talked about their study being a hybrid comparative effectiveness trial to measure the effectiveness of a family-based intervention versus traditional care management. The setting includes three urban primary care sites in the Boston Medical Center, Yale University, and Children's Hospital of Philadelphia. The outcome measures include the number of days to diagnosis, time to engagement of services, social support, family stress, family functioning, and other symptom related data. The population is largely minority and there is a difference between sites, where New Haven has a large population of Latinos, Boston has a large proportion of parents born outside of the United States, and Philadelphia has large population of U.S. born black families. The children come in around the age of 22 months and are disproportionately male. About 44 percent have received early intervention services. They also tend not to be as low functioning as the previous studies.

There are four components in the study model including universal screening, activated screening, routine screening, and engagement with a proactive practice team. They assess at baseline, post-diagnosis, post intervention, and at 12 months of age. At the time of universal screening, there are some screening enhancements for positive screens, including a centralized referral process, screening completed in the family's primary language, use of electronic health records to communicate results to loop back to the providers, and the move to activate screening component. The results of the primary care screening and referral process showed that the approach is acceptable and efficient. It was effective for addressing literacy and linguistic barriers, it reduced the time from referral to confirmatory screening, and it identified children for whom further follow up was not indicated.

The Family Navigation Study looked at the Family Navigation model versus traditional care management. The Family Navigator conducts proactive family engagement. They schedule the ASD evaluation, ensure referrals are followed through, and provide telephone supports. Families with a confirmed risk are randomized to one model or the other. Dr. Feinberg introduced the Navigators and talked about their experiences with their work. They are excited to take this work to the next step. Dr. Feinberg and her team are looking at number of contacts, the type and location, the time and issues addressed, and the fidelity to the model.

Dr. Feinberg ended by talking about the overlap with this program to the USPS Task Force analytic framework. They follow the same process of screening and are collecting data to look at contextual issues and the differences between racial and ethnic subgroups. Dr. Feinberg talked about a supplemental grant to convene a formal expert panel to address these ongoing task force questions. Dr. Feinberg thanked her team and how they looked forward to working within the larger network in the future.

Committee Discussion

Dr. James Ball thanked the panel for their important research and asked if they use multiple treatments or a consistent set of strategies, and if they are looking at long-term outcomes-based research. Dr. Feinberg answered that none of the grants were designed to provide intervention. Although they do not provide interventions, they are trying to follow outcomes longitudinally.

Dr. Carter talked about their partnership with the Department of Public Health to document data such as exit scores, even though they do not administer interventions. Dr. Ball asked if they encourage them to use the webinars from the navigator. Dr. Wetherby answered that they are encouraging use of the webinars and that they also conduct individual meetings after to ensure they are continually engaged. When everything is done online, it is easier to have data about their engagement behaviors. As they wind down this study, they hope to plan a treatment study as a next step.

Dr. Pintello invited the Committee to provide their insight and expertise for the network. Dr. Feinberg responded to the question about the Act Early program and the difference in the missions with Birth to 5: Watch Me Thrive. She suggested that their study is looking at the more detailed skills with milestones at every two months. Dr. Feinberg suggested that the two approaches together may be very complementary.

Dr. Gordon thanked the panelists.

Round Robin

Dr. Gordon asked members to report out to the Committee. Dr. Shapira talked about the SEED studies that were reviewed at the last meeting. The presentations shared at the last IACC meeting were just a small part of all the studies. Since that meeting, there have been four studies published with more to expect next year.

Dr. Dawson reported from her role as past president of the International Society for Autism Research (INSAR). They are publishing their first policy brief about employment issues in adults with autism. There will be a call for proposals at the next regional meeting, which closes on February 1. The annual INSAR meeting is May 9-12 in Rotterdam this year.

Ms. Singer talked about an RFA for undergraduate summer research fellowships, which is a great opportunity for individuals with autism or siblings.

Dr. Wexler talked about the research funded through the Office of Special Education that looked at kids with disabilities who engage in online instructions, and the outcome was basically that there was no specialized instruction, nothing to meeting the individual needs of kids with disabilities. There is now an effort to design software to adapt digital content that will provide access and customized materials that meet the needs of these kids. This program will be for both the children and the parents. The software can be embedded in the development of commercial materials. It will be available for free to any publisher. It could provide user preferences and controls that automatically adapt to the user.

Dr. Laura Mamounas talked about the NINDS and NIH workshop in December addressing issues around physiological and biological markers associated with autism. They will put together a white paper of the recommendations that came out of that workshop

Dr. Alice Kau talked about the new Autism Centers of Excellence, which is working on early screening. One is at Duke which looks at co-morbid ADHD and ASD. The other is at Drexel University is conducting randomized clinical trials of autism screening.

Closing Remarks and Adjournment

Dr. Gordon thanked the Committee and adjourned the meeting at 4:36 PM.

The next meeting is on Thursday, April 19th at a location to be determined.