



## Minutes of the Interagency Autism Coordinating Committee Full Committee Meeting

October 24, 2017

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The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Tuesday, October 24, 2017, from 9:02 a.m. to 4:35 p.m. at the National Institute of Mental Health, 6001 Executive Boulevard in Rockville, 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., JB Autism Consulting (attended by phone); **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); **Samantha Crane**, J.D., Autistic Self Advocacy Network; **Gwen Collman**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Linda Birnbaum, Ph.D.); **Geraldine Dawson**, Ph.D., Duke University; **Ruth Etzel**, M.D., Ph.D., Environmental Protection Agency (EPA); **Tiffany Farchione**, M.D., U.S. Food and Drug Administration (FDA) (attended by phone); **Melissa Harris**, Centers for Medicare and Medicaid Services (CMS) (attended by phone); **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Laura Mamounas**, Ph.D., National Institute of Neurological Disorders and Stroke (NINDS), (representing Walter Koroshetz, M.D.); **Walter Koroshetz**, M.D., National Institute of Neurological Disorders and Stroke (NINDS); **David Mandell**, Sc.D., University of Pennsylvania; **Edlyn Peña**, Ph.D., California Lutheran University; **Laura Pincock**, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Robert H. Ring**, Ph.D., Vencor Therapeutics (attended by phone); **John Elder Robison**, College of William and Mary; **Marcella Ronyak**,

Ph.D., L.C.S.W., C.D.P., Indian Health Service (IHS); **Robyn Schulhof**, M.A., Health Resources and Services Administration (HRSA) (representing Laura Kavanagh, M.P.P.); **Stuart K. Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC); **Melissa Spencer**, Social Security Administration (SSA); **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD); **Carrie D. Wolinetz**, Ph.D., NIH (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, OARC, NIMH, and Executive Secretary, IACC

Dr. Joshua Gordon called the meeting to order at 9:02 a.m., and Dr. Susan Daniels took roll call.

## **Welcome and Introductions**

Dr. Gordon welcomed the Committee and reported that two members have left—Amy Goodman and Brian Parnell. He welcomed Dr. Carrie Wolinetz, Acting Chief of Staff and Associate Director for Science Policy at NIH, representing NIH Director Dr. Francis Collins.

The minutes from the last meeting were approved without comment.

## **Update from the Office of the National Autism Coordinator The HHS Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder**

**Susan Daniels, Ph.D.**, Director, OARC, NIMH, and Executive Secretary, IACC

Dr. Daniels explained that Dr. Thomas Novotny stepped down from his position as National Autism Coordinator in August 2017. His major project while in this position was to lead the development of the U.S. Department of Health and Human Services (HHS) report to Congress, [Young Adults and Transitioning Youth with Autism Spectrum Disorder](#). Dr. Daniels has stepped in to continue the implementation and dissemination of the report, which has been completed and is available either electronically online or hard copy by request to the Office of Autism Research Coordination (OARC).

Dr. Daniels described two different reports to Congress that are required in the Autism CARES Act. The first is a requirement to submit a report on all federal activities related to autism spectrum disorder (ASD). In addition, the CARES Act requires a separate report to Congress focused specifically on young adults and youth transitioning to adulthood. The purpose of this report is to summarize existing federal investments in transition research and federal activities that support transition services for youth and young adults on the autism spectrum.

With regard to the Report to Congress on transition, Dr. Daniels described the Steering Group that was formed to lead the development of the report, which she co-led. The steering group included representatives from several federal agencies within HHS, as well as representatives from the U.S. Department of Education (ED), the U.S. Department of Labor (DOL), the U.S. Department of Transportation (DOT), the U.S. Department of Defense (DoD), The U.S. Department of Housing and Urban Development (HUD), the U.S. Social Security Administration (SSA), and the U.S. Department of Justice (DoJ). An expert stakeholder panel was convened by the Steering Group to provide additional input for the report, which included experts from academia and private foundations involved in autism research and services.

The Report to Congress on transition has four parts. Part 1 is background information for ASD and the transition to adulthood. Part 2 is an overview of relevant federal programs and activities. Part 3 covers perspectives from key stakeholders, which the Steering Committee felt would be helpful and important but was not required in the statute. Part 4 provides conclusions and recommendations.

The report also included a review of the literature that characterized the population. For instance, an estimated 50,000 youth with ASD turn 18 each year. About 450,000 youth with ASD ages 16–24 are currently living in the United States. Young adults who had an Individualized Education Program (IEP) in high school will have specific needs, such as assistance with independent living. According to literature cited in the report, only 1 in 5 young people with ASD have ever lived independently after high school. Only 36 percent of youth with ASD have ever participated in education or training of any kind between high school and their early twenties. This population also faces specific risks, such as a greater likelihood of dying prematurely or having co-occurring diagnoses such as anxiety or depression.

On behalf of the IACC, OARC gathered public input regarding this transition period for the preparation of its 2016-2017 Strategic Plan update, and OARC shared with the steering group the input received on topics such as service and support, employment opportunities, transportation, and housing. Most public comments came from family members of individuals with ASD, advocates, and people with ASD.

The stakeholder panel convened identified several gaps in research, programs, and access to high-quality services and planning. Dr. Daniels discussed the ongoing research on transition that is covered in the report. Four federal agencies (NIH, HRSA, ED, and DoD) funded 18 research projects on transitioning youth with ASD between fiscal years 2013 and 2016. The OARC portfolio analysis for 2015 indicated that 2 percent of autism research funding went toward research on lifespan issues, and if narrowed down to the specific topic of transition, the funding represents only 1 percent of combined federal and private autism research funding of \$342 million.

Dr. Daniels reviewed the service and support programs within the report. There is a drawback

in that the many federal service and support programs do not track the diagnosis of ASD specifically. ASD is often grouped with many other disabilities. This can make it challenging to obtain ASD-specific funding information.

The report concluded that there is a need for coordinated, comprehensive support and services. The report includes specific recommendations across data collection and monitoring, evaluation of services and support needs, outcomes research, and program delivery.

The HHS Office of the National Autism Coordinator was leading efforts to develop and follow up on this report, but the office is currently vacant. In the interim, Dr. Daniels recently co-presented the Report to Congress on transition with Dr. Scott Robertson (DOL) in a meeting of the [Federal Partners for Transition](#) (FPT) working group. This working group is addressing ways in which the federal government can address the needs of all youth in the U.S. for services to facilitate successful transition to adulthood. One of the working group's major projects was the [2020 Federal Youth Transition Plan: A Federal Interagency Strategy](#). There may be an opportunity for the IACC to engage with FPT members in the future to identify areas of mutual interest for future activities.

Dr. David Mandell congratulated Dr. Daniels on the final report on transition in youth with ASD. He described the report's recommendations as broad, and asked if the group had ideas about specific next steps this group should be advocating. Dr. Daniels responded that the Committee can be a part of the follow-up effort.

Ms. Alison Singer asked if there were plans to appoint a new National Autism Coordinator. Dr. Daniels said that the change in administration is ongoing, and that HHS may appoint a new national autism Coordinator in the future.

Dr. Gordon remarked that there are hundreds of programs and wondered how individuals identify the programs that are right for them. He noted that very few of the programs are specific to autism, and although that is good in that there are co-occurring issues, addressing ongoing challenges that need continued support could be difficult without central coordination.

### **Update on CDC Study to Explore Early Development (SEED)**

Dr. Stuart Shapira introduced the [CDC Study to Explore Early Development \(SEED\)](#) and the speakers describing this study.

#### **Autism Activities at CDC**

**Nicole Dowling, Ph.D.**, Chief, Developmental Disabilities Branch and Epidemiologist, Division of Congenital and Developmental Disorders, National Center on Birth Defects and Developmental Disabilities (NCBDDD), CDC

Dr. Nicole Dowling said that the timing of this presentation is fortunate because CDC is about to publish several studies. SEED is one of the largest studies of ASD risk factors in the United

States. Over 6,000 children and their families have enrolled. A key strength of the study is that the researchers are simultaneously looking at characteristics, environmental factors, and genetic factors. They work with the Division of Congenital and Developmental Disorders (DCDD) within the CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD). Their vision is healthy birth and optimal development for all children, with a mission to be the public health leader in preventing the occurrence of adverse consequence of birth defects, developmental disabilities, and genetic conditions. Dr. Dowling reviewed the organization chart for DCDD.

The focus of CDC autism programs is to track, research, and improve early identification so that families and children can get the help they need. The SEED study is a case-controlled study conducted over five sites and one additional site led by the CDC. The study has three phases, and they are currently collecting data for phase 3. They also have a biorepository and a Data Coordinating Center.

Dr. Dowling provided a brief overview of the studies that were presented and asked the Committee to hold questions until the discussion period.

### **SEED: Overview of Methods and Data Collection**

**Laura Schieve, Ph.D.**, Epidemiologist, Developmental Disabilities Branch, NCBDDD, CDC

Dr. Laura Schieve thanked Dr. Daniels and the Committee for the invitation to present the SEED study. The CDC researchers have completed two phases (SEED 1 and SEED 2) of the study. The objectives of the study are to look at risk factors of ASD, to characterize the ASD phenotype, and to assess the health of children with ASD and other developmental disabilities. It is a case-control study, and all phases follow a common protocol, with enrollment of three groups: an ASD group (identified from various schools and special education programs or clinics) and two comparison groups: children with other developmental disabilities (DD), and the population comparison group of children without disabilities (POP). All children are screened with the Social Communication Questionnaire (SCQ). A high SCQ score or a previous ASD diagnosis indicates a child who might have ASD, which is confirmed with follow-up assessment.

The SEED 1 protocol includes a questionnaire, maternal interview, in-person assessment, blood and buccal samples, dysmorphology exams, diet and stool diaries, and medical records. The SEED 2 protocol is streamlined, without the dysmorphology exam and diet and stool diaries. Other forms were also consolidated in SEED 2, and a form addressing residential history was added. Additional saliva samples were also taken. The SEED 3 protocol was streamlined even further by taking out medical records, which had been very resource intensive and often were not completed.

SEED 1 is ongoing and more than 40 papers have been published from it. SEED 2 is in the data analysis stage. CDC began SEED 3 in August 2017. The SEED Teen study is a follow-up of SEED 1 participants. For that study, data collection begins when the children are 14-15 years old. They

hope to invite around 1,400 children to participate. The researchers plan to ask mothers or other primary caregivers to complete two questionnaires, which will help determine the children's trajectories. They are also asking for consent to share genetic data with the NIH repositories.

Dr. Schieve said that some of the highlights from the SEED study have led to novel findings, which will be reviewed next.

### **Highlights of the Findings of Five SEED Studies**

Dr. Shapira introduced the presentation of five SEED studies, which represented a small sampling of several ongoing studies.

#### **ASD Risk Factors Study: Autism Spectrum Disorder and Birth Spacing**

**Laura Schieve, Ph.D.**, Epidemiologist, Developmental Disabilities Branch, NCBDDD, CDC

Dr. Schieve talked about how previous studies on birth spacing have been limited in methodology. In the study she presented, they looked at children who were second or later in birth order. They looked at short and long birth spacing (time between birth and conception of the study child). They looked at the underlying mechanisms of ASD. There was a modest association between ASD and short birth spacing. This effect was slightly more pronounced among term babies. There was a big difference depending on autism symptom severity. There is a distinct u-shaped association where both short- and long-inter-pregnancy intervals are associated with increased risk for ASD, and the lowest risk was across 18-60 months. When they looked at other non-ASD developmental disabilities, there was no association in birth spacing. In conclusion, ASD is associated with both short- and long-birth spacing, especially in ASD with highest symptom severity. This association was not explained by unplanned pregnancies, infertility, or other factors.

#### **ASD Risk Factors Study: Maternal Infection and Fever during Pregnancy and Risk of Autism Spectrum Disorder**

**M. Daniele Fallin, Ph.D.**, Sylvia and Harold Halpert Professor and Chair, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Joint Appointment in Medicine (on behalf of **Lisa Croen, Ph.D.**, Senior Research Scientist, Kaiser Permanente)

Dr. Daniele Fallin presented on behalf of Dr. Lisa Croen. This study looked at the risk posed by maternal infection during pregnancy. This is not a new idea, as this risk factor has been suggested in the past and by more recent studies. Some recent studies hint at an association with flu and fever. For fever, there are wide bars on the comparison graph, which means it is not precise, but the data is consistent. The study asks whether the trimester or the infection is the more important to the level of risk. Using SEED 1 data, these researchers characterized infection and fever during pregnancy. They interviewed mothers about 36 specific infections, medications taken, and associated fever. They also conducted medical chart review.

Across any infection, about 60 percent of mothers in the ASD group were exposed to some type of infection. Infection in the genitourinary system, infection of unknown origin, and bacterial infection were all significant. The researchers adjusted for potential confounders and medication use. The association is specific to ASD risk, but was not seen in DD or POP. They found an increased risk of ASD associated with infection plus fever, which was significant in trimester 2. In summary, there was a significant risk of ASD in women with infection with fever in second trimester, and women with infection without fever in the three months prior to conception.

### **ASD Genetic Associations: Peripheral Blood DNA Methylation and ASD**

**M. Daniele Fallin, Ph.D.**, Sylvia and Harold Halpert Professor and Chair, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Joint Appointment in Medicine

Dr. Fallin talked about a paper coming out today on methylation data from 2- to 5-year-old children in SEED. This study looked at the integration of ASD genetic and epigenetic information. The epigenetic modifications help regulate expression of the DNA sequence. The researchers looked at the integration of these data, which is inherently tissue- and timing-dependent. If they look at methylation, the researchers could see grouping by genotype and a pattern where some genotypes correlate with epigenetic ranges. This creates a type of cross-map between genetics and epigenetics. Therefore, these maps will be different between child blood, infant (cord) blood, and fetal brain tissue. The study sought to examine what might be learned from these maps.

One specific study question asked whether common variants associated with ASD are enriched for methylation quantitative trait loci (meQTLs), and whether the results would be the same in blood versus brain. The study determined that they are enriched, finding statistically significant enrichment in peripheral blood that they did not see in lung tissue.

Another study question asked whether ASD-associated meQTL targets point to a particular biology. The answer is that one can potentially learn more about a particular biology and the immune system by looking at the meQTL targets. This is consistent with previous ASD findings of DNA methylation.

A third study question asked whether ASD-associated meQTL targets point to genes not previously implicated. The researchers see a pattern, potentially in peripheral blood, and will be looking at other samples in the future.

Dr. Fallin mentioned that these are not primary findings, but can help interpret findings. The researchers are still building the maps and “hit lists.” They are now genotyping SEED 1 mother and child data. Although this is not a discovery set on its own, these data contribute to collaborative efforts. The researchers are already participating in other genome-wide association studies (GWAS), epigenome-wide association studies (EWAS), and meta-analyses.

Dr. Fallin acknowledged and thanked members of the research team and collaborators.

### **ASD and Child Health Effects: Gastrointestinal Symptoms in 2-5-Year-Old Children**

**Ann Reynolds, M.D.**, Associate Professor, Department of Pediatrics, Developmental Pediatrics, University of Colorado School of Medicine

Dr. Ann Reynolds talked about gastrointestinal (GI) symptoms in 2- to 5-year-old children. SEED researchers wanted a community-based sample to avoid bias. GI symptoms are complex—cognitive and behavioral issues can affect the GI system, and so can motility, dysregulation, anxiety, and microbiome issues. They conducted a questionnaire with parents, collected stool diaries, checked GI medications, and obtained data on associated anxiety, aggression, and sleep issues. From the parent report and the stool diary they created a complex algorithm for GI diagnosis and found that children with ASD were significantly more likely to have GI symptoms than children in the POP group. There were some differences within the ASD population, where children with ASD using treatment for constipation were less likely to have a stool diary.

The researchers found there was an association between GI symptoms and anxiety, aggression, and sleep issues. Children with ASD and regression were 1.5 times more likely to have GI symptoms, although there was no difference in autism severity scores between children with and without GI symptoms. The take-home message is that GI symptoms were more frequent in ASD groups. This study controlled for cognitive skills. In the future, they hope to look at the microbiome, genetics, and diet data.

Dr. Reynolds thanked the families who participated and their collaborators.

### **Characteristics of Children with ASD: A Novel Protocol for Characterizing Dysmorphology to Enhance the Phenotypic Classification of ASD**

**Stuart Shapira, M.D., Ph.D.**, Chief Medical Officer and Associate Director for Science, NCBDDD, CDC

Dr. Shapira talked about dysmorphology—physical features that do not follow the normal pattern of growth or formation. There are hundreds of dysmorphic features, including ears protruding, eye fold differences, birthmarks, and long fingers. It is important to study this as clues about cause, prognosis, and distinctive phenotypes. Clusters of features can provide important information, for instance, in Down's syndrome.

The presence of multiple dysmorphic features could also identify ASD subtypes. In this study, they measured features during a clinic visit and from photographs of the children. There was a genetic review process, where each geneticist reviewed a specific body region. Some features were easy to assess, such as ear tags. Many features were not easy to classify as dysmorphic or not, but were on a spectrum (e.g., ptosis, or dropping of the eyelid). The researchers categorized features that existed on a spectrum as dysmorphic or not based on a score. They concluded that there was no significant difference by race/ethnicity (Non-Hispanic White, Non-

Hispanic Black, and Hispanic); about 17 percent of children in each group were dysmorphic. This classification will allow researchers to stratify ASD phenotypes and patterns of dysmorphic features.

Dr. Shapira thanked the families and collaborators for this study.

### **Committee Discussion**

Dr. Diana Bianchi asked if someone is looking at all the features within the genetic studies. Dr. Shapira answered that some studies are looking at clusters from genetic evaluations.

Ms. Singer thanked the speakers for the presentations and commented that they are important findings. She asked why it has taken 14-15 years to share these findings. Dr. Schieve agreed that such studies can take a long time. There is a lot of planning involved, and in this case there was an interruption in funding. They are about to celebrate the tenth year of the study. There is a massive amount of data, and the Data Coordinating Center needed time to do proper quality control of the data. It also takes time for the medical records to be extracted. With SEED 2, they just finalized the data collection phase, and data files are now ready, so there has been a lot learned from SEED 1. Ms. Singer asked if there is anything the Committee could do to expedite the process. Dr. Schieve suggested that they are getting faster, and they now have more graduate students to help.

Dr. David Amaral mentioned a gap area identified in the *IACC Strategic Plan*, which is the need for more epidemiological studies. He asked if any effort had been made to collaborate with genomic studies to foster cross-study integration. Dr. Fallin said that they do not have whole exome or whole genome data; they currently only have GWAS data. They are figuring out how to collaborate with genomic studies using the current consent model. Dr. Schieve reiterated that they do not have dedicated funding to finish the genotyping. They are re-consenting SEED 1 participants so they can share this data in the repository. They do have that consent for SEED 2 and 3. Dr. Amaral encouraged them to contact organizations leading genome sequencing initiatives to explore possible collaborations.

Mr. John Robison thanked them for their presentations. His assessment of these and earlier studies is that these mutations in the genome and significant illness or injury in mothers can result in severe autism in children. He also mentioned the association of fevers and autism as a valid finding, and said that concern was raised in the new Strategic Plan that when people hear about these associations, they may ask what the government will do about it. The second question is what should be done as a follow-up study. Mr. Robison believes that they should deploy this knowledge to explore the unknown issues in adults. Because of the studies' focus on children, lawmakers read the results of this work and may believe that autism is only a childhood problem. He hopes that these tools can be applied to research with adults.

Dr. Schieve thanked Mr. Robison for the comment and agreed. She suggested they could look at how this information might inform the limitations that autistic individuals experience as

teenagers. CDC is getting permission to contact these children and mothers in the future. Part of the discussion at CDC has been about how to continue to learn from the SEED kids who are now becoming teenagers. Mr. Robison reiterated that data from SEED Teen may not come out until 2030, and these results are needed sooner. Dr. Shapira agreed that studies with adults are very important. There are some constraints in terms of funding, where particular language restricts the areas they focus on. They are taking it a step further for a longitudinal study, which has not been done before. CDC researchers are learning about issues in children that can progress in adulthood, such as GI symptoms or risk for suicide. They are planning to investigate these issues in the SEED Teen project. Mr. Robison reiterated that this is a vital subject.

Dr. Mandell talked about the possibility of a handoff of this cohort, and asked if studies focusing on adults could be handed over to other study teams. He also asked if there is an opportunity to look at multiple environmental factors that result in impairment, and how could this be a next stage in the study. Dr. Fallin talked about their working groups that target these hypotheses. The topics are very intertwined, and the issue is defining a centralizing theme. Dr. Gordon asked Dr. Gwen Collman from NIEHS to talk about the environmental factors. Dr. Collman answered that child environmental exposure analyses can be looked at individually or by gene-environment interaction.

Dr. Bianchi asked what plans they have for sharing the data. Dr. Shapira talked about the data sharing policy as a requirement, and said they have reviewed data collected from SEED 1 and 2 and are investigating how the consent forms will make this data accessible for other investigators. Dr. Gordon suggested that NIMH would be happy to work with them to support this collaboration and data sharing.

## **Committee Business**

**Susan Daniels, Ph.D.**, Director, OARC, NIMH, and Executive Secretary, IACC

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

Dr. Gordon thanked Dr. Daniels, her team, and all of the working group participants for their work on the [2016-2017 IACC Strategic Plan](#). Some of the recommendations are already in progress. Dr. Daniels thanked the Committee and the working groups and said that she is excited to have this report ready for the community. Dr. Daniels welcomed Matthew Vilnit to the OARC team. There are three new publications available at the IACC website:

- The [2017 Report to Congress: Young Adults and Transitioning Youth with ASD](#). Dr. Daniels reviewed this publication earlier in the meeting.
- The [2016-2017 IACC Strategic Plan for Autism Spectrum Disorder](#). Dr. Daniels described this as a new plan, not an update, because it has entirely new text and objectives. It is a blueprint to guide autism-related efforts across federal agencies and partner private

organizations. The new objectives are listed in a table in the report as well as at the end of the chapters. One important decision of the Committee was to recommend that the new budget increase total federal and private autism research funding to \$685 million by 2020, representing a doubling from the 2015 funding level. This increase in funding would help jumpstart the new objectives in the *Strategic Plan*.

- The [2014-2015 IACC Autism Spectrum Disorder Research Portfolio Analysis Report](#). This is the 8th year of data and reporting on U.S. ASD research funding. The project data used in the analysis can be accessed through the [Autism Research Database](#) at the IACC/OARC website. There has been a general upward trend in the autism research funding level, which has increased by 35 percent since 2008. This report also summarizes progress toward completing the objectives that had been set out in the *2011 Strategic Plan*.

Dr. Daniels described three new IACC Working Groups:

- The Health and Wellness Working Group has a scope of health and general wellness, co-occurring physical and mental health conditions, practitioner training, and parental mental health.
- The Safety Working Group covers wandering, self-injurious behaviors, seclusion and restraint, and interactions with law enforcement.
- The Housing Working Group looks into research and best practices for housing issues and implementation of federal regulations.

Dr. Gordon asked the Committee to discuss and plan the goals and activities for these working groups. He recommended the Committee consider three things for this discussion: 1) what products does the IACC want these working groups to develop as outcomes?, 2) what structure would be most efficient to develop these products?, and 3) what is required to allow work to be completed by September 2019? Running the three working groups in parallel may be challenging, and a serial method is worth considering.

Dr. Amaral talked about a focus on training medical practitioners—he frequently hears that families are affected by the lack of this training. He suggested that the Health and Wellness working group could develop a consensus about the issues that need to be addressed within medical care, and then produce a white paper to be distributed to medical practitioners. A list of recommendations for families seeking medical care would also be helpful. Dr. Gordon thanked Dr. Amaral for his advocacy for this topic, and suggested a white paper to publish and distribute in collaboration with a professional organization.

Dr. Geraldine Dawson talked about how one of the Autism Centers of Excellence will focus on the co-occurrence of ADHD and ASD. She suggested that the working group could make recommendations for medical school training. Medical students do not have opportunities to work with people with ASD. Some good papers from the Autism Treatment Network give practice guidelines that are useful in terms of treating co-occurring conditions.

Mr. Robison was concerned that the Committee is charged with reporting to Congress, and that the Congress still labors under the misunderstanding that autism is a childhood issue. He would like to address this before making budget recommendations. Dr. Gordon said that NIMH does not make recommendations to that specificity, but does believe that this issue is important and that the Committee can talk about how to highlight the importance of adult issues.

Dr. Amaral suggested talking about how autism is a childhood problem, but that those children do grow up. There are adult issues, such as suicide, that show this as an ongoing problem throughout the lifespan. Mr. Robison reiterated that this is a lifespan issue, and other agencies such as HRSA and SSA need to understand this. Dr. Gordon pointed out that the Report to Congress about transition was requested by Congress. Ms. Melissa Spencer added that it is important not to just educate the doctor, but also the entire medical community. Dr. Gordon suggests that if a white paper is produced, it should be distributed to the medical community at large, not just the doctors.

Ms. Singer suggested that white papers tend to focus on recommendations for what others can do, and that this Committee might also focus on what they can do—for example, with the wandering issue. The topic of wandering was raised through public comment, and they worked together to identify the problem of lack of data and then were able to receive that data. She reiterated that they should focus on what the Committee can do and not what others can do. Dr. Gordon pointed out that important advances can be made via working group ideas.

Dr. Marcella Ronyak talked about webinars, which can be open to anyone, such as providers nationwide. The education system is another target. She talked about getting questions from special education teachers about her son's struggle with ASD in the classroom. She has asked those educators if they get funding for education and support, and they have said no. They may need to reach out to national organizations with tangible products for people like this. Dr. Gordon commented that this type of product, such as a slide deck or a written curriculum for educators, is another potential focus.

Dr. Ruth Etzel talked about the importance of pre-constructed questions that can be easily inserted into board exams, and mentioned that one possible product is a list of questions for these boards, which she suggested would be welcomed by the board examination committees.

Dr. Dawson followed up on the webinar idea, suggesting there are already a lot of good webinars in existence. She wondered if having the working groups collect and review these would be more efficient. Dr. Gordon asked about the current reach of such webinars and why they would not be reaching their target now. He liked the idea of a white paper because it puts ideas out there, but other products beyond that can also be useful.

Dr. Gordon moved to the second question about structure, activities, and timing, and asked again about the idea of staggering the working groups. Dr. Larry Wexler suggested that it can be hard to focus first on health and not on safety, which is not any less important than health, and he said that prioritizing one over the other would be challenging. Dr. Gordon reiterated that

this structure would not take any one topic out.

Dr. Gordon said that they will launch the Health and Wellness working group within the next few months so that all working groups can be finished by September 2019. The next step is for the working groups to meet. In the past this was handled by WebEx or teleconference. Sometimes groups want to do workshops, and that could probably be accommodated that with sufficient time for planning. Dr. Daniels explained that working groups can have external members. The Committee can put a list of those names together now, and then add goals and structure for each teleconference. She asked the Committee if this is the way they would like to conduct the working groups.

Dr. Amaral suggested an agenda would help bring closure to each action item. Dr. Daniels suggested that upcoming IACC meetings could feature speakers to discuss certain topics that could inform the working groups. Dr. Amaral asked if a meeting like that can be extended beyond its normal time. Dr. Daniels said that it can be hard to obtain approval for a meeting that goes beyond one day. Dr. Gordon suggested thinking about having it as a separate meeting and asked the Committee to make these suggestions to himself and Dr. Daniels. Dr. Daniels suggested that a 6- to 8-month timeframe might be too short for the planning required to bring experts in for a separate meeting.

Dr. Gordon summarized that the Health and Wellness topic could be the first working group, there would be a strategically planned method for conducting these meetings, and potentially some outside experts would be included. He asked if chairs have already been identified for this working group. Dr. Daniels said Dr. Amaral had volunteered to be a chair, and that they still need to determine whether anyone would like to serve as a co-chair. Later, Dr. Julie Taylor volunteered to serve as co-chair. Dr. Daniels added that [Autistica](#) in the UK is also looking at education products for adult health issues, and there may be a way to collaborate with them to prevent duplication of efforts.

Dr. Gordon said that the next working group topic would be announced in January. Dr. Daniels mentioned the requirement for the IACC to produce annual strategic plan updates, and that the working group outcomes can potentially be incorporated into that.

## **Summary of Oral Public Comments**

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

Dr. Gordon introduced the [Oral Public Comments](#) presentations.

Ms. Karla Shepard Rubinger introduced a new, forthcoming journal, *Autism in Adulthood*. Mary Ann Liebert, Inc., is the largest biomedical publisher in the world, and all their journals are peer-reviewed. Because they are independently owned, they are able to turn around actions very quickly. Autism in adulthood was addressed in the July 2017 IACC meeting, and now they are looking at soon launching this journal focused on the topic. Ms. Rubinger introduced Dr.

Christina Nicolaidis as the new editor-in-chief and the parent of a transition-aged son on the spectrum. Dr. Nicolaidis said that it is good to see the increased interest in the needs of transitioning adults, but that they still have a long way to go. This journal will be the home for research on autism in the transitioning adult. The journal will focus on new insights to guide clinical practice and policy. Dr. Nicolaidis has multiple appointments across disciplines and understands the need for a multidisciplinary approach for this journal, which will include autistic adults, so that perspectives from adults with ASD both in and outside of academia are included. Autism does not exist in a vacuum, so they aim to address the intersection of several issues in ASD. The aim is to publish the first journal in 2018. There will be an open-access option. Dr. Nicolaidis is looking for an editorial board, peer reviewers, and other people who may be interested in getting involved. She believes this journal can help serve the goals of the IACC by addressing the issues of ASD in adulthood.

Mr. Robison commented that it is great to see that the publishing world sees the importance of autism in adulthood.

Dr. Edlyn Peña asked if there is a website for the journal yet. Dr. Nicolaidis said that there is not yet one, but the development of a website is underway. The publishing company (at [maryannleibert.com](http://maryannleibert.com)) intends to publish a preview issue next spring.

Dr. Micah Mazurek from University of Virginia talked in her public comment about the importance of access to high-quality, evidence-based care. Children with ASD experience barriers to care, due in part to a shortage of trained professionals and specialists. Families in rural areas or with limited transportation options have significant unmet needs. Even those who are near specialist-care often face long wait lists. The goal of the ECHO Autism program has been to test a new model for access to care. [Project ECHO](#) (Extension for Community Healthcare Outcomes) was a project initially created for hepatitis C. They are using this model to translate to autism services. They use technology such as videoconferencing and training to provide assessment and care to populations with limited access to care. They are conducting a study of this model and encourage the Committee to consider the ECHO model as a way to close the research-to-practice gap and improve outcomes.

## **Summary of Written Public Comments**

**Karen Mowrer, Ph.D.**, Health Science Policy Analyst, OARC, NIMH

Dr. Karen Mowrer summarized the [Written Public Comments](#).

Fourteen individuals made written public comments, which were organized under seven broad topics. The first topic was the role of the IACC, with three comments. Comments included that previous written comments have not been addressed adequately and suggested that more time be set aside to discuss them. The second topic was autism research priorities, also with three comments. Commenters suggested that researchers prioritize individuals with severe impairment and their families, links between autism and brain injury, and the effects of soy on

brain development. The third topic was resources and support, including awareness about support services for transition-age individuals, and recognition of hyperesthesia in ASD. The fourth topic was heterogeneity, with two comments—one on the subject of neurodiversity, and one criticizing on the use of the DSM-5 definition in autism research studies. The fifth topic was concerns about medical practice, including umbilical cord clamping and brain injury from hypoxia. The sixth topic was vaccines in autism, which included comments about mercury and glyphosate, and a suggestion that the MMR vaccine be investigated. The last topic was wandering and suicide, which the commenter suggested often is a result of loneliness and isolation in ASD.

## **IACC Committee Member Discussion of Public Comments**

Mr. Robison discussed the concern about the Simon Baron-Cohen editorial about whether autism is a disorder or a difference, and how to characterize it. He suggested that, for any parent of a child who is unable to advocate for himself, the Committee must recognize its role to do their best to represent the best interests of all people with ASD. The Committee must be careful in their advocacy about speaking out for rights as well as for beneficial tools. There are social problems in ASD, but there are also other medical issues, and they must never lose sight of that.

Ms. Samantha Crane said that categorizing individuals by their level of functioning limits the diversity that exists across the spectrum. There may be an idea that, if she is here at this meeting, she must not have the medical needs that others do. Many people also deal with similar medical issues.

Dr. Amaral suggested that these points are well taken, and that the initial concern was about the general public's perceptions. If the families of those severely affected see autism as represented only by the adults with ASD serving on the Committee, then there is a perception that their children are not being represented. The issue is balance. Civil rights are an important issue, and there is a responsibility to represent people across the spectrum. Ms. Crane talked about how the Autistic Self Advocacy Network ([ASAN](#)) was the only agency to advocate during the latest reauthorization for increased inclusion on the IACC of those with significant needs. People with significant needs have to be empowered to speak for themselves.

Ms. Singer said that many people with that level of need are not able to come to the table and advocate for themselves, and instead they rely on their parents to represent them. Her daughter would not be able to sit at the IACC meeting table for more than five minutes. She asked if it makes sense to use the term ASD to also describe adults like those on the Committee who are able to represent themselves. To use the same terminology across the ASD population makes no sense. The needs that her daughter has are very important, just as the needs of people who are higher-functioning. Their needs are equally valid but still different. Members of the Committee need to talk seriously about bringing back the term "Asperger's" or perhaps a new word for ASD with more serious issues.

Ms. Crane talked about her own self-injurious behaviors and the compensatory approaches she uses daily. There are people who look like her but also need serious and intensive support at home. It is important not to make assumptions about level of need based on how people look. The IACC might look different if it included people with greater needs. Ms. Crane felt that the IACC is barely accessible to her, and wondered if that means changing the way the IACC looks and operates.

Dr. Gordon talked about the importance of this discussion and pointed out how intently focused the audience is on this topic. Unfortunately, there is no other way currently to describe the spectrum. He imagined that the decision was made because people in the room during the decision-making process could not agree on where the dividing lines are.

Mr. Robison responded to Ms. Singer by talking about their decade of experience advocating for autism science together. He talked about taking part in studies and learning about genetics, but that these biomarkers cannot separate him from an individual with much more significant needs. The wider community needs to know that they all want the best for everyone on the spectrum.

Ms. Singer reiterated that using a single term for such a heterogeneous population can affect services because the individual does not look a certain way. Mr. Robison asked if they should bring back the term “Asperger’s.” Ms. Crane disagreed and said that the term is too specific and that one of the reasons why the “autism” and “Asperger’s” terms were merged is that by adulthood, clinicians could not reliably tell the difference between the two populations. Dr. Dawson said that the DSM-5 now has specifiers, and that the Committee should start using those. Dr. Peña talked about how these specifiers were an important way to describe these differences. She also suggested that the Committee start using this language and talked about the importance of representation from minorities and individuals who communicate through technology-assisted language.

## **Autism and Suicide**

### **Suicidality in Autism**

**Sarah Cassidy, M.Sc., Ph.D.**, Assistant Professor, University of Nottingham, United Kingdom

Dr. Sarah Cassidy talked about her gratitude to the Committee for the focus on this very important topic. She introduced the [Mental Health Autism](#) (MHAutism) study and said that there have been very few studies about mental health and autism. There has been a priority-setting effort with families, educators, and researchers to ensure that research is more impactful. The key strategic areas identified from this effort include:

- Assessment and measurement
- Risk and protective factors
- Intervention/prevention

One highlight of the research they have been conducting is the application of models of suicidality to autism risk factors. One finding focused on the terminology that people with ASD use to describe themselves. In general, “autistic person” was most preferred by the autism community.

The majority of autistic adults also have a mental health diagnosis. Of those surveyed, 66 percent of 374 newly diagnosed adults with ASD had suicidal ideation, 35 percent had made suicide plans or attempts, and 31 percent had been diagnosed with depression. This is significantly higher than other known at-risk groups. A Swedish study found that autistic adults are significantly more likely to die by suicide than the general population. Being female, having autism without a learning disability, and depression are the most significant risk factors for suicide. This is a completely flipped risk profile, as in the general population most people who die by suicide are male. Most intervention and prevention strategies in the UK are aimed at men, but different strategies should be considered for autism. There are a growing number of “counting” studies, but there is not enough research about “why.”

These researchers first looked at assessment and measurement of suicidality in individuals with ASD. There were a number of challenges to this approach. Alexithymia could account for an under-reporting of suicidality. The question of “how do you feel” can be a difficult question to answer. Theory of Mind is another challenge, such that a literal interpretation of the question might affect assessment. Rigidity or reduced cognitive flexibility could also affect assessment of suicidality. This study had four stages: Stage 1 focused on a systematic review of assessment tools; Stage 2 used focus groups, interviews, and surveys; Stage 3 looked at measurement properties; and Stage 4 will establish the prevalence of suicidality in autistic adults in the UK.

The researchers are about halfway through these stages. From Stage 1 and 2, they learned there were difficulties with language, which could be addressed by breaking up the questions and having fewer options. There were difficulties with memory and time, which could be helped with the use of a diary or calendar. There was use of insensitive language, such that “commit suicide” can cause worry about the assessment. Color-coding of questions also created worry and distrust.

In terms of risk and protective factors, there were three studies. One looked at the Interpersonal Psychological Theory of Suicide, which states a person who dies by suicide must experience feelings of thwarted belongingness and perceived burdensomeness. They looked at whether autistic traits, such as social difficulties, social exclusion, and unemployment, are associated with these constructs. They found that autistic traits significantly predicted these constructs. However, this model was developed based on the general public, and there may be a difference when applied in the autistic population.

The researchers formed a steering committee of eight autistic adults who had experienced mental health issues and/or suicidality. They developed a survey to capture these experiences. The key themes that emerged were isolation—both social and not social (i.e., not being able to

get on the bus), lack of belonging, lack of opportunities in employment and education, social and communication difficulties, and camouflaging these difficulties (which led to limited access to care). Late diagnosis or misdiagnosis is also an issue because there is often no post-diagnostic support. Not having a positive identity during childhood and a sense of lack of resilience were also main themes.

The survey described in this study was completed by 168 autistic adults (67 male, 101 female) and 108 control females. It was a challenge to get a control group of males from the general public to complete the survey. The researchers found that Suicide Behavior Questionnaire – Revised (SBQ-R) scores were significantly higher than the recommended cutoff for psychiatric populations. There were specific risk factors in the autistic group, specifically related to camouflaging and non-suicidal self-injury (NSSI).

The researchers are also in the process of conducting the psychological autopsy study, which currently involves gathering data from coroner reports and interviews with family and friends. Analyzing these records for evidence of autism, the researchers found high inter-rater reliability in determining this evidence, which was categorized by the following groups: definite diagnosis, strong evidence of diagnosis, possible diagnosis, and no evidence. They found that 11 percent of those deaths ruled a suicide had evidence of autism, which is higher than the general population rate of 1 percent.

Suicidality is significantly higher among people with autism than in other psychiatric groups, but whether assessment issues make this an under- or over-estimation is not known. There does appear to be an increased vulnerability to risk factors for suicidality. This could potentially be related to autism-specific factors such as camouflaging.

Dr. Cassidy thanked the collaborators and the steering group who helped with this research.

### **Screening for Suicide Risk in Youth with Autism Spectrum Disorder and Other Neurodevelopmental Disorders**

**Lisa Horowitz, Ph.D., M.P.H.,** Staff Scientist and Clinical Psychologist, NIMH

Dr. Lisa Horowitz presented research that she conducted with Dr. Audrey Thurm. She focused on youth suicide and the unique challenges of screening in the ASD population. They are trying to adapt a suicide screening tool to be sensitive to individuals with ASD.

Dr. Horowitz reviewed the epidemiology related to suicide. She stated that suicide is the second leading cause of death for youth ages 10-24. More kids die by suicide than from the other seven leading causes combined. Over two million adolescents attempt suicide annually. Nine percent of high school students attempted suicide in the last year. Children under 12 years old do plan, attempt, and die by suicide, and it is a leading cause of death for this age range. There is scarce research in suicide in ASD populations. People with ASD are at risk for many disorders, with 123 percent higher rates of depression and 433 percent higher rates of suicide. As risk factors, a previous suicide attempt is the most potent factor. Medical illness is a risk factor that is often

overlooked, and isolation is another common issue that people with ASD experience. Some studies show that people in the ASD population with higher IQs tend to be at higher risk for suicide. People with comorbid Axis 1 disorders and recent psychosocial stressors are also at risk for suicide and suicidal ideation.

With regard to medical illness as a risk factor, these researchers have looked at the medical setting to determine whether suicide assessment helps save lives. Studies have shown that people who die by suicide are more likely to have been in contact with a medical professional in the 3 months before death—and 80 percent of adolescents do have a medical encounter before dying by suicide. There is a difference between screening and assessment, however; screening flags individuals who require further evaluation, and assessment is a comprehensive evaluation that confirms risk. This study used the Ask Suicide-Screening Questions (ASQ) in a medical setting, as compared to the gold standard of the Suicidal Ideation Questionnaire, to identify the questions needed to have a shorter assessment tool. The ASQ tool takes 20 seconds and has high specificity.

The researchers then looked to adapt this tool for the ASD population. People with ASD present with different challenges, and they are often excluded from screening studies. The researchers looked at both the intellectual disabilities (ID) and the ASD populations. In one study, they looked at a single question about the frequency of time periods in which a child with ASD talked about death or suicide, finding that 23 percent had talked about death or suicide “often” or “very often.” If these children had mood or anxiety disorders, they were more likely to talk about death or suicide. Those with comorbid ADHD were less likely to talk about death or suicide.

These researchers have launched an effort to test the ASQ for youth and adults with ASD. The Suicidal Ideation Questionnaire-Child Version (SIQ-CV) has also been adapted for ASD. A pilot study of ten participants found that six screened positive on the SIQ-CV, but only one had reported being asked about suicide in the past. On the modified ASQ, 100 percent were positive on the question “Have you ever thought about killing yourself?”

As a result of these findings, the researchers are calling for more population-specific tools that include youth with ASD. They are currently testing the ASQ for implementation with the ASD population.

### **Aligning National Efforts to Prevent Suicide**

**Colleen Carr, M.P.H.**, Deputy Director, National Action Alliance for Suicide Prevention

Ms. Colleen Carr talked about the efforts of the [National Action Alliance for Suicide Prevention](#), which started in 2010 but existed in concept before then. In 2001, there was the first national strategy for suicide prevention. In 2010, a coordinating body was launched, which became the Action Alliance. Their goal is to reduce the annual suicide rate by 20 percent by 2025. They work toward this goal along with their national partners. They use the [2012 National Strategy for Suicide Prevention](#) (NSSP) as a roadmap for action. Their partners include the federal and

private sector agencies, and some non-traditional industries represented by corporations such as Facebook, Kaiser, and Johnson & Johnson. These agencies and organizations come together to collectively make a difference.

Objective 12.1 from the NSSP, developing a [National Suicide Prevention Research Agenda](#), was accomplished recently and was followed up by a [Portfolio Analysis for Prevention Research Efforts](#) from 2008 to 2013. The average annual combined investment in suicide prevention research is \$71.6 million. Because suicide is the tenth leading cause of death, this investment is critical to reduce the suicide rate. They will be updating the research portfolio analysis in the coming years.

The Action Alliance has two guiding principles. One is reaching at-risk populations (including veterans, Service members, attempt survivors, survivors of suicide loss, and American Indians/Alaska Natives). The other is engaging with individuals with lived experience to inform and enhance future prevention strategies.

There has been the assumption that, once a person enters the healthcare system, that system is ready for people who are struggling with suicide. The Action Alliance is working to ensure that the healthcare system is ready by focusing on acute care transition practices, standards of care, workforce preparedness, follow-up care, and crisis services. They have also launched the [Zero Suicide](#) initiative, which is an evidence-informed quality improvement approach to improve suicide care in healthcare and behavioral health systems.

The Action Alliance focuses on community strategies by engaging with faith leaders and workplaces to become a part of the response effort. They also focus on media, entertainment industries, and other suicide prevention messengers to ensure that stories include accurate portrayals of suicide and that the content is a safe and responsible depiction. They have moved towards a shift from death and despair to hope and connectedness.

Ms. Carr talked about using a strategic approach towards suicide prevention. The Action Alliance also has a number of task forces to support their goal of reducing suicide by 20 percent. Ms. Carr has reviewed various suicide prevention resources and noted that each state has a local suicide prevention coordinator.

## **Committee Discussion**

Mr. Robison thanked the panel for this important discussion and reiterated that suicide is a big problem for the ASD community. He talked about personal experience with thoughts, and he believes that every autistic person has had similar thoughts. People like himself are absolutely at risk for suicide just as much as any other issue in autism, and being “good speakers” does not change that risk. Ms. Crane talked about how this ties in with a recent Kaiser study showing that people with ASD hospitalized for a psychiatric crisis are being poorly served. When people do not feel confident that suicide risk can be managed, they stay in the hospital longer. Also not knowing how to answer suicide assessment questions is an issue, and modifying these tools is

critical. Some research shows that people with intellectual disabilities (ID) are seen as less at risk, and Ms. Crane suggested that might be because their risks are not recognized because of communication issues. Self-harm might be confused with other injurious behavior. It may be hard to recognize when someone is intentionally harming versus not knowing the danger of behaviors.

Dr. Mandell asked about the implications of changing practices within care systems, including the education system, where suicide screening risk and safety planning may not currently be used, and how to approach this. Dr. Cassidy talked about how their steering group discussed and developed a training package, including videos and guidelines on how to conduct these assessments with people with ASD. Dr. Horowitz said that people used to whisper the word “cancer,” and in a way it is similar to how people talk about suicide now. Adding ASD to this anxiety makes the issue even more difficult. Adding structure and guidance will help.

Dr. Mandell wondered if they are missing an opportunity. He said that, for example, in a population that has perseveration in thoughts, using clinical settings may be a mistake because of the infrequency of the contact these individuals have with clinical services. But people with autism have more frequent contact with other professionals, such as in the school system or job coaches. He noted that this is a gatekeeper approach, but you have a more defined population. Ms. Carr talked about how this aligns with their efforts supporting communities. Life transitions, specifically something like job loss, may be a target. Dr. Horowitz mentioned that some schools do have programs to learn the signs of suicide. Peer-to-peer counseling has had some success with kids, who are taught to go to an adult if they recognize these signs.

Dr. Dawson wondered if their working group can call on this panel as they talk about tools. She is working with ER departments at Duke regarding the possibility of adding a questionnaire, and said that the results depend on the setting, timing, and who is administering it. She talked about visual supports with the questionnaire because even individuals with language ability could benefit from pictorial visualization. Dr. Horowitz talked about how they considered something like the pain scale with faces. Ms. Crane suggested that they check the self-reported literature about people with ASD having a hard time with the pain scale. Dr. Gordon asked about the risk in terms of learning disability and how confident they are in those results. Dr. Cassidy talked about one study with the ID population showing that there could be an issue with what is ruled a suicide in that population. There is a paucity of research on that topic.

Dr. Gordon asked about self-injurious behavior as it differs from suicide ideation and behaviors. Dr. Cassidy talked about a study with individuals who are minimally verbal and the challenge of teasing out those behaviors in these individuals. Dr. Horowitz talked about how, at their hospital, a nurse had accidentally assessed a child for suicide, and the parent did not think her daughter understood the questions. It turned out that she probably was not at risk for suicide, but she was depressed and needed to talk about some at-home issues. Suicide screening may also pick up emotional distress that needs attention, even if it is not specific to suicide.

Dr. Taylor talked about adult diagnosis and suicidality, and asked if there is research about the

effect of timing on these. Dr. Cassidy said that the steering group was made mostly of females who had been diagnosed as adults after previously being misdiagnosed. These women with ASD described a journey of self-discovery and relief with the diagnosis. They talked about masking one's autism and how that took a toll on their self-identity. And once they received the diagnosis, their sense of belonging went up, and they felt more hopeful. Some powerful statements came out of these descriptions. They do need to look at it more systematically in the future.

Dr. Gordon thanked the panelists for their presentations.

## **Summary of Advances Discussion**

**Susan Daniels, Ph.D.**, Director, OARC, NIMH, and Executive Secretary, IACC

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

Dr. Daniels reviewed the latest set of nominations for the [Summary of Advances](#), which are on the IACC website. These will be put up for a vote early next year.

[Question 1: Screening and Diagnosis](#) The Committee reviewed studies for neuroimaging in infants. NIMH is looking for evidence from neuroimaging studies on the screening tools for earlier diagnosis and for following the progression of the disorder. Dr. Dawson discussed the reasons why she nominated a study on social pragmatic communication disorder.

[Question 2: Biology](#) Dr. Bianchi reviewed a study about genetic control of where on someone's face one directs his/her eye gaze. Dr. Gordon talked about the importance of narrowing down behavior in genetic studies. This may be an example of how a specific behavior has a stronger genetic component than the complexity of multiple behaviors.

[Question 3: Risk Factors](#) Dr. Collman reviewed the study of teeth and environmental exposures to more precisely link them to windows of exposure. She also reviewed a study about air pollution exposure. Dr. Shapira reviewed a study about serum and cerebrospinal fluid and cytokines. Dr. Gordon talked about a cohort study of maternal antidepressant use. Dr. Dawson talked about the importance of this study in terms of the general public's understanding of these outcomes.

[Question 4: Treatments and Interventions](#) Dr. Wexler talked about a 4-year follow-up study for a LEAP intervention.

[Question 5: Services](#) Dr. Dawson reviewed a study about a cost-effectiveness model of early intervention services. Children with early intervention used fewer services later on, and the cost of the intervention was recouped. She also reviewed a study comparing ethnicity barriers in services.

[Question 6: Lifespan Issues](#) Dr. Taylor reviewed a vocational rehabilitation study in which the researchers used social network analysis to identify clustered groups. She also reviewed her study of job loss or college disruption, and what people transitioned into. Importantly, characteristics of the family predicted job status. Finally, Dr. Taylor reviewed another study looking at the relationship between adolescents' social media use and friendship quality, and the effect on anxiety.

[Question 7: Infrastructure](#) Dr. Gordon talked about studies focused on disparity. Dr. Dawson mentioned that this is another look at populations in geography. Dr. Wexler suggested that the study on male-to-female ratio may be a game-changer in terms of what is known about autism.

## Round Robin

Dr. Wexler provided clarification on the Department of Education rollback of rights of kids with disabilities. He said that these are guidance and policy documents that are no longer in effect or relevant. The regulations superseded this guidance, nothing was rescinded, and there is no rollback of rights.

Dr. Alice Kau talked about the [NIH Autism Centers of Excellence \(ACE\) program](#), which supports very large research projects with the goal of understanding underlying biological mechanisms and developing novel interventions. She reviewed the nine principal investigators and the collaborating sites.

Dr. Collman mentioned an ongoing funding announcement from the [National Institute of Environmental Health Sciences](#), which is specifically related to environmental exposures, including immune outcomes and metabolic outcomes.

Dr. Shapira talked about the CDC announcement of a new free app called [Milestone Tracker](#) to track developmental milestones, identify delays, and better enable sharing of that information with healthcare providers.

Ms. Singer mentioned the availability of research fellowships from the [Autism Science Foundation](#) (ASF) and the date of the [Fifth Annual ASF Day of Learning, which will be April 11, 2018](#).

Dr. Dawson talked about the [2017 Regional International Meeting for Autism Research](#), which took place in Africa, where the discussion focused on how to address needs despite having very few resources. She also mentioned the next meeting of the [International Society for Autism Research Annual Meeting](#), which will take place May 9-12, 2018 in Rotterdam, Netherlands.

Dr. Laura Mamounas mentioned an upcoming NIH-hosted workshop scheduled for December 7, 8, and 9 to discuss biomarkers that could be used in autism-related neurodevelopmental disorders.

Dr. Gordon talked about a new NIH initiative that will seek to look at the efficacy of screening 18- to 24-month-olds for ASD. A webinar on this topic will be held in March 2018.

### **Closing Remarks and Adjournment**

Dr. Gordon thanked the Committee and adjourned the meeting at 4:35 PM.

The next meeting is on January 17, 2018, at a location to be determined.