Minutes of the Interagency Autism Coordinating Committee
Full Committee Meeting

July 26, 2017

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a meeting on Wednesday, July 26, 2017, from 9:01 a.m. to 4:58 p.m. at the National Institutes of Health, 31 Center Drive, Building 31 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, 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; **Diana Bianchi**, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); **Linda Birnbaum**, Ph.D., D.A.B.T., A.T.S., National Institute of Environmental Health Sciences (NIEHS); **Josie Briggs**, M.D., National Center for Complementary and Integrative Health (NCCIH), National Institutes of Health (NIH), (representing Francis S. Collins, M.D., Ph.D.); **Judith Cooper**, National Institute on Deafness and Other Communication Disorders (NIDCD), (representing James Battey, M.D., Ph.D.); **Samantha Crane**, J.D., Autistic Self Advocacy Network; **Ruth Etzel**, M.D., Ph.D., Environmental Protection Agency (EPA); **Tiffany Farchione**, M.D., U.S. Food and Drug Administration (FDA); **Laura Kavanagh**, M.P.P., Health Resources and Services Administration (HRSA); **Walter Koroshetz**, M.D., National Institute of Neurological Disorders and Stroke (NINDS); **David Mandell,** Sc.D., University of Pennsylvania; **Meghan Mott**, Ph.D., National Institute of Neurological Disorders and Stroke (NINDS), (representing Walter Koroshetz, M.D.); **Kevin Pelphrey**, Ph.D., George Washington University and Children's National Medical Center; **Edlyn Peña**, Ph.D., California Lutheran University; **Laura Pincock**, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Louis Reichardt**, Ph.D., Simons Foundation Autism Research Initiative (SFARI); **Robert H. Ring**, Ph.D., Vencerx 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); **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) (attended by phone).

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 9:01 a.m. and Dr. Susan Daniels took roll call.

Welcome and Introductions

Dr. Gordon introduced two new members to the Committee: Dr. Marcella Ronyak, Deputy Director for the Division of Behavioral Health, Indian Health Service (IHS) Headquarters, whose focus is to increase access and awareness for IHS, and Dr. Laura Pincock, Pharmacist Officer for the Agency for Healthcare Research and Quality (AHRQ), who joined in January but was not introduced at that time.

The minutes from the last meeting were approved without comment.

Update from the Office of the National Autism Coordinator

Thomas E. Novotny, M.D., M.P.H., National Autism Coordinator & Deputy Assistant Secretary for Health (Science and Medicine), Office of the Assistant Secretary for Health, Department of Health and Human Services (HHS)

Dr. Thomas Novotny remarked that the interagency review of the report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorder was completed on Friday. It was a well-researched exploration of all the issues related to the transition phase that was sent around to several federal agencies for review. Dr. Novotny thanked the Committee for the substantive comments and said that they hope to have a public rollout in the next few weeks. The NIMH Office of Autism Research Coordination will support the effort with production of the report, and HHS also hopes to produce an accompanying journal article, which will help make it publicly accessible. There were recommendations from the Government Accountability Office (GAO) report about collaboration and interaction with the Federal Partners in Transition, which addresses the topic of transition generally, and HHS has made progress connecting with that group. Dr. Novotny said that the interagency working group that worked on the report to Congress established a good forum that he hopes will continue, and he believes the group has answered the recommendations from the GAO report. Dr. Novotny also thanked HHS Secretary

Dr. Thomas Price for his recognition of autism awareness, especially with a previous blog posting in April.

Dr. Gordon asked if the full report on the transition of youth with ASD to adulthood will be published on the IACC site. Dr. Daniels confirmed that it will.

There were no questions from the Committee for Dr. Novotny.

Mortality & Risk in ASD Wandering/Elopement: 2011-2016

Lori McIlwain, Co-Founder and Board Chair, National Autism Association

Ms. Lori McIlwain introduced the National Autism Association (NAA) as a parent-run organization and explained that this update represents the NAA's fourth update on wandering and elopement in ASD. The NAA addresses the most urgent needs of the community, looking at lethal and higher-risk outcomes first and then towards prevention across a range of issues. The NAA offers various educational and training programs. Since 2011, they have shipped almost 40,000 Big Red Safety Boxes to families in the United States in an effort to prevent wandering. They also work with the National Center for Missing and Exploited Children to notify them of missing minors with ASD, and have helped them with almost 400 cases.

The NAA started collecting data on wandering-related outcomes in 2009, and then began collecting data on all ASD missing person cases in 2011. From 2011 to 2016, they recorded over 800 cases of children and adults "found missing" (not reported missing but found while wandering) or missing. This is an underrepresentation of what is happening, but it represents those cases that were serious enough to report to the media. NAA used reliable media and agency information to determine the outcomes of these cases.

From 2011 and 2016, the outcomes included 139 lethal cases, 105 cases that required medical attention, 309 close calls (rescued from high-risk situations), 5 still missing, and 250 cases with minimal or unclear risk. Across the 139 lethal cases, 71 percent died from drowning and 18 percent died by vehicle. Six individuals died by train, four from hyper/hypothermia, two from falls, and four from other trauma. Across the higher-risk categories, the highest threat was water, followed by traffic. The "other" risk categories included abduction or predator involvement, suicide ideation or completed suicide, and the use of Tasers, physical restraint, or other police involvement.

Children aged 5-9 have the highest number of deaths, and children under age 5 have the highest lethal risk, with almost 60 percent of cases ending in death. Lethal risk drops after the age of 14. The lethal risk among females with ASD is higher than males with ASD, which is similar to findings in their previous reports. The NAA has seen a recent increase in average age for lethal cases, but the average age for non-lethal cases is relatively consistent with previous years. Drowning deaths tend to occur in younger ages and in females, and traffic deaths occur in older ages and in males. Race is also a risk factor, and the NAA is seeing a disproportionate risk among black individuals with ASD.

The year 2012 was exceptional in terms of risk, which is possibly attributed to higher temperatures. Risk of death was highest in summer and spring, and lower in fall possibly due to school transitioning. Time of day is a risk factor, where times of transition, commotion, or stress represented 39 percent of wandering. Between 9:00 P.M. and 9:00 A.M. is also a vulnerable time. The top place people left from was home, a school/school bus, or a relative's home. The top places people were found were near water or on streets. Increased lethal and injury risk occurred within residential settings, especially those that are unfamiliar, or near water. This is especially so in times of transition or commotion. Decreased risk occurred in more populated areas such as hospitals or schools, areas not near water, and in areas that supported quicker response time and response tools (i.e., silver alerts, tracking, Reverse 911). The NAA hopes that availability of these alert tools can be expanded.

Currently, about 20 cases of missing persons with ASD occur per month. Ms. McIlwain reviewed some example cases from July 2017. She remarked that the good news is that there is now more awareness and more rescues, but they are also seeing an increase in the risk of death. Awareness is still not widespread, especially in the southern states. There is also a disproportionate risk among African American individuals on the spectrum. The Alzheimer's community faces similar problems, but wandering does not result in as many deaths. That could be the result of training and awareness programs and initiatives.

Ms. McIlwain reviewed some technological solutions. Radio frequency tracking technology is a helpful technology—it does not use GPS, does not require a smart phone, and works under water. Proposed legislation known as Kevin and Avonte's Law would have expanded a radiofrequency tracking program to include people with developmental disabilities at risk of wandering or eloping. Ms. McIlwain emphasized the need to recognize that the effect of these cases goes beyond our communities, and thanked the members of Congress who have supported this bill.

Ms. McIlwain said that implementation of more widespread training programs and initiatives would help the pediatric community warn caregivers of the risk. They know that these children go to water, and they know that holidays and gatherings pose a risk—information like this should be known by caregivers and responders. They want to promote outreach and awareness for the ASD African American community. Ms. McIlwain also wonders if the Department of Justice can become more involved with the Committee. They are now seeing a crossover between elopement and suicidality, and it needs to be studied and discussed. Ms. McIlwain reviewed a case of a young adult who died by suicide after elopement, whose family members have become advocates. She suggested that the IACC should address this issue at future meetings. There are more materials available at awaare.org, and the NAA encourages people to download their toolkits.

Dr. Gordon thanked her for the compelling and important presentation.

Injury Prevention Strategies for Wandering in Families of Children with ASD

Paul Lipkin, M.D., Director, Interactive Autism Network at the Kennedy Krieger Institute

Dr. Paul Lipkin thanked Ms. McIlwain for her important presentation, and spoke about the process of developing the Interactive Autism Network (IAN). IAN is focused on ways to decrease morbidity and mortality for children and adults with autism. They conducted a survey of parents registered in IAN and asked about wandering behaviors in their children. About a thousand surveys were completed across the United States, and this was some of the first data showing high rates of wandering behaviors. The overall wandering rate is 49 percent in ASD, which is significantly higher than in neurotypical children. Of those who attempted elopement, 53 percent succeeded and were missing long enough to cause concern about safety. Police were called 31 percent of the time, 65 percent were a close call with a traffic injury, and 24 percent a close call with drowning. They saw the higher functioning children tending to escape because of anxiety and lower functioning children wandering for exploration or to a favorite place.

It was apparent that this is a common occurrence and needs more attention. There was some action—an ICD-9 code was extended from Alzheimer's to include ASD. There has been some research from the CDC and National Center for Health Statistics that verified these findings. The CDC study found that one-third of ASD children were wandering. Another study looked at preventive measures used by parents, finding that parents tend to use physical or electronic measures to prevent ASD wandering.

They collaborated with Johns Hopkins University and Kennedy Krieger Institute to learn more about elopement patterns and caregiver strategies. Using a survey, they looked at the preventive strategies deployed by caregivers and their perceived effectiveness, burden of use, and cost. The survey was launched a year ago from about March to September 2016. They surveyed parents of children age 4-17. The fundamental question of the survey was: "Does your child try to leave safe spaces and/or the supervision of caregivers?" They collected survey data from 867 people. Of those, 526 used ongoing preventative interventions and/or their child had elopement behavior. The average age of their children was about 11, and were mostly a male, white population.

The autism severity of this population was on the higher side with a mean Social Responsive Scale T-score of 90.3. There was also a high rate of co-occurring disorders. Parents reported high rates of intellectual disability, language disorder, ADHD, and anxiety. About one in four children had problems with aggression or self-injury. Twenty-two percent of the parents said that their child had no attempt at elopement within the last two years, but nearly half said that their child had an attempt in the last two years. About one-third of the children were attempting at least once a week. The patterns of elopement behavior showed that location was important, where most occurred from home, but also in public places such as stores, the classroom, or during transition. Forty-three percent were escaping an anxious situation, 40 percent from a stressful environment, and 24 percent during a conflict. Sensory situations such as noise or discomfort were high-risk situations, at 38 percent. The pursuit of a special interest was also a risk factor, at 27 percent. Other children exhibited behaviors due to impulsivity.

Ninety-six percent of parents used at least one intervention to stop their children from wandering. Environmental strategies used included deadbolts, special latches, or gates. Many employed other services such as behavioral psychology or the use of social stories. A small but significant number used technology such as GPS trackers, and those that did not use electronic devices used IDs. Overall, parents felt that these were basically effective tools. However, the families with high rates of elopement rated the effectiveness of their strategies lower. The higher the rate of elopement, the more strategies the family will tend to try. Parents were concerned about the financial burden of using these strategies, where those families whose child eloped at least once a week sometimes spent more than $5,000 out of pocket to keep their children safe.

Access to some strategies can be limited or costly, such as home behavioral specialists, school aides, or service animals. Security cameras and GPS did not show as much effectiveness as the lower-tech devices. School aides were considered very effective with few burdens, but could be limited by the school. Service animals were also considered effective, but high-burden. About half the parents reported their child taking a medication, with 16 percent using medications specifically for elopement behavior. Of the medications, benzodiazepines were found to be the most effective.

Dr. Lipkin concluded that simple interventions are generally rated as cost effective. Medications are perceived as ineffective. He suggested looking at strategies that were rated as highly effective but not commonly used.

Dr. Lipkin spoke about the topic of suicidality in ASD as a health crisis that needs to be considered going forward. There is little research on suicidality in ASD. There are few studies done, but the results one of study show about two-thirds of the adult ASD population in the U.K. contemplated suicide, as compared to 17 percent in the general population. In the U.S., there is some data from the emergency department at Johns Hopkins Hospital showing that 31 of 104 children with ASD screened positive for suicide risk. Of these, 12 were suicide attempts. Another study from Sweden showed that the leading cause of premature death in children with ASD is suicide.

In April, for Autism Awareness Month, IAN launched a survey called the Mental Health and Suicidal Behavior Questionnaire, looking at suicide behaviors and related factors for children and dependent adults with ASD. They have had 680 responses to date, and are running the survey through this September. Preliminary results show about 40 percent of children or dependent adults have suicide ideation, 10 percent had had some sort of plan for suicide, and 4 percent had an attempt. When asked when the first ideation occurred, the youngest age was 8 and median age was 10. Median age for an attempt was 14 and earliest attempt was age 9. Dr. Lipkin thinks this is very important data for the Committee. Wandering is an issue that needs to be addressed, and so is suicide.

Dr. Gordon thanked Dr. Lipkin for his presentation and agreed that adding suicide as a concern is important.

Committee Discussion of Wandering Presentations

Mr. John Robison commented that suicide in combination with elopement is a major problem and that there are statements from people who articulate why they run away, which is mostly to escape a stressful situation. But the parents have suggested that their children on the spectrum run away because they are curious, which may be an incorrect interpretation. In his view, it is the stressful situations that cause autistic children to flee. He wondered why it is attributed to curiosity. Mr. Robison suggested that there needs to be recognition that the stress response is an ordinary behavior, but that kids who have no other coping mechanisms respond by running away.

Dr. Gordon commented that the high number of cases is remarkable and asked the presenters what the research says about stress as an inducer of elopement and/or suicide and what the best protective measures might be. Dr. Lipkin said that the way the question was framed may be why it looks like parents attribute it to curiosity, but that this is the data they have now, and they do not currently have an answer for why.

Ms. McIlwain talked about case studies of children leaving a car and walking into traffic. There was an article about suicidality in a girl who did not get a chicken dinner that she loved and talked about hurting herself. In another case study, a child left his home because he did not get the dinner he wanted. These seem like small triggers, but they are huge to those kids. They are leaving the home because of some type of acute stress. It is an impulsive response, and they do not fully understand or care about the potential threats. Researchers need to decipher this behavior, especially in non-verbal individuals.

Ms. Laura Kavanagh talked about her family using the Big Red Safety Box and thanked Ms. McIlwain for the free resource. She asked if there is a way to disaggregate their data to attribute causes as being from parent report of children who are not able to articulate why. Dr. Lipkin said that it has been both a strength and a criticism that the data is strictly on parental report, rather than clinical information or patient report.

Dr. David Amaral agreed with Mr. Robison that stress and anxiety is underappreciated in ASD, and especially in those with lack of language. They have been focusing on differentiating anxiety from ASD. Once clinicians determine that a child has severe anxiety, in a lot of cases, the parents did not know and assumed it was part of the autism. There needs to be increased awareness. Parents may be misinterpreting why their children elope.

Dr. Gordon asked Dr. Lipkin if there was data that showed that benzodiazepines were the most efficacious medication, and whether that related to the treatment of anxiety and a reduction of the stress response. Dr. Lipkin said that the survey did not provide that level of granularity, but he thinks it is telling that those medications were considered effective.

Ms. Samantha Crane mentioned the elevated risk to the African American community. Her organization's research shows that there is a greater risk for police involvement in this community and that alternatives to deploying the police are needed. She suggested that in addition to talking about training police, they also need to talk about interventions that do not involve police at all. They need to be sure the training is truly relevant to the situation and that they are not perpetuating myths about autism. Some of these risk factors, like tending to go to water, can be normal behavior and not just about ASD. Ms. Crane suggested the need to be more precise in messaging. Water is a dangerous situation for all children. With respect to suicide, conflating suicidality and wandering could be a real problem. People with ASD have been dying from suicide for a long time. There is just now a heightened awareness of wandering. People with suicidality are not lost. Preventing wandering will not necessarily prevent suicide. She was concerned that the survey is asking the parent about suicidality rather than asking the child with ASD. Parents do not always know. Ms. McIlwain responded that they are helping first responders understand where to go to look for those who have wandered as quickly as possible.

Dr. David Mandell asked if anyone knew if safety planning was effective and if it has been adapted for people with ASD or disabilities. He believes it is a logical fit and perhaps should be a consideration for the Committee. Maybe they need to be talking about safety planning, especially in groups known to be high-risk. Dr. Gordon mentioned a study about a suicide screening being adapted for people with ASD and reiterated that if you do not screen, you will not know who has an elevated risk.

Dr. Ronyak spoke about her child who has high-functioning ASD. Her child was also diagnosed with ADHD and had to acclimate to ADHD meds. She asked if unmanaged co-occurring disorders would affect wandering. She wondered if his wandering is caused by the ADHD, anxiety, or social skills. She wondered about asking the child about suicidality—considering her own child thinking about running away and death. She wondered if this something he picks up at school, and if you can be as young as seven and think about running away because of something you cannot handle at home. She said that she realizes that there may be IRB problems with the question, but reiterated the need to be able to ask the child because parents just do not always know this information.

Dr. Edlyn Peña asked if there have been any studies about black families being disproportionately affected by wandering. Ms. McIlwain pointed out that most reported outcomes were based on media reports, and that it is important to focus efforts on specific outreach to the African American population. She talked about the need to put out warnings during holidays that wandering tendencies may increase and guidance about what can be done to prevent it. They need to find ways to reach this population – to prepare and not scare. If programs can be established through law enforcement and fire fighters, they can reach more on the ground, since not enough is happening with pediatric physicians.

Dr. Larry Wexler asked Dr. Lipkin how they identified participants because parents of kids with more significant autism are on the lower bound of the survey since those kids are identified early. He suggested that it is important to track the identification age in research. Dr. Lipkin said that participants are invited, and that the level of severity is in the data. Dr. Lipkin said that the mean age of their study is about 13-15 and they are not representing a younger cohort. Every large population-based survey has strengths and weaknesses.

Dr. Linda Birnbaum brought up the lack of participation in African American, Hispanic, and other communities and said that they have to actually engage with these communities, not just provide outreach.

Mr. Robison reminded the Committee that childhood is only one quarter of the lifespan, and that they need to keep pressing researchers to include autistic adults because this is most of the population. The true numbers of suicide are likely higher because of this population. Dr. Lipkin said that his survey only covered dependent adults, and that there was no data directly from those adults. Dr. Louis Reichardt mentioned the SPARK Study had recruited both dependent and independent adults. Dr. Lipkin said that about 2,500 adults have registered and that IAN was an active partner in the SPARK study.

Dr. Julie Lounds Taylor said that it is important to think about embedding suicidality in mental health surveys. However, she wondered if a question about suicide would prevent parents from participating. She felt that researchers need to embed these questions into larger surveys. Dr. Lipkin said that the research community is very nervous about this issue; it’s very difficult to ask families these questions and therefore hard to conduct research. The same goes with wandering—it is not easy research to do. But these are life and death issues and organizations like the NIMH and CDC need to perceive these issues as critical.

Dr. Diane Bianchi asked whether biological research has been done about the attraction to water, and if there is an opportunity to address prevention. Ms. McIlwain said that there has not been any research of that topic, and it is still an outstanding question. These children are trying to get to a quiet place, to libraries, gardens, or cemeteries. The drowning cases may be the kids going to a quiet place.

Ms. Crane asked about the suicide survey. There are suicidality surveys for the general population, there is a robust effort to screen, and the data is available from the NIMH and CDC. She asked if there an extra hurdle preventing researchers from tracking this in the ASD population. Some researchers say that the IRB says that autistic adults cannot consent to this type of study and that is alarming. She asked if that is the reason this data is not being tracked or if there is there another reason. Dr. Lipkin said there is a lack of awareness on this issue, and they are hoping to bring further awareness. He would maintain there are some obstacles in asking these questions, but the obstacles to doing the research are mostly about limited funding and limited researchers in the field. Dr. Gordon mentioned that the CDC tracking is based on death certificates, which would not show a diagnosis of autism. Ms. Crane stated that she believed there was also a tracking of suicide attempts. Dr. Gordon suggested that attempt data would come from emergency wards and not in-depth surveys that would reveal diagnoses.

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. Daniels introduced the OARC newsletter, as a new effort to keep people informed about the work of the IACC. They hope to include new features such as interviews and videos, and they welcome feedback from the Committee. OARC and the NIMH Office of Research on Disparities and Global Mental Health have collaborated to organize an upcoming event in the fall, which will be a panel discussion on autism in girls and women. The tentative date for the seminar is September 19 in Rockville, MD. Speakers will be discussing different aspects of this issue, and it will also be webcast and accessible to the general public. There will be an announcement in upcoming emails and posted on the website.

Dr. Daniels gave an update about the portfolio analysis. They are in process of completing the 2014-2015 IACC ASD Research Portfolio Analysis Report and hope to have it published for the October meeting. She requested that three to four Committee members volunteer as consultants to determine if they should add new funders or refine definitions in the 2016 version of this report.

Dr. Daniels reviewed the new 2016-2017 Strategic Plan that covers services and research issues. The OARC staff has edited the seven chapters. The goal now is for the Committee to review and approve the new Strategic Plan. There are 13 sections to the new plan, including chapters for Questions 1-7, a section on duplication of effort, and a budget recommendation. Dr. Daniels led the Committee through all section reviews.

Introduction: Dr. Reichardt thought the introduction was quite good. Mr. Robison, who created the first draft of the introduction, said that a good job was done by OARC to make this section a coherent whole. Mr. Robison said there were minor edits that he will email to Dr. Daniels. Dr. Daniels asked to receive edits and comments for the entire strategic plan by August 4.

Vision, Mission, and Core Values Statement: OARC took comments from the last review of the statement and incorporated some of the new ideas. Dr. Bianchi asked if the term “consumer” is required. Dr. Daniels said that this was the original language, but that it could be changed. They did not want to use the term “patient,” but “community member” or “community focused” could be an alternative. Ms. Crane wants to keep the focus on the autistic individuals, and that the family and individuals can also be specifically named. She said that “consumer” is a very common term in mental health. Dr. Daniels suggested using “individual” and “family member.” Mr. Robison said, in the core value on “spirit of collaboration,” they should specify that they will listen to diverse people, but also specific autistic views. He suggested that, in the core value on “sense of urgency,” they should focus on steps to rapidly and efficiently address the needs of people with ASD, but they cannot lose sight of the importance of long-term gains from research. In the “ethics” portion of the statement, he requested that quality of life be listed as the first thing rather than the third.

Dr. Gordon asked to focus on the language—to change “consumer” to “community” or to “individual and family-focused.” Dr. Birnbaum did not want to lose the word “community” in the top paragraph. Ms. Crane agreed to include it and there was no objection to this from the Committee. Dr. Gordon asked for proposed wording about spirit of collaboration and if “thoughtfully consider public input” included everyone else. Mr. Robison suggested “individuals with autism and their families.” There was no objection from the Committee to this language. Mr. Robison suggested adding, “we will focus on responding rapidly and efficiently to the needs and challenges of autistic individuals and their families,” to address the sense of urgency and then cover the long-term aim in the paragraph on excellence. Dr. Gordon wanted to ensure that “autistic individuals” in place of “individuals with ASD” covers everyone, and suggested “people on the autism spectrum and their families.” There were no objections by the Committee to this language.

Dr. Gordon reviewed the language and said that he wanted to be sure to communicate the respect for people with autism and what they bring to the table. He also felt that “the public” adequately includes the scientific community as well. Dr. Birnbaum suggested that “community” is an inclusive word and that the ASD community includes a broader group that exclusively autistic individuals and their families. Dr. Gordon reviewed the final language, “We will treat others with respect, listen with open minds to the diverse views of people on the autism spectrum and their families, thoughtfully consider public input, and foster discussions where participants can comfortably offer opposing opinions” under Spirit of Collaboration. Dr. Gordon suggested that it is unnecessary to add “community” to this sentence because the community is addressed well in the next slide. The new language conveys the notion that they want to include multiple perspectives and that individuals are distinct from the others. Dr. Gordon moved to approve this language. There were no further comments from the Committee.

Overview of ASD Research Funding**:** This is a summary based on the portfolio data. Dr. Amaral said that the OARC did a great job on this section and that he sent in some minor edits. He thought that, at the end of this section, increased funding shouldn’t come at the cost of reducing funding elsewhere. In other words, it should not be a zero-sum game. Dr. Daniels agreed that this point could be reiterated. No further comments were made on this section.

Question 1 - Screening and Diagnosis: The objectives presented to the Committee were streamlined so as to be in a consistent format and to address redundancies. Dr. Kavanagh had two minor suggested changes that she will email. Dr. Mandell wondered if someone could help him understand how one of the examples associated with objective 1 fits there, as it seems to be a value statement and does not make a recommendation about what should be done or how it can benefit the evidence base. Dr. Mandell wanted this issue to get the attention it deserves, because the tools and programs are lacking, but this does not seem to be the appropriate place to call it out. Dr. Daniels asked the writers of this section for comments. Dr. Walter Koroshetz asked for clarification about whether the problem was the wording or the placement under the first objective. Dr. Mandell confirmed that his comment was related to placement. Dr. Gordon suggested that reducing disparities means that they exist and need to be reduced. Dr. Mandell said that the goal should be to ensure that the benefit of universal screening is equal among subgroups, specifically to improve early detection in girls and those with intellectual disability. Dr. Kevin Pelphrey said that there is a scientific component to this that should not be lost; they want research redirected at this gap and also want to test if there are differences in outcomes as a result of that early detection. Dr. Mandell agreed those are important questions and suggested that the Committee think about the goal and how they are meeting this goal when the annual portfolio analysis is discussed. Objective 1 is not about improving early detection, but rather increasing the evidence base. Dr. Gordon suggested "these designs must pay attention to special autism populations such as…" Dr. Mandell agreed on this language, if that language is the intent. Ms. Crane suggested "individuals with intellectual disability." Dr. Daniels agreed with this language and there were no other comments by the Committee on this specific section.

Dr. Reichardt expressed concern and suggested that there should be another round of discussions prior to approval of the Strategic Plan. Dr. Daniels reminded him that the entire Committee is required to be involved in the approval process and asked if there should be an extension for another round of revisions. Dr. Reichardt suggested a two-step process including another set of conference calls, followed by final approval in October. Mr. Robison reminded the Committee that this is six months late and suggested that the Committee vote for approval today. Dr. Daniels pointed out that the role of this document is to help set priorities for ASD research and services, and unless it is completed, it cannot be used to advise anyone. Dr. Gordon suggested the Committee continue the review chapter by chapter and then discuss whether to accept the document or not.

Question 2 - The Underlying Biology of ASD: There were three objectives presented for this question area. The Committee had highly prioritized research in women and girls, and wanted to propose a cross-cutting objective to support the underlying sex differences in biology, specifically for girls and women. They called it "cross-cutting" so that projects looking at ASD in females can eventually be coded to their appropriate Question area while still allowing funding to be mapped to this cross-cutting objective. Dr. Reichardt and Mr. Robison supported this. Dr. Taylor asked why this proposed objective was placed under Question 2, and Dr. Daniels suggested it could go anywhere because it is cross-cutting. Dr. Pelphrey supported the concept, and felt it belonged at the beginning, or maybe even earlier in the report. Dr. Koroshetz asked if there were certain edits that removed draft language, and Dr. Daniels confirmed that some sections were shortened to conform to a uniform length across chapters. Dr. Reichardt suggested that there are some topics, such as sex differences, were not included and should be added, but that they could likely be addressed with just a few sentences. He will email Dr. Daniels with specific suggestions. Dr. Amaral mentioned that some of the topics Dr. Reichardt is suggesting be added to Question 2 may already be covered in Question 3, and felt that the topic of animal models was covered well in the chapter on Question 2.

Dr. Bianchi suggested that the topic of genetics is covered in Objective 3 and that they have to consider that complete health records for an individual must include the health records of the individual's mother, in order to include the *in utero* period. As written, she felt the language was imprecise. She suggested, "preconceptual screening data" and "prenatal records" might be good language. Ms. Crane felt concerned about this language and that it may be politically charged. Dr. Birnbaum mentioned that there is data that shows that it is also important to consider environmental exposures, not just genetics. Dr. Gordon argued that the language read by the community writ large matters, and that "complete health records" means all of the data. Ms. Crane asked to finesse that language to "health records to the child and parents." She was concerned that language could bring fears of eugenics and other sensitive issues. Parental health is relevant, but it will not necessarily be read in the way it is meant. Dr. Bianchi suggested that since the embryonic stage is within the mother's health data, it would be appropriate to use "complete health records from the child and parent" and strike the time period.

Question 3 - Risk Factors: Dr. Koroshetz asked for a point of clarification about the survey of twins with autism that was cited. Dr. Amaral answered that it was a review paper describing a meta-analysis that showed 45 percent concordance for monozygotic twins. Dr. Reichardt said that there were a few sentences about evolution in the sex chromosomes that he wished were in this section and that he will send suggestions by email.

Dr. Daniels added that since the last meeting, revisions had been made to this chapter about environmental factors and reducing disabilities. Ms. Crane added that the language on genetic counseling may be interpreted in a way that causes alarm in the community. Dr. Amaral answered that this point is important and that there are still many questions about how this kind of genetic information should be delivered to individuals, but we find out more from genetics studies about autism and other long-term diseases, there will be implications for lifetime health. He felt the Committee should not ignore the issues if the benefit of this research could help someone. Dr. Reichardt added that genes identify targets for treatment that people would find positive. Ms. Crane asked if it can be worded as "gene-targeted interventions" to specify why they are focusing on this. Dr. Bianchi added that for any fetal sonographic abnormality, a chromosomal microarray is the standard of care. This test is able to identify variation in parts of the genome associated with some forms of ASD. Part of the research community's responsibility is to provide an evidence base of accurate information to help doctors provide solutions. Dr. Amaral said that the benefits go beyond gene-targeted interventions. Some of the mutations may have long-term implications that the family may want to be aware of. They need to think about how to present this kind of data, although it is a complicated question. He suggested they think about how to inform a family about the implications of these findings.

Ms. Crane said that the question is how to capture that nuance with one sentence in this report. Dr. Bianchi said that one wants to communicate the need for an evidence base to provide data on the complexity of risk genes to inform family discussions. Ms. Crane said that being accurate about the risk is not enough to make a decision without also informing about quality of life and resources available. It is not enough to say that your child will have a disability without also talking about what the implications are. Dr. Amaral said that the primary point of the sentence is to identify risk genes and clinical outcomes. It is impossible to answer that question now, in terms of cause and effect, until there is more information.

Ms. Crane was not sure they can come to consensus about genetic counseling that will fully address the needs and concerns of the community. Dr. Daniels suggested taking out "clinical effect" and "causal relationship" and addressing the topic later in the text. Ms. Crane added that parental concerns and attitudes can remain in the objective. Dr. Peña suggested the sentence end after "clinical outcomes," rather than "causal relationship" and "genetic counseling." Dr. Bianchi added that this wording is about adding to the evidence base and is important. Dr. Pelphrey suggested changing "causal" to "complex." Dr. Stuart Shapira added that this topic is larger than genetic counseling. By the time genetic testing is done, the child is often a little older, so the counseling is to best understand the relationship between the genotype and the potential phenotypic outcomes. It is more about what it means to have a specific genetic variant as opposed to affecting prenatal counseling. Dr. Koroshetz talked about his work with Huntington's disease, and there was fear among the community that the genetic information would be given out without the counseling. Dr. Amaral said that both sides of the discussion are important, and how you explain the presence of a mutation is important.

Dr. Gordon refocused the Committee to approve the language that is there. He suggested they can appreciate the nuances involved, but can agree that understanding the genetics and the potential outcomes is important. Dr. Wexler suggested that this counseling is being done, and that the Strategic Plan is a public statement referred to by people applying for grants. Excluding counseling might not be the right message to send to people writing grants to do research. From an organizational standpoint for what this Strategic Plan is supposed to do, he suggests the Committee should consider the language from this point of view. Dr. Gordon took a vote to approve the language as is, and the Committee voted to approve.

Question 4 - Treatments and Interventions: Dr. Daniels received feedback that more robust discussions about certain therapies and interventions in diverse populations should be included in this chapter. She asked if there were additional items to discuss. Dr. Amaral said that all of the topics mentioned in the feedback will need substantial revision. In terms of this document leading the way for research over the next few years, he said they need to highlight that this represents a big gap in research and need to invest more resources in this area. One issue is that stratification of the autism population is important, but this does not come into play in terms of clinical trials. Dr. Daniels said that there are members of the Committee that can contribute language on the use of stem cells. Dr. Mandell said that it is not clear from the summary what the gaps are in behavioral research. Perhaps this is leading to objectives that are broad, except for on the topic of technologies. If this is going to set the research agenda for the next few years, he does not think these gaps have been adequately addressed. Dr. Reichardt added that they need ways, similar to what is being done in cancer, to direct drugs specifically to where they are needed. Dr. Amaral mentioned that the biomarkers of treatment outcomes are important and should be seen as a remaining gap. Dr. Daniels suggested that this chapter needed substantial revision.

Question 5 - Services: There were no comments from the Committee about this section.

Question 6 - Lifespan Issues: Dr. Mandell said that this is a good chapter, and his only question was about the need for a prevalence study in adults. Unless they think the prevalence has changed, the bigger issue is the need to identify individuals with autism. Ms. Crane does not think the prevalence has changed over time, but there is debate on the topic, and it is therefore something that needs to be studied to settle the question. Policy advocates need this information to identify the scale of need for autistic adults. They also need studies on identifying and developing better measures. Dr. Daniels said that the need for identification of autistic adults should already be included in the draft.

Question 7 - Infrastructure: There were no comments from the Committee about this section.

Duplication of Efforts Statement: There were no comments from the Committee about this section.

ASD Research Budget Recommendation: Dr. Daniels said that the Committee discussed the requirement to have a budget recommendation. They addressed lifetime costs, research opportunities, and other rationales in the narrative. OARC has been collecting data on research funding and has tracked this to see how much purchasing power the autism research budget has lost over time. They do have an idea of the important research areas that need additional investment. For developing a specific budget recommendation, there are four options to consider, reviewed by Dr. Karen Mowrer: 1) to maintain a steady growth in the research budget, 2) to recoup dollars lost to inflation since 2008, 3) to return to the historic high of 2010, and 4) to significantly grow the autism research budget.

Dr. Reichardt asked if it is possible to have a fifth option based on a calculation of the cost of doing science because the rate of inflation in science is somewhat greater. Dr. Mowrer explained that their calculations used the rate of inflation for research. Mr. Robison asked about how the Congress and Senate determine budgets for research and about how the President's proposed cuts to the NIH budget affects this. The Committee decided to look at the entire autism research budget as a whole because each objective is so broad and complex. The Committee's job is to make a recommendation on the budget. Dr. Reichardt added that, in this context, they should be aspirational. Dr. Gordon suggested that in order to accomplish everything in the plan, the budget requirements would need to be a lot higher than a doubling of the 2015 autism research budget to $685 million. They do not want to give the false impression that whatever number they pick would cover everything proposed in the Plan. Dr.

Peña reminded the Committee that federal employees in general cannot make recommendations to Congress, but they can make recommendations when serving in the role of a Committee member on this Committee. Dr. Gordon reminded the Committee members that all members, including those that are agency representatives, have been asked to recommend a budget for the Strategic Plan. Dr. Daniels added that federal employees are also permitted to abstain from voting on recommendations, if they prefer.

Dr. Gordon reminded the Committee that there were four options on the table. Option 4 was the most ambitious, and the least ambitious was Option 1. He asked for the discussion to be a concrete discussion of a new option, or a discussion about these four. Dr. Gordon asked the Committee if there was a motion to approve Option 4 to double the budget. Mr. Robison asked if they should ask for three years to double. Dr. Reichardt recommended to double the budget within five years from last year. The Committee approved Option 4. Dr. Gordon summarized that this recommendation will be made, along with additional text explaining that the recommended is not enough money to do everything in the Plan, but that it is a reasonable start.

Dr. Daniels asked if there should be a shift in the balance of the autism research portfolio. Mr. Robison suggested there should be a shift to more lifespan and services to correspond to the new Strategic Plan. Ms. Crane agreed and added that research in the other areas that pertain to adults are put into Question 6. Only 2 percent of funding is currently going toward this need. Dr. Taylor added that they might want to focus on Question 4 as a short-term goal. Dr. Gordon asked to go on record against making recommendations on a shift in balance. He said that they do not know what research proposals will come in and that his preference is to keep recommendations general rather than picking out specifics.

Dr. Mandell was concerned about not having good scientists to go into some of these areas and would like to add language about the importance of developing the science workforce in specific areas of need. Ms. Crane agreed that getting too specific is not a good idea, but that 2 percent of research funding for research on adults with autism is much too low. Dr. Koroshetz agreed that 2 percent was not defensible and that this area of research requires more attention. Dr. Daniels suggested that language can be added about the need to prioritize translational research and research across the lifespan. Dr. Gordon agreed that 2 percent is not defensible, but other Question areas such as 2 and 3 also address the adult population. Dr. Daniels asked for comments to be submitted by August 4, and OARC will incorporate those into a draft that will be shared among the working group chairs. There could then be the possibility of a phone call with the Committee, in needed, rather than bringing the draft back for discussion at the October meeting. After the discussion, the Committee voted in favor of approving the Strategic Plan with the changes discussed and a review from the working group chairs.

Oral Public Comment Session

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

Dr. Gordon introduced the Oral Comments Session and said that there will be opportunities to have brief discussions about each of the presentations.

Thomas Frazier, Ph.D., Chief Science Officer at Autism Speaks, provided an update of their science portfolio. The goal of the Autism Speaks MSSNG project is to collect 10,000 genome sequences and make the data freely available for autism research. They currently have 5,205 genomes on Google Cloud. A 2017 study that was published in Nature Neuroscience used this data to identify 18 new risk genes. The Autism Network has achieved a few milestones, including 100 published manuscripts and 7,000 participants enrolled in the Autism Treatment Network. There are eight new pre-doctoral fellows being supported by Autism Speaks for 2017, dedicated to autism science. A number of the fellows provide blogs on the Autism Speaks website. As part of their strategic planning process, they have made created a survey for the full range of autism stakeholders. To date, they've received more than 5,000 responses, most of which came from mothers of children with ASD. They hope to disseminate results from this study soon. They have a unique role in funding novel projects to target autism subgroups, and are talking about transitioning the Autism Treatment Network to a Learning Health Network with clinical trial capabilities.

Carol Weinman, Esq, is a criminal attorney and mother of a son with autism. She brings her expertise in law and autism together to specialize in crime in autism. She hears a lot about victimization and wandering, but a lot of people are not aware of how many of these people are becoming criminal offenders. Part of this issue is related to the unique characteristics of individuals on the spectrum, and they do not always understand the consequences of their behaviors. There are those who are getting arrested and those who are interviewed by police or in the courtroom. There are unique concerns with approaching this issue, and there needs to be a heightened awareness. There can be police training, so that when they see this behavior, they recognize the autism. And there is a need to train the prosecutors to not handle these cases in court in the same way that they handle other cases. Prosecutors and judges do not understand autism, and do not understand that there is no intention of criminal activity. Their main concern about an individual is if will they do it again. They find that when they teach individuals with ASD that these behaviors are considered criminal, they will not do it again. She also spoke about the occurrence of sex crimes and that there is not enough education on this issue. Many take to the Internet out of curiosity. It is mostly males who are getting arrested, and once they enter the federal system, many of them have to be registered as sex offenders. This is a vulnerable population with so many challenges and on top of that they are given a criminal record. She said that her job is to prevent them from getting that criminal record. Dr. Koroshetz asked if there is data out there about involvement with the justice system. Dr. Daniels said there has been some published research, and they can potentially follow up on this topic at future meetings. Mr. Robison said that he also serves the judiciary branch as an expert in autism in criminal cases, and one problem in unraveling autism and other psychiatric conditions is that this information is sealed, and so there are restrictions on speaking about or publishing information about these kinds of cases.

Mary Jo Lang, Ph.D., P.N.P., B.C.B.A.-D, talked about antecedent management before an individual gets to the criminal system. One of the challenges is that teachers are not properly prepared. She has a school with 100 students, and the problem is that the teachers may have had one course addressing autism, which is not enough to apply knowledge to a complicated situation. The parents too are grieving and angry, and there is limited mental health resources for these parents to learn to deal with this. Even those with resources do not learn how to fare well in dealing with autism. She talked about serving students who are moderately to severely affected and have been through crises. If this happens at a young age, by the time the child is an adolescent and they are ready to transition to the workplace, it is very difficult to educate the public. The news does not give the necessary information about the integration and resources that are needed to take place for support. Inappropriate sexuality is a problem that will keep people from public benefits, jobs, and from experiencing an overall quality of life.

Margaret Gautier is a parent of a child with autism who is in the public school system. Part of the issue she has encountered is that the school system is unable to properly determine each child’s level of functioning and that there needs to be a way to pull the information from specialists, teachers, and tests to come up with a way to educate these kids. The State of Virginia has the Standards of Learning (SOL), but it is not a functional curriculum for kids like her child. The teacher is responsible for coming up with his or her own curriculum to map to the SOL. There is a lot of inconsistency in the public school system. They do not have centers, or a place for teachers to come together and discuss how to address these kids. Sometimes teachers are so burnt out that they do not have the energy to remain dedicated to the cause. There is a benefit to having more technology in the classroom. The public school system is inconsistent about whether and how they use technology. In addition, training on how to use technology to better serve these children is not mandated. The government needs to help more to standardize autism as a service and to make it a specialty within the medical field. Her son can learn and interact through technology because he does not have to interact with people. She has asked her public school system to use programs to help him, and funding is always a problem or they do not know enough about the technology. There needs to be more oversight in the school system, and it needs to be from a higher authority and not left to the states themselves.

Link to the list of Oral Public Comments

Summary of Written Public Comments

Karen Mowrer, Ph.D., Health Science Policy Analyst, Office of Autism Research Coordination, NIMH

Dr. Mowrer summarized the Written Comments. The IACC received comments from 17 commenters organized under six broad topics. The first topic was autism research priorities, and they had nine comments for this topic as described in the Written Comments list. The second topic was the role of the IACC, with five people commenting. The third topic was transition to adulthood and adult services. The fourth topic was autism resources and support, and there were two comments. The fifth topic was vaccines in autism, with two comments. The last topic was the IACC Strategic Plan for Autism Disorder, with one comment. The IACC thanked everyone who submitted written comments.

Link to the list of Written Public Comments.

IACC Committee Member Discussion of Public Comments

Dr. Gordon encouraged the Committee to discuss the oral and written comments, especially since it was raised as a request. Mr. Robison asked if they could do a roundtable discussion to address these concerns at greater length. He recognizes how important it is to the people who write or present comments or in person. Dr. Gordon suggested that the Committee discuss some of these comments in more detail today.

Mr. Robison asked what is the tradeoff between acceptance, prevention, and cure as a topic. Some have said that if their autistic child could speak the way he does, they would consider them cured. He gets letters from people on the spectrum who say they want to be cured and that the IACC is made up of neurotypical people. Mr. Robison asked what others on the Committee thought. Dr. Daniels said that the topic is in the Strategic Plan and could be highlighted further. Dr. Bianchi mentioned that this topic also comes up in Down’s Syndrome. Prospective parents make a distinction between an unborn child with no personality and a born child who experiences life and has a personality. She said they do not use the word “cure” either, they say “growth.” Treatment is a complicated issue, and there may be different points across the lifespan where it may be more appropriate to think about treatment. It is very difficult to think about changing a personality that is intrinsic. Treatment may be more ethical and appropriate at certain points of the lifecycle.

Ms. Crane said they need to hear from people on the autism spectrum and include those non-speaking individuals. They have opinions that can be ascertained and need to be taken into account. Mr. Robison said that people like himself do not believe they are free from disability. Dr. Gordon said this needs to be made explicit. In a doctor-patient relationship, the doctor provides advice on medical decisions. There are ethically more straightforward decisions where a treatment decision is being made by someone other than the individual affected, because that is how to act in the best interest of the patient. What is tricky about talking about prevention or cure in the case of ASD, is that it is the parents making that decision very early life. Ms. Crane brought up parallels in the deaf community and, for instance, cochlear implants. Individuals have very strong opinions about whether they wanted those implants as a child.

Dr. Mandell asked about the underlying assumptions that guide those spoken and unspoken decisions that they make and prioritize. Some of those assumptions are related to prevention and cure. He asked how important it is that they have consensus about those issues or if they should just have discussion and maintain diversity in opinion. He said he does not know whether it is healthy to have to come to consensus on the issue. Dr. Pelphrey said that this is an important point. He said that the Committee makes recommendations about funding for autism research and services, which requires putting forward concise, clear statements about what they think should be funded, and that is the only time they need to stand in unison. The community is not going to get anything, if they do not spend time building and presenting a coherent set of "asks". Mr. Robison explained that people all have different challenges because of autism, where one person might wish to change one thing, or at a different age, one might just learn to live with it. If they can all agree with that, then they should agree that they develop the tools and therapies that can assure the best quality of life for every autistic person. Dr. Gordon said that this is what is in the vision statement. Dr. Amaral mentioned that Question 3 is about prevention, so when parents say "I want to cure my child," in many cases they may be really saying "I want to rid my child of the gastrointestinal problems" or any other specific issue. The IACC should be developing a research agenda that addresses these things, such as sleep disturbances or cognition. This is what the Strategic Plan is meant to do.

Ms. Crane asked about services, which are impacted by policies being debated in the administration right now, such as special education and jobs. These are all funded by Medicaid, and there may be a significant cut in Medicaid. These services are at risk. Today is the anniversary of the passage of the Americans with Disabilities Act. That law has done so much to bring individuals with disabilities out from institutions and into integrated jobs and communities. Medicaid is almost always the main funder for those services.

Dr. Amaral commented about Dr. Eileen Nicole Simon and her theory of brain regions that may be most damaged. He would like to say on the record that these are all interesting ideas. The problem is that they do not have the raw materials to prove some of these theories. It is not that she is necessarily wrong, but that researchers do not have the resources to prove these theories. Dr. Gordon underscored this statement with the need for the development of brain banks. NIMH has a brain bank that includes autism samples and Dr. Amaral at the Simons Foundation has a registry. They have had the 100th donation to the brain bank and invite more people to participate.

Dr. Mandell commented on Ms. Gautier's insightful remarks. There is a need to train teachers to be experts in autism, and there needs to be a model where teachers can "dip their toe in the water" before they teach these kids. They know there is a high burnout rate and that there is no in-service consultation or support. They "train and pray," where they get one day of training and then are sent back out to the classroom to teach. Congress has never full appropriated funds for special education. They should keep in mind when talking about race, they are talking about place in terms of these disparities. He hopes this is foremost in the Committee's mind when they consider the research and practice agenda. If research does not make it into practice, then the research does not have the impact it could.

Dr. Gordon wants to reiterate that even if they do not have the opportunity to discuss all of these comments today, the Committee does consider them important and discusses them outside this forum.

Autism After 21

JaLynn Prince, President and Founder, Madison House Autism Foundation
Adrienne McBride, Executive Director, Madison House Autism Foundation
Desiree Kameka, Director of Community Education & Advocacy, Madison House Autism Foundation

Ms. JaLynn Prince talked about starting Madison House ten years ago. They did a marketing survey locally, statewide, and nationally, and found there is a great need to serve the adult population. She described a story that underscores why they do this work. Her family was doing a head count on their way to an event, and her husband asked where Madison was, and she said that Madison does not count, thinking he had already been accounted for. And then they heard a voice from the back saying, "1, 2, 3, 4…" and then they realized "Madison counts."

She talked about wanting to put out a plan for autism, specifically for the adult experience of autism that takes up three-fourths of one's life. She showed the Committee some videos of Madison. Every ten minutes a child with autism becomes and adult with autism. At age 21, people lose access to services. Due to insufficient social support, these people have difficulties in housing, jobs, education, and more. Madison House Foundation raises the visibility of adults on the spectrum and the challenges they face.

Ms. Prince then reviewed some statistics: there are 2 million adults in the U.S. on the autism spectrum, 50,000 individuals who become an adult with autism each year, more than 2,000,000 children who will age out of the system by 2020, and this results in an estimate cost of $300 billion, which is estimated to double by 2025. There has been much progress, but there are still challenges, such as lack of appropriate and affordable housing, excessive under- and unemployment, insufficient post-secondary education or vocational training, and lack of medical care by informed providers. When she speaks of medical care, she does not mean treatment, but instead is referring to the need for more clinicians who are trained to work with typical conditions in adults with autism. This is important to help make these adults comfortable enough to go back to a provider. Autistic children grow up to be autistic adults, and this is a fact that still suffers from a lack of awareness. She asked the Committee, "How can we create solutions if we don't recognize the need?"

She mentioned the Autism After 21 Day, and that they are now going into their third year with this event. During the month of April, and on April 21 specifically, they have established an observance to recognize the abilities of and issues facing adults with autism. They are challenging people in each state to have this special day be declared officially. They have had a community breakfast to increase consciousness, and many positive results have come from that community connection. They also have a mini-documentary series about adults who are on the spectrum. She showed the Committee two sample documentaries. The first was about David, who is a cartoonist, and his family. The second documentary was about Adam, and how job support has changed his life. Ms. Prince introduced Adam, who was in the room, to the Committee. For the next presentation, she asked that the Committee and other people in the room recognize April 21, to have these conversations and breakfasts, and to support awareness.

Ms. Desiree Kameka spoke about the Autism Housing Network and the Coalition for Community Choice. The Autism Housing Network is the culmination of many years of research and site visits. It is an outgrowth of the Opening Doors study. This network is an interactive database, which serves as a directory of housing to help people connect. They believe that housing is a key issue and need that affects many other aspects of quality of life. In other words, if someone loses their housing, all of the resources put into other services and support has been lost. This resource can be found at www.autismhousingnework.org. The website has various sections, including a virtual tour of housing options and a map view of a housing directory. There are currently over 300 resources listed on the website. Several individuals on the spectrum will not qualify for Medicaid but still need financial support for housing. She asked the Committee, "If an individual is isolated, living with their family, and has no access to jobs—what does that do to the suicide rate? And giving people resources to live independently — how does that influence suicide rates?" She wonders if there is a difference in outcomes in private pay models in comparison to publicly funded options—that might be a question worth looking into.

Campus-based models of housing need to be considered as viable options for autistic adults. The opportunities listed on this website have been recommended by people all over the nation. She asked the Committee to please list an opportunity if they know of one. There is a section for survey and assessment tools, which can be useful for tracking how quality of life changes as these adults move into the community. They offer phone consultations, and every week she gets a consult request from a family member who has no experience navigating the system because a caregiver passes away, for instance. As a next step, they will be combining forces with First Step AS Global Leadership Institute to conduct a market study on the foundational nomenclature for policy and housing models.

Ms. Prince talked about an attorney who put Madison House in his will, which supports the Madison Fields Farm. They want to encourage research dollars to look at the effect of participation in the farm on education and employment. They also partner to support other at-risk populations such as veterans with PTSD. They would like to increase their impact and encourage collaboration to best support their mission.

Committee Discussion

Ms. Crane was surprised that the presentation suggested that the adult autistic population has not been addressed when the Autistic Self Advocacy Network has been talking about autistic adults for years. She is concerned that when they talk about housing, they are only talking about intentional communities. These are not the only choices that allow people to move out of a parent's home. Ms. Kameka replied that they do not only support intentional housing but that they also support a broad range. Dr. Mandell suggested that there are very few networks to support adults with autism and housing. There is a paucity of research in housing option for autism. He asked if there enough variability within the network to lend itself to research and looking at outcomes in different housing settings. Ms. Kameka replied that research can be done with subpopulations or with variability, and that it can inform how the market survey is developed. Ms. Crane talked about living in a shared housing model with another autistic person. She said that if households like this would be missed by the survey, the results would be biased. She would like to know how to make sure that the full range of housing models can be included. Ms. Kameka suggested that consumer-controlled housing and provider-controlled housing are two very different models. Dr. Mandell added that the ability to use a network like this in combination with a survey of adults on the spectrum could really help to understand some of the questions around housing. Dr. Amaral suggested that having a network and experimentally looking at groups of individuals and conducting a longitudinal study could be a good approach. Ms. Crane suggested that there are serious policy situations if they were to study one kind of housing but not others.

Dr. Taylor said that these are highly complicated issues and encouraged people to keep grappling with these issues and not give up. She suggested the community find ways to move forward because any progress is huge progress. Ms. Kameka said that, for research purposes, there are two cohorts: individuals who can afford and access services and housing, and individuals who cannot or who live off limited income and waiver supports and need to find intentional housing. Dr. Mandell replied that if they artificially constrain these attributes, that they end up with the bell curve. There needs to be enough overlap in the presentation of the individuals living in these different housing models. Ms. Crane said that this relates to Section 8 vouchers—if they can get data about this, they can make policy recommendations.

Ms. Adrienne McBride said that if anyone is interested in partnering with the market study, please see her after the meeting. Ms. Prince reminded the Committee that during this presentation, four and half more individuals became adults with autism.

Dr. Daniels thanked the members of the Madison House Autism Foundation for their presentation.

Summary of Advances Discussion

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

Karen Mowrer, Ph.D., Science Policy Analyst, Office of Autism Research Coordination, NIMH

Joshua Gordon, M.D., Ph.D., Director, National Institute of Mental Health (NIMH) and Chair, IACC

Given the time, this topic will be discussed at the next meeting.

Round Robin

Dr. Tiffany Farchione talked about the patient-focused drug development meeting at the FDA that took place at the beginning of May. These are half-day meetings with individuals with autism, their families, and caregivers, who participate in panel discussions about what would be clinically meaningful in drug treatment. It was interesting to discover what was important to these individuals versus what the drug companies are focused on. One example was stimming. People did not want to have their repetitive behaviorsstopped. Some issues do not necessarily affect everyday life. The FDA will use this information to possibly redirect end results. The outcome of this meeting was a Voice of the Patient Report which should be ready by the end of the year. The full transcript is available online.

Dr. Denise Pintello reviewed the Autism Spectrum Disorder (ASD) Prevention, Early Detection, Engagement, and Services (PEDS) Network meeting. The ASD PEDS Network was developed from recommendations in the 2013 IACC Strategic Plan. One of the questions from the report, "When should I be concerned?," resulted in research to test the development of interventions and to reduce disparities. Five research studies were funded on early identification and linkage for services for ASD. They compared the differences and similarities in these studies, and in 2014 they invited these researchers to work together to form the ASD PEDS Network. The Journal of the American Medical Association (JAMA) has highlighted the potential of this study. They are now in year three. In the 2017 ASD PEDS meeting, participants identified potential scientific opportunities to leverage their data to address research gaps such as impact of parental concern, treatment tracking, onset of ASD symptoms, and an implementation project. There is more to come. The study should be completed in the Fall of 2019. They would like to explore future studies using this cohort and possibly present findings to this Committee.

Dr. Shapira said that Dr. Brenda Fitzgerald was recently appointed the 17th Director of the CDC. She is an obstetrician/gynecologist and has an interest in early brain development. They may continue to see work in that area, which would include ASD. At the October meeting, the CDC will be sharing results from the Study to Explore Early Development (SEED) to evaluate genetic and environmental risk factors in ASD.

Closing Remarks and Adjournment

Dr. Gordon thanked the Committee and adjourned the meeting at 4:58 PM.

The next meeting is on October 24 at the Neuroscience Center at 6001 Executive Boulevard, Rockville, MD.