Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

October 17, 2018

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a meeting on Wednesday, October 17, 2018, from 9:00 a.m. to 3:57 p.m. at the National Institute of Mental Health (NIMH) Neuroscience Center 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*, 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; **Linda Birnbaum,** Ph.D., D.A.B.T., A.T.S., National Institute of Environmental Health Sciences (NIEHS); **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD); **Samantha Crane**, J.D., Autistic Self Advocacy Network (ASAN); **Melissa Harris**, Centers for Medicare and Medicaid Services (CMS) (attended by phone); **Elaine Hubal**, Ph.D., (representing Ruth Etzel, M.D., Ph.D.) (attended by phone) Environmental Protection Agency (EPA) ; **Jennifer Johnson,** Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) (representing Diana Bianchi, M.D.); **Walter Koroshetz**, M.D., National Institute of Neurological Disorders and Stroke (NINDS); **Cindy Lawler**, Ph.D., NIEHS (representing Linda Birnbaum, Ph.D.); **David Mandell,** Sc.D**.**, University of Pennsylvania; **Andrew Morris,** ACL (representing Jennifer Johnson, Ed.D.); **Laura Mamounas**, Ph.D., NINDS (representing Walter Koroshetz, M.D.); **Kevin Pelphrey,** Ph.D., George Washington University and Children's National Medical Center (attended by phone); **Edlyn Peña**, Ph.D., California Lutheran University; **Laura Pincock**, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ) (attended by phone); **Robert Ring**, Ph.D., Vencerx Therapeutics; **John Elder Robison**, College of William & Mary; **Robyn Schulhof,** M.A., Health Resources Services Association (HRSA) (representing Laura Kavanagh, M.P.P.); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC); **Alison Tepper Singer**, M.B.A., Autism Science Foundation (ASF); **Melissa Spencer**, Social Security Administration (SSA); **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD); **Carrie Wolinetz,** Ph.D., (representing Francis Collins, M.D., Ph.D.), National Institutes of Health (NIH).

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 9:00 a.m. and Dr. Susan Daniels took roll call. The minutes of the last meeting were approved.

Welcome and Introductions

Dr. Gordon welcomed the Committee and introduced Dr. Judith Cooper from the NIDCD and Jennifer Johnson from the ACL as regular members of the Committee. He introduced Dr. Ann Wagner and talked about her new role as the National Autism Coordinator for the United States (US) Department of Health and Human Services (HHS).

Report from the HHS National Autism Coordinator

Ann Wagner, Ph.D., HHS National Autism Coordinator and Chief, Biomarker and Intervention Development for Childhood-Onset Mental Disorders Branch, Division of Translational Research, NIMH

Dr. Wagner reminded the Committee about the role of the National Autism Coordinator and its authorization by the Autism CARES Act of 2014. She reviewed the 2017 Report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorder (ASD), an effort that was led by Dr. Thomas Novotny, the previous HHS National Autism Coordinator. She talked about the work she has done since taking the role of HHS National Autism Coordinator, including the convening of the Federal Interagency Workgroup on ASD (FIWA), which currently consists of government representatives across different departments and agencies related to autism. Members of the FIWA have been reviewing specific recommendations from the 2017 Report to Congress. She reviewed two new CDC activities: a pilot of the Study to Explore Early Development (SEED)-Teen survey and a funding announcement for the Autism and Developmental Disabilities Monitoring (ADDM) Network. Dr. Wagner reviewed the wide range of topics for funded research in transition-aged youth, including successful employment, healthcare, transition, engaging siblings, and family future planning. One of the recommendations from the 2017 Report to Congress was a need to develop better measures of functional outcomes for transition-age youth and adults; FIWA is convening a subgroup to examine these measures and ensure that efforts are not duplicated. Dr. Wagner's next step is to conduct meetings to discuss federal strategies to influence policy and programs at state and local levels.

Dr. Gordon noted that OARC helped lay the groundwork for responding to recommendations and that Dr. Susan Daniels and Dr. Frank Avenilla from NIMH have also provided support to Dr. Wagner in carrying out her role.

Dr. Gordon welcomed Dr. Jack Scott to present on unintentional injury in children and youth.

Autism Society Presentation: Unintentional Injury in Children and Youth with ASD

Jack Scott, Ph.D., B.C.B.A.-D., Member, Panel of Professional Advisors, Autism Society; Executive Director, Florida Atlantic University Center for Autism and Related Disabilities

Dr. Scott talked about his role in the Autism Society of America. The Autism Society of America has developed and implemented safety programs and has addressed the intersection of autism and law enforcement by training more than 20,000 first responders.

Dr. Scott reviewed the high risk of unintentional injury, wandering, and death in individuals with autism. He suggested that these safety issues could be the result of early problems in understanding social cues that can cascade throughout development. He referenced a number of studies indicating that people with autism are at high risk for mortality. Although many factors contribute to the high mortality rate among individuals with ASD, Dr. Scott's presentation focused on young children with autism who typically lack self-preservation skills and do not understand rules of conduct.

Dr. Scott talked about a young boy who had been a frequent wanderer and whose family struggled to keep him from eloping. Now, at age 12, the boy wears a Project Lifesaver tracking device that allows the Palm Beach County Sheriff's Department to track him and return him home safely.

Dr. Scott also pointed out that drowning is a critical issue for children who wander. In the U.S., drowning is the most common cause of death for one- to four-year-old children. Yet for children with autism, drowning remains the most common cause of death up to age ten. Dr. Scott reviewed a graphic that represented the incidence of drowning for all children, and referenced a spike in risk among children aged one- to three-years-old. Dr. Scott cited research showing that 37.7 percent of children with autism and intellectual disability have wandered in the last year.

Dr. Scott talked about a young boy with autism named Jared who drowned after eloping from his home in 2006. He said that, at the time he learned of Jared's death, he was unaware that the mortality rates for children with autism are three times higher than those for typically developing children. He considered that if he, an established expert in the field of autism, wasn't aware of this risk, then many professionals and parents are likely also unaware.

Dr. Scott talked about how the deaths of these children places great strain on first responders and families. He noted that some schools often have relaxed policies for notifying law enforcement of missing students, and that some schools may fail to fully embrace students' needs as outlined in their individual education plans (IEPs).

Dr. Scott reviewed various technologies that can help minimize the risk associated with wandering such as the personal locator technology at Project Lifesaver International, which uses radio tracking technology to guide searches for missing children. He also noted that some developing technologies require more research before they are made available to the public. Many technologies tend to be unavailable to some families because they are expensive, but there are nonprofits that can help lower-income families access them.

Dr. Scott reviewed several very recent cases of children with autism who had wandered and died by drowning. Their early deaths are tragic and the issue needs to be addressed.

Dr. Scott reviewed law enforcement training programs such as the Safe & Sound and Take Me Home programs from the Autism Society of America. There are other safety training programs such as the Autism Safety Initiative, Autism Safety Project, Be Safe, and Experience Autism. He said that there is not currently a national agenda that trains first responders, police officers, and federal officers in safety for children with autism. An autism emergency contact form may help with the planning and procedures in the home to help keep a child safe. The contact form could provide law enforcement with information about the child's appearance, propensities, and special interests, all of which can be valuable during a search.

There are also issues at schools, as some resource officers think that a missing child case can be handled internally. Dr. Scott pointed out that a comprehensive search for a missing child with autism or other vulnerabilities cannot be achieved by school staff alone. Project Lifesaver International can provide schools and local law enforcement with the tools and training necessary to institute a search.

Dr. Scott hopes that the Committee will support the creation of better methods for data collection on deaths in children with autism. Some researchers have resorted to using newspaper articles to gather information, which is a poor substitute for the data needed to understand the issue. A standardized nationwide reporting system should be implemented to address the data gap. In many states, calls to first responders and their outcomes are not tracked, so it is unknown how many of those are related to children with autism. Furthermore, autism status is not indicated on death certificates. Dr. Scott said better standardization of these reporting formats would allow researchers to access solid data on mortality for people with autism. Dr. Scott talked about Canada's national effort to review available tracking technologies for at-risk populations, and pointed out that tracking technologies are most effective when used in conjunction with law enforcement.

Dr. Scott discussed the importance of early swim instruction for children with autism. Unlike most other developed countries, the US does not implement universal swim instruction, with the exceptions of Juneau, Alaska and Fort Lauderdale, Florida. The program in Fort Lauderdale is funded cooperatively by the public school district and county funding agencies. Despite the comprehensiveness of the swim instruction initiative, there are no solid data on the status and outcomes of this program. Additionally, Dr. Scott pointed out a need for funding of elopement research. He suggested that a nationwide conference on unintentional injury and elopement would be very useful.

Dr. Scott also noted that children with autism are 7.6 times more likely to experience poisoning than typically developing children. Some children with autism are tempted into ingesting visually tantalizing objects, or have pica, an eating disorder that causes urges to eat inedible objects. Although poisoning is typically not fatal, it still poses a significant problem for this population.

Dr. Scott talked about Kevin and Avonte's Law of March 23, 2018. He said that sufficient funding is imperative for the law to function effectively. Accordingly, first responder training has increased in many states, but it is still not a national or mandatory effort. Many communities believe that the training is currently too shallow and doesn't fully address the issues at hand. Dr. Scott also suggested that tracking devices should be made available to all families. Enhanced 911 systems should allow parents to register a child with autism so that these children are preloaded in the system. Another priority is making information about risk and intervention available to families, who need to understand that lack of self-preservation skills is a common trait of people with autism. Families and clinical professionals also need to be aware that individuals with autism have a three times greater risk of mortality. Dr. Scott encouraged federal agencies such as the CDC to increase cooperation between developmental disability and child injury to create interventions. He mentioned the success of a project supported by IHS that identified the Native American and Alaska Native populations as high-risk for injury and unintentional injury. The project received significant federal response, and Dr. Scott expressed hope that an initiative to investigate injury in children with autism would receive a similarly vigorous return. He pointed out that excellent efforts exist within the CDC but that cooperation across efforts is insufficient. For example, the 2012 Child Injury Agenda made no mention of disability or autism, even though children with autism are at significantly higher risk of injury than typically developing children.

The CDC cites drowning as the third leading cause of death from unintentional injuries, but it does not address wandering or elopement for children with autism. Dr. Scott noted that the CDC surveillance effort is extensive and could be extended to include mortality for children with autism. He also noted the potential for the NIH to take a leadership role in recognizing autism safety issues and improving tracking systems.

Regarding education policy, state education agencies should address elopement in students with autism and other vulnerabilities. No policies addressing this issue are currently in place, and schools often have to rely only on their own judgment to resolve these problems. Schools have already implemented extensive active shooter protocols and active abduction policies. There is a need for specialized training and provisions for children with autism in emergency drills and active shooter drills. Eighty-one percent of parents say that their child's IEP does not include safety goals in the event of emergency situations. Teaching safety skills, such training the child to answer questions such as "What is your name?" or "What did you eat?" can help in cases of emergency and should be included in the child's program. Extending behavioral requirements is another possible improvement to school safety policies. Currently, there are requirements that children receive a function-based assessment (FBA) for problem behaviors. This should also be applied to children's elopement behavior, which could increase children's safety in the event of elopement from school.

Dr. Scott reviewed the Autism Society's specific requests to the Committee: the creation of a nationwide data tracking system, which would mine data to support better public policy; strategies to fund and implement Kevin and Avonte's Law, education on elopement and other safety issues; funding from the CDC to target safety and autism issues with better collaboration between injury prevention and developmental disability; and NIH and NIMH coordination to address autism safety as a national health issue.

Dr. Scott talked about how these efforts would ultimately result in a decrease in cases of elopement and wandering in autism, as well as a decrease in deaths and injuries related to these behaviors. The efforts would also serve to inform parents of safety issues for children with autism, subsequently reducing family stress and ensuring that people with autism are safer in their homes and their communities. Dr. Scott expressed further hope that their continued efforts will increase safety for all individuals with autism, including children and adults.

Committee Discussion

Dr. David Mandell asked why further research is necessary on well-known issues, such as the benefits of tracking children's location for their safety. Dr. Scott answered that there is not much research now to describe why or how various technologies differentially benefit these children. It takes time for any of these systems be fully implemented and to draw responses from law enforcement agencies. Right now, most of the information on this issue is anecdotal, and there is not sufficient evidence to support the efforts he had talked about.

Dr. Judith Cooper asked if there are any data, surveys, or questionnaires targeted to determine which preschoolers are at highest risk for elopement or wandering. She also asked about the cost of tracking systems and if there were funding programs from insurance agencies. Dr. Scott answered that nonprofit organizations offer subsidized devices for lower income and that Medicaid can also provide support in certain situations. Unfortunately, disadvantaged families may not be able to access these devices through federal funds at this time. Dr. Scott responded to Dr. Cooper's question about using surveys to identify risk for wandering, suggesting that the Rice study showed that children aged four- to six- years-old, who have intellectual disability, and who already show a propensity for wandering or have an interest in locks have been found to be high-risk. The Interactive Autism Network study of 2012 showed that most children who wander are simply adventurous and want to explore, rather than wandering to escape an undesired sensory situation. Some behavioral functional assessment techniques can determine on individual basis of risk whether a child is at risk of wandering and what conditions might compel a certain child to elope.

Mr. John Robison thanked Dr. Scott for his presentation and talked about his experience as an autistic person and as a parent of a child on the autism spectrum who was a wanderer. In listening to the proposal, he suggested that, beyond the potential problem of intrusiveness, children may desire to "beat the system" by overcoming the tracking device. He suggested that children do not wander to escape abuse or because they are unintelligent, but because they are inquisitive. He said that these children should be taught how to explore the world safely. For instance, they should be taught how to stay safe in traffic or around water. These children do not wander for no reason or out of desperation, and it troubled him that a simple response to the problem had not been implemented.

Ms. Alison Singer said prevention is the primary intervention and that tracking is secondary. She also wanted to focus on what the Committee is able to do to address wandering. The studies that were reviewed in the presentation were commissioned by the Committee and in some cases implemented by past Committee members. Ms. Singer asked if it was possible to have an official from the DOJ attend Committee meetings. Dr. Daniels responded that officialsfrom the DOJ and National Center for Missing and Exploited Children had attended Committee meetings in the past and that a DOJ representative could be invited if the Committee wanted one to attend the January or April meeting.

Dr. Edlyn Peña thanked Dr. Scott for his presentation and talked about her experience as a parent of a child with autism and as director of an autism center in California. Nearly 400 people attended their last conference, two of whom were children under the age of 18 who left the conference unattended to explore the college campus. One of those students was found at the pool, which was a frightening and potentially dangerous situation. Dr. Peña said she is now working proactively with campus safety officers, who were called five to seven minutes after the children were reported missing. She asked if there were any other recommendations for service providers and parents about how to report a missing child and what other training could be beneficial for officers. She also reiterated Mr. Robison's point about wandering being attributed to explorative curiosity rather than children's lack of intelligence or desire to escape a bad situation. She also supported the idea of providing children with safety training for exploration. Dr. Scott responded that swim instruction is important in such situations. He also noted that elopement may be more likely when a child is bored or experiencing heightened stress, and that security could be heightened when these situations are identified. He said that children's desire to roam and explore should be respected, but safety talks may not be possible for the demographic of children he discussed in his presentation. He addressed the issue of intrusiveness by noting that parents need to be completely in favor of a technology before it is implemented, and they need to respect a child's feeling that a device is too intrusive. He noted that children could easily remove the devices by cutting or tearing them off. Dr. Scott talked about his experience as a wilderness camp counselor for emotionally disturbed children. He said that these children had intact self-preservation skills in the event that they became lost in the Appalachian Trail, but children with autism would be at tremendous risk because they may lack these skills.

Ms. Samantha Crane talked about not discounting the fact that wandering can sometimes be an escape response to abuse or conflict. She also talked about still having a wandering problem and referred to her smartphone as her tracking device. She said that children who are taught to recognize danger will respond to it appropriately. Once a child has wandered far enough to become lost, they may panic and not know how to get back. The best way to address these cases may be orientation training to teach children what to do if they become lost. Some children with autism may also exhibit an instinct to hide in these stressful situations. She suggested being careful about using technology solutions that fail to account for the voices of people with autism who have histories of wandering and can now discuss their experiences. Devices should also be designed according to the child's development. Dr. Scott responded that officers are trained to understand that most children will not help with their own recovery and that the child usually is found in a place that has already been searched. In many cases, children play in community water features, and they may panic when they find themselves too deep in the water. The concern about abuse may be offset by the fact that parents call in the missing child, as abusive parents may be reluctant to invite police or community involvement. Additionally, police officers are trained to recognize potential abuse. Officers who are not educated about these issues may take missing child cases less seriously if the child has autism, so first responder training remains critical.

Dr. Stuart Shapira talked about recent studies that have addressed co-occurring conditions such as attention-deficit hyperactivity disorder (ADHD), as risk factors related to wandering. He pointed out that the CDC does recognize that safety is a significant issue for children with autism and reiterated Ms. Singer's point that the CDC has partnered with the Committee to develop the ICD-9 and ICD-10 health care administrative codes for wandering, which has prompted conversations with caregivers and providers about safety for individuals who wander. The CDC has also partnered with others to understand the prevalence of wandering among children with autism and other developmental disabilities. He also mentioned the CDC's surveillance work that builds on a broad spectrum of factors related to the well-being of children with autism, including safety and wandering. CDC's existing platforms of the SEED and the ADDM Network monitor data and quantify the risk and protective factors of children with autism. The CDC has heard the concerns of the community and is working to expand knowledge about autism from childhood into adolescence and adulthood. Both the ADDM Network and SEED have developed longitudinal components to gather data about the well-being of adolescents with autism and factors that increase the risk for mortality and morbidity in this population.

Dr. Gordon returned to the committee's earlier discussion of whether to invite the DOJ to attend a

Committee meeting to address first responder training and issues of wandering for children and adults with autism. Dr. Gordon clarified that the Committee would ask the DOJ representative to hear the Committee's concerns about safety issues, individuals who have gone missing, and law enforcement's interactions with people who have autism. Ms. Crane said that she would also support adding a member of the DOJ to the Committee. Dr. Daniels said that the Committee cannot compel an agency to join the Committee, but they can invite them to participate. Dr. Gordon requested that a volunteer or two develop a short presentation for this invitation, and Ms. Crane and Ms. Singer responded. Dr. David Amaral wondered if a discussion about people with autism and the judicial and penal systems should be included in the upcoming meeting. Dr. Gordon responded that he would like to focus solely on the issue of safety.

Committee Business

Susan Daniels, Ph.D., Director, OARC, NIMH, and *Executive Secretary*, IACC
Joshua Gordon, M.D., Ph.D., Director, NIMH, and *Chair*, IACC

OARC Update and 2018 IACC Strategic Plan Update

Dr. Daniels introduced and thanked the OARC staff in the coordination of successful meetings and activities. On behalf of the Office of the Secretary of Health and Human Services, the OARC is coordinating responses from various agencies to develop a Report to Congress on federal activities related to autism, as required by the Autism CARES Act. She reviewed the progress of the *Report to Congress on Activities Related to Autism and Other Developmental Disorders* and the *2016 IACC Portfolio Analysis Report*, both of which are in the final stages of preparation and should be released in the near future. The data set for the 2017 IACC Portfolio Analysis Report is currently being collected from various federal agencies and private organizations.

Dr. Daniels reviewed that the Committee spent the previous two years working on the *2016-2017 IACC Strategic Plan for ASD*, which was extensive.For the required 2018 Update of the *IACC Strategic Plan,* Dr. Daniels presented a proposal to have the update prepared in a shorter format and to include summaries of the Health Outcomes Working Group and workshop, the *2016 IACC Portfolio Analysis Report*, and the Autism CARES Act *Report to Congress*. These three summaries would be prepared within OARC and the compiled update document would be sent to the Committee for review and approval. This would ensure efficient and timely completion of the 2018 update.

Dr. Daniels clarified that an annual update is required and that there was no need to alter the strategic plan with new objectives, but to describe progress made to date and the Committee's current work. Mr. Robison made a motion that the OARC draft the summaries and the Committee review the compiled document; the motion passed unanimously

Dr. Daniels reviewed the outcomes of the first workshop of the Improving Health Outcomes for Individuals on the Autism Spectrum Working Group. She reviewed the objectives and scope of the Working Group, which included heath and general wellness for people with ASD, co-occurring physical and mental health conditions, premature mortality, patient-provider interactions, medical practitioner training, and parental and family mental health. Dr. Daniels referred to the roster of Working Group members on the IACC website. There was one conference call held prior to the workshop, and the day-long workshop, titled Addressing the Health Needs of People on the Autism Spectrum, was held on September 27. They expected that the outcome of the Working Group would be a written document that provides an update of issues and continued discussions. The Working Group will run through September 2019. Dr. Daniels asked Dr. Amaral to review the outcomes of the workshop.

Dr. Amaral said two primary objectives were identified at the workshop. The first was identifying the extent of the problem of co-occurring conditions and the extent to which they cause problems for families and individuals with autism. The second was how to get the word out to practitioners and community members who may be less aware of health issues in autism than academic physicians. He summarized the topics of the workshop, which included an overview of the different health conditions that affect people with autism, such as epilepsy, gastrointestinal disorders, and sleep disturbances. They also talked about approaches to improve patient-provider interaction and programs that have been piloted to improve awareness. They discovered that there were a number of health-related programs already in place, such as ECHO (Extension for Community Healthcare Outcomes) Autism, but there needs to be a better way to raise community awareness about them. The Working Group also talked about policy issues such as the need for better tools for primary care physicians, easing the transition from pediatricians to adult physicians, standard guidelines for common health conditions, developing a team approach that includes specialty consultation, and longer and more accommodating clinical appointments for people with autism. There are supports for making a person with autism more comfortable in a research setting, but no such protocol exists in clinical care.

Dr. Amaral reviewed the key takeaway from the workshop, which was that families, clinicians, and researchers all agreed on the importance of treating co-occurring health conditions to improve the quality of life for individuals with autism. The next steps of the Working Group were to address other co-occurring mental health conditions including anxiety, suicide, ADHD, and self-injurious behaviors. The Working Group acknowledged that there were still unanswered questions to consider, such as the relationship between the biology underlying autism and the co-occurring health conditions, and the extent to which reducing co-occurring conditions could help to ameliorate core features of autism. Dr. Amaral ended by saying the Working Group was enthusiastic about developing and disseminating the white paper on these topics and improving awareness about the various tools.

Committee Discussion

Mr. Robison talked about addressing the public misconception that the underlying biology of autism is not inherently connected to co-occurring conditions. Many co-occurring conditions can be harder to treat in people with autism and may therefore require different strategies. He emphasized the need to recognize how autism is more than a mix of disability and exceptionality; that it also can include treatment-resistant health complications. He wondered how to address that in their communications. Dr. Amaral responded that some of the treatments used for typically developing people have not been adequately studied in people with autism. He added that the Working Group did touch on this topic, and that more experimental data is required to understand health issues in autism.

Ms. Singer discussed aging out of pediatric care and highlighted the workshop discussion about the need for the equivalent of a developmental pediatric specialist for adults. She talked about how the Working Group could advocate for a new medical specialty for adults in the white paper.

Ms. Crane added that people with autism were often excluded from studies for treatments for epilepsy or other conditions and therefore these studies were limited in their ability to predict the effectiveness of treatments for people with autism. She noted that there was good research on sleep strategies, but that those studies were conducted with typically developing people, and researchers did not know how these strategies worked for people with autism. She discussed the epidemic of both individuals with autism and individuals who do not have autism using their smartphones at night, which is known to disrupt sleep patterns, but that this phenomenon did not explain why people with autism have such intractable sleep issues.

Dr. Amaral addressed the issue of epilepsy and autism, where much remains to be understood about the basic epidemiology and underlying biology. He discussed Dr. Spence's presentation on the difficulty in predicting the risk of having a seizure because approximately half of people with autism have their first seizure before the age of 10 years and half have their first seizure in late adolescence or adulthood. He added how difficult this could be for families who, after handling a child or adolescent with autism, suddenly experience their child's first grand mal seizure at age 19 years. It would be useful to have a specific genotype or other predictor for identifying that risk. The Committee should encourage broader inclusion in these studies. Dr. Kevin Pelphrey concurred that this would be important research for the future. Dr. Amaral added that there has been talk over the last 15 years on the impacts of subclinical epileptic activity without a seizure and whether this could be contributing to autism symptomatology. He highlighted a study of individuals with tuberous sclerosis who have a high prevalence of epilepsy. The study aimed to understand if reducing epileptic activity would reduce the number of individuals who develop autism symptoms. He asked if surveying for epileptiform activity in people with autism earlier would be useful for developing prophylactic interventions.

Dr. Shapira talked about behavioral supports in a clinical setting. The Joint Commission requires competent translation services in clinical settings and a similar approach may be helpful in institutionalizing behavioral supports for autism in hospitals. Dr. Mandell discussed how Medicare implemented three new codes for behavioral health integration and primary care, including one for implementing a collaborative care model. He added that it could be interesting to determine whether that collaborative care model code could be applied to the behavioral support. He also asked if they could incentivize primary care doctors to take advantage of this code to bill for behavioral support in order to make them more willing to take on patients with autism and other developmental disabilities. He finished by saying that the Committee could learn from clinicians who have worked with individuals with Down's syndrome and other intellectual disabilities about strategies they have used for transitional care and care for adults with chronic conditions that emerged in childhood.

Mr. Robison added that there were several medical problems that autistic people suffer from. He recommended that they educate clinicians to be aware that, even if someone is not interested in addressing their autism, they may still be interested in reducing the co-occurring conditions. Tolerance, acceptance, or understanding should not preclude the need to address treatment of real medical problems. Dr. Gordon asked if the workshop discussed collaborative care models. Dr. Amaral responded that they talked about it in abstract but not specific models. The issue of collaborative care would be a component of one of the subcommittees.

Dr. Amaral said they could continue to work through conference calls, but he was impressed with how productive working together in person was. He wondered if there should be a second in-person workshop dealing with the other health issues that were identified by the Working Group. He suggested that having two in-person workshops would generate the information needed for a comprehensive report.

Ms. Singer asked when the Housing Working Group would begin. Dr. Daniels said that they would start at the beginning of 2019 and would include some kind of in-person activity. She added that potential in-person meetings would need to be prioritized due to the limited time left under the CARES Act authorization of the Committee, which ends on September 30, 2019. Dr. Amaral suggested that a second Health Outcomes Working Group in-person meeting would need to be completed early in 2019 to allow time for preparing the written document. Ms. Singer said that the Housing Working Group hoped for at least one in-person meeting. Dr. Gordon suggested that there would likely be overlap between the rosters of both Working Groups. Dr. Daniels said that the external partners for this group would be very different than for the Health Outcomes Working Group.

Summary of Advances Discussion

Dr. Daniels opened the Committee for discussion on the nominated articles submitted for consideration for the 2019 Summary of Advances. Dr. Gordon pointed out that multiple proposed papers address the complexity of etiological factors from both genetic and environmental perspectives. There was a lot of promise in these papers and it would be challenging to pick just a few.

Dr. Daniels asked Dr. Amaral to talk about the first nominated study for Question 1: Screening and Diagnosis. Dr. Amaral reviewed the methodology and outcomes of an EEG study and individual differences of people at high-risk for autism. This is the second or third report showing EEG predictors of autism risk, and it highlights early brain signal alterations.

Dr. Daniels asked Dr. Cindy Lawler to review the nomination from Dr. Linda Birnbaum for Question 2: Underlying Biology. Dr. Lawler said the study used mouse models to understand the clinical association between a mother's pattern of autoantibodies and their children's social and behavioral features. Ms. Singer reviewed the study of self-injurious behaviors in children with autism, which demonstrated it is possible to conduct research in this understudied population and extended the understanding of risk factors for self-injurious behaviors.

Dr. Laura Mamounas reviewed a study of behavioral deficits seen in SHANK3-deficient animals, a model of Phelan-McDermid syndrome. The mice were treated with a histone deacetylate 2 (HDAC2) inhibitor, romidepsin, and showed improvement of social behavior after only three days of treatment. She noted some caveats, that social behavior assays do not examine brain circuitry and it was still unknown whether the animal behavioral measurements were analogous to human social behavior, but the study included several rigorous assessments of the underlying mechanisms. Dr. Gordon added that because of those mechanistic details, they were not relying just on the social behavior output, which are problematic. He suggested that this study could set the stage for more relevant models such as human cells or non-human primates with more analogous social behaviors as humans, which are already being developed. Dr. Mamounas said that, from a treatment perspective, this had long-term effects. Dr. Gordon suggested that what was long-lasting in mice was not necessarily long-lasting in humans, but that this was still an exciting finding.

Dr. Daniels reviewed Question 3: Risk Factors. Dr. Lawler talked about the study of maternal insecticide exposure based on a population cohort in Finland. Most people's bodies have quantifiable levels of this insecticide, even though it has been banned. The researchers were able to collect serum samples mid-pregnancy to look at the levels of DDT, and they found an increased risk for mothers in the top quartile of exposure. This study provided a good example of direct measurement of a biomarker. Dr. Lawler also reviewed a study on the use of baby teeth as a record of metal uptake. This study was novel because it was able to capture the features of the natural cycling of metals.

Dr. Mamounas reviewed the study on damaging de novo mutations in a very large cohort of approximately 8,000 individuals with neurodevelopmental disorders. A small fraction had de novo mutations in intronic non-coding regulatory regions, suggesting that these were enhancers or splicing effectors. The caveat was that only one to three percent of patients that did not also have a diagnostic coding variant carried these do novo mutations in the intronic region. Still, the study helped to understand what they call the dark matter of the genome.

Dr. Daniels reviewed nominations for Questions 4, 5, and 6, but their nominators were not available to review the studies.

Summary of Oral Public Comments

Joshua Gordon, M.D., Ph.D., Director, NIMH, and *Chair*, IACC
Susan Daniels, Ph.D., Director, OARC, NIMH, and *Executive Secretary*, IACC

Dr. Gordon stated that there were no requests for Oral Public Comments for this meeting.

Summary of Written Public Comments

Oni Celestin, Ph.D., Science Policy Analyst, OARC, NIMH

Dr. Oni Celestin reviewed the Written Public Comments. The IACC received feedback from 22 commenters that were organized into six broad topics. The first topic was about medical practices and potential causes of autism, with six comments on the effectiveness of applied behavioral analysis therapy (ABA), vitamin D as a treatment, the need for more accurate assessments, the negative effects of strobe lighting, the use of anti-psychotics, and the brain's susceptibility to certain environmental factors. The second topic was vaccines and autism, with six comments related to vaccine injury, vaccination schedules, and oxidative stress. The third topic was service needs, resources, and policy implication with three comments on employment, poverty, and the organization Autistic Adults and other Stakeholders Engage Together. The fourth topic was about Title X funding with three comments in support of Title X funding for health and safety. The fifth topic was safety of individuals with autism with two comments police training and treatment within the criminal justice system. The sixth and last topic was the role of the IACC, with two comments on the concern about time limits to public commentary and the need for diversity within the IACC.

IACC Committee Member Discussion of Public Comments

Dr. Daniels reminded everyone that the full text of the Written Public Comments was on the IACC website.

Ms. Crane said she takes self-advocate concerns about ABA very seriously. She advocated for better engagement with the self-advocacy community in designing studies on the long-term effects of ABA, including on mental health, and ensuring other interventions also get research funding. Dr. Gordon asked her if there were particular concerns for long-term effects of ABA. Ms. Crane said that there were concerns from self-advocates about a variety of aspects on how ABA is implemented. One significant concern was how often ABA was targeted towards masking behaviors rather that building skills. There were also concerns about the effect of the 30 – 40-hour per week length, which could encroach on children's unstructured playtime ability to follow their own interests. There was also a concern that ABA could reduce people to behaviors and result in more control-focused relationships between parent, educator, and child that what self-advocates often consider appropriate.

Ms. Crane also talked about the case study of Darius McCollum, a person with autism who had a long history with the criminal justice system because of special interest in transit. Subway operators taught him how to use subway controls and allowed him to drive. But, he was arrested for impersonating a subway officer. He spent a lot of time in solitary confinement, and the prison conditions were not good for him as an autistic person. Medical professionals in the prison misdiagnosed him with obsessive compulsive disorder. In another instance, he was tried for driving a Greyhound bus along its scheduled route. The judge found him not guilty by reason of mental disability, but ruled that he was a danger to society and recommended his commitment to a psychiatric hospital. This can be a life sentence because one cannot be discharged unless one has been "cured," which is not possible for people with autism. The ASAN wrote a letter recommending home- and community-based services as an alternative to manage his behavior, but the judge refused. She noted the need to address stereotypes about autistic people in the criminal justice system and make sure judges understand of the various resources available to help people like Darius live safely in the community.

Mr. Robison added that his concerns about ABA stem from the responses he had seen from his students in high school and college programs. He was not opposed to all forms of ABA. There were Board Certificated Behavior Analysts (BCBAs) who engaged in respectful, interactive, and productive therapy to teach students to behave in various setting such as in class. These therapists responded to students' concerns about life and it generally worked. He also had students cried recalling a therapist who forced them to act normal, for instance, not flapping their arms or not rocking. Mr. Robison believed that this could cause lasting damage to people with autism. He suggested they learn how to change the ABA profession to include a consent-based framework.

Dr. Gordon asked if there were any other thoughts on the ABA discussion. Ms. Singer pointed out that the population mentioned by Mr. Robison was one that was able to attend college, and individuals with autism who were able to attend college might not be representative of the demographic as a whole. Mr. Robison said he was also talking about students in special education high school. Ms. Singer said that she would like to address individuals, children, school-aged children, and teenagers who were severely affected by their autism and for who ABA was the only intervention for which there is any meaningful progress reported. She added that not all ABA programs focused on eliminating behaviors, but rather on fostering basic skills of daily living, taking turns, waiting in line, and doing a less preferred activity before engaging in a more preferred activity. She discussed her own personal experiences with her daughter who is on the autism spectrum. She was finally able to understand certain life skills after ABA, enabling her to participate more meaningfully in community activities. She added that she understood that there were adults with clear and heartbreaking stories about their experiences with ABA, which was unfortunate and eroded their relationships with their parents, blaming them for putting them in the program. But for those with no other recourse for learning language skills and life skills, there was clear benefit. Mr. Robison said that the goal should be to eliminate the hardships created by these programs.

Dr. Mandell commented that this discussion was describing ABA as it was implemented in the 1970s rather than current understanding of appropriate ABA practices, which focuses on targeted skills. He added that for the Committee to address this issue, it would be beneficial to develop a clear distinction between current ABA best practices and bad application of ABA. Ms. Crane said that her own concerns were based on concerns from people who were non-verbal. If 40 hours of intervention was tiring for a child with minimal disability, it would also be tiring for those with more significant disability. This is an ongoing issue and is not limited to the 1970s.

Dr. Gordon asked whether there was any advantage to having the ability to control certain behaviors when one chooses. Ms. Crane agreed that strategies for reducing unwanted behaviors were useful when the behavior was unwanted by the person with autism, but that ABA therapy too often focused on masking behaviors to satisfy others' desires. Dr. Gordon reiterated Dr. Mandell's point that ABA that did not consider the needs of the individual could be considered poorly implemented ABA, rather than being representative of ABA as a whole. Dr. Peña talked about her 10-year-old son, who had ABA from various providers since he was 2-years-old. Two of five programs considered the interests and needs of the client while the other three did not. She noted an example of one program that taught parents to yell "no" at the child when certain behaviors were expressed. She finished by saying such practices were an ongoing national issue. Dr. Gordon thanked the public commenters who raised the issue and said that there was a lot to be discussed. He added that the issue was too significant to comprehensively address at the current meeting and said that, although ABA currently has a monopoly, there were other intervention options to explore in the future.

Mr. Robison talked about the comment from Yuval Levental about vitamin D and Mr. Levental's previous comment about his experience with Botox. Mr. Robison said that he valued Mr. Levental's thoughts and questions, and it bothered him that the Committee did not have a mechanism for scientists to provide thoughtful responses to members of the public. Mr. Robison noted that another commenter, Ms. Eileen Nicole Simon, wondered why the IACC never answered her questions. Mr. Robison felt that commenters were their constituents and that they deserved answers to their questions. He mentioned that, during every public comment session, there were a number of comments about vaccines and the functioning of the IACC. He suggested that he would be willing to assist in crafting the responses, but he did not feel as qualified as others who were researchers.

Dr. Mandell agreed that the same points came up repeatedly and that an effort like this would go a long way toward making people feel heard. Dr. Gordon suggested that, although resources were limited, there could be a way to answer at least some questions from the public. An alternative was to offer a frequently asked questions (FAQ) page. Dr. Daniels said that the purpose of the public comment was for the Committee to be aware of the public's concerns. For the Committee to answer individual inquiries, there would need to be consensus about the answer, which is not feasible for the large number of inquiries received. Dr. Daniels added that the OARC responded with resources and information when they received inquiries addressed to the office

Dr. Walter Koroshetz proposed providing information on specific topics on the IACC website. Dr. Daniels said that the Committee would need the authority to officially respond with such statements. Dr. Gordon acknowledged that the Committee desired to have a mechanism to respond collectively to some of the public comments and that the NIMH and the IACC will try to find a solution that is both adherent to regulations and upholds the responsibilities to their constituents. Ms. Melissa Spencer reiterated that the issue was people not feeling heard and suggested including information on the website about how the Committee manages and responds to public comments. Dr. Daniels reminded the Committee that there was information about public comments on the website and that it states that the Committee does not give individual responses to comments—a standard procedure for all federal advisory committees. Dr. Ball asked if there was a way to synthesize information from the public commentary discussions to share with the public. Dr. Daniels responded that the information was in the meeting minutes, which were always posted on the website. Dr. Gordon said that in recent meetings has the Committee engaged in extensive discussion on public comments, and that he hopes these open discussions help the public realize that their comments are taken seriously.

Dr. Amaral said there was not enough data or literature available to support concrete answers for some of the public comments. He proposed that it would be beneficial to educate academic institutions on the research gaps that need to be filled. He suggested that the Committee better articulate that sometimes there was no clear answer to a public comment. Dr. Amaral talked about comments regarding vaccines and that, to date within this flu season, there have been a record 172 deaths of children from influenza. He expressed his heartbreak to hear that children were still dying from preventable illnesses because of the misconception that autism is caused by vaccines. He reiterated that no research supports this claim, that there was research that actually supported a reduced risk of autism in vaccinated children.

Dr. Cooper asked about the feasibility of using Skype as an alternative way for the public to submit oral comments as families have difficulty traveling to the DC Metro area. Dr. Daniels talked about the ability for anyone from any location across the country to submit a written public comment via e-mail or the online web form without needing to travel. She said that the office had previously explored alternate technologies such as video and found them not to be feasible for this use. Dr. Gordon suggested that if the Committee wanted to revisit the possibility ofalternate technologies, that it could be discussed internally. Dr. Gordon asked if other federal committees accepted public comments via phone. Ms. Spencer said that she was on a committee that accepted oral comments by phone, but that it did not always work well. Mr. Robison added that using a live closed captioning system would be helpful. Dr. Daniels said that there was captioning on every webcast.

Dr. Gordon discussed the scientific process that the NIMH uses for pursing questions and grant-making. There are relevant, novel hypotheses that are put forward, but that it takes more than a reasonable hypothesis to initiate a study. There also needs to be a good reason to believe that the hypothesis will be true in order to justify the significant investment of funding and other resources. For example, a new study on vitamin D would need significant funding because vitamin D deficiency is currently rampant. It is the role of the IACC to determine which research questions were a priority, and which hypotheses had a body of evidence to support it. For every hypothesis that is communicated through the public comments, there are hundreds of others that the scientists within the autism community are putting forward.

Dr. Gordon said that the NIMH is currently conducting research on diagnostics and has, for example, recently awarded a small business grant for a salivary test to diagnose autism in children. Other potential diagnostic tools have been introduced by way of nominations to the Summary of Advances. Dr. Gordon also addressed the comment about increased urgency to address autism, and he reminded listeners that they recently argued for a significant increase in funding. He acknowledged that some may not feel the IACC's sense of urgency as the research process is lengthy and has not gotten to the point where novel therapies are affecting people's lives.

Dr. Gordon introduced the panel on the Achieving a Better Life Experience Act of 2014 (ABLE Act) and financial planning.

Panel: The ABLE Act and Financial Planning for People with Disabilities

Stuart Spielman, Esq., Senior Vice President, Advocacy, Autism Speaks

Mr. Stuart Spielman began the panel presentations by talking about the financial insecurity that many American families experience. He talked about the history of the ABLE Act, an idea which originated within the 529 college savings plan that originated in the 1980s. After legislation passed in 1996, the 529 industry grew to the approximately $330 billion that it is today.

However, 529 plans were not broad enough to address the specific needs of families of people with disabilities, as participating in the program prohibited people from receiving Supplemental Security Income (SSI) and Medicaid. This prevented people with disabilities and families from achieving financial security.

The financial ramifications of autism can extend from significant expenses to reduced earning potential on the job market. There was a coalescence of people on Capitol Hill who agreed that an approach specific to families of people with disabilities would be useful. The ABLE Act originated and passed in Congress, and continues to get broad Congressional support today. The ABLE Act requires continual effort to understand and remove challenges for people who want to make an investment that is helpful to them. Mr. Spielman reviewed the historical assets and growth in ABLE accounts within its two-year existence. Current assets are well above $100 million and continue to grow significantly every quarter.

Bette Ann Mobley, Director, Maryland ABLE

Ms. Bette Ann Mobley introduced herself as the Director of Maryland ABLE and also as a representative of the National Association of State Treasurers. The ABLE program is under the Internal Revenue Service (IRS) tax code, but not the Social Security or Medicare laws and has its own federal regulations. The ABLE program provides people with disabilities an opportunity to accrue savings and assets for the present and future . The federal law does not mandate that states provide ABLE programs. Currently, 39 states and D.C. have ABLE programs. The federal law also allows for US citizens to invest in an account in any open state, although there are some states that may limit enrollment to investors within that state. The program is relatively new, but there are currently 25,619 ABLE accounts nationwide, with $120 million invested in them. These figures are significantly lower than the 529 program, which is attributed in part to the short existence of the program, but also to this to the disability community's historical distrust of government programs. They are currently conducting outreach to provide education about the benefits of the ABLE program. It can take a number of outreach attempts before someone is ready to invest in the program.

ABLE accounts do not affect eligibility for SSI and Medicaid programs, which means that ABLE assets are generally protected, but there are still caveats to consider. For instance, the ABLE program shields assets from the reduction of benefits but not income. SSI sets a limit on assets to $2,000, but ABLE allows individuals to accumulate assets up to $100,000, helping them save substantially more money before their SSI benefits are impacted. Ms. Mobley discussed another benefit of the ABLE account, which is that

SSI is only suspended – not terminated – when their balance reaches $100,000. That suspension is indefinite, and SSI benefits resume when the balance dips below $100,000 again. Medicaid benefits will remain intact even when the SSI benefit is suspended.

Ms. Mobley emphasized that the beneficiary of the ABLE account is the person with the disability, which provides that person with a sense of ownership. She added that ABLE accounts offer savings as well as investment opportunities, and that earnings in an ABLE account are not subject to federal or state taxes. Eligibility for an ABLE account requires that the person's disability occurred before age 26. Those who did not receive a diagnosis before age 26 are still eligible if there is evidence that the disability would have been present before age 26. Other eligibility requirements include that the condition be listed on the SSA List of Compassionate Allowances and Conditions or self-certification, which can be obtained through doctor certification.

When developing the ABLE program, they understood that enrolling federal programs often poses a burden to people with disabilities, and therefore the application for an ABLE account was designed to be accessible. There is no fee to open an account, but there is a beginning minimum deposit amount of $25 to $50, depending on the state. The account can be open by either the individual with the disability or by a parent, guardian, or power of attorney. Ms. Mobley emphasized that a RETT payee, a Social Security designation, is not an authorized legal representative for an ABLE account because ABLE accounts have the capacity to have more than Social Security funds in them. Being a RETT payee does not give that person the authority to access the account.

There are contribution limits, both annually and over the lifetime of the account. The lifetime limits depend on the state and range from $300,000 to $500,000. The annual limit ranges from $15,000 if the accountholder is unemployed and up to $27,060 if employed. The $15,000 limit is tied to the current federal gift limit, which could change with future tax laws. As a result of tax law changes in December 2017, an additional benefit was allowed for people who were employed, allowing them to contribute the lesser amount of their earnings or $12,060 dollars, which is the federal poverty level wage. This amount would change every year as the poverty level changes. She noted that Hawaii and Alaska have different poverty levels than the contiguous US.

Ms. Mobley added that parents who opened 529 accounts are now able to rollover those funds into an ABLE account, within the $15,000 annual limit, without tax penalty. The funds in an ABLE account can be spent on the array of expenses that contributes to the health and independence of the individual, such as housing, living expenses, transportation, education, financial and legal management, assistive technology, and health and wellness. Housing expenses have a caveat in that the funds need to be used within the same month as withdrawal. Expenses that are considered to be non-qualified are taxed in addition to a 10 percent penalty on any earnings. Monies that were not spent on qualified expenses would be considered an asset in terms of SSI. People could withdraw funds through a bank transfer, to a third party, or from a pre-paid debit card. It was important that people keep receipts in the case of a tax audit or a request for supporting documents.

Ms. Mobley asked Mr. Colin Meeks to speak about the advantages and disadvantages of opening an ABLE account versus a special needs trust. He said that the ABLE account has lifetime limits and restrictions on what money can be used for but is inexpensive. Special needs trusts have upfront costs. Ms. Mobley said if an ABLE account holder passes away the money would become a part of the normal probate process if there was not a designation for transfer. There is a payback clause in federal law that allows Medicaid to file a claim against the money in the ABLE account for any services paid by Medicaid since the time the account was opened. The limitation to the clause is that payback can only occur after any outstanding bills and funeral expenses had been paid. Some states have minor differences to this payback clause.

To learn more about ABLE accounts, she suggested visiting www.nast.org/able and also the National ABLE Network.

Colin Meeks, C.F.P., CH.F.C., C.L.U., Certified Financial Planner, Maryland Financial Advocates; Host, Special Needs Connection Podcast

Mr. Meeks talked about the basics of financial planning and the three necessities for every family. He recommended that each family have updated legal documents, liquidity and a protection plan for it, and a financial strategy that mirrors the family priorities. He noted that special needs families also need these three elements, but that there are some differences. One difference is the question of what happens to the person with special needs when a parent is gone, which means that financial plans should to account for two lifetimes. This can add an entirely different perspective to planning.

The benefits associated with planning include relief of family stress and ensuring that means-tested public benefits are there when needed. Financial planners consider anything that can avoid disqualification from public benefits, which is where ABLE accounts become useful. The financial planner will also aim to provide an ongoing system for advocacy and a system to prevent predators who try to separate the beneficiary from their money, for when the parent is no longer there. The planning timeline is one of the most important financial tools they provide for special needs families. The timeline includes different pressure points throughout an individual's life, each requiring a definite plan of action.

Mr. Meeks mentioned some common misconceptions in terms of financial and legal planning. He said that one misconception is that financial planning is expensive, but he emphasized that there are various ways to plan, including online help or advocates, and that not planning at all can be much more expensive in the long term. Another misconception is that someone else, such a sibling, will always be there to help. Mr. Meeks added that the recent provision of ABLE accounts has been helpful in financial planning for special needs families, and he closed by providing contact information for the Maryland Financial Advocates.

Phoebe Ball, Esq., Legislative Affairs Specialist, National Council on Disability

Ms. Phoebe Ball noted that she was presenting on behalf of Mr. Neil Romano, the chair of the National Council on Disability (NCD). She discussed the role of the NCD in financial planning for people with disabilities. They are a nonpartisan, independent federal agency that has been in existence for almost 40 years. The NCD started with a focus on education and later moved to other issues. She noted that the NCD wrote the first draft of the Americans with Disabilities Act (ADA) and had a significant contribution to the ADA Amendments Act of 2008. The NCD works to further the goals of the ADA, which are equality of opportunity, full participation, independent living, and economic self-sufficiency. With regard to the ABLE program, the NCD has been advocating for changes to asset restrictions in SSI, Medicaid, and other means-tested benefit programs since the early 2000s.

Ms. Ball added that the ABLE program was one of the first things she was able to work on within the NCD. People who worked on ABLE see it as one of the crowning achievements of their legislative careers, which is a testament to the importance of the ABLE Act. She talked about improving the ABLE program going forward and making it an opportunity that more people can take advantage of. Empowering people with disabilities to save money to achieve their goals is important. The fact that people with disabilities are the owners of the ABLE accounts is critical because this empowerment can pull the person out of the poverty that is common among people who are on SSI and Medicaid.

Ms. Ball highlighted the 2017 National Disability Policy Progress Report, which talked about poverty and its intractable connection to disability. She said that the NCD has identified the ABLE program as one way out of the poverty. Ms. Ball recognized that there is real fear and distrust about benefits eligibility and the NCD tries to work towards overcoming that fear. The ABLE program can improve the quality of life and the ability to meet goals far beyond the typical $750 a month provided by programs such as SSI.

Ms. Ball said that more accountholders are needed to make the ABLE program more sustainable in states that have adopted it. This would also encourage the few states that currently do not provide the ABLE program to join. She said the House Appropriations Committee, within the 2019 budget, charged the NCD to conduct information sessions on ABLE accounts when convening stakeholders, serve as an interagency coordinator to ensure consistency across federal agencies and programs, and work with disability organizations to raise awareness about the eligibility and benefits of ABLE programs. Ms. Ball noted that the NCD has taken steps to address these charges already. They did an initial assessment of guidance issues by various agencies that had programs that may be impacted by ABLE and found that the IRS had issued detailed guidance early in the program. CMS and SSA also issued guidance in 2017. However, there has not been input from others such as the Department of Education or Housing and Urban Development. They would continue to reach out to those agencies to ensure they were providing helpful, consistent guidance. The NCD had recently hosted a meeting of federal partners and were pleased to see agencies such as SSA, CMS, and ACL work together to identify the gaps and plans for the future. The NCD is also providing information sessions across the country to learn what makes the program successful or not, and to provide helpful guidance.

From a legislative perspective, the NCD will also be supporting the ABLE Age Adjustment Act, which is Senate Bill 817, and makes the ABLE program more faire by raising the age limit for disability onset from 26 to 46 years. There was hope that this would enable more people to use the program, which would also make the program more sustainable.

Committee Discussion

Ms. Crane talked about how they attempted to get an ABLE accountholder on the panel but were unable to do so. She added that she wanted to share some concerns from the self-advocacy community because ABLE accounts are a valuable tool, but they are not seeing high enrollment numbers. One problem was that doctors do not understand the standards needed to certify a person for an ABLE account, especially for those over age 26 years. Many people who should have been on SSI before age 26 are not because of the difficulty of the enrollment process or because they were employed at the time. This is one reason they have advocated for raising the age limit. She added that some people were also reluctant to open an ABLE account because it requires an intensive tracking of expenses, in case of a Medicaid audit or to avoid losing benefits. They had worked with some ABLE administrators to develop smartphone applications to track expenses and help remind people to save receipts. She suggested that they also need more accountants who are knowledgeable about ABLE to ensure people were getting accurate information on eligibility. There is also a need for better education for Medicaid social workers because, while the accountholder may understand their ABLE account, the Medicaid worker may not, which can result in loss of benefits for months.

Ms. Singer offered a parent's point-of-view of the ABLE account. She said there is a sense that 529 accounts are intended for saving for college, while the ABLE account was seen more as a spending account with immediately available funds. As a result, there was a sense of less benefit in terms of a long-term accumulation of funds. She asked if there was a way to position the ABLE program, perhaps re-marketing it to families with younger children, to ensure that funds were not spent too soon and allowing the account time to grow. Ms. Mobley answered that, as program administrators, they do not dictate how people use the program. She added that there were benefits to having immediate access to the account, such as to maintain their SSI benefit. For people with young children, there was time for the fund to grow before the child needed to access the account. Because each family situation is different, and the ABLE account can be applied in a number of ways, it would be difficult to market it one way or the other.

Dr. Gordon asked what it meant that Florida had chosen to "fund" their effort. Ms. Mobley replied that it meant that the state pays for the administration of the program so there would be no need to charge an administrative fee. Dr. Gordon asked if there was a mechanism to provide supports beyond the resources provided by individuals and their families. Mr. Spielman responded that employers were able to make contributions to a 529 account, which the family could use within the ABLE program. Mr. Meeks added that the ABLE account might not be the best long-term savings tool, in part because of the annual contribution caps. Ms. Crane said some people have special needs trusts that deposit money into an ABLE account.

Mr. Robison commented that they should remember that, while the ABLE plan has many benefits, this may be a tool for the 1 percent. Only a small fraction of the autism community opening ABLE accounts and the average 529 account contains $220,000, but the average family does not have that amount to their name. He offered no criticism to the program, but asked for a discussion on the ways that they could provide tax credits to employers who hire people on the autism spectrum. Mr. Robison said that service availability needs to increase. Mr. Spielman responded that the goal was to provide one way to improve a complex problem that would put more wealth in the pockets of people who face severe challenges. He acknowledged that the ABLE program was never intended to solve all the problems. They were continually exploring ways to get more funds into the system, to get more contributors into the system, and to have a broader economic impact to benefit the people with the most financial difficulties. He emphasized that the ABLE program was a start and that there previously had not been a lot of movement in financial empowerment within government for a long time. Mr. Robison acknowledged the good being done with the program and said that his comments were ones of general frustration rather than criticism.

Ms. Crane clarified that the average size of an ABLE account was actually $4,000, which suggests that it is not necessarily an account limited to the 1 percent but is rather a tool to help people develop a bridge from the dire poverty enforced by the $2,000 asset limit for most government benefits. She continued that a lot of people would never have more than $10,000 in their ABLE account but that money would provide a cushion if their benefits were ever interrupted, or if they needed to move or make a major purchase. She added that it could also be useful to people who were not in the worst poverty, to achieve at least moderate financial stability. Ms. Ball added that having that $2,000 in an ABLE account was aspirational rather than an ominous number hanging over a person's head. A person could start with $50 in their account and look forward to the day when they would have over $2,000 and not have to worry about potentially losing benefits. She added that ABLE does not exist in a vacuum, but rather works in conjunction with other programs. An individual who lives on $750 a month can see a dramatic improvement in quality of life with even a little extra income. She conceded that the ABLE Act was not perfect and may not address entrenched poverty, since a person cannot save money unless they have it, but that even small advancements offered by the ABLE Act are meaningful. Ms. Mobley talked about a person who receives SSI and who had been struggling as a new homeowner. Her monthly expenses exceeded $2,000 but, with ABLE, she was able to cover household expenses and have a sense of security. Dr. Gordon asked if it wouldn't be better to raise the limit, as $2,000 was not enough to cover rent in some areas. Ms. Mobley agreed this was a problem that should be addressed, but at least the ABLE program was there as a helpful tool in the meantime.

Round Robin

Dr. Gordon invited the Committee to speak about their current efforts.

Dr. Alice Kau talked about the NICHD's collaborative process to revise their strategic research plan. She mentioned that there are ways for the public to help shape the research agenda. They can visit the NICHD website or review their strategic plan webinar from October 31, 2018.

Mr. Robison said he has ideas for addressing adult issues in autism, but added that these ideas may not be fully developed at this point to share them now. He may wait until the January meeting.

Dr. Ball thanked Dr. Scott for attending and representing the Autism Society's Panel of Professional Advisors, adding that Dr. Scott had a book coming out in a few months. The Autism Society was looking into funding some aspects talked about that day to help families and get this information into IEPs.

Dr. Nicole Williams talked about how the application receipts for the autism research program would be reviewed over the next several months, and that they would complete their funding recommendations after the first of the year. Also they received another $7.5 million for the program this year and would come out with solicitations in the late winter/early spring.

Dr. Lawler said NIEHS was wrapping up their revised strategic plan. The autism programs that the NIEHS supports cover many of the important themes including individual susceptibility, environmental exposures, big data approaches, community engagement, and a translational framework directed at public health efforts as opposed to clinical interventions.

Dr. Jennifer Johnson mentioned the National Institute on Disability, Independent Living and Rehabilitation Research within the ACL and two new research grants they funded related to adults with autism and community living. One grant was at Temple University, titled "Enhancing Community Participation for Adults with ASD through Peer-Mediated Transportation Interventions." The second grant went to Pennsylvania State University, titled "Increasing Community Participation in Young Adults with ASD." The ACL also supports the President's Committee for People with Intellectual Disabilities and that the meeting on November 8 and 9 and would focus on employment.

Dr. Mamounas said NINDS had no updates to share.

Ms. Spencer discussed SSA's recently awarded five-year task quarter with the National Academies'

Health and Medicine Division to consider policies they want to change in the disability arena. They have a standing committee that advises them every quarter over a period of five years and consensus committees to help form an evidence base on a variety of subjects.

Ms. Crane mentioned two toolkits that were recently released. One was a white paper on how supported decision-making can help adults transition from institutional settings to the community. The other was an easy-read toolkit on employment policies. The toolkit was designed to be accessible to people with limited literacy on the importance of competitive integrated employment and toto teach people with disabilities about the employment policies that affect their lives and how to be more effective advocates for access to employment. She added that they were working on two white papers with the National Council on Disabilities. One was on discrimination in organ transplants and the other was on how the use of quality adjusted life years could lead to discriminatory health coverage decisions. There was also a summit of self-advocates to discuss their ideas on community living. She finished by saying their gala was coming up in mid-November and she encouraged everyone to attend.

Dr. Peña reviewed the annual conference of the Autism and Communication Center at Cal Lutheran University the past week, in which the theme was preparing students on the autism spectrum for higher education programs. Their keynote speakers were people who used augmentative and alternative communication devices and who were college students at four-year universities including UC Berkley and Cal State Channel Islands. Their center also developed a transition program, a four-day workshop to prepare students with autism who use augmentative and alternative communication for college in post-secondary programs. There was one workshop in California and another will be in Maryland.

Dr. Shapira talked about the next cycle of funding for the Autism and Disabilities Monitoring Network beginning in 2019. He added that applications in response to the funding announcements had been due by October 1 and would be reviewed soon. Dr. Shapira highlighted the Spanish app for Learn the Signs, Act Early, which was just launched. There were also studies published on the CDC's SEED and updates were included in newsletters on the website.

Dr. Larry Wexler said that they did not have specific grant programs for autism but that they were funding doctoral training grants and master's training grants, of which a number have an autism focus. The Department of Education has a data center that is in its fifth year, which has led to innovative solutions for analyzing data across data bases. For instance, there was a question about how many students with disabilities on free and reduced lunch. However, the federal government is not allowed to merge data streams, so they were unable to answer. States can merge data streams, so the Department of Education funded the development of software that enables states to look at data across streams, such as data on lunch, homelessness, and other demographics. They are piloting software this in several states, and it will help them understand the children with autism or other disabilities who come from very poor families.

Dr. Elaine Hubal talked about the Children's Health Protection Advisory Committee that met the week prior and posted materials. The EPA administrator also posted a memo on children's environmental health. The Office of Children's Health Protection at EPA, jointly with a CDC or Agency for Toxic Substances and Disease Registry (ATSDR) sponsor, have ten Pediatric Environmental Health Specialty Units throughout the country. The directors are pediatricians with specialties in environmental health and the centers provide a lot of community and science translation resources that the Committee may think about tapping into or expanding.

Dr. Robert Ring talked about recently developed devices and medicines that might have a real impact on the autism community. Roche just launched a phase 3 study of balovaptan for social deficits in autism, which is the most advanced industrial trial for autism that has taken a new compound and moved it forward. Janssen has kicked off a large phase 2 proof-of-concept study for a fatty acid amide hydrolase inhibitor (FAAH), which work on the cannabinoid system of the brain and has been evaluated for social anxiety in the past. Both studies are the leading edge of development and may be worth tracking.

Dr. Gordon said that the NIMH had two new funding opportunities. In response to IACC's recommendation that NIMH establish a body of research to support interventions for transition-aged youth. However, there were not enough high quality proposals in response to the announcement, and they realized that there were not enough people in the field. This has led to the creation of two career development opportunities for those who have been trained in other areas of clinical psychiatry research to learn about this population. One of those opportunities was for engaging in a clinical trial and another focused on other issues. Additionally, there was a recent request for information (RFI) on proposed provisions for a draft data management and data sharing policy for NIH. The NIH recognized the need for individual investigators and groups of investigators to share data publicly in order to maximize both NIH investments and to see returns in terms of public health impact. The RFI was release on October 10 and would close on December 10, 2018.

Dr. Daniels mentioned the Special Needs Connection Podcast from Mr. Meeks, which was a series that he conducts, as a parent of a child with autism, on financial planning and other resources for the autism community.

Closing Remarks and Adjournment

Dr. Gordon thanked the Committee and adjourned the meeting at 3:57 PM.

The next meeting will be on January 16, 2019 at the Hilton Washington DC/Rockville Hotel in Rockville, MD.