



Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

January 16, 2019

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Wednesday, January 16, 2019, from 9:00 a.m. to 4:39 p.m. at the Hilton Washington DC/Rockville Hotel and Executive Meeting 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*; **Melinda Baldwin**, Ph.D., *LCSW, Administration for Children and Families (ACF)*; **James Ball**, Ed.D., B.C.B.A.-D., *JB Autism Consulting (attended by phone)*; **Judith Cooper**, Ph.D., *National Institute on Deafness and Other Communication Disorders (NIDCD)*; **Geraldine Dawson**, Ph.D., *Duke University*; **Melissa Harris**, *Centers for Medicare and Medicaid Services (CMS)*; **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.)*; **Laura Kavanagh, M.P.P.**, *Health Resources Services Administration (HRSA)*; **Christy Kavulic**, *U.S. Department of Education (ED) (representing Larry Wexler, Ed.D.)*; **Walter Koroshetz**, M.D., *National Institute of Neurological Disorders and Stroke (NINDS)*; **Cindy Lawler**, Ph.D., *National Institute of Environmental Health (NIEHS) (representing Linda Birnbaum, Ph.D.)*; **Kevin Pelphey**, Ph.D., *University of Virginia*; **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 Ring**, Ph.D., *Kaerus Bioscience*; **John Elder Robison**, *College of William & Mary*; **Stuart Shapira**, M.D., Ph.D., *Centers for Disease Control and Prevention (CDC)*; **Alison Tepper Singer**, M.B.A., *Autism Science Foundation (ASF)*; **Julie Lounds Taylor**, Ph.D., *Vanderbilt University*; **Cheryl A. Williams**, *Social Security Administration (SSA) (representing Melissa Spencer)*; **Nicole Williams**, Ph.D., *U.S. Department of Defense (DoD)*; **Carrie Wolinetz**, Ph.D., *National Institutes of Health (NIH) (representing Francis Collins, M.D., Ph.D.)*.

Call to Order, Roll Call, and Welcome

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

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

Dr. Joshua Gordon called the meeting to order at 9:01 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 new member Dr. Melinda Baldwin, representing the Administration for Children and Families at HHS, and a new alternate, Ms. Cheryl Williams, representing the SSA. Ms. Melissa Spencer of the SSA is retiring this month, and Dr. Gordon expressed his appreciation for her service on the Committee. Ms. Williams introduced herself and briefly discussed her position as Director of the Office of Medical Policy within the Office of Disability Policy at the SSA.

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 thanked the representatives who are participating in the Federal Interagency Workshop on ASD (FIWA). This effort has helped her understand the strategies federal programs use to influence policies and programs across the state and local levels, which were discussed at the last FIWA meeting.

First, they are engaging directly with state and local entities. The Department of Labor (DOL) has worked with state and local associations and councils on disability employment initiatives, policy, and legislature. Additionally, the Indian Health Service (IHS) has addressed the opioid crisis by convening the [HOPE Committee](#), which brings together local providers, community leaders, and Federal partners on critical, health-related topics.

FIWA is also working on targeted grant programs. For example, the Administration for Community Living (ACL) is using [System Change Grants](#) to support positive changes in social systems and service delivery programs. These include state councils on developmental disabilities, state protections and advocacy systems, and the [University Centers for Excellence](#) in Developmental Disabilities Education, Research, and Service (UCEDDs).

Other initiatives include education and professional development to support teachers, masters- and doctoral-level scholars, and other professionals. The Department of Education (ED) has implemented [IRIS Centers](#) to provide teachers with free online learning modules, including Autism-Focused Intervention Resources and Modules (AFIRM). Meanwhile, the Health Resources and Services Department (HRSA) has created [Leadership Education in Neurodevelopment and other Related Disabilities](#) (LEND) and [Developmental-Behavioral Pediatrics](#) (DBP) programs to provide training and technical assistance to Title V and other MCH professionals.

One of the ongoing activities is to focus on supports and services recommendations from the 2017 [Report to Congress on Young Adults and Transition Age Youth with ASD](#). They are also evaluating

government-sponsored survey data sets and outcome data on transition age youth and adults with ASD, with a focus on identifying gaps. The DoD, ACL, and NIH are planning a special FIWA meeting regarding outcome measures.

HCBS Final Rule: Current Issues and Future Directions

Melissa Harris, Acting Deputy Director, Disabled and Elderly Health Programs Group, Centers for Medicare and CHIP Services, Centers for Medicare and Medicaid Services (CMS)

Ms. Melissa Harris discussed the 2014 [Home and Community-Based Settings \(HCBS\) Final Rule](#), a regulation which defines criteria for home and community-based settings provided by Medicaid. Additionally, HCBS aims to ensure that individuals receiving services have freedom of choice for a qualified living setting and qualified service provider.

Ms. Harris explained that CMS began developing this regulation by issuing an Advanced Notice of Proposed Rulemaking, which asked stakeholders to communicate their desires for criteria of home and community-based settings. CMS used those recommendations and public comments to develop a [final rule](#) in 2014. Although some requirements were effective immediately, a built-in transition period allowed states sufficient time to comply. The original transition period was five years, but it was [extended to March 2022](#) in recognition that significant reform efforts are underway and that current compliance activities remain transparent and collaborative.

Ms. Harris reviewed the contents of the Final Rule. By 2013, Medicaid programs saw home and community-based service expenditures surpass expenditures for institutional care. Over time, an enormous amount of variation in home and community-based settings across states developed. States had no standard language to describe which providers were receiving Medicaid funding or which settings were receiving services. CMS felt that the increasing amount of tax dollars allocated to these services necessitated a state-to-state standardization of home and community-based settings. At the same time, CMS wanted to ensure that the criteria facilitated person-centered care.

The criteria for home and community-based settings included integration in and access to the greater community, as well as opportunities to seek employment and work in competitive integrated settings. The criteria ensure that individuals receive services in the community with the same degree of access as those who don't receive Medicaid HCBS. Additionally, individuals must be able to select their residential setting from a number of setting options, which are identified in the person-centered service plan and are based on their needs and preferences. Ms. Harris reiterated that all of these setting options ensure the individual's rights of privacy, dignity, respect, and freedom from coercion and restraint, and they are intended to optimize initiative, autonomy, and independence.

Some additional criteria apply to provider-owned or controlled settings. This can include group homes, assisted living facilities, or host homes. These extra criteria are necessary because there are specific implications for day-to-day decision-making and autonomy when the individual receives services directly from their place of residence. For example, this second set of criteria includes legally enforceable lease agreements to prevent inappropriate discharge and evictions.

Ms. Harris also reviewed some state laws that ensure lease, residency agreements, or other protections. Some of these specific criteria include privacy in the individual's sleeping or living unit, locked entrances,

choice of roommates, freedom to furnish and decorate their room, the freedom to control schedules, and the power to invite visitors at any time. Ms. Harris summarized the core of these criteria as the ability to choose.

CMS has spoken with providers to ensure that they recognize the autonomy of the individuals under their care. According to Ms. Harris, providers have been receptive to the criteria and are eager to understand federal expectations so that they can adhere to them. CMS also aims to ensure that providers receive any necessary technical assistance.

Ms. Harris discussed how these criteria can be modified to accommodate different populations with varying needs. She said that CMS does not aim to create a one-size-fits-all plan. Instead, the federal regulation includes extensive consideration of person-centered planning. There have been discussions about balancing provider abilities with the autonomy of the individuals receiving services. As a result, any modifications to the regulatory criteria are to be documented in the individual's person-centered plan. These modifications, which might include provisions for food access or room privacy, are based on the individual's health needs and are to be expected. Ms. Harris clarified that the regulation recognizes that needs are not universal, and that some individuals need significant and specialized supports.

Documenting modifications to the person-centered service plan include describing conditions appropriate for the assessed need, ongoing data to measure the effectiveness of the modification, and established time limits for periodic review. The modifications require the individual's informed consent, as well as assurance that these interventions will not cause harm. Some individuals have time-limited modifications, which would ensure that restrictions only remain in place as long as the relevant health conditions are ongoing.

Ms. Harris talked about the status of activities across [statewide transition plans](#) (STPs) for adhering to the new requirements. There are two types of approvals in a statewide transition. They are currently missing approval from eight states. Forty-two states and Washington, D.C. have received initial approval of their STPs, which means that they have laid out the timing of any remediations to current regulations and infrastructure, including statutes and provider manuals, across the transition period. Ten states have received final approval, which means they have additionally laid out a process and timeline that allows providers to perform self-assessments, which will be verified by the state and returned to providers for necessary remediation. Ms. Harris recommended that stakeholders should be aware of the status of their state's STP, which can be found on the Medicare website

Within a year of the publication of the Rule (by March 2015), states should have submitted their STPs for CMS to review. Ms. Harris reviewed the criteria for initial approval of STPs, which determines if the state plan is aligned with the federal regulation. A key component of this review is stakeholder engagement, wherein the STP is released for public comment as the state moves toward final approval. Final approval occurs when the state can detail provider duties, service timelines, and interaction with the provider community. This ensures that by the end of the transition plan, the state is comfortable with the provider's ability to comply with the regulation. The STP should also address provisions for how the state will work with settings that are presumed to have institutional characteristics, a component which can require a lot of attention and energy.

Some other components needed for STP initial approval include a communication process for beneficiaries for non-compliance by March 17, 2022. Additionally, there is a need to identify settings

subject to the rule in the STP; assessing outcomes; remediating outlined strategies; and drafting the STP to be disseminated for a 30-day public comment period.

Ms. Harris said that the regulation defines some institutional settings, which are not home and community-based, which cannot be funded by Medicaid provisions for HCBS. These settings can include nursing facilities, institutions for mental diseases, intermediate care facilities for individuals with intellectual disabilities, hospitals, or any other location with qualities of an institutional setting.

CMS has included provisions for settings that are assumed to have institution-like qualities, which may or may not be related to the setting's proximity to an institution. These include settings those that are on the grounds of or adjacent to a public institution, or are in the same building as a public or private institution. Because these settings share a space with an institution, they require special attention to ensure that the provided services are truly home and community-based. Finally, some settings isolate HCBS beneficiaries from the larger community. Ms. Harris explained that these settings need the most sub-regulatory guidance from CMS.

To conclude, Ms. Harris reviewed the key points of her presentation. She acknowledged that there is a lot of uncertainty and fear about the Rule, as some businesses believe that these regulations would harm them. However, the Rule is not intended to target particular industries or provider types. In 2015, CMS released a [guidance document](#) to explain concepts like isolated settings or HCBS beneficiary settings. Public comments indicated that providers took issue with the descriptor "isolated," perceiving that the government was using this label to highlight them and lump them together. Ms. Harris said that CMS took this feedback to heart and has spent the last year working on revised guidance for heightened scrutiny provisions, which can include a Heightened Scrutiny Review to determine if a setting is presumed to have institution-like qualities.

Ms. Harris said that one of the main intentions of the regulation is to avoid disruption. She said that CMS would not declare the Rule a success if it required providers and the individuals receiving services to make significant, unwanted changes to their lifestyles. The primary goal of the Rule is to ensure that services are provided with an emphasis on person-centered care while allowing states flexible decision-making. Ms. Harris concluded by encouraging people to understand their states' rationale and vision for implementing the regulation.

Committee Discussion

Ms. Alison Singer expressed her appreciation for CMS's flexibility and her anticipation of the new guidance. She said that they are facing a capacity issue and the guidance is important for building new settings and providing people with new living options. She wondered who would be involved and affected by the transition plans. Her state of New York has identified 72 settings that cannot be modified (which affects 6,900 beneficiaries) and 579 that settings that either fall under heightened scrutiny or have the potential to. She asked if CMS is prepared to ensure that individuals receive their necessary benefits. Ms. Harris agreed that this question is one of the most significant issues under consideration. New York has initial approval of their transition plan. New York has a lot of providers, and the large number of settings requiring heightened scrutiny may be a result of the language of the state statute. Ms. Harris said that CMS is working with the state to determine how to address this issue. In settings that can't be modified, the state makes a determination about a provider's ability to comply with the regulation by the end of the transition period. Ms. Harris explained that some providers might choose

not to make changes for compliance because that the remediations are not financially viable.

Ms. Harris said that services are currently provided under three authorities: the 1915(c) Home and Community-based Waiver, the 1915(i) Home and Community-based State Plan Option, and the 1915(k) Community First Choice State Plan Option. These authorities require services to be provided in a home and community-based setting. However, a setting that does not meet the HCBS criteria can still receive dollars from other Medicaid funds. If some settings no longer receive Medicaid funds after the transition period, then CMS and the state need to have conversations about funding these settings and ensuring that providers will be able to meet the new criteria by the end of the transition. This is the reason that states are required to use the STP to detail a process for communicating with providers about regulation compliance.

Ms. Harris concluded by saying that CMS likely will not involve itself in decision-making processes that impact individual placement in settings. However, CMS aims to guide states and providers through potential options for maintaining federal Medicaid funding.

At the end of the session's allotted time, Dr. Gordon noted that the topic could be revisited later if time allowed. Ms. Harris provided her email address for further questions: Melissa.Harris@cms.hhs.gov.

TRICARE Autism Care Demonstration

Capt. Edward Simmer, M.D., Chief Clinical Officer, TRICARE Health Plan, Defense Health Agency, DoD
Krystyna Bienia, Psy.D., Clinical Psychologist, Senior Policy Analyst, Defense Health Agency, DoD

Capt. Edward Simmer presented an overview of the Military Health System (MHS) and TRICARE Health Plan (TRICARE). The MHS is focused on health and readiness of US service members, military retirees, and their families. About 9.5 million people rely on the MHS for medical care, and some individuals who are born into the military and choose a military career receive coverage for the entire lifespan.

Capt. Simmer said that the MHS has both a direct and a purchased care system worldwide. The MHS aims to establish a medically ready force, meaning that troops are up-to-date on their medical needs, vaccinations, and physical fitness. The MHS also works to ensure the presence of a ready medical force, a group of physicians and providers who are specially trained to treat service members.

Capt. Simmer stated that the MHS is currently focused on integrating network care with direct care. Currently, standards of care can differ between military hospitals and civilian programs, so MHS aims to standardize rules and benefits across these entities. In addition to optimizing services, MHS is moving towards a high value system of care. Deployed services members are often concerned with the health of their families back home, and therefore taking care of family members is a way to ensure a ready force. Capt. Simmer said that, for active duty family members in the HMO program, most medical care is cost-free. He made the distinction that MHS is not health insurance, but rather a benefit earned for service provided to the country.

About two million beneficiaries covered by this system are under the age of 21. Individuals with ASD receive [treatment for ASD](#) under TRICARE Prime or TRICARE Select, which cover medically or

psychologically necessary, evidence-based treatments. These primary care services can include occupational therapy, physical therapy, speech and language therapy. In addition, MHS recently expanded the mental health benefit, which further assists individuals who need medical services for ASD. Most of these services and prescription medications are available without copay, especially if the services are provided by a military treatment facility.

Capt. Simmer said that Medicaid waiver programs are a challenge for active duty families, who tend to move across states every two to three years, which is too frequent to get to the top of Medicaid waiver waiting lists. To remedy this problem, MHS provides an [Extended Care Health Option](#), which provides specific benefits only to active duty family members. This provides some additional benefits to children with ASD, including respite care, vehicle modification, and translation services.

Federal regulation determines what can be considered a benefit under this program. This decision process is founded on evidence-based research with clinically meaningful outcomes. The MHS prefers to base benefit decisions on well-controlled studies published in peer-reviewed journals. However, pediatric populations may pose ethical and practical challenges to this kind of research, so the MHS relies on other factors to determine if child-centered research is well-grounded in evidence. To meet the standard of reliable evidence, a treatment or procedure must be tested in a well-controlled study or be published in reports national professional medical associations or expert opinion organizations.

Meeting this standard means that a treatment is deemed safe, effective, and eligible to be considered a medically or psychologically necessary treatment under the TRICARE Basic Program. Currently, applied behavioral analysis (ABA), a common treatment for ASD, is not covered under the basic benefit because it does not meet the evidence standard required by the MHS. Capt. Simmer said that a recent literature review found that research on ABA is not sufficiently evidence-based to make the determination that ABA is an effective treatment. The MHS is working to allocate DoD funds towards new research to fill these gaps.

Capt. Simmer cited a group survey of 8,000 parents of children with ASD, who responded that occupational therapy, speech and language therapy, and ABA were most helpful for their children. He wondered if some combination of these services might best benefit a child with ASD. However, he pointed out that not all children with ASD will benefit from the same combination of treatments and services. As a result, there is need for a way to target a child's needs efficiently and accurately.

Dr. Krystyna Bienia reviewed the [Autism Care Demonstration \(ACD\)](#), which provides ABA services to TRICARE eligible beneficiaries diagnosed with ASD. Because this is a demonstration benefit, services can be provided based on ABA research that doesn't meet the hierarchy of reliable evidence. Most ABA services are provided under purchased care, meaning providers are contacted through regional contractors.

She reviewed the history of providing ABA services under TRICARE. In 2001, ABA services were first provided as an educational benefit. Over time it evolved from educational to other than educational to other than medical. Now they are figuring out how to move the service to a medical benefit. Currently, only half of the 30,000 diagnosed beneficiaries are receiving ABA, and they do not currently know why beneficiaries are not using the available services. Dr. Bienia reviewed the cost of the ACD, which is about \$268 million per year and is expected to grow to \$40 million before their demonstration authority ends December 31, 2023. There are no age, dollar, duration, or cap limits on the ACD benefits.

Dr. Bienia said that outcome measures have consistently been a challenge to the ACD. Currently, they use the Vineland, the Social Responsiveness Scale, and the Pervasive Developmental Disability Behavioral Inventory to assess outcomes. These three measures were selected for their applicability and accessibility, but Dr. Bienia said that there are potentially better, more reliable measures. She encouraged the Committee to think about and suggest measures that may be more useful than the three that are currently used by the ACD.

Dr. Bienia summarized several initiatives within the ACD and the Defense Health Agency. There is significant engagement with stakeholders, including providers, advocates, and lobbyists, who provide the ACD with information resources and upcoming research projects. There is also an ACD email, dha.acd@mail.mil, which is monitored daily. The ACD is also involved in a contractor review of quality metrics to ensure that they are providing high quality care. In 2017, they hosted an Industry Day to solicit best practices for delivering efficient services.

She reviewed initiatives at the Fort Belvoir Community Hospital and Walter Reed National Medical Center, which both have programs that engage directly with parents to pass on knowledge and resources after receiving an ASD diagnosis. She reviewed the services provided at other military treatment facilities (MTF) across the country, including Joint Base Lewis-McChord at the Madigan Army Medical Center, which offers a multidisciplinary clinic for in-hospital assessment, and the Wright-Patterson Air Force Base [PLAY Project](#). This parent-mediated program is a supplement or alternative to some ABA services.

Dr. Bienia reviewed the outcomes of two audits, which found that two-thirds of the ACD's reimbursed services were inappropriately paid. She attributed this to lack of or insufficient documentation. Because ACD providers are trying to move from educational benefits to medical benefits, some providers are still learning how to accurately fill out medical records. She said that information on the audit is [publicly available](#).

Finally, Dr. Bienia talked about the [Congressionally Directed Medical Research Program](#) (CDMRP), a five-year study that aims to compare standard of care, early intensive behavioral intervention (EIBI), with an adaptive ABA model. They are interested in determining if kids improve as well or better with EIBI than ABA, the impact of EIBI and ABA on families, any predictive factors for which service is most beneficial to any child and family, and obstacles to implementing services. Another CDMRP study looks at how EIBI can benefit the larger community. Dr. Bienia said that they want to know how to lower costs and increase access to EIBI services so that families can confidently choose an effective intervention approach.

Capt. Simmer talked about the future of the ACD. One of their main goals is to make the ACD a truly comprehensive benefit for families. Currently, the ACD section of the TRICARE Operations Manual is focused on providers, rather than beneficiaries and their families. He said that they are working toward a more family-focused ACD, and he hoped that these changes would be published and announced by July 2019. The biggest change will be provisions for increased family and parental support with a holistic, beneficiary-centered approach. He said that the ACD will begin to expand beyond ABA into providing occupational therapy, speech and language therapy, respite care, and other evidence-based practices that can help children with ASD. The ACD also intends to implement individualized case management and care coordination as well as services usage management. Additionally, they want to increase quality

oversight by incentivizing providers to use the highest value care.

Capt. Simmer ended by asking the Committee suggest research or data on outcome measures, medical necessity criteria, and utilization management. They want to ensure that they are using the most recent evidence and making the best use of their funds to serve the needs of children with ASD and their families.

Committee Discussion

Mr. John Robison said that, for many people in the autism community, the first priority is identifying and treating other medical issues that commonly occur in children with ASD. Some of these issues, many of which cause pain and discomfort, can be the underlying cause of what are considered ASD behavioral symptoms. He suggested that this is a fundamentally different priority that the ACD should consider incorporating into their primary goals. Mr. Robison then said that millions of dollars have been invested in autism research, resulting in new therapies that are more modern and effective than ABA. He expressed concern that TRICARE might only cover ABA, and he suggested that the ACD should use studies of ABA that don't rely heavily on parent or clinician report. They should also consider that many people with ASD who received or are receiving ABA have strikingly different opinions of ABA than parents and clinicians.

Capt. Simmer agreed with these comments and talked about the high prevalence of seizures and other medical conditions in the autism community. Consequently, MHS requires all autism providers to have CPR or BLS training. He said that ABA is just one component of TRICARE's comprehensive medical benefit, and he hoped that other therapies will be incorporated when the ACD is rewritten over the next six months. They plan to hold a summit with care providers to see if innovative treatment plans could be implemented by MHS. Dr. Bienia addressed Mr. Robison's concern about reporting methodologies by noting that they intend to move past parent and provider reporting, as well as focus on actual needs.

Dr. Geraldine Dawson said that she supports the new program and its direction. She recalled her testimony at the senate hearing for the TRICARE Benefit and said that Senator Kristin Gillibrand had suggested a review of the evidence base. Dr. Dawson said it is important to remember that ABA is a broad term that encompasses a wide range of evidence-based treatments, including play-based and naturalistic approaches. Although she agreed that evidence needs to be stronger, she does believe that the presentation omitted some meaningful outcomes shown in some randomized clinical trials. She mentioned one study that showed that children who received two years of ABA were able to make and sustain progress to cognitive, language, and adaptive behaviors. After two-year intervention program, the children required fewer services and saved an estimated \$19,000 per year. Dr. Dawson also pointed out that NIH has funded a number of studies that will be released in the coming years, including a randomized clinical trial of early intensive interventions and a study comparing play-based versus traditional ABA interventions.

Dr. Bienia stated that they had identified six randomized controlled trials that showed good outcomes for ABA. However, they determined that these studies were not adequately replicable. Dr. Dawson responded that mental health benefits seem to require a much higher standard of research than other benefits, which might limit people's ability to access the services they need. Capt. Simmer suggested that the Committee can send studies for their review. He said that they actually use a slightly different standard of evidence for pediatric research because they understand that the same level of evidence

may not be practical in pediatric populations as compared to adult populations. Dr. Bienia said that they are looking for provider justifications for their prescribed hours of therapy. They do not have these criteria yet.

Dr. Gordon talked about the [US Preventative Taskforce for Screening for Autism](#). They have been engaging in a dialogue about research that would move recommendations in favor of universal autism screening. They would benefit from engaging with health care funders about the kind of evidence that could motivate providers toward universal screening.

Dr. Louis Reichardt commented that genetics may be one of the best predictors of future risk and may be a low-cost way to provide families with the comfort of knowledge. He also wanted to discuss incentives to persuade families to participate in autism scientific research.

Dr. Daniels requested a moment of the Committee's time to announce that IACC member Ms. Samantha Crane's baby arrived today.

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 thanked the OARC staff for their work and talked about a new option for submitting public comments. Currently, an individual can submit a written comment or come in person to deliver an oral comment. She reminded the Committee that closed captioning is available through NIH VideoCast. She also mentioned that in April 2018 they initiated a quiet room for anyone who might need it, and in October 2018 they initiated CART services.

The [2016 IACC ASD Research Portfolio Analysis Report](#) has been published and is now available in print and online. This is the first Portfolio Analysis Report that aligned projects to the 23 new objectives in the Strategic Plan. The analysis includes data from 18 federal agencies and private organizations. Dr. Daniels reported that research funding totaled about \$364 million and included 1,360 studies spanning all seven of the IACC Strategic Plan question areas. Question 2 (biology) received the most funds. The [2016-2017 IACC Strategic Plan](#) calls for doubling the 2015 ASD research budget to \$685 million by 2020, which would cover federal agencies and private organizations that fund the research. She said that ASD research funding has increased by 6.3 percent since 2015. In addition, the 2016 Portfolio Analysis Report includes a map of institutions involved in ASD research, a list of countries who received ASD research funding from US funders, and research funding trends aligned with each of the seven Strategic Plan questions.

Dr. Daniels updated the Committee on the progress of activities of the Autism CARES Act Reported to Congress. She also shared an update on the Strategic Plan Update, which will include short summary reports of IACC activities in 2018. This would include a summary of Health Outcomes Working Group activities, a summary of the IACC Portfolio Analysis Report, and a summary of the Autism CARES Act Report to Congress. Committee members will receive a draft for review and comments soon, and they expect final publication in spring 2019. Dr. Daniels reviewed other IACC reports that are currently in

progress, including the 2017 IACC Portfolio Analysis Report and the 2016 International Portfolio Analysis Report.

Dr. Daniels provided an update on the [IACC Working Group](#) on Improving Outcomes for Individuals on the Autism Spectrum. Co-chaired by Dr. David Amaral and Dr. Julie Taylor, this Working Group is focused on health and wellness for individuals with ASD. They aim to support research on health conditions affecting individuals with ASD, to increase community and provider awareness, and to foster development of practice guidelines, policies, and service approaches. The Working Group held conference calls on [September 5](#) and [December 17](#), 2018, and a day-long workshop on [September 27](#), 2018. The remaining activities of this Working Group include developing a written report and a workshop focused on mental health conditions, which will take place in spring 2019.

The IACC also voted to convene a Working Group on housing issues for individuals with ASD. Dr. Daniels said that the scope will be research and best practices on housing, implementation of current federal regulations, and housing issues faced by autistic individuals with more severe disabilities. Ms. Alison Singer will chair this Working Group. Their activities, which will run through September 2019, will potentially include working group phone calls, in-person meetings and workshops, and written documents. Dr. Daniels requested that the Committee provide any nominations for the Working Group by email, with a deadline to be determined.

Committee Discussion

Dr. Reichardt asked if the Committee could receive the portfolio analyses that are using more recent data. Dr. Daniels said that there is a necessary lag because they cannot collect federal data until the fiscal year ends, and some agencies have additional time restrictions on data collection. They are currently working on 2017 data.

Dr. Dawson offered appreciation for the work and the analysis, and she expressed understanding that these are time-intensive processes. Dr. Daniels thanked the OARC for their work to make the information as comprehensive and accurate as possible.

Mr. Robison expressed his disappointment that in the government's position that those with ASD who receive government housing assistance do not have the same freedom of choice as those without developmental disabilities who use this service. He said that, except in cases in which a guardian makes decisions, individuals with ASD should have freedom of choice in their living situation without government interference. Dr. Gordon asked for clarification about Mr. Robison's point about eligibility restrictions for disability housing, which were discussed in a previous presentation. Mr. Robison said that there are no other groups that face these same restrictions and that these criteria infringe on basic human rights.

Ms. Harris said that the same HCBS criteria also apply to all populations using that service, including people with developmental disabilities, traumatic brain injury, aging-related health care issues, and substance use disorders. The regulations are designed to allow individuals to make their own decisions and to remove infringements on individual rights. The goal of the regulations is not to restrict the types of housing that are available; rather, it is to center the individual and provide services to people with different types of disability needs. She suggested that there is no reason why existing settings, such as farmsteads or other specific types of facilities, would not be able to meet regulatory criteria and

continue to provide services in the long term.

Dr. Dawson suggested that there is need for a transition plan that analyzes the impact of the change in philosophy regarding what constitutes a supported housing options. She expressed concern, given the example of New York, that the regulations will limit in the types of settings available to families, and there are already too few options. Ms. Harris said that a shared goal of the regulation is to ensure that existing options are not limited. This why they want to know why a setting might not be able to comply with criteria by the end of the transition period. She hoped that the Working Group on housing will address these issues.

Dr. Gordon said that the transition period, which allows states three years to work on reaching compliance, is a helpful approach. He addressed Mr. Robison's earlier comment about freedom of choice by saying that HCBS provide extra services to address individual health needs.

Mr. Robison read aloud a tweet from Sara Luterman, a person with ASD who frequently attends Committee events. In this tweet, Ms. Luterman expressed concern that weakening of CMS rules could eventually result in involuntary institutionalization of autistic people. Dr. Gordon suggested that complete free choice could result in someone ending up in an inappropriate or even harmful housing setting. Mr. Robison said that it seems clear that, despite best intentions, the issue is far from settled and more work is needed.

Ms. Singer commented that the word "institution" needs to be addressed with more care. She said that the intentional community centers today for people with ASD are nothing like the institutions of the 1970s. Many of these new centers provide important social and communal opportunities, and they need to be among the spectrum of choices. Ms. Harris agreed and said that the regulation would put intentional communities on the same level as other types of settings. It is up to the government to determine if the service provisions in a particular setting isolate HCBS individuals. For example, an intentional community might have a host of available on-campus resource, which a person should be able to use whenever they choose. However, problems arise when the setting discourages people from using off-campus services because similar services are available on campus, effectively isolating the individual. Ms. Harris explained that this is why they developed criteria for an isolating setting. There may be stakeholders who do not agree that a particular setting requires heightened scrutiny, and CMS likely will not involve itself with such a disagreement. They do hope that the new guidance, which is in the final stages of clearance, will demonstrate that they have incorporated prior guidance and feedback into the new regulation.

Mr. Robison commented on the TRICARE presentation and the idea that genetic information could provide insight and comfort to families. He said that genetics may not only give information about the children, but could also provide valuable insight into their families, who could also receive screening. Within the population of service members and retirees, there could be a tremendous opportunity to access a large population and conduct high impact research.

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. Daniels welcomed the five public commenters and stated that [Oral Public Comments](#) are also posted online.

Dr. Eileen Nicole Simon talked about language disorders as a serious problem for children who receive an autism diagnosis. She said that many parents of non-verbal children have attended the IACC meetings to plead for more attention on this issue. The IACC was formed to seek reasons for the increasing prevalence of autism, and she expressed concern that the Committee has abandoned this mission. Her son is now 56 years old, and she said that she is told that to accept his disorder. She argued that autism is a serious neurological disorder, comparable to cerebral palsy or spinal cord injury, and that research should be conducted to determine causes and prevention of perinatal brain damage, which could be adopted to prevent brain damage in children and adults.

Ms. Shari Chase is a mother of two young men, one of whom has autism. She said that her son Alec, a bright 22-year-old, has been experiencing meltdowns and SUNCT headaches that have limited his ability to thrive. Alec's neurologist said that SUNCT headaches are common among people with autism, and Ms. Chase said that she has been searching ways to detect precursors to these headaches as meltdowns and outbursts. Her older son, who is an engineer, has developed a startup company called Gaia Wearables, which uses a device to detect pre-markers of anxiety. She suggested that there is a need to fund students who are creating technologies that can help people with autism live fulfilling lives. She cited CBD oil as one such helpful intervention, but noted that it is currently illegal for caregivers to administer this treatment on federal property. Ms. Chase also pointed out there is a lack of health care professionals who are trained to work with individuals who have autism. She said that physicians are unwilling to treat health conditions such as traumatic brain injury in children with autism, and she suggested that rehabilitation doctors need additional education on treating patients with ASD. Ms. Chase also suggested a national job training program for individuals with autism, which would involve skills-based learning in classrooms followed by practical application and independent employment. Finally, she suggested a collaborative residential program that would pair retirement-age individuals with people who have ASD. She believed that senior citizens could pass on their expertise and training to younger people with autism. Currently, Ms. Chase runs a television show called Making a Difference, in which she reviews existing programs and approaches. She thanked the Committee for their dedication and asked the psychiatrists in the audience to consider that certain medications might cause fits of rage in people with autism.

Dr. John Martin was not available for his oral presentation.

Ms. Aimee Doyle is an attorney and a mother of a child with autism. She spoke on behalf of the national autism nonprofit organization [SafeMinds](#). They are concerned about the federal government's lack of urgency to address autism disability. She said that there is a significant need to improve outcomes related to increased mortality and lower quality of life associated with ASD. In the summer of 2018, SafeMinds, in collaboration with Autism Action Network, TACA, and the Thinking Moms Revolution, developed an online survey and sent it to constituents. Almost 1,500 stakeholders in the autism community responded. Ms. Doyle reviewed the survey responses, which centered around effectiveness, responsiveness, and accountability. She said that more than half of the respondents had never heard of the IACC before completing the survey. The respondents reported concern that the IACC had not

coordinated or promoted research that would identify the causes of autism, prevention and treatment, or addressed co-occurring medical and psychiatric conditions. Only six percent of respondents expressed belief that the IACC is improving the lives of stakeholders. Ms. Doyle said that the full report is available on www.safeminds.org.

Summary of Written Public Comments

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

Dr. Oni Celestin summarized the [Written Public Comments](#). The IACC received 17 written public comments, organized into five broad topics. The first topic was medical practices and potential causes of autism. The five comments under this topic included concerns regarding fetal brain injury, the potential contribution of glyphosate to ASD symptoms, the use electroshock therapy at the Judge Rothenberg Center, prenatal ultrasounds, x-rays, and electromagnetic radiation. There was also a recommendation that the Committee advocate for changes to the standard of care for individuals with intellectual and developmental disabilities.

The second topic was vaccines and autism, and there were four comments received on this topic. Comments included concern about mercury in vaccines, and the association between autism and several environmental toxins, including mercury. There were also suggestions to investigate allegations of fraud and obstruction of justice in the Omnibus Autism proceeding and that the National Childhood Vaccine Injury Act of 1986 be revised. There was also a recommendation for a clinical study to compare neurotypical children with children who have regressed into autism.

The third topic was the role of the Committee and the Federal government. There were four comments received on this topic, including a link to an online commentary expressing concern about the Committee's progress, a request that the Committee facilitate a survey of autistic parents in order to better identify research needs, a recommendation that the Committee make a formal request to Congress to investigate the CDC whistleblower issues, and a comment that the Committee should work harder to identify causes and treatments for autism.

The fourth topic was service needs, resources, and policy implications. The Committee received three comments on this topic, including a link to an online commentary advocating for an increase in sensory-friendly opportunities, concern about the need for group housing with properly-trained staff, a recommendation for special education programs for the increasing autistic population in schools, a request for assurance that the Supplementary Security Income (SSI) and Social Security Disability (SSDI) programs would continue to be available to her teenage grandson and other young people with ASD into adulthood, and a shared press release announcing the creation of the National Council on Severe Autism, a new organization that aims to advocate for the needs of autistic individuals with severe disabilities.

The final topic, which received two comments, was transition to adulthood and adult service needs. Comments included a shared blog post detailing the experiences of a young man with ASD who started his own woodworking business, and commentary about the various employment challenges an individual with autism has faced.

Dr. Celestin concluded by thanking the commenters.

Summary of Live Feedback Public Comments

Dr. Daniels reviewed the three comments received from the [Live Feedback](#) platform, which will also be available on the IACC website. Ms. Karla Shepard Rubinger asked a question about the TRICARE presentation, Ms. Rose Walker expressed concerns with ABA, and Ms. Luterman commented on employment issues in the autism community.

IACC Committee Member Discussion of Public Comments

Mr. Robison addressed the concerns and survey results from Safe Minds, expressing that everyone on the Committee wants to do as much as possible for the autism community. He said that he is troubled that numerous autism community stakeholders, such as SafeMinds, Autism Speakers, Simons, and the Autism Science Foundation, have been represented on the Committee but do not work together in the public world. He pointed out that each organization only represents a fraction of the community, and that working together as a group would be most effective. He said that the public commenters provide thoughtful research questions, but it is not always feasible to develop these into full studies. However, he said that the Committee could make better use of these public comments to be more responsive to the autism community.

Dr. David Amaral said that he found it disheartening that despite the well-intentioned efforts, such as the health outcomes Working Group, there is still a sense that the IACC is not doing enough. He wondered how to better translate these efforts to the public.

Dr. Kevin Pelphey talked about Ms. Rodger's comment on the topic of prenatal exposures. He mentioned a [study](#) conducted by Dr. Pasko Rakic, which showed changes in neuronal migration in mice who received prenatal exposure to intense prolonged ultrasound, although follow-up studies published in JAMA Pediatrics found no association. Dr. Pelphey pointed out that randomization is difficult in ultrasound trials because intense ultrasounds are typically only necessary when there are preexisting problems with the pregnancy. Dr. Pelphey said that the hypothesis is interesting, but the studies done so far have shown no association. The conclusion may be that a family should not be concerned about a medically necessary ultrasound.

Ms. Singer added that Dr. Lisa Croen has studied prenatal ultrasounds and also found no association to autism. She talked about the press release from the [National Council on Severe Autism](#) (NCSA), a group that is focused on the needs of the autism community who are severely disabled, nonverbal, self-injurious, and/or aggressive. This population has very different needs than the rest of the community, and they tend to have difficulty advocating on their own behalf. She encouraged the Committee to look at the NCSA website, where one can find important topics facing the autism community, such as guardianship, abuse prevention, health care access, crisis care, and personal safety. She said that recent research indicates that this population of individuals with autism are often excluded from research studies, so the NCSA is working to ensure that the needs of this population is accounted for in policy, research, and services.

Dr. Amaral gave an update on [Autism BrainNet](#), a program within the Simons Foundation that asks individuals to consider donating brain material post-mortem so that researchers can better understand

the causes and treatments of autism. They currently have 146 donations from individuals who had autism and an appropriate sample of control donations. Now that Autism Brain Net has obtained a sufficient number of donations, they are planning to distribute the tissue samples to researchers worldwide. This is an ongoing program, and they are actively soliciting funding and promoting awareness that would allow for a better understanding of genetics and neuropathology of autism. Dr. Amaral suggested that anyone interested should visit autismbrainnet.org.

Dr. Stuart Shapira reviewed the [CDC Study to Explore Early Development](#) (SEED), which has collected prenatal development data through maternal interview and prenatal ultrasound records. SEED is unique because it includes an additional control group of children who have developmental disabilities other than ASD, which provides valuable information about the potential role of prenatal ultrasound in non-ASD conditions.

Dr. Gordon commented that it has been difficult to obtain definitive data that rule out certain predisposing factors, such as ultrasound. He said that there are plenty of hypotheses in autism research, but there is no collection of hypotheses strong enough to justify the cost of pursuing research studies. Given limited funding, there is a need to choose the strongest hypotheses with the highest impact, and he suggested that the effects of prenatal ultrasound on the development of ASD are relatively low impact.

Mr. Robison reminded the Committee that while they may agree in principle, there are people who are severely impacted by autism and their needs are very different than others in the community. He said that there is no solid knowledge about the proportion of these severely affected individuals in the autism community, and he asked the Committee to think about learning more about the population so that they can make well-informed decisions about how to best serve their needs.

Dr. Gordon said that while some population demographics are known, such as distribution of IQ or social function, determining a percentage of individuals with severe autism is more difficult because outcomes may vary based on the threshold that defines “severe” disability. He asked Dr. Pelphrey for insight and Dr. Pelphrey confirmed that certain factors related to autism, such as IQ and social function, are well known, and that extensive work on the Vineland has provided information about clinically meaningful differences in impairment. He added that shifting definitions of severe autism have caused challenges to determining the prevalence in the autism community, and he expressed frustration that there is no united definition of the autism spectrum.

Mr. Robison asked if the autism that Ms. Singer described is medically or biologically the same as the autism that he often describes in his own life. Dr. Amaral added that autism is a developmental disorder that changes over time, so a child who is severely impaired at age three might show significant improvements by age six. He said that it is important to consider the life course when creating definitions for autism severity.

Ms. Singer said that individuals with severe autism have different service needs than individuals whose autism enables them to participate in policymaking and employment. She said that general media tends to portray only individuals with very high-functioning autism, which can spread public misinformation about the necessity of research funding for ASD. However, members of the autistic community with more severe disabilities are underrepresented and often left behind. She said that the Committee needs to remember this population when talking about research, services, and policy. Mr. Robison agreed that

they need to be mindful of autism in all forms and expressed concern that his clear and articulate speech may create a false impression of autism.

Dr. Gordon reviewed the issue of clarifying the difference between severe and less severe autism. The data currently refer to those with intellectual disability in addition to social disability. These individuals tend to show significant differences in the genome, but the presence of rare gene mutations doesn't automatically signify an autism diagnosis. Those on the more severe side of autism have some genetics that set them apart, but also some genetics that are shared with all on the spectrum. The genetic aspect can complicate definitions of severe autism, and this is true throughout the mental health spectrum.

Dr. Reichardt agreed that the underrepresentation of people with severe autism is a significant challenge in research.

Dr. Walter Koroshetz responded to the critical comments about the Committee, suggesting that they all feel frustration at the slow progress.

DOJ Presentation: Kevin and Avonte's Law, and Disability Programs

Alison Singer, M.B.A., IACC Member, President, Autism Science Foundation

Ms. Singer provided an overview of wandering in individuals with ASD. In 2018, there were 224 reported cases of wandering, resulting in 19 deaths. Monthly, there are about 20 searches and 2 or 3 deaths. Although the number of wandering cases has remained steady over the years, there has been a recent increase in the average age of people who die as a result of wandering.

There has been an increase in training and awareness for water risk, but many agencies – particularly those in rural areas – can be unaware of and uneducated about the special risks posed by water. In October 2010, Ms. Lori McIlwain, President of the [National Autism Association](#) (NAA), first brought the issue of wandering to the attention of the Committee. They immediately formed a safety subcommittee, which was chaired by Ms. Singer and Ms. Lyn Redwood of SafeMinds. The next month, they formed a consortium, composed of the Autism Science Foundation, Autism Speaks, the Autism Research Institute, the Global Autism Collaboration, and the National Autism Association. They used the Interactive Autism Network to write and distribute a survey on wandering, which surveyed 1,218 parents of children who had ASD. At the same time, they worked to draft a letter to the then Secretary of Health and Human Services, Kathleen Sebelius. Five months later, they presented preliminary data on wandering to the Committee. Ms. Singer cited these activities as an example of urgency and immediate response.

Ms. Singer reviewed the data collected from the survey. They found that 49 percent of children with ASD had attempted to elope at least once after age four, which was four times higher than the rate of their unaffected siblings. Fifty-three percent of those who did elope were missing long enough to raise concern, and children ages 8 to 11 years were 27 times more likely to wander than their siblings without ASD.

Six months after the launch of the NAA's presentation on wandering, the CDC worked to get an ICD-9 medical subclassification code for wandering, which allowed doctors to note this behavior in medical records. In May 2012, data from the wandering study were presented at the International Meeting for Autism Research, and by October those data were published in the journal *Pediatrics*. Despite extensive

press coverage on the study, more than half of parents still reported that health care providers did not give them advance guidance about wandering in their children with ASD. In response, the Safety Committee reached out to the American Academy of Pediatrics (AAP), and the CDC worked with the AAP to develop factsheets about wandering to be included in the [AAP Toolkit](#). Although these factsheets were designed for parents, they found that they helped to educate pediatricians, too.

Dr. Susan Hyman and Dr. Susan Levy were invited to give a keynote presentation about wandering at the 2017 AAP annual meeting. In March 2018, thanks to the advocacy of people in the Committee, [Kevin and Avonte's Law](#) was passed. The law revised and extended the Federal Missing Patient Alert Program, which was initially established to meet the needs of Alzheimer's patients. Kevin and Avonte's Law expanded it to cover individuals with dementia and developmental disabilities, and it was renamed the [Missing Americans Alert Program](#).

Ms. Singer explained that the law authorizes the government to provide grants for first responder training and for the purchase of tracking technology. Unfortunately, there is still no appropriation for funds for Kevin and Avonte's Law, but there are many individuals in the Committee who are working towards that goal.

Lori McIlwain, Co-Founder, Board Member, National Autism Association

Ms. Lori McIlwain reviewed the current statistics on wandering among people with ASD. Since 2011, there have been more than 1,300 missing and found missing cases in the United States, 180 of which were reported as fatalities. On average, there are 20 cases per month, and 2 to 3 result in death. Drowning remains the most common cause of death in wandering cases. The average age of fatality has also risen from 13 years old in 2016 to 15 years old today. The six-year sample indicates that the risk factors for wandering cases, which include residential settings, times of transition, and heightened response to stress, have generally remained the same.

She reviewed several case studies in which people with ASD had been found near water or had died by accidental drowning. Some people wonder how a child can get away from a caregiver so quickly, but there are cases of children getting away from even EMS, and it is therefore clear that wandering happens quickly and is not caused by parental negligence. She reviewed another case in which a child wandered because he was deeply upset that he lost his cell phone. She said that these meltdown reactions, which are out of proportion to the event, can cause acute suicidality which dissipates after some time. This issues can further complicate wandering.

Ms. McIlwain talked about the need for more funding and further research to understand these behaviors and the technologies needed to prevent them. She said that once they gathered data, they were able to use resources to send nearly 50,000 [Big Red Safety Boxes](#) and provide more than \$100,000 to agencies for [Project Lifesaver](#). Kevin and Avonte's law needs to be appropriated in order to receive this kind of funding.

She reviewed some evidence that prevention-centered programs and technologies, such as tracking devices and door alarms, are critical for ensuring the safety of children with ASD who are prone to wander. Unfortunately, some of these technologies have age restrictions. For example, in some areas, individuals must be at least 60 years old in order to receive a Project Lifesaver tracking bracelet. Other initiatives, such as the [International Association of Chiefs of Police \(IACP\)](#)'s Alzheimer's Initiatives, could be translated to training for wandering searches. However, IACP also needs funding.

Ms. McIlwain summarized the findings from the NAA. Wandering is an urgent issue in need of federal support. Although there are major differences in Alzheimer's versus autism, similar resources are needed, especially as the average age of lethal cases continues to increase. More agencies have requested training for cases of wandering, and they have expressed particular interest in training centered on interactions with children with ASD. Finally, Ms. McIlwain added that co-occurring mental health conditions, intellectual disability, and communication challenges complicate the issue, and these unique, hidden challenges need to be a part of the discussion. She said that understanding the risk factors is a priority.

Maria Fryer, Policy Advisor for Substance Abuse and Mental Health, Bureau of Justice Assistance, Office of Justice Programs, Department of Justice

Ms. Maria Fryer reviewed recent ASD-related initiatives from the Bureau of Justice Assistance (BJA). She discussed the background and roles of the BJA and its role in helping communities address state, county, local, and tribal responses to people with mental illness and intellectual and developmental disabilities. She cited the [National Center on Criminal Justice and Disability](#) (NCCJD) and [Serving Safely](#) as two examples of growing initiatives that aim to help vulnerable populations, including people with disabilities in the juvenile justice system.

According to the NCCJD, people with disabilities represent 4 to 10 percent of the prison population, and 2 in 10 prisoners and 3 in 10 jail inmates report having a cognitive disability. By age 28, people with disabilities face a 43 percent chance of arrest compared to 29 percent for those without disabilities. Men of color with disabilities are at particular risk, and 55 percent of this population will be arrested by age 28. People with disabilities are also three to four times more likely to be victimized. [NPR's recent Abused and Betrayed series](#) estimated that people with disabilities are seven times more likely to be sexually assaulted than non-disabled peers.

Ms. Fryer described the purpose and goals of Serving Safely, which was awarded in 2017. This program provides expertise to local law enforcement and prosecutorial districts on improving responses to people with intellectual and developmental disability and mental illness. For example, the [Pathways to Justice](#) program offers specialized training for law enforcement.

Ms. Fryer provided an overview of the NCCJD, which was created in 2013 under the BJA. Their mission is to ensure equal access to justice, ADA accommodations, and effective treatment for defendants, victims, and witnesses with IDD who come in contact with the justice system. This is necessary because people with IDD are overrepresented in prisons, and they are often hidden populations because the justice system does not identify them as having a disability.

She explained that when people with disabilities are victims or serve as witnesses, assumptions are often made about their ability to recall events or testify effectively, potentially leading prosecutors to ignore crimes. As suspects, individuals with IDD are frequently used by other criminals to assist in lawbreaking activities, because the individual may not understand that they are participating crimes with legal consequences.

Ms. Fryer said that they are developing more responses to address these issues and engaging with law enforcement agencies, communities, and disability response teams. These teams help raise awareness

and disprove myths related to disability. They also help criminal justice professionals identify disabilities, provide supports and accommodations, and sustain training efforts. To date, the NCCJD has trained over 500 participants. Pathways to Justice has held over 20 webinars with 4,500 participants and 250 requests for assistance over the last year.

Ms. Fryer spoke more on the Serving Safely program, a new national center launched by BJA to assist law enforcement in their response to people with mental illness and IDD. They currently take training and technical requests from members of the justice system as well as community stakeholders.

The [Justice and Mental Health Collaboration Program](#) (JMHCP) was authorized through the [Mentally Ill Offender Treatment Crime Reduction Act](#) (MIOTCRA) and was reauthorized by the [21st Century Cures Act](#). Funding levels are typically between \$10 and \$12 million per year, which grew to \$30 million in 2018. Their focus has shifted toward system-wide improvements, and they aim to systemically address the needs of people with IDD in the criminal justice system.

Ms. Fryer reviewed the three categories of grantees within the JMHCP. The first category focuses on collaborative county approaches, encouraging data collection and attempting to prevent people with IDD from further involvement with the criminal justice system. The second category primarily focuses on the needs of law enforcement, training, and improving response. The last category is implementation and expansion of already established programs, specifically enhancing direct and wraparound services. One of their goals is to ensure that incarcerated individuals with disabilities have appropriate resources and comprehensive care management to reduce recidivism.

The BJA also supports an initiative called the [Law Enforcement-Mental Health Learning Sites](#), which provides help law enforcement agencies respond safely and effectively to people with disabilities. They deliver peer-to-peer learning through a cooperative agreement with the Council of State Government's Justice Center. Currently, there are 10 agencies that serve as national learning sites, representing diverse strategies and methods of police-mental health collaboration.

In 2016, they launched the [Police-Mental Health Collaboration Toolkit](#), an online compilation of available resources and foundational documents. They are also working to release the Police-Mental Health Collaboration Framework, which provides metrics and guidance in evaluating readiness and ability to respond to people with special needs. They are focused on using data and metrics to improve performance.

The [Stepping Up Initiative](#) was launched in 2015 to reduce the number of people with mental illness and co-occurring disorders in local jails. To date, 461 counties have passed resolutions to work on key outcome measures including reducing jail bookings of people with IDD, reducing length of stay, reducing recidivism, and increasing connections to treatment. The [Six Questions Guide](#) helps counties implement the Stepping Up program and meet their goals to reduce involvement with the criminal justice system. The Stepping Up Initiative also provides a county online assessment, Coordinator's Handbook, and screening and assessment tools. Ms. Fryer said that they want communities to use these tools to reach a 100 percent screening and assessment rate.

Ms. Fryer reviewed their activities going forward, and said that they are interested in the gaps in knowledge, services, and resources. She provided the Committee with a list of additional resources and

her contact information: Maria.Fryer@usdoj.gov.

Leemie Kahng-Sofer, Program Manager, Missing Children Division, National Center for Missing and Exploited Children

Ms. Leemie Kahng-Sofer reviewed the efforts of the [National Center for Missing and Exploited Children](#) (NCMEC). They are a non-profit organization, and they have partnered with the DOJ to perform 22 specific tasks.

She reviewed [ASD-related data](#) from the NCMEC, which came from cases reported to them between 2007 and 2016. She acknowledged that the data set did not include information from cases that were never reported. In their dataset, there were 952 missing children with ASD, 74 percent of whom were male. Additional data from the same period showed that 48 percent of children reported missing were recovered with a day and 70 percent recovered within a week. Forty-three of the missing children were recovered deceased, 72 percent of whom died of accidental causes. Sixty-five percent of those who died accidentally had drowned.

In response to these trends, NCMEC trains case managers to follow specific protocols for missing children with autism and distribute awareness materials to law enforcement. Ms. Kahng-Sofer reviewed some of NCMEC'S recent initiatives. In 2016, they partnered with schools and the Palm Beach County Sheriff's Office to host a [Sensory Friendly First Responder](#) event to familiarize children with autism with first responder environments. In conjunction with the Center for Autism at Texas Tech, they also conducted a three-part conference series for caretakers of individuals with special needs.

Ms. Kahng-Sofer said that they receive call center notifications from the National Autism Association and other agencies. Next, they offer resources and protocols to local law enforcement. In the event that law enforcement is unresponsive, they assign the case to the on-call case manager and immediately deploy resources. They also partner with [NIXLE](#), a community notification service that reports on missing children, with and without autism. In 2017, they partnered with Next Door, a notification system that disseminates urgent information, including missing children's cases, to communities.

Ms. Kahng-Sofer reviewed one of the last cases they had received in 2018. They reached out to law enforcement and the child was successfully found after [Team Adam](#) consultants were deployed. Team Adam is a set of retired law enforcement who are available to deploy onsite in crisis cases. They also provide local law enforcement teams with a number of resources, including making referrals to families via the Family Advocacy Division or [Team Hope](#). The [Child Abduction Response Team](#) (CART) is a similar initiative. Liaisons from CART are included in trainings and exercises, allowing streamlined communication and collaboration between agencies.

Ms. Kahng-Sofer reviewed their activities to raise awareness of safety initiatives for high-functioning individuals with autism. Although high-functioning individuals are at much lower risk of accidents and fatalities, they can be vulnerable to crime, sexual assault, and sex trafficking, especially those that are perpetrated online. She also wanted to spread awareness about awareness and resources for children with autism in the foster community, who are at high risk.

Finally, Ms. Kahng-Sofer reviewed the results of the Train the Trainer initiative, which ended in 2016. They were able to reach and train more than 1,300 first responders and law enforcement. They received

feedback from one state trooper who had encountered a young girl who had left home and was approaching a lake. The trooper and his team used the skills they had learned from Train the Trainer to engage the girl and return her home safely.

Committee Discussion

Dr. Reichardt asked about the implications of diminished capacity on severely affected individuals who are interacting with the legal system. Ms. Fryer responded that their law enforcement officers are trained to de-escalate situations in which a person has diminished capacity or lacks emotional control. She said that in addition to the Pathways to Justice program, they are working on a set of response models for police to deal with mental illness or disability, including co-responder models and mobile crisis teams. Dr. Reichardt asked what happens to those individuals once they are in the criminal justice system; for example, he wondered if a person with intellectual disability might be more likely to falsely self-confess. Ms. Fryer responded that the Serving Safely program includes prosecutors who serve as subject matter experts and are receive training in disability rights.

Mr. Robison commented on the issue of tracking children with autism. He said that he serves as an expert on autism and behavior in federal court cases, and he receives correspondence from families who are often concerned about sex crimes and child pornography in the autism community. He said that because people with developmental disabilities may see children as peers, their ideas about romance, friendships, or sex may be illegal. He asked Ms. Fryer if there are any justice systems set up to work with people with autism who have been labeled as dangerous child sex predators. Ms. Fryer responded that Pathways to Justice provides advocacy to parents and families of people with disabilities who have been charged with sex crimes and provides parents with guidance on talking to their children about relationships and boundaries.

Dr. Gordon commented on the fact that Kevin and Avonte's Law is authorized by the Federal government but has yet to be appropriated. He wondered how the DOJ is carrying out these initiatives and what kind of reach is possible with the current level of funding and support. Ms. Fryer responded that the programs she talked about have already been funded. She reviewed the JMHCP financial statistics, noting that funding for the organization dramatically increased to \$30 million in 2018. However, there is a percentage cap on funds for training and technical assistance, and therefore they try to make their current initiatives as impactful as possible. She said that they now avoid funding smaller, low impact programs in order to drive system-wide change with the limited dollars. They want to stretch their resources as far as possible to reach as many people as they can.

Dr. Gordon asked if Ms. Fryer knew how much of their program funding goes towards autism and wandering. Ms. Fryer said that the funding for this issue falls under Serving Safely. They are recompeting the effort to support law enforcement in their response to people with mental illness and intellectual or developmental disabilities, which will be up to \$4.5 million. Dr. Gordon asked about capped programs. Ms. Fryer responded that they typically receive about 120-150 applications under JMHCP, of which they can usually fund between 35 and 45. Category 2 provides small planning grants to law enforcement, and they have scaled back the dollars to fund more of those. She said that currently there are separate funding streams and that they are funding about a third of their applications. Dr. Gordon commented that funding only one-third of applications may seem like a small proportion, but he pointed out that the NIH only funds about one-fifth of their applications.

Summary of Advances Discussion

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

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

Dr. Daniels opened the Committee Discussion for the [nominated articles](#) submitted for consideration for the 2018 Summary of Advances. The final publications will be prepared for release for the April 2019 meeting during Autism Awareness Month. Dr. Daniels said that this year, 10 Committee members submitted a total of 43 nominations, which is about half the number of nominations submitted last year. Dr. Gordon suggested that the Committee has been nominating higher quality studies with fewer rejections.

Dr. Gordon reviewed the two new articles nominated under Question 1, which is Screening and Diagnosis. The first was a study of ASD diagnosis in children older than five years, and the second was a longitudinal study of sensory responsiveness in toddlers.

Dr. Koroshetz reviewed his nominations under Question 2, which aims to understand the biology underlying ASD. One of the studies, which was nominated previously, investigated neuron counts in the amygdalas of children and adults with ASD, was conducted by Dr. Amaral. Dr. Gordon added that this study addresses one of the public comments made about the need for post-mortem studies. He nominated two new studies, one of which used induced Pluripotent Stem Cells (iPS) and CRISPR to study the effects of knocked-out ASD-associated genes on neural networks. The second study investigated the Fragile X protein by looking at animal oocytes. Dr. Gordon said that these papers highlight the need for different experimental systems to answer different questions. He said that NIMH tries to emphasize this kind of scientific diversity across their portfolio.

Ms. Singer asked about a study of stem cell growth and ASD that was recently published in *Nature Neuroscience*. She wondered if it was possible to nominate this study for the 2018 Summary of Advances rather than waiting a year. Dr. Daniels said that she could send the study to the OARC to determine its eligibility.

Dr. Gordon introduced Question 3, Risk Factors, which had four new nominations. Dr. Shapira reviewed the paper he nominated, which was a meta-analysis of three different blood samples that were analyzed for genome-wide methylation to determine the differences in gene regulation in individuals with and without ASD. Dr. Koroshetz reviewed the second study, which analyzed transcriptomes and genomes in patients with different neuropsychiatric conditions, primarily schizophrenia, bipolar disorder, and ASD. Researchers found overlapping patterns of gene expression across different diseases, which potentially point to networks involved in innate immunity in the brain, particularly the microglia. Dr. Gordon said there are currently some challenges to researching microglia, but that these cells could be an important locus for ASD. Dr. Reichardt suggested that they should not be optimistic about a single-cell analysis technique for microglia studies.

Dr. Gordon reviewed the third nominated study, which involved prenatal exposure to medication as a potential contributor to the development of ASD. Dr. Shapira reviewed the final study for Question 3, which was a risk factor analysis from the Study to Explore Early Development (SEED). In this study, researchers looked at the relationship between the length of time between pregnancy with an ASD child and a following pregnancy with a child without ASD to determine if birth spacing can increase risk. Dr. Gordon pointed out that although these advances cannot yet be used to inform parents' decision-

making, they still play an important role in scientific understanding of causal relationships associated with ASD.

Ms. Singer reviewed the one nomination for Question 4, Treatment and Intervention. This was a review of 367 treatment studies to determine the representation of severely affected children. This study is important in informing inclusion in future research so that researchers can gain a more comprehensive understanding of autism. Dr. Gordon countered that the extent of underrepresentation is unknown because they do not know the percentage of individuals in the population who are more severely affected. This study points to the need to include a population that represents the entire spectrum.

Question 5, Services, had one nomination on a study of healthcare utilization and cost among adults with ASD. The researchers found that adults with ASD have significantly higher rates of utilization across most health care services, but that this population may not be getting the kinds of treatment and screening services that other adults receive, potentially contributing to increased mortality and other adverse outcomes in people with ASD.

Question 6, which deals with Lifespan Issues, had no new nominations.

Question 7, Infrastructure and Surveillance, had four new nominations. Dr. Shapira described his two nominations. The two studies were complementary surveillance reports of prevalence of ASD. One study reviewed health and educational records of eight year old children to determine if their behaviors fit the surveillance diagnosis for ASD. This study is responsible for the commonly cited statistic that 1 in 59 children has ASD, suggesting higher prevalence than in previous years. The report also noted the disparity in prevalence between non-Hispanic white people versus non-Hispanic black and Hispanic people, specifically that the prevalence gap between white and Hispanic people is narrowing. The study also analyzed ASD criteria differences between the DSM-4 and the DSM-5. Dr. Gordon made a comment about increasing prevalence rates, and Dr. Shapira responded that the recent dramatic increase in ASD prevalence could be attributed to an increase in diagnoses among high-functioning individuals with ASD who have no intellectual disability. Dr. Gordon added that, although the results are not definitive, the increase in prevalence is likely due to case ascertainment rather than increase prevalence of risk factors.

Dr. Shapira reviewed the second study, which used a national parent-reported survey to determine the prevalence of ASD diagnosis in children aged 3 to 17 years of age. Because the researchers used different analytical techniques than those in the first study, their prevalence estimate for ASD in children was 1 in 40 rather than 1 in 59. They found that 27 percent of children with ASD were taking a medication for related symptoms and that 64 percent received behavioral treatments in the last year. This study allows for a lot of stratification. Dr. Gordon reviewed the third study, which found that children with ASD and/or intellectual disability are at heightened risk for maltreatment. The fourth study gave a cumulative incidence rate of ASD in Danish adults.

Dr. Gordon asked that the Committee also include any comments to the OARC staff about any nominated studies when submitting their ballots.

Round Robin

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

Dr. Shapira spoke about new CDC funding for the [Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#). Ten selected sites will monitor eight-year-old children and, for the first time, four sites will follow up on adolescents aged 16 years. Dr. Gordon added that this was a good example of how the Committee, which advocates for studying autism in transition-aged populations, has influenced the CDC's research decisions.

Dr. Judith Cooper reviewed activities within the National Institute of Deafness and Other Communication Disorders. Dr. Cooper said that they address issues of underrepresentation by prioritizing minimally verbal children who are ineligible for other studies. Finally, the research they supported last year showed a number of beginning and early stage investigators, which is encouraging for the next generation of researchers.

Dr. Alice Kau said that the National Institute of Child Health and Development (NICHD) is [soliciting feedback](#) of their revised research strategic plan. One of the themes under consideration is improving health during the transition from adolescence to adulthood.

Dr. Reichardt said that they spent part of the last year evaluating the success of different grant categories. They have funded one-year explorer, two-year pilot, and three-year research awards, and they found that the two-year pilots and three-year research awards had significant impact. He also said that two-thirds of the grants resulted in follow-up funding. Because the one-year awards did not have similar success, they have been abandoned. Additionally, research awards have been extended to four years. He added that there are now more than 57,000 individuals with ASD who have enrolled in [SPARK](#), their autism cohort recruitment effort. They are also using Clinical Research Associates LLC to pursue Arbaclofen as a potential pharmacological therapy, and they are planning to study 16p11.2 deletion in an animal model.

Dr. Koroshetz reviewed NINDS' current clinical trials. He said that one study involves language development in three- to six-year-old children, and another is monitoring EEG abnormalities to administer antiepileptic agents to patients with ASD to prevent epilepsy before a seizure episode can occur. He also said that they are studying vasopressin, a drug used to treat Huntington's Disease that may be applicable to ASD treatment.

Dr. Gordon said that NIMH is looking forward to funding new efforts to develop research on screening in the first year of life. He also mentioned that [PsychENCODE](#) is a valuable tool for releasing data related to the association between genetics and neurobiology.

Closing Remarks and Adjournment

Dr. Gordon thanked the Committee and adjourned the meeting at 4:39 PM.

The next meeting will be on April 17, 2019 at the Neuroscience Center in Rockville, MD.