



## Minutes of the Interagency Autism Coordinating Committee

### Full Committee Meeting

April 17, 2019

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The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Wednesday, April 17, 2019, from 9:00 a.m. to 4:57 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; **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); **Leslie Caplan**, Ph.D., Administration for Community Living (ACL) (representing Jennifer Johnson, Ed.D.); **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD); **Samantha Crane**, J.D., Autistic Self Advocacy Network; **Geraldine Dawson**, Ph.D., Duke University School of Medicine (attended by phone); **Tiffany Farchione**, M.D., Food and Drug Administration (FDA); **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA) (attended by phone) (representing Ruth Etzel, M.D., Ph.D.); **Alice Kau**, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) (representing Diana Bianchi); **Laura Kavanagh**, M.P.P., Health Resources and Services Administration (HRSA); **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; **Edlyn Peña**, Ph.D., California Lutheran University (attended by phone); **Laura Pincock**, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ) (attended by phone); **Louis Reichardt**, Ph.D., Simons Foundation Autism Research Initiative; **John Elder Robison**, College of William & Mary; **Marcella Ronyak**, Ph.D., L.C.S.W., C.D.P., Indian Health Service (IHS); **Nina Schor**, M.D., Ph.D., NINDS (representing Walter Koroshetz, M.D.); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC); **Alison Tepper Singer**, M.B.A., Autism Science Foundation; **Julie Lounds Taylor**, Ph.D., Vanderbilt University (attended by phone); **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Cheryl Williams**, Social Security Administration (SSA); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD) (attended by phone).

### Call to Order, Roll Call, and Welcome

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

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

Dr. Joshua Gordon called the meeting to order at 9:00 a.m. and Dr. Susan Daniels took roll call. Dr. Daniels made a motion to accept the minutes for the last Committee meeting. There was a unanimous move to accept the minutes.

## **Welcome and Introductions**

Dr. Gordon welcomed the Committee and introduced the Honorable Mike Lake, who is the father of an adult son on the autism spectrum and one of Canada's leading autism and disability advocates. Mr. Lake's son, Jaden, was also in attendance. They were in attendance to give the Committee a message in recognition of Autism Awareness Month.

## **Expect More: An Autism Adventure**

### **The Honorable Mike Lake, P.C., M.P.**

Mr. Lake introduced his son, Jaden, and began his presentation by showing [a short video clip of himself and Jaden singing](#). He also showed [a clip of his one-minute statement to the House of Commons](#), in which he discussed Jaden's life as a nonverbal individual with autism spectrum disorder (ASD). He discussed the importance of recognizing self-determination in individuals on the autism spectrum. In his speech, Mr. Lake said that, although his son is nonverbal, Jaden still has valuable things to communicate. The third clip he showed detailed another scene from the House of Commons, in which members implored the Prime Minister to reverse the decision to reject the Canadian Autism Partnership. Mr. Lake described challenges to implementing autism advocacy in Canada and said that IACC, which represents a group of authoritative and credible voices, is important because it supports and advises the government on autism advocacy. He said that successful advocacy critically depends on to be able to find a common voice and to translate knowledge into information that someone with little knowledge of ASD can understand.

Finally, Mr. Lake showed [a clip of himself and Jaden at a 2016 We Day event](#). In this brief speech, Mr. Lake spoke about the unique aspects of Jaden's personality, as well as the challenges he faces as a nonverbal teenager with autism. The We Day video ended with a short news interview clip of then 13-year-old Janae, Jaden's sister, who said that Jaden is her standard for normal and that if he didn't have autism, he wouldn't be the same person she knows and loves. Mr. Lake said that he likes to show this clip because it leads to interesting discussions about what "normal" means. With encouragement from Mr. Lake and his wife, Jaden's school decided early on that Jaden would complete his education in the classroom with the support of a full-time aide. Mr. Lake said that every one of the students that graduated with Jaden agrees that their lives are better because Jaden was there with them in the classroom. He explained that many people's concept of what is "normal" has never included individuals who are different from them, and Mr. Lake said that this lack of diversity is fundamentally limiting.

He concluded his presentation by discussing the importance of the diversity of the Canadian population. Canada aims to be as inclusive possible in recognition that society benefits greatly from the skills, abilities, and perspectives that diverse individuals contribute.

## **Committee Discussion**

Dr. Daniels thanked Mr. Lake and welcomed the Committee to ask questions. Ms. Alison Tepper Singer thanked Mr. Lake for his presentation, and she wondered what issues had prevented Canadian Autism Partnership from moving forward. Mr. Lake said that the Working Group was established in 2015 before a change in government, and that although the Partnership received widespread support, politics got in the way of renewing the legislation.

Dr. David Mandell thanked Mr. Lake for his presentation and his advocacy. Dr. Mandell asked Mr. Lake if there were any lessons to be learned from the ongoing changes and developments to Canada's autism service system. Mr. Lake replied that it is preferable to structure autism services using a lifespan approach. However, standard two- or four-year government cycles can pose challenges to this endeavor. He said that in his experience working with the government in Ontario, there is a need to remove silos and to unite ministers of health, science, and children's services with a panel with ASD experts so that they can collaborate on the issues. Mr. Lake pointed out that successful services for children with autism operate best within an array of services; for example, prevention programs are strongest when they are coupled with education programs, and intervention services are made more impactful when effective diagnostic systems are in place.

Mr. Lake continued that it is also important to consider the large number of adults with autism who have not received a diagnosis. Post-secondary education, housing, and employment also need to be part of the conversation, but there is a challenge to incorporate perspectives from legislators who don't live in or understand that world. Overall, he urged a comprehensive approach to packaging these services, which may aid in communicating these needs to policymakers who are unfamiliar with issues related to ASD.

Ms. Samantha Crane thanked Mr. Lake and Jaden for attending the meeting. She asked about the current challenges that Canadian adults face as they attempt to access home- and community-based services. She explained that in the United States, these services tend to have long waiting lists and can be difficult to access for many adults with ASD. Mr. Lake replied that the Canadian experience with these services is similar. Much like the United States, where service delivery tends to be state-based, most service delivery in Canada is provincial. He said that existing systems are struggling to accommodate the large cohort of individuals who were diagnosed with ASD in the mid- to late-1990s, all of whom are now transitioning from pediatric to adult services. Mr. Lake said that in general, these services should always consider the individual's needs and desires. This critically includes issues related to unemployment. He said that in Canada the unemployment rate among individuals with ASD is approximately 80 to 85 percent, necessitating initiatives and policies aimed at increasing employment.

Ms. Singer added that the [International Society for Autism Research \(INSAR\) Annual Meeting](#) will be in Montreal, and she hoped that Canadian scientists and advocates who specialize in ASD will be in attendance. Mr. Lake noted that because he is a legislator rather than a scientist or researcher, it is difficult for him to find an opportunity to speak at such events, but he still hopes to attend. He said that they are trying to move in the direction of a Global Autism Partnership. He explained that he is a

conservative member of Parliament and that he functions as the lead on Youth, Sports, and Accessibility. Through his work, he gets the chance to talk to youth, students, and other organizers, and he has had the opportunity to meet with organizations such as UNICEF and Save the Children. His ideal global partnership would draw funding from governments and have organizations partner on the ground to introduce evidence-based interventions. They have also been focused on established autism-specific programs in organizations that do not primarily focus on autism. Mr. Lake pointed out that the International Disability Alliance lacks an autism partner because no global autism organization currently exists, representing a critical need to establish such an organization.

## **CDC Autism Data Visualization Platform**

**Stuart Shapira, M.D., Ph.D.**, Chief Medical Officer, Associate Director for Science, National Center on Birth Defects and Developmental Disabilities (NCBDDD), CDC

Dr. Stuart Shapira introduced the [Centers for Disease Control and Prevention \(CDC\)'s Autism Data Visualization Platform](#).

The CDC Autism Data Visualization Tool is an interactive website that provides up-to-date ASD prevalence data among children in the United States. The tool draws data from four different sources: the Autism and Developmental Disabilities Monitoring Network (ADDM), the Special Education Child Count, Medicaid data, and the National Survey of Children's Health. Dr. Shapira explained that the tool includes a description of how each data source was used to estimate ASD prevalence. Information is organized by year and by state.

Dr. Shapira said that the tool is designed to visually organize ASD prevalence data by highlighting changes over time for specific states or communities. In addition to presenting data in a simple and accessible format for public use, the tool improves access to data for public health researchers and state health officials. Additionally, the tool aims to improve understanding of ASD and its impact, and it can be used to plan services and guide policymaking.

Dr. Shapira went into more depth about each of the four data sources from which the visualization tool draws information. The first of these is the ADDM Network from the CDC. He said that the data visualization tool features published ADDM prevalence estimates between 2000 and 2014 in participating ADDM sites, which includes record reviews of eight-year-old children and combines information across communities. He explained that the large sample sizes in the ADDM Network allow for more detailed data at the state and community levels.

Dr. Shapira discussed the second data source, which was drawn from the ED's special education information including primary exceptionality classification of autism. The data include 6-to-17-year-old children with disabilities and/or autism classification. The data source also includes information from the National Center for Education Statistics School Enrollment Counts for grades 1 through 12. Dr. Shapira explained that these publicly available data exist for almost every year, but that current data have only been updated through 2015. However, the tool will soon be updated with another year of data from 2016.

The third data source was Medicaid data drawn from CMS. Dr. Shapira said that this source is also known as Medicaid Analytic eXtract (Medicaid MAX), which counts children with an ASD medical billing code or an ICD code for one or more inpatient (or two or more outpatient) claims in a given year. Data are available between 2000 and 2012 for most states.

The fourth and final data source used to build the data visualization tool was the National Survey of Children's Health from HRSA. The estimates in the tool match the National Survey of Children's Health Data, which are mined from a complex survey designed to provide national averages. This survey includes a nationally representative sample.

He then discussed some outstanding features of the tool. Dr. Shapira said that the data can be downloaded into spreadsheets to allow for custom analyses. He also explained that the tool contains links to primary data sources, as well as deeper technical notes and other information relevant to each data source. The tool stays up to date by incorporating new, updated data as they become available. Dr. Shapira said that the website is designed to be user-friendly and easy to navigate for all users who seek to learn more about national and state ASD prevalence.

Dr. Shapira thanked the individuals from the CDC who were involved in the development of this tool. Then, he briefly showed the Committee what the website looks like and how to use it. He reviewed some features of the website and showed the Committee how to change the visualization to display information by community, year, and/or data source. He also explained how to access a heat map visualization of ASD prevalence and how to sort by demographic data.

Finally, Dr. Shapira gave the Committee a preview of the "Explore" feature of the data visualization tool, which allows users to compare two data sets or to compare components within a single data set. For example, users can compare prevalence in a single state to prevalence in the US overall. The tool also enables users to compare individual states in the US or estimates between two different data sources for a given year.

## **Committee Discussion**

Dr. Gordon thanked Dr. Shapira for his presentation and pointed out the importance of such a resource. He expressed his appreciation that the visualization tool includes descriptions of the quality and manner by which data were acquired and how these factors inform the estimates, which are critically important to understanding prevalence estimates, which differ depending on methodology.

Mr. John Robison expressed concern that data from ADDM reports, which estimate prevalence only among eight-year-olds, are being compared to prevalence data gathered from children up to ages 17. Furthermore, he pointed out that age was absent from the demographic information provided by the website. He suggested that they could improve the data tool by clarifying what age group each measure includes. Dr. Shapira took this into consideration.

Dr. Louis Reichardt wondered about the value of estimating prevalence for a disorder with a high genetic contribution. He expressed concern that the data visualization tool captures differences in access to health care or differences in data interpretation rather than actually capturing differences between states or over time. He said that there is a potential for people to misinterpret the data.

Dr. Shapira replied that these data capture all of the factors Dr. Reichardt mentioned, including differences in access to services, recognition of autism, classification of autism, and coding for autism in claims data. He said that despite the large number of working variables, it remains important to provide this information for researchers and public health officials. He also said that these data can help the public understand that there is no one single prevalence estimate for ASD.

Dr. Reichardt worried that these data might contribute to the false impression that autism is a spreading “epidemic” such as measles and that certain states are safer. Dr. Shapira said that this is a good point.

Dr. Gordon said that this is an issue other advocacy and public committees have experienced before. He pointed out the press often chooses to cite only the ADDM estimate, despite disclaimers about the data. As a result, it is important to remind the public that prevalence estimates vary by methodology and that one data source is likely not representative of autism across the country. Dr. Gordon suggested that the data visualization might make a note that there are many reasons why prevalence might vary by geography across the country, reassuring the public that they are not more vulnerable to ASD if they live in certain high-prevalence areas.

Dr. Shapira said that they try to emphasize that the ADDM estimate is representative of communities that are involved in collecting data on autism prevalence; it is not representative on a national or even statewide level. However, the data provided by ADDM is so rich and detailed that researchers still find it valuable.

Dr. Mandell complimented the data tool’s visual appeal and its ease of navigation. He echoed Dr. Reichardt’s point that the data are presented almost without comment despite the fact that they often show contradictory prevalence estimates. He suggested that the CDC refer to these estimates not as “prevalence data” but as “surveillance data” in order to emphasize the limitations of the methods used to collect data. Dr. Mandell expressed his opinion that an estimate is not truly a “prevalence estimate” if it is driven by differences in access to services or other similar factors. He said that the CDC should approach these issues more critically and should put more emphasis on the importance of differences in data ascertainment to avoid providing the public with misinformation.

Dr. Shapira agreed that the issues aren’t black and white and said that he values the Committee’s input. He said that although the data can be contradictory, it is important to inform people that prevalent estimate numbers are increasing across data sources, indicating an escalating need to provide services for individuals with ASD who are aging into adulthood.

Ms. Singer agreed with Dr. Shapira’s assessment and said that in the advocacy community, the tool would be valuable for planning for services and effecting policy change at the state and federal levels. For years they have felt that the CDC needs to take a more granular approach to estimating prevalence for ASD with co-occurring intellectual disabilities or psychiatric conditions. She mentioned that in 2014 the ADDM Network began to collect this granular level data and suggested that these data be included in any future updates to the data visualization tool.

Mr. Robison expressed his belief that Americans should be able to trust information disseminated by public health agencies. He said that, unfortunately, there has been a fundamental breakdown of trust between CDC and the autism community, and he is concerned about the potential for this tool to foster further distrust. Although Mr. Robison agreed with Dr. Reichardt’s concern that although there is little

evidence to suggest a meaningful difference in ASD prevalence across the country, the CDC's new data visualization tool suggests dramatic differences in prevalence on a state-by-state basis. He suggested that the CDC should take an active role in explaining that any state-based prevalence differences are related only to differences in data ascertainment methodologies.

Dr. Shapira agreed that differences across states can be confusing to people who are unfamiliar with the unique challenges of identifying children with ASD. He addressed Mr. Robison's concerns by pointing out that the CDC does make an effort to codify differences in prevalence estimates across states. He said that there are challenges to communicating this information effectively and that the CDC will strive to make these issues as clear as possible, both in the data visualization tool and in future reports.

Dr. Gordon said that although the data are valuable, the community needs answers that the data cannot always provide. For many other disorders as well, prevalence estimates are a poor way to identify information that can be critical for policymaking decisions, such as the genetic, biological, or social mechanisms underlying a disease.

Dr. Larry Wexler commended CDC for this effort, but admitted a personal bias because he has worked on one of the data sets that is included in the tool. He pointed out the importance of recognizing that no data set can ensure methodological purity, and that is more important to understand that data are fundamentally different when they are used for scientific purposes versus policymaking purposes. Dr. Wexler expressed his belief that the tool is strengthened by its differences and variances because these drive critical questions to be addressed by further research and policies.

Ms. Crane pointed out that determining prevalence does perform an essential role in allocating resources to particular services. However, she reminded the Committee not to assume that all people with a certain intellectual disability want or need a certain kind of service. She said that there is a need for methodologies that measure the level of intensity of services that individuals require. Dr. Shapira thanked Ms. Crane for her perspective. He concluded by thanking his colleagues who collaborated to design and release the data visualization tool.

## **Update from the Federal Communications Commission: Agency Activity Concerning Rights of People with Cognitive Disabilities**

**Theodore Marcus, J.D.**, Deputy Chief, Federal Communications Commission (FCC) Disability Rights Office

Mr. Theodore Marcus began by sharing an anecdote in which he received a call from a father of two children with autism. The family lived in a trailer development, and the father found out that their landlord had entered into an internet service provider (ISP) exclusivity arrangement that did not provide the broadband his two sons required to support their needs. Mr. Marcus stated that it is important to consider where and how much broadband is provided, and which underserved populations face barriers to accessing it. The FCC wants to use data to learn where to devote resources and to find where universal services can be best deployed to serve individuals with ASD. Mr. Marcus said that their goal is to empower persons with ASD and other intellectual disabilities to have full access to and easy use of technologies. The FCC is well known for its work to ensure telephony and computer services for people who are deaf and blind, but their work extends to include those with cognitive disabilities, too.

Mr. Marcus discussed the background of the FCC. To begin, he defined *telecommunications* as the making and receiving of calls over a telephone network. Their foundation was the Communications Act of 1934, which was amended in 1996 when Congress said that telecommunications services and equipment must be accessible and usable for peoples with disabilities. There is a caveat that accessibility should be readily achievable, or else services and technologies must be compatible with assistive technologies. For example, any phone should be accessible to a person with a hearing aid. Accessibility also includes user manuals, instructions, product documentation, customer services and help desks, and any other resource that is provide to persons without disabilities. In 2007, they extended these protocols to Voice Over Internet Protocol (VoIP) telephony.

Mr. Marcus further explained that the [21<sup>st</sup> Century Communications and Video Accessibility Act \(CVAA\)](#) is also central to the core mission of the FCC. This Act was established in 2010 when Congress amended the Communications Act to include accessibility requirements for persons with disabilities consistent with advances in the communications marketplace, called Advanced Communication Services (ACS). ACS includes text messaging, instant messaging, video conferencing, and VoIP. Under the CVAA, these technologies must both be *accessible* and *achievable*, meaning available at normal costs and operable with limited cognitive skills.

The FCC is concerned primarily with functional abilities related to accessing ACS, meaning all mechanical functions of a given technology should be easily locatable, identifiable, and operable with little or no hearing, sight, color perception, or speech; with limited manual dexterity, reach, strength, or cognitive skills; without time limits; or with prosthetic devices.

Mr. Marcus discussed the FCC biannual report, which has been submitted to Congress since 2010. The report assesses industry compliance with accessibility requirements. It also addresses accessibility barriers to new communications technologies, effective accessibility-related recordkeeping, and enforcement requirements. The report also provides information about the number and nature of actions taken to resolve complaints alleging violations of these requirements. The FCC invites the public to contribute to the material included in the biannual report, and Mr. Marcus explained that there is an option to request assistance through the FCC's Consumer Complaint Center.

Mr. Marcus discussed how the FCC has applied these mandates. He explained that the FCC is well known for their work on *relay services*, which are phone services that allow persons with hearing or speech disabilities to place and receive telephone calls. He also discussed *closed captioning*, which displayed the audio portion of a television program as text on the television screen. Mr. Marcus also explained *audio description*, a technology that assists people who have visual processing disabilities by inserting brief descriptions of what is happening in a video. For example, these insertions might provide background context, facial expressions, or costuming.

Mr. Marcus explained that audio description can be a useful tool for persons with autism. For example, video descriptions can identify the emotions that characters are expressing, which a person with autism may need help to understand. However, Mr. Marcus pointed out that video descriptions might lead to audio overload, although to date the FCC has not received complaints or comments from the autism community regarding video description.



The FCC has also expanded their mandates related to emergency and crisis information on television. Mr. Marcus said that vulnerable persons might need better, faster access to this information so that they have adequate time to arrange for care. He explained some of the FCC's requirements for televised emergency information. For one, it must be presented visually. This includes scrolling text on the screen that might give visual information about where to access resources during a crisis. Critically, scrolling text cannot block closed captioning, as this can cause additional barriers to access. Emergency text must also be audible to ensure that persons with visual impairment can receive the information they need. Additionally, the FCC would like to know if the autism community has unmet needs regarding televised emergency information.

Mr. Marcus updated the Committee about the FCC's activity related to cognitive disabilities. In October 2015, the FCC convened a summit on telecommunications needs for persons with cognitive disabilities. They also have a Disability Advisory Committee and Cognitive Disabilities Working Group that has produced best practices recommendations regarding accessibility and usability for persons with cognitive disabilities, including ASD. In 2016, they used these findings to produce and disseminate a white paper. The FCC is also working to address dispute assistance, consumer complaints, and outreach efforts.

Mr. Marcus concluded his presentation by explaining how people can help the FCC with these initiatives. He said that people can influence policy change by informing the government of critical issues to consider; he suggested that individuals make use of open meetings, comment boxes, and proceedings in to present their comments to policy makers. People can also help by engaging with product manufacturers and providers, advising them on how to increase accessibility. Last, Mr. Marcus said that individuals with complaints about accessibility can contact the FCC to receive direct assistance. He informed the Committee how to access the [FCC website](#), how to contact the [Disability Rights Office](#), and how to access the [online complaint form](#).

## **Committee Discussion**

Mr. Robison pointed out that the presentation didn't address that people with cognitive disabilities often have communication disabilities. He said that in the last 20 years, the internet has provided a mechanism of communication for such individuals. He wondered, given that many people with significant cognitive disabilities also have limited financial means, if the FCC has done anything to ensure that broadband providers are required to provide those services to people with disabilities at any cost they can afford.

Mr. Marcus replied that the FCC has a few key mandates that address Mr. Robison's question. First, the FCC is dedicated to providing universal service to ensure that communication services are available to everyone, including persons with disabilities and persons who are part of underserved and underprivileged populations. Mr. Marcus explained that the FCC has four programs that address this to some degree. For example, the E-Rate program is a Schools and Libraries program designed to ensure internet access and connectivity for K through 12 at various levels of need. He also mentioned the Lifeline program, which was established to ensure affordable telephone connections for people at or near the poverty level. This initiative was recently expanded to include broadband.

Dr. Mandell wondered if the FCC produces any best practice guidelines that can support people attempting to make technology more accessible. Mr. Marcus said that their 2016 white paper addressed some of these issues and that they are constantly working to develop and identify best practices by engaging with individuals at the provider and product manufacturing level.

Dr. Wexler pointed out that the [Office of Special Education Programs \(OSEP\)](#) invests millions every year in captioning and description, specifically in programming that the FCC does not require. They do this in multiple languages and support research on efficient and effective communication methods. Dr. Wexler also mentioned his involvement with [National Institute on Disability, Independent Living, and Rehabilitation \(NIDDR\)](#) within ACL. Mr. Marcus asked Dr. Wexler about their spending. Dr. Wexler estimated about \$8 to \$10 million per year.

Dr. Gordon asked if the FCC monitors the use of some of these technologies, such as closed captioning and video description programming. Mr. Marcus said that the FCC does not officially monitor usage of these services beyond anecdotal experiences.

Dr. Wexler added to his previous comment. He said that the organizations he participates in have stretched their money by crafting agreements with major networks. These agreements mandate that they will supply the program for free, and organizations like OSEP will return the programming to them with improvements made for accessibility.

## Committee Business

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

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

Dr. Daniels thanked Mr. Marcus and said that the Committee looks forward to working with the FCC in the future. She acknowledged the staff at OARC and thanked them for their work.

Dr. Daniels updated the Committee on activities that are taking place in recognition of World Autism Awareness Month. She described the [Autism Awareness Interagency Roundtable](#) that took place at IHS. The United Nations held a special event on assistive technologies. The NIEHS held a [Reddit “Ask Me Anything” event](#) to answer the public’s questions about ASD. Dr. Daniels announced the event OARC will hold on behalf of NIMH, [A Woman’s Voice: Understanding Autistic Needs](#). The event will feature authors and editors from two books about the experiences of women on the autism spectrum.

Dr. Daniels mentioned that the [2018 IACC Summary of Advances](#), which offers lay-friendly summaries of the top 20 advances in ASD biomedical and services research as selected by Committee members, is now available online and in hard copy.

She also talked about the [Report to Congress](#), which was published and made available to the public a week prior. The report covers the activities of all federal agencies doing autism-related work, including ongoing programs, initiatives, and activities. They produced the report in partnership with 21 different federal agencies and departments.

Dr. Daniels reviewed an upcoming report, the *IACC International ASD Research Portfolio Analysis Report*. OARC is leading a collaborative effort to produce this first report, which will use a 2016 data set describe and compare trends in ASD research funding across the US, UK, Canada, and Australia. The final publication is expected before July 2019. Data will be added to the [IACC Autism Research Database](#).

She updated the Committee on the INSAR Autism and Suicide Research Priority Setting Workshop at University of Nottingham, UK. Researchers are familiar with the phenomenon of high suicide rates among people with ASD, but there is little research about why this occurs or how it can be prevented. The goal of this meeting was to narrow down 48 existing priority research areas into a list of top 10 research areas to inform a research agenda. This list will be released at the upcoming INSAR meeting in Montreal. Dr. Daniels said that one of the strengths of this process was involvement of community stakeholders, who provided strong accounts of the personal and generational impact of suicide on people with ASD.

Dr. Daniels updated the Committee on the [IACC Health Outcomes Working Group](#), which was convened to discuss health and wellness issues for individuals with ASD. Co-chaired by Dr. David Amaral and Dr. Taylor, the scope of this Working Group involves health and wellness, co-occurring conditions, premature mortality, patient provider interactions, and parental and family member health. Their previous activities include conference calls and a workshop that covered on health epidemiology and several co-occurring physical health conditions. The upcoming workshop will take place on May 21, 2019 from 8:30 to 5 at the Hilton Washington Hotel. It will focus on mental health-related topics such as anxiety, depression, suicide, self-injury and aggression, and mental health services. Next steps include continued discussions in conference calls and a written document providing an update on the issues. Working group activities will conclude in September 2019.

Dr. Daniels talked about the IACC Housing Working Group. They are in the process of convening it to cover research and best practices on housing, implementation of current federal regulations, and housing issues faced by autistic individuals with more severe disabilities and across the spectrum. There will be conference calls and a town hall meeting with a tentative date of June 2019. The group activities will run through September 2019, when the current iteration of the Autism CARES Act of 2014 expires. They are awaiting reauthorization and will convene a new Committee based on new requirements.

The IACC Strategic Plan 2018-2019 update will provide a summary of the Committee's recent activities and progress related to the strategic plan, including summaries of: the Health Outcomes Working Group and Workshops, the [2016 Portfolio Analysis Report](#), the *Report to Congress*, and the Housing Working Group and Townhall. Committee members have received a draft for review and comments, but additional 2019 activities still need to be added.

Dr. Daniels mentioned that Mr. Robison had an issue he would like to share with the Committee. Mr. Robison said that he had published a [commentary](#) about autism in adulthood in the most recent issue of *Autism Research*. He explained that although data for adulthood ASD outcomes can be alarming, he questions which populations these data actually apply to. Mr. Robison said that there is a potential disconnect between credible ASD prevalence data sources and other public health studies that make alarming predictions about autism. He pointed out that many of these studies, such as Dr. Lisa Croen's study on autistic adults' use of Northern California's Kaiser's Health System, are not nationally representative and many of the sample sizes are too small. However, if Dr. Croen's study is nationally representative then there is potentially a major, longstanding public health problem that has not been addressed. Mr. Robison pointed out that some adults with autism do not need to be identified because

they do not have sufficient medical problems to warrant diagnosis in adulthood. He concluded that there is a vital need for a large-scale adult prevalence survey to address these issues.

Dr. Gordon commended Mr. Robison for producing this paper. From an NIMH perspective, it is more difficult to make prevalence estimates for adults than children because delivery of care tends to be more fragmented. In Dr. Gordon's opinion, there is less need to know about how many adults have autism, but rather what are their unmet needs of adults.

Dr. Nina Schor wondered if researchers are correct to think about adults and children only as discrete populations. She pointed out that appropriate, timely, complete provision of services to children may result in some of them needing fewer services in adulthood.

Mr. Robison responded that in his paper, he raises the issue of emergence of disability. He said there are a number of adults with autism who may have consistent ADOS scores over their lifespan, but their practical ability to function in society is transformed dramatically for the better. However, he also pointed out that autism spectrum is very broad and that many individuals with ASD do not see improvement over time. He said that he would like the community to unite and pursue common goals.

Ms. Crane responded to the concern that early services eliminate the need for later services. She said that in many cases, it is more beneficial to focus on outcomes. Even though some people with ASD might not need services to engage in basic functions of life, they might still require significant services usage in order to experience rich, fulfilling lives.

Dr. Gordon concluded the discussion by expressing hope that reauthorization will allow the Committee to continue these important discussions after September 30, 2019.

## **Summary of Oral Public Comments**

Dr. Gordon began the public comments section by reviewing a live feedback comment responding to Mr. Lake's presentation. The commenter said that she has been profoundly impacted by a kindergarten teacher who actively worked to normalize special needs children in her classroom.

The first oral public commenter was Ms. Lisa Wiederlight, who spoke on behalf of [SafeMinds](#) to present comments related to the reauthorization of the Autism CARES Act. They support the Committee's recommendation to increase funding to \$685 million as outlined in the [2016-2017 Strategic Plan](#). She said that although autism prevalence has increased from 1 to 88 children to 1 in 59 children, research spending on ASD has been flat since 2012.

Ms. Wiederlight also pointed out the need for accurate prevalence estimation. To this end, she suggested that the Autism CARES Act should direct the CDC to enhance its ADDM epidemiology research methods. Ms. Wiederlight said the Committee should recommend that the CDC restore the ADDM budget, which had been cut for the current data collection cycle.

She continued that autism research should be responsive to clearly defined policy priorities and result in findings that are relevant to the needs of people with autism. She pointed out the need to improve diagnostic tools, ensure timely treatments and interventions, improve referrals to well-trained medical and educational professionals, and identify best treatment practices. To support these policy goals, Ms.

Wiederlight said that SafeMinds supports the creation of a National Autism Strategy, which would set priorities, goals, and outcomes for the federal autism response. This initiative would include appointment of a full-time Federal Autism Coordinator in the Executive Office of the President. She urged the Committee to make these recommendations for proposed changes to the Autism CARES Act.

The second oral public commenter was Dr. John Martin, a pathologist who specializes in immunopathology and medical microbiology. In his research, Dr. Martin has described a class of “stealth-adapted viruses” that are unique because they do not cause inflammation. He expressed his opinion that these viruses may be present in standard immunizations and may play a role in the diagnosis of autism in childhood. Dr. Martin said that the Committee has an opportunity to culture these viruses and study viral pathways in children on the autism spectrum.

## **Committee Discussion**

Mr. Robison responded to Ms. Wiederlight’s comments about ADDM funding and said that he interpreted her statement as asking for a more sophisticated version of efforts that currently exist. Ms. Wiederlight replied that SafeMinds is asking that there be one person within the federal government who is responsible for working to leverage resources to ensure coordination and collaboration.

Dr. Reichardt asked Dr. Martin how these viruses invade the immune system, which has the ability to detect cytoplasmic DNA and RNA. Dr. Martin responded that the viruses were inoculated from the animal into patients without causing tissue inflammation. Dr. Reichardt asked about the characteristics of these viruses. Dr. Martin said that the best characterized stealth-adapted virus is the cytomegalovirus derived from the African green monkey. He said that the immune system would not respond to cytomegalovirus because it lacks certain genetic components that would trigger an immune response.

Mr. Robison pointed out that many Committee members and members of the public lack the scientific or medical knowledge to fully appreciate the discussion between Dr. Martin and Dr. Reichardt. He asked Dr. Gordon to provide context to help others understand the debate. Dr. Gordon said that although he is not intimately familiar with the science underlying stealth-adapted viruses, he has seen research that suggests that viral infection in the prenatal period probably plays a contributing role to the development of autism. He said that it is possible that the mother’s immune response to the viral infection – rather than the viral infection itself – could raise the child’s risk for neurodevelopmental disorders, including ASD.

However, Dr. Gordon was unable to find any scientific reports about stealth-adapted viruses that were not authored and published by Dr. Martin himself. In fact, Dr. Martin’s own report discussed only a single case study of one stealth virus that was isolated from one child with autism. Dr. Gordon said that although current consensus suggests that viruses and immune response do play a role in autism, there is no evidence to support Dr. Martin’s hypothesis about stealth viruses and autism. Furthermore, Dr. Gordon pointed out that there have been innumerable studies of the relationship between vaccines and autism; none of these studies have found a causative link between the two, and certainly none have identified a relationship among vaccines, stealth viruses, and autism.

## Summary of Written Public Comments

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

Dr. Oni Celestin reviewed the 28 written comments that the Committee has received since their January meeting. These comments can be grouped in four broad categories.

The first topic was assistive technologies and communication supports. There were 18 comments received on this topic. Fourteen commenters commended the United Nations for highlight assistive technologies and active participation at their recent World Autism Awareness Day event, and they requested that the Committee focus on these issues at a future meeting where non-verbal autistic people would be invited to present. They expressed hope that calling attention to the needs of this population will result in greater support for and understanding of alternative communication methods. Other comments under this category included special education programs for non-verbal autistic children, using alternative and augmented communication (AAC) methods, and using typing/letter boards as a mode of communication. The [Autistic Self Advocacy Network \(ASAN\)](#) commented that the Committee should use caution when claiming that any particular form of communication is “evidence based.”

The second category was potential causes of autism, which received six comments. Commenters expressed concern about the relationship between autism and vaccines, vitamin B12 deficiency, folic acid supplements, radiofrequency energy, and/or Tylenol. One commenter thanked the Committee for discussing her proposed research investigating the role of inferior colliculi in autism.

The third category was service needs, resources, and policy implications. There were five comments received on this topic. One commenter wrote that he was prevented from joining the military because of his autism diagnosis, and another commenter wrote about her son’s experiences as a man with ASD in the criminal justice and mental health systems. One commenter was concerned about the practices of her local social services agency. ASAN expressed concern that the Committee’s [2016 Portfolio Analysis Report](#) revealed insufficient research funding devoted to improving services and supports. They are also concerned that too much funding on lifespan-related issues is focused on transitioning to adulthood, as well as the large amount of funding devoted to understanding the biology and causation of autism. They instead suggested that the Committee recommend more funding to research that examines gender, sexual orientation, and racial and socioeconomic disparities among people with autism.

The final topic was treatments and interventions, which received one comment. This commenter called for the Committee to discuss the potential for intrathecal autologous adult stem cell therapy in the treatment of ASD.

Dr. Celestin concluded by thanking the commenters for their feedback.

## Committee Discussion

Dr. Edlyn Peña responded to the comments related to the UN panel on assistive technology. She was heartened to read these comments and said that she is passionate about assistive technologies for people who otherwise would not be able to advocate for themselves. She discussed her research and advocacy work on this topic and commended the UN for holding this panel because there has been

been controversy about the authenticity and validity of people who use facilitative communication and rapid prompting to communicate. She encouraged the Committee to consider inviting speakers who use these forms of communications to present and share their perspectives.

Ms. Crane acknowledged the commenter who said that he was unable to join the military due to an autism diagnosis. She said that many of these restrictions on military service or pilot's licensed are not based on an individualized assessment of the person's abilities but only on the presence of a diagnosis. She said that this warrants a conversation about areas of life that people with autism are still barred from. Ms. Crane agreed with Dr. Peña that controversy provides a critical opportunity for scientific investigation. She said that most current studies of alternative communication methods have small, non-representative sample sizes. Ms. Crane agreed that there is a continuing need to find new ways to assess the validity of communication.

Dr. Judith Cooper commented that the [National Institute of Deafness and Other Communication Disorders \(NIDCD\)](#) has been involved in supporting this kind of research for many years. They are soliciting research in augmented and alternative communications, not just focused on autism but all people with severe communication disorders. They have held workshops and have compiled a research portfolio. Their institute is interested in and would support more applications in that area. Dr. Gordon commented alternative communication could be a good topic for Committee discussion in the future.

Dr. Mandell responded to comments from SafeMinds and ASAN about the need for more of the budget to be apportioned to comprehensive services research. He said there is a growing number of junior investigators who are interested in these issues who do not have the experience needed to conduct research that is relevant to policy. He suggested that the Committee could create training, mentorship, and support opportunities to build infrastructure for investigators who are interested in studying these issues, helping to bridge the divide between research and practice.

Dr. Gordon said that training is an interesting topic for the Committee to consider. He asked Dr. Ann Wagner, who was recently appointed National Autism Coordinator by the Secretary of Health and Human Services, to comment on the development of a services portfolio in autism research. She responded that they have had a series of requests for applications with set-aside funding designed to support exploratory research for growing areas. The requests aimed at older adolescents and adults had a much smaller response than the one aimed for early childhood. She said as a result there were three RFAs to fund career development awards, but the number of applications was less than they hoped. They are open to hearing suggestions.

Dr. Mandell reiterated his point about translating research into practice and proposed that the Committee could have a more specific, pointed role in this endeavor. Dr. Gordon suggested that they wait until Dr. Wagner gives her presentation to address the issue. He said that the fractured nature of health care delivery in the United States causes challenges in practice implementation across the entire NIMH portfolio.

Mr. Robison also spoke on the commenter who couldn't join the military because of his diagnosis. He said that he has communicating with people at various service war colleges about changing the current service ban on people with autism diagnoses. However, many people in the military are resistant to these efforts. On the topic of assisted communication, Mr. Robison also pointed out that there is tremendous potential for abuse, particularly sexual assault, when someone purports to speak for



another person who cannot speak directly.

Ms. Crane commented on soliciting research on services. She suggested that the Committee hear the experiences of researchers who study services use in adults with ASD. She said that researchers who become discouraged by the process are less likely to stay in the field and are unlikely to advise others to enter the field.

Dr. Reichardt said that they could welcome social scientists to use the [SPARK cohort](#), which is intended to facilitate scientific and social research. The Simons Foundation began this cohort a few years ago and has already enrolled more than 60,000 individuals with autism through 25 clinical centers and online. They have worked on about 40 projects so far, but only one of these has been a services research project.

## **Panel Presentation: Disability Employment**

### **Introduction**

**Julie Lounds Taylor, Ph.D.,** Vanderbilt University

Dr. Julie Taylor introduced challenges, current research, and future directions related to disability employment. She discussed a number of studies that have been conducted to estimate employment rates among people with intellectual disabilities; estimates have ranged from 19 to 60 percent. However, little research has focused specifically on unemployment and underemployment among adults on the autism spectrum, even though employment-related issues are well known in this population.

Dr. Taylor said that she and her postdoctoral mentor, Dr. Marsha Mailick, aimed to address this research gap by conducting a study of 400 families of adolescents and adults on the autism spectrum. They followed these individuals over time to determine employment trajectories among adults with ASD, and found that over a 10-year period, these adults participating in vocational activities became less independent. Specifically, Dr. Taylor found that the sex of a person was the only factor that could predict independence. Men with autism tended to stay stable in their independent work, while women with autism significantly declined in vocational independence over time.

Dr. Taylor described their additional research with this data set, which examined employment patterns among adults with ASD who did not have an intellectual disability. Over a 12-year period, they found that 25 percent of these adults were constantly employed or in college, 42 percent were sometimes employed or in college, and 33 percent were never employed or in college. Again, they discovered that employment differences occurred by sex. While 30 percent of the men in their sample were consistently employed across the 12-year period, none of the women in the study were consistently employed.

Dr. Taylor described another study she conducted to investigate the stability of job-related activities in this population. They collected data from young adults with ASD during their last year of high school and at two time points after exiting school. They found that half of these young adults experienced a disruption – such as dropping out of college or being fired from a job – within two-and-a-half years of exiting high school. Dr. Taylor explained that the only predictive factor for disruption was the family's functioning and mental health, such as depressive symptoms, anxiety, and quality of life. They determined that when parents and families struggle, they are less able to effectively support the needs



of their children with ASD.

She discussed the importance of understanding the needs and supports for diverse subgroups, such as sex/gender, cognitive functioning, social behavior, and co-occurring conditions. In order to best support employment, there is a need to consider these individual differences to develop personalized, multi-faceted processes that support individuals, their families, employers and workplaces, and systems.

Dr. Taylor concluded by introducing the panel speakers.

### **Competitive Employment for Youth with Significant Autism: A Multi-Site, Randomized Clinical Trial**

**Paul Wehman, Ph.D.**, Director, Rehabilitation Research and Training Center; Professor, Physical Medicine and Rehabilitation, Virginia Commonwealth University

Dr. Paul Wehman began his presentation by discussing the benefits of a strengths-based approach to employment among adults with ASD rather than a deficits-based approach. He said that, in his experience, people with autism or autism-like characteristics are strong, powerful people with unique gifts with potential to contribute significantly to workplaces and communities. To demonstrate this point, Dr. Wehman showed a short video of a young man named Dillon, who is successfully working as an intern in a hospital setting with supports from staff and an autism coordinator. The video demonstrated the success of employment specialists who are trained in ABA, job construction, and supported employment.

Dr. Wehman explained that he and his research team wanted to discover evidence-based pathways to competitive integrated employment for people with ASD. They used an internship model based on [Project Search](#), a program founded in the Cincinnati Children's Hospital. Between 2009 and 2013, Dr. Wehman's team enrolled 54 individuals with ASD in a hospital internship program that required the participants work a total of 900 hours between Labor Day and Memorial Day. Dr. Wehman found that 90 percent of people who completed the supported employment program were offered jobs three months after graduating, while only 6 percent of people who did not participate in the program were offered jobs. Additionally, nearly three-quarters of individuals who received supported employment and treatment were able to retain their jobs for a year after leaving the internship program, compared to much lower retention rates among controls.

Dr. Wehman discussed the importance of work for people with intellectual disabilities. Using the American Association of Intellectual Developmental Disabilities Support Intensity Scale, he found that the group who received the supported employment almost immediately became more independent in areas such as employment, community and home living, health and safety, and lifelong social activities.

He explained that after receiving supported employment, students were able to acquire jobs across diverse sectors, including health care, food service, retail, hospitality, distribution, manufacturing, entertainment, sports/recreation, education, and facilities management. Dr. Wehman said that employees with ASD are also known to have a positive impact on their employers and coworkers. Workplaces that employ people with ASD are more likely to have increased morale, an improved sense of mission among staff members, and increased productivity. Dr. Wehman expressed his excitement that employers are beginning to embrace individuals with intellectual disabilities with warmth and acceptance.

## The TennesseeWorks Partnership: Changing the Employment Landscape for Young People with Disabilities

**Erik Carter, Ph.D.**, Cornelius Vanderbilt Professor of Special Education, Vanderbilt University

Dr. Erik Carter began by explaining that meaningful employment is an important part of flourishing for many young people, who benefit from the connections, relationships, and valued roles associated with work. As a result, researchers and policymakers in Tennessee are working to change the employment landscape for young people with ASD and other developmental and intellectual disabilities.

Dr. Carter said that in 2012, funding from the Administration on Intellectual and Developmental Disabilities allowed the launch of the [TennesseeWorks](#) initiative. He explained that this partnership is a systems change effort that involved more than 50 state agencies, organizations, and community groups who work together to provide employment supports and opportunities for young people with disabilities. Dr. Carter said that he was able to categorize his experiences and observations from working with TennesseeWorks into broad thematic categories.

The first of these is *chasing aspirations*. He said that in his work, he has found that young people who are on the autism spectrum do not have a separate set of dreams and do not require substantially separate pathway to achieve them. Dr. Carter showed a [brief clip](#) of young people with disabilities discussing their aspirations for employment, which included “ordinary” answers such as farmer, working with animals, and tour guide.

However, he said that data from the 2012 National Longitudinal Transition Study indicate that only 47 percent of young people with autism were actually employed four years after leaving high school. Those who were employed had the lowest hours per week of any disability category, and only 38 percent reported enjoying their jobs. Dr. Carter said that contributors to the TennesseeWorks partnership aim to address these distressing data by striving to ensure that young people with disabilities are at the forefront of systems change work, as well as ensuring that they have a strong presence and voice in employment summits and advocacy work.

Dr. Carter emphasized the importance of *elevating expectations* among families, educators, and professionals. He said that parental and educator expectations can be a critical predictor of employment among children with autism and other intellectual disabilities. Young adults with disabilities whose parents expected them to obtain work after graduating high school were almost five times more likely to find successful employment in the four years after exiting school. Furthermore, high school students with disabilities whose teachers expected them to obtain paid summer jobs were 15 times more likely to obtain one. As a result, there is a critical need to teach families and educators of young adults with disabilities about the importance of high expectations and supportiveness.

Dr. Carter said that they also focus on *changing introductions* to emphasize the unique talents and assets of people with disabilities rather than their potential struggles. He said that it is important to shift employers’ paradigms towards matching these young adults with jobs that showcase their strengths and gifts. He cited the [Hire My Strengths](#) campaign, developed for October Disability Employment Awareness Month, as a prime example of this endeavor.

Dr. Carter discussed current efforts to *align policies* with high aspirations and expectations. To this end, they have established a state employment roundtable policy workgroup, which is comprised of agencies and state leaders who are working to align policies towards integrated competitive employment. Dr. Carter said that they successfully encouraged their governor to sign the Employment First Executive Order in 2013, which established a [taskforce on employment](#) that became a catalyst for strategic statewide movements, policy changes, and annual progress reports. Currently, the workgroup is attempting to address a number of other necessary policy changes, such as support for higher education.

Dr. Carter discussed the importance of *equipping professionals* to implement best practices. He said that employers need to be fluent in effective training and accessible, practical resources. They work with the Department of Education to develop [Transition Tennessee](#), a free, online professional development series for secondary and transition educators that has enrolled more than 5,000 middle and high school teachers to date. He said that they are also working with the Department of Human Services to create a companion module for pre-employment transition services.

He next emphasized initiatives to *make information accessible* for anyone at any time. He said that sharing research in peer-reviewed journals, policy documents, and academic circles is not an effective way to disseminate information to the public. Rather, they focus on practice guides, downloadable resources, websites, videos, and apps to increase accessibility for employers and community leaders who are not otherwise connected to disability networks. The [TennesseeWorks website](#) organizes content by stakeholder group (such as self-advocates, family members, or employers), features upcoming events, highlights success stories, and provides a searchable resources database.

Dr. Carter said that TennesseeWorks also aims to innovatively *engage communities* to drive policy and practice changes at the local level. He said that a hallmark of their work has been their efforts to engage and raise awareness at the community level to bring together civic leaders, employers, businesses, community groups, faith communities, and families. To this end, they have launched [Community Conversation Events](#), which helps them learn from and listen to local community members. Previous topics of discussion at these events have included integrated employment, access to postsecondary education, independent living, family engagement, and community inclusion. Dr. Carter said that so far they have held 60 of these events around Tennessee.

He continued by discussing the importance of *measuring well* with the goal of collecting meaningful data and sharing them with stakeholders. They have created a [Data Dashboard](#) to make information readily available, and they have developed clear measures that every state agency and community can use as a reference point. Additionally, he said that TennesseeWorks has partnered with the research community, which has developed a series of studies to evaluate elements of the partnership.

Dr. Carter concluded by talking about *investing in partnerships*. He said that systems change work relies on strong connections among stakeholders and state agencies, so it is critical to foster these relationships wherever possible. He said that systems change work is a slow process, but that strong partnerships among agencies, organizations, and communities can effectively lead to high-quality employment outcomes that enable young people with disabilities to flourish.

## Autism-Ready Workplace: Creating and Scaling Autism Hiring Initiatives

**Hala Annabi, Ph.D.**, Associate Professor, University of Washington

Dr. Hala Annabi explained that her work tries to understand employment opportunities in the autism community from the perspective of employers, businesses, and for-profit organizations. She said that they need to include all partners in order to provide equal opportunities and address the challenges of unemployment in the autism community. Many industry members have begun to engage the autism community to utilize their unique skills, including productivity, analytical thinking, visualization, and systemizing. Employees on the autism spectrum are also known to be trustworthy, reliable, and innovative.

She said that autism-specific hiring initiatives that identify strengths and break down traditional recruitment barriers have great potential. She cited [SAP's autism hiring program](#) as a successful initiative to provide employment opportunities for individuals with ASD. However, challenges still persist in creating true equity and inclusiveness for those entering the workplace. To address these issues, she collaborated with the Employer Roundtable, which represents many companies engaging in these programs, to understand how organizations can change, develop supportive programs, develop inclusive interventions, provide opportunities, and to examine the organizational characteristics that maximize opportunities and minimize barriers to employment for individuals with ASD. These efforts lead to the development of an [Autism@Work Playbook](#) for other organizations interested in developing autism hiring programs.

They began by studying four companies – Ernst & Young, J.P. Morgan Chase, Microsoft, and SAP – to better understand key organizational characteristics and best practices. They found that companies tend to begin engaging in autism hiring programs because they want to make social impact and adhere to core values, such as accessibility and sustainability. Companies also wanted to meet the needs of talented individuals in the field that can benefit their business. Additionally, they found these programs to appeal to socially-minded millennials. Dr. Annabi said that companies typically decide to engage in these programs only after investigating the current ecosystem to determine if community resources and state policies are sufficient to support the initiatives.

In terms of implementation methods and practices, Dr. Annabi said that organizations rely on leadership support to catalyze and reinforce culture changes. Companies must also take care to design programs that align within the company's values and existing diversity initiatives. She explained that the most significant factor in building a culture of diversity is educating employees on ASD and training them to engage productively and improve supervisory relationships. Research suggests that managers who are trained to effectively lead neurodiverse teams become better managers overall. She said that another best practice is providing systematic accommodations, such as noise-canceling headphones or different interview structures. Dr. Annabi explained that organizations also benefit from thinking about the life cycle of an employee, from onboarding to retention. Companies should consider that employees with ASD may require additional mentorship and support systems during these processes.

Dr. Annabi said that she and her team still have a number of open questions. They want to know how to encourage schools to begin early workplace preparation. The team is also interested in discovering best practices for including the voices of self-advocates and establishing systematic measures for assessing the impact of these programs on employees and organizations.

She concluded by expressing her excitement about the potential of these programs to support employment opportunities for members of the autism community.

## **Committee Discussion**

Dr. Wexler asked the presenters if any of the study participants were on Supplemental Security Income (SSI), a Federal income supplement program designed to help people with disabilities who have little or no income. Dr. Wehman said that some of his participants were on SSI, and he noted that almost all of the employees in the study did not work more than 23 hours a week. He expressed his opinion that these individuals should be able to earn as much as they can while keeping their SSI, and then begin easing off the benefits once they have a steady career.

Mr. Robison said that in his experience as an advisor to Autism@Work efforts, he has found that companies with autism-specific hiring initiatives assume that autistic people will be eased into the workplace by government-funded vocational counseling. He said that many young people with ASD are uncomfortable with the stigma of formally qualifying for vocational disability, which they need before they can receive services from the state. Mr. Robison wondered if there is potential for the Education and Labor departments to collaborate to allow young people who received special education services in high school to qualify for employment benefits without requiring them seek full disability support. Dr. Wexler replied that not much can be done, as once someone graduates high school they are out of their realm.

Dr. Wehman said that one solution to scaling issues is to encourage companies to hire staff within their own HR departments who are trained in ASD-related issues. Dr. Annabi agreed that hiring programs are the bridge to connecting candidates and breaking down interview barriers. She said that her preparation program at the University of Washington allows students to request special accommodations around the mainstream interview process. These practices also help individuals already existing within organizations who do not disclose their ASD diagnosis. She said that these programs help to drive organizational change and building capacity.

Dr. Wehman said that the first phase of these changes is to show that people with autism can have significant, meaningful contributions to an organization. He continued that the second phase is to encourage corporations to hire HR specialists who are trained to work with neurodiverse employees. Dr. Annabi added that she has seen individuals who are hired through autism-specific programs begin to carry out some of the awareness training and to coach managers on leading a neurodiverse team.

Ms. Singer asked why employment research seems to compare only individuals with ASD who did or did not receive a given intervention, rather than comparing individuals with ASD to typically developing individuals. Dr. Carter replied that this research does exist, but that his own research has focused on comparing treatment groups to non-treatment groups.

Ms. Singer expressed concern that this enterprise sets homogenous expectations and goals for a homogeneous population. She cited statistic that one-third of individuals with autism reported that having a full-time job would negatively impact their quality of life, so it might be incorrect that everyone with autism should strive for full-time employment. Dr. Wehman responded that ultimately the best barometer for the success of transition services is to understand the individual's personal goals for living

and working, and to ask if an individual attained their own personalized objectives. He said that this is a panel for maximizing opportunities to work, not for speaking on whether people should be required to work if they can.

Ms. Crane expressed her surprise about Dr. Taylor's findings on the relationship between work independence and gender, and she wondered how Dr. Taylor operationalized the concept of work independence. Dr. Taylor explained that her team developed a nine-point rating scale that determined the independence of a given position. The most independent being working without community supports or enrollment in post-secondary education, with a point deducted if they worked minimal hours. The next level was supported employment, with those working in the community receiving higher points than those in sheltered work. Individuals who required higher levels of support to maintain employment were considered to have less work independence than individuals who were able to live and work in the community with little or no supports.

Dr. Taylor said that she is still working to build hypotheses about the relationship between female sex and reduced work independence, suggesting that higher disease burden among autistic women could be partially responsible. Ms. Crane agreed with Dr. Taylor's point about health challenges among women with ASD, many of whom become too tired or disabled to work.

Dr. Gordon asked the panelists to speak on sustainability and cost effectiveness.

Dr. Annabi responded that technology firms are grappling with sustainability and scalability, which becomes increasingly difficult as companies expand in size and location. She said that models are evolving to engage self-advocates in diversity training. She also pointed out that organizations are working to determine what services they should provide to support challenges related to mental and physical health. All of these factors are related to program scalability and sustainability.

Dr. Wehman said that there is no one-size-fits-all solution. He suggested that progress is driven by peer-to-peer, business-to-business communication about best practices. He said that organizations could benefit from taking cues from other companies such as Walgreens and Dominion Energy, which are taking steps towards developing these programs. Dr. Wehman also said that in some cases, external job coaches are used too extensively beyond their intended function as employment consultants.

Dr. Carter said that his aim is to work within local communities rather than corporations. He said that in the absence of external funding and supports, their work relies on engaging community members to improve employment outcomes in the absence of a supportive service system.

Dr. Annabi responded to Dr. Wehman's point by clarifying that the external job coach is temporary and only used during the onboarding process. She agreed with his point that capacity building within organizations is critical, but she expressed uncertainty about best practices for achieving this goal. Dr. Wehman said that companies often face significant challenges in the first 90 to 100 days after onboarding a new employee, which may persist for six to eight months.

Dr. Gordon said that it is logical for companies to invest thousands of dollars in onboarding a valuable employee with a high earning potential. However, he pointed out that these processes are necessarily different for employees who work smaller, minimum-wage jobs. Dr. Gordon said that although they are committed to maximizing individuals' capacity to contribute to society by doing meaningful work, it is difficult to make the case to corporations and governments that funding for supported employment is a

cost-effective investment.

Dr. Reichardt asked about the role of resiliency in a time of relative economic prosperity and stability. He wanted to know if acceptability and buy-in change when overall employment rates change. Dr. Wehman replied that whenever there are economic downturns, there is almost always a drop in pay and employment among people with disabilities and that they are usually among the first to lose their jobs. Dr. Carter said that employment rates for people with disabilities rise and fall in tandem with employment rates for the overall population.

Dr. Gordon concluded the discussion by thanking the panelists and Committee members.

## **Report from the HHS National Autism Coordinator**

**Ann Wagner, Ph.D.**, HHS National Autism Coordinator and Chief

Dr. Wagner briefly reviewed the activities of the Federal Interagency Workgroup on ASD (FIWA), which has representation from HHS and other federal departments and agencies. They convened a meeting on outcome measures for transition youth and adults with ASD in response to the [2017 Report to Congress, Young Adults and Transitioning Youth with Autism Spectrum Disorders](#), which identified gaps in outcome measures for evaluating services and supports as well as quality of life. Dr. Wagner explained that FIWA has identified researchers working in this area whose research is supported by grants from the Department of Defense, ACL, and NIH. On March 19, 2019, FIWA held a special meeting to focus on these issues. Dr. Wagner reviewed the presenters who spoke at the March FIWA meeting and commended the quality and diversity of their research. Their goal is to disseminate these findings more widely in the form of a white paper, which will be discussed in the next FIWA meeting.

Dr. Wagner also noted current government interest in smoothly transitioning adolescents into adulthood. To this end, she mentioned three ongoing efforts: [Federal Partners in Transition](#), [Trans-NIH Pediatric Research Consortium](#), and HHS coordination efforts on youth in transition.

She concluded by thanking the Committee.

## **2019 Summary of Advances Nominations**

Dr. Gordon introduced the 2019 Summary of Advances nominations process by opening Committee discussion of the [nominated articles](#).

There were no nominated articles for Question 1.

For Question 2 (Underlying Biology), Dr. Gordon explained his nomination for an article discussing the Shank3 mutation. Shank3 is a known high-risk, high-impact gene that predisposes individuals to autism and plays a role in sleep cycles. Dr. Gordon expressed his belief that the biological mechanisms of sleep can translate into multiple effects on neural function and development.

Dr. Walter Koroshetz and Ms. Singer nominated the same article about developmental gene networks and their relationship to neurons in autistic subjects. Dr. Koroshetz explained that the researchers studied stem cells derived from adult tissues, or iPS cells. The researchers demonstrated that iPS cells derived from people with autism began abnormally organizing and patterning themselves before the cells ever become neurons. These results point to a defect in the early stages of brain development. Dr. Gordon said that this suggests that there is some programmed development course that is responsible for changes associated with autism, as opposed to something taking place in the neural cells themselves.

For Question 3 (Risk Factors), Dr. Gordon discussed his nomination for a study that provides evidence that the MMR vaccination does not cause autism. Dr. Geraldine Dawson commented on her nominated study that shows that families with a member with ADHD show an increased risk of ASD in younger siblings and vice versa, suggesting a shared genetic overlap between the two conditions. Dr. Cindy Lawler discussed her nominated study about the association between maternal prenatal vitamin use with risk for ASD recurrence in younger siblings. The study suggested prenatal vitamin use reduced autism risk in the new baby and that folic acid may be driving this association. She pointed out that this is a modifiable risk factor and an exposure that can be protective.

For Question 4 (Treatments and Interventions), Dr. Dawson talked about her nominated research article. The study was a randomized, multi-site controlled trial of the Early Start Denver Model (ESDM), a comprehensive early intervention that targets all domains of behavioral development. The researchers assessed standardized language ability and rates of language acquisition, as well as secondary outcomes such as IQ and ADOS symptoms. They found that children who received the ESDM showed an advantage in language development compared to children who received community-based interventions.

For Question 5 (Services), Dr. Gordon discussed the NIMH nominated article about treatment patterns in children with autism in the US. One of the important results is that half of the caregivers of individuals of children with ASD reported at least one barrier to treatment, such as waiting lists or lack of coverage.

For Question 6 (Lifespan Issues), Dr. Gordon discussed a 20-year study of suicide death in a statewide autism population. Women with ASD were three times more likely to commit suicide than women without ASD. In the ASD population, women were as likely to commit suicide as men. Dr. Leslie Caplan talked about Dr. Jennifer Johnson's nominated article, which studied competitive employment for transition-aged youth with autism. Researchers found that a specialized internship program for young adults with ASD successfully provided employment experiences, specialized instructions, and supports.

## Round Robin

Dr. Gordon invited members to update the Committee on their ongoing institutional activities.

Dr. Shapira had two updates from the CDC. First, he reported on the [Morbidity and Mortality Weekly Report](#) that was published earlier this month. The report reviewed a number of ongoing ASD surveillance and prevalence estimation efforts since 2010, including ADDM Network surveillance. Their goal is to investigate the age of first developmental evaluation with the goal of diagnosing children with ASD as early as possible. He said that these surveillance efforts reinforce the need to recognize early signs of developmental delay and evaluate children early.



Second, Dr. Shapira mentioned that in March 2019, the CDC and the [Association of University Centers on Disability](#), with support from [HRSA's Maternal and Child Health Bureau](#), announced a new cohort of [Act Early Ambassadors](#). They work with the CDC's [Learn the Signs, Act Early Program](#) to improve early identification of developmental delays and disabilities, including ASD. The Ambassadors also promote the adoption and integration of Learn the Signs, Act Early resources and materials to support developmental monitoring in systems that serve young children and their families.

Dr. Lawler talked about an upcoming NIEHS event as part of their Partnerships for Environmental Public Health initiative. They will host a [webinar](#) featuring two autism grantees, Dr. Craig Newschaffer and Dr. Anny Xiang, who will speak on the challenges that scientists face in communicating environmental risk factors for autism.

Dr. Marcella Ronyak thanked the Committee, Dr. Daniels, Dr. Wagner, and Dr. Shapira for supporting the Interagency Roundtable. She encouraged members to look forward to an upcoming Interagency Roundtable webinar, currently scheduled for April 2, 2020. She also thanked Autism Speaks for their presentation.

Ms. Singer said that the Autism Science Foundation held its sixth annual [Day of Learning](#) two and a half weeks prior. All of the [videos](#) from the presentations are now available on their website; topics included wearable technologies, autism recurrence risk, the role of the microbiome, suicidality, and self-injury in people with ASD. She said that their next Day of Learning will take place in San Francisco on October 17, 2019.

Dr. Dawson encouraged Committee members to remember the upcoming [INSAR meeting](#) in Montreal May 1-4, 2019. There is also an autism neuroimaging workshop to be held in Montreal right before the meeting.

Dr. Gordon informed the Committee of the [Adolescent Brain Cognitive Developmental \(ABCD\) study](#), a large research effort spanning multiple NIH institutes to study neurodevelopment in children ages 11 to 19 years old. He said that the NIH is beginning to plan a complementary initiative that would start at birth and extend to age 10. They aim to study neurodevelopment from a behavioral perspective and the effects of adverse experiences and substances, specifically prenatal opiate exposures. He mentioned that the Autism CARES Act, which authorizes the Committee, is expiring this year and that Congress is working to renew it. He said that they are planning to reinstate the IACC, requiring the Committee to re-enroll members. He said that the Committee will plan another meeting as soon as Secretary of HHS gives authorization.

Dr. Daniels stated that July 24, 2019 will be the last planned full Committee meeting for this iteration of the IACC, and she will provide an update regarding the legislation at that meeting. She said that upcoming activities will include the IACC-sponsored Mental Health Workshop in May 2019 and the Housing Working Group in June 2019. NIMH has a few more Autism Awareness Month items planned, but they have not yet been announced. She reminded the Committee that the following Tuesday was [Autism Awareness Month's special event \*A Woman's Voice: Understanding the Autistic Experience\*](#).

## **Closing Remarks and Adjournment**

Dr. Gordon thanked the Committee and adjourned the meeting at 4:57 PM.

The next meeting will convene on July 24, 2019 in Rockville, Maryland.