



Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

April 19, 2018

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Wednesday, April 19, 2018, from 9:01 a.m. to 4:34 p.m. at the Bethesda Marriott Hotel on 5151 Pooks Hill Road in Bethesda, Maryland.

In accordance with Public Law 92-463, the meeting was open to the public. Joshua A. Gordon, M.D., Ph.D., Director, National Institute of Mental Health (NIMH) chaired the meeting.

Participants

Joshua Gordon, M.D., Ph.D., *Chair*, IACC, NIMH; **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), NIMH; **James Ball**, Ed.D., B.C.B.A.-D., JB Autism Consulting (attended by phone); **Linda Birnbaum**, Ph.D., D.A.B.T., A.T.S., National Institute of Environmental Health Sciences (NIEHS); **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing James Battey, M.D., Ph.D.); **Samantha Crane**, J.D., Autistic Self Advocacy Network; **Allison Cruz**, Administration for Community Living (ACL) (representing Jennifer Johnson, Ed.D.); **Geraldine Dawson**, Ph.D., Duke University School of Medicine; **Tiffany Farchione**, M.D., Food and Drug Administration (FDA); **Melissa Harris**, Centers for Medicare and Medicaid Services (CMS) (attended by phone); **Elaine Hubal**, Ph.D., Environmental Protection Agency (EPA) (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; **Laura Pincock**, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Louis Reichardt**, Ph.D., Simons Foundation Autism Research Initiative; **Robert Ring**, Ph.D., Vencor Therapeutics (attended by phone); **John Elder Robison**, College of William & Mary; **Marcella Ronyak**, Ph.D., L.C.S.W., C.D.P., Indian Health Service (IHS) Headquarters; **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; **Melissa Spencer**, Social Security Administration (SSA); **Julie Lounds Taylor**, Ph.D., Vanderbilt University (attended by phone); **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD); **Buck Wong**, NIDCD (alternate for Judith Cooper, 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.

Welcome and Introductions

Dr. Gordon welcomed the Committee and introduced Dr. Melinda Baldwin representing the Administration of Children and Families, Ms. Alison Cruz serving as an alternate for Dr. Jennifer Johnson from the Administration for Community Living, and Dr. Elaine Hubel serving as an alternate for Dr. Ruth Etzel from the Environmental Protection Agency. The meeting minutes were approved with one correction.

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. Gordon introduced Dr. Ann Wagner and talked about her experience and appointment as the National Autism Coordinator for the Department of Health and Human Services (HHS), a role previously filled by Dr. Thomas Novotny and in the interim by Dr. Susan Daniels.

Dr. Wagner spoke about her role and its close coordination with the IACC. She talked about her background and interest in autism spectrum disorder (ASD), which began as a care provider for people with developmental disorders. In her work, she came to appreciate the unique challenges that people with ASD and their families face. Since coming to the NIMH in 2001, she has maintained a focus on ASD and the testing of interventions for childhood developmental disorders. One of her roles at NIH has been to coordinate the NIH Autism Coordinating Committee, which works with all the NIH institutes that fund ASM research on multi-center initiatives. She hopes to take these experiences and apply them towards her work as the HHS National Autism Coordinator. She is re-convening the working group for the transition report to expand its focus, and they will have their first meeting in June.

Panel on Employment for People on the Autism Spectrum

Dr. Gordon introduced the panel on employment for people with ASD and talked about how employment has been a topic of interest for the Committee.

Scott Michael Robertson, Ph.D., Policy Advisor, Youth Policy Team, Office of Disability Employment Policy (ODEP), U.S. Department of Labor

Dr. Scott Michael Robertson said employers have a great interest in autism and neurodiversity and recognize both the challenges and benefits in hiring people with ASD. ODEP is a federal agency in the U.S. Department of Labor that was set up in 2001 under the Bush administration. The mission of ODEP is

to increase employment opportunities for people with disabilities. There is currently significant unemployment and underemployment in the ASD community, and ODEP is working to shift this into hiring opportunities for employers and service provider organizations by highlighting the benefits of hiring employees on the spectrum. ODEP provides guidance, best practices, and support to other federal agencies, and coordinates with employers to help match job seekers and employees with disabilities to employment opportunities. A complex set of systems must connect to ensure that these individuals have access to employment opportunities and that their skills and talents are matched to those opportunities.

Dr. Robertson reviewed some of ODEP activities, including the [Workforce Innovation and Opportunity Act](#) (WIOA) of 2014, which built upon the Workforce Investment Act (WIA) of 1998, which promotes integrated competitive employment, the enhancement of services, and collaboration across government agencies at a local level in order to provide customized employment opportunities. ODEP provides technical support and assistance at the state and local level in order to effectively implement WIOA. A lot of the initiatives under this law can be mapped back to people with ASD, who may have challenges directly related to specific initiatives such as transportation, education, and on-the-job training.

Dr. Robertson talked about a recently published systematic review that showed that employers could increase their profitability and their competitive advantage in terms of employee loyalty, productivity, and work ethics by hiring individuals with disabilities. A 2017 Australian study found that their employees with ASD generally had above average work performance, including high attention to detail, high work quality, and strong work ethic with no significant additional cost. Dr. Robertson said it is important to understand the evidence and the employer's perspectives.

Dr. Robertson spoke about the job seeker perspective, in which job seekers with ASD tend to have specialized gifts, skills, and talents that, if provided with appropriate supports, can contribute to the workforce. Some of these supports include specialty training, enhanced hiring, mentorship, enhanced onboarding processes, and other approaches customized to ASD challenges. It's also important to employers not just that people are hired, but that they are retained. Dr. Robertson spoke about how people with ASD tend to jump from job to job and that can be because there is a lack of those supports.

Dr. Robertson talked about the resources that the ODEP provides for employers, service providers, policymakers, and job seekers. The ODEP website has a [page dedicated to autism](#) and also funds the [Job Accommodation Network](#) (JAN), which is a resource for job seekers with ASD and employers. Dr. Robertson talked about the support he received through JAN in becoming the first person with ASD to work as a federal employee at ODEP.

Dr. Robertson talked about other initiatives including the ODEP's [Pathways to Careers Demonstration Grants](#) and the Department of Labor's [Employment and Training Administration Grants](#). There is literature showing that people with ASD tend to see success with community colleges, technical schools, and trade schools. The Pathways to Careers project currently runs at two different community colleges and prioritizes things like co-ops, accommodations, work-based learning and, importantly, a persistence to complete the degree. There is a high percentage of people with ASD who participate in these programs, and ODEP is learning best practices for success in community college from these programs.

Finally, Dr. Robertson mentioned other grant programs that support job development for people with

ASD, such as the [TechHire Program](#) for the [Exceptional Family Center](#), which supports job training in technology and the [American Apprenticeship Grant](#) to the [AHIMA Foundation](#), which supports a medical coding apprenticeship for people with ASD.

Jose Velasco, M.S., Vice-President of Operations and Strategy, Global Co-Lead, Autism at Work, SAP

Mr. Jose Velasco talked about [SAP](#), which is one of the largest software companies in the world. He explained that there are about 50,000 unfulfilled science, technology, and engineering jobs in the Bay Area of California alone, and another 50,000 unfulfilled jobs in the New York metropolitan area. Conversely, the rate of unemployment for people with ASD is about 85 percent even though many have average to above average cognitive skills. This illustrates that the STEM industry has not been able to bridge the gap between supply and demand. The gap could be explained by biases during interviews, such failure to make eye contact or a weak handshake. These can keep people with ASD out of the workforce, and SAP questioned if everyone should be measured the same way. Customer-facing jobs may require high level social skills, but there are other jobs that may not. Instead of an economy to scale model, where all inputs look the same, employers have to think about talent in a different way.

The SAP [Autism at Work](#) initiative was developed to bridge this gap. Mr. Velasco spoke about SAP's 2013 aspirational goal of having 1 percent of their work force represented by people with ASD and presented a video of the SAP staff talking about the benefits of the Autism at Work program. There are many reasons SAP hires people with ASD: to attract the best talent in their industry, to bring a different perspective to their creative process, to reflect the diversity in their customers, to tap an underutilized source of talent, and to help their pipeline. Retention is another important reason that SAP hires people with ASD, whose retention rate is close to 100 percent.

SAP currently has 132 people with ASD employed across ten countries. They have 300 job opportunities that include both paid opportunities and training internships for high school students with ASD. These opportunities range from one-day experiences to semester-long engagements. All 18 high school seniors who participated as interns have positive plans for after graduation, such as going to college, joining the military, or getting a job. People with ASD who are employed at SAP do a range of jobs that include graphic design, software development, legal support, and IT support. Some people are in IT management. Generally, management positions require that a person has social skills, communication skills, and organizational skills; all of these can be challenging for people with ASD. SAP provides accommodation and support to certain people with ASD so that they can eventually become managers.

The roadmap of Autism at Work includes spans three different areas: learning via pilot locations, mainstreaming the process to the rest of the company, and to finally be able to provide employees paths to success without identification of autism. The first step involves learning about labor laws and other issues across the world by implementing pilots at select locations. Autism at Work applies what is learned to develop and refine onboarding and training programs across the company. As an organization, SAP implemented a lot of change management and an integration of best practices. From a high-level perspective, their onboarding process includes a position search, a candidate search, a one-week soft-skills training, and then a five-week pre-employment training. They start with fewer hours and incrementally build up endurance to an eight-hour day. This prepares employees to be enterprise-ready, not just training for a specific job but trained across the board. They then look at the accommodations people with ASD need to stay employed and provide support circles that promote awareness in the teams and managers. They appoint a team buddy and a mentor who is an employee

volunteer from outside the team to engage the employee with ASD. There is also a life skills coach who comes from a non-governmental organization who helps support the personal life of the employee with ASD. This helps with job retention.

Mr. Velasco talked about an employee who came in with a high GPA but had some personal and family issues, and the life skills coach helped him find an apartment. He reviewed other case studies of successful SAP employees with ASD, including a man who used to be homeless. Mr. Velasco talked about how sitting next to a person who used to be homeless can transform your perspective and help value your job. These examples highlight how unique perspectives and life experiences are transformational to the company.

Marjorie Madfis, M.B.A., President, Executive Director, Yes She Can, Inc.

Ms. Marjorie Madfis introduced herself as an advocate for inclusion and a parent of a 22-year-old daughter with ASD. She founded [Yes She Can](#), which teaches transferable job skills, because as a child her daughter wanted to work at the American Doll store, and Ms. Madfis wondered if this was ever going to be a possibility. Her daughter was given opportunities in high school to have employment experience, but the focus was on task completion and not on transferable job skills. Ms. Madfis thought about what skills makes an employee successful, which included good communication skills, cognitive and emotional flexibility, adaptability, and emotion regulation. These are all challenges for people with ASD. Ms. Madfis observed that people with ASD who are in special education tend to rely on their special education teacher and the structured environment, whereas in the workplace there is no such structure or environment to rely on.

Ms. Madfis felt that she needed to create a model from a business perspective to address the skills that are required to be successful at a job. This model includes the “why” about a task, the process for getting the work done, problem-solving, collaborative decision-making, and responsibility and commitment. She teaches that when a person is employed, the work is not about them but about the customer, and this can be a challenge for people with ASD. Yes She Can’s first program, [Girl AGain](#), is a resale boutique for American Girl dolls that provides a training curriculum for job skills. The program specifically serves women with ASD. Women in the workplace are particularly judged harshly for the lack of social skills. The program focuses on immersive learning experiences and utilizes professional staff to teach new skills, such as self-advocacy. They teach marketing, sales, merchandising, administrative skills like QuickBooks, and other transferable skills such as emotion regulation, information gathering, problem solving through rational thinking, negotiating skills, communication with management, participation in team meetings, and sensitivity to customers and other employees. They also teach how to execute “non-preferred” tasks and how to ask for a break. Participants learn that they may be in a fun environment, but they must remain focused as they are still in a job environment and are accountable for their tasks.

Ms. Madfis reviewed some case studies from the Girl AGain program, including a college graduate who showed improvement in technical, social emotional, and general work skills. Even though this person now has a regular part-time job, she still participates in the Girl AGain program because she knows that it helps her. Ms. Madfis talked about another case study of a high school graduate who improved significantly in social engagement after the program and is currently enrolled in community college. Participants of the program show improvement in flexibility, stamina, and social engagement. Parents report that participants have increased independence at home. These girls tend to be depressed and

isolated, and it is important for them to see the results of their effort. Even though they have the intellect and ability to learn skills quickly, they have limiting factors such as limited perspective taking, inflexibility, and anxiety. This program helps them learn to overcome these challenges and provides an opportunity to socialize.

Ms. Madfis wants to expand the program. She has observed that other job development agencies do not “get” autism and may not understand that these skills need to be developed before employment. Additionally, employers may worry that program participants are a “burden,” so outreach and education are needed. Smaller businesses in particular may have the flexibility to customize employment. Technology that helps people become a little more independent may also be helpful.

Ms. Madfis showed a [video](#) of the young women with ASD who have participated in the Girl AGain program.

Lori Ireland, M.B.A., Co-Founder and Board Member, Extraordinary Ventures

Paige Morrow, Managing Director, Extraordinary Ventures

Ms. Lori Ireland introduced herself as a founder of [Extraordinary Ventures](#) and Ms. Paige Morrow as a Managing Director. Ms. Ireland is also the Vice Chair of the [Autism Society of America](#). Extraordinary Ventures is located in Chapel Hill, NC. Ms. Ireland referenced the previous panel presentations and said there is a huge number of people with ASD who do not have the skills to work in the IT fields. There are many people with ASD who are extraordinary workers, but they are not heard about because they cannot talk in front of a crowd or discuss their job. Ms. Ireland suggested that the Committee consider facilitating the coordination of all the different employment regulations and departments. For instance, a person may need to limit the number of hours they work to maintain their benefits, and a regulation like this can be a disservice to people with ASD.

Ms. Ireland showed a short film about Extraordinary Ventures and the creation of self-supporting business ventures to support employees with ASD. These businesses ventures include laundry services, gift-making, and postal services. Their mission operates on the idea that all people need equal opportunity for employment. Extraordinary Ventures creates opportunities to match skill sets to a job or business need.

Ms. Ireland talked about the challenges of starting Extraordinary Ventures. For instance, when asked about the inclusiveness of their facility, they could not answer, because not being a clinical facility meant that they did not know anyone’s diagnosis. Their employment opportunities range from working in the community to sorting laundry at their facility, and this range means that they can employ people on any part of the spectrum. Some people can drive to work independently, and others require assistance coming through the door. Working at Extraordinary Ventures can also be a stepping stone towards more independence. Ms. Ireland talked about a young man who started out in their laundry business and is now working as a bookkeeper and has his own apartment. Everyone has an ability to contribute to society in some way.

Extraordinary Ventures also provides a voluntary social program that includes dances, picnics, yoga, and basketball camps. The participants are diverse, but everyone works together despite their differences. Their business model focuses on quality, not efficiency, and they can compete at the same level as any other local vendor. They don’t market on the fact that they employ people with developmental

disabilities; instead, they focus on the high quality of their services. Another part of their business model is to hire young social entrepreneurs, such as college students, who learn how to start and run a business. There are a lot of talented people coming out of college who have no experience with autism or developmental disorders, and this is a great way to engage them. Ms. Ireland said it is important that government agencies stop working at cross-purposes and coordinate, for instance, Social Security with vocational rehabilitation services.

Ms. Morrow said Extraordinary Ventures is a self-sustaining business model, which is one unique solution to the employment crisis. They have been operating for ten years, have a budget of about one million dollars, and employ about 60 people with ASD. They are now a significant contributor to their local economy. They use four core philosophies for running Extraordinary Ventures. First, they are a business and provide quality service and products. For the market place to support them, they need to sell the service first and the mission later. Second, they found that a portfolio of businesses is the best model for sustainability and currently operate six small businesses. One of their businesses, a laundry service, currently has 150 customers and a waiting list. They also operate a dog-walking business, a gift-making business, a mailing business, a clean and detail service for local transit, and an event center. Their portfolio brings a variety of job opportunities for their employees. The businesses were built around the interests and abilities of the employees and the needs of the community. About 30 percent of their workforce works across different businesses, which helps to build an employee's endurance. Third, every employee makes minimum wage or higher. Fourth, they employ across the full spectrum of disabilities. About 70 percent of their employees need some type of job support, but the jobs at Extraordinary Ventures are real and offer valuable experience.

Ms. Morrow said their challenges are not unlike other businesses, such as marketing, customer retention, and quality of service. For Extraordinary Ventures, employee retention is not an issue. Ms. Morrow sees the impact that having a job has on their employees, where they are less likely to self-harm, less likely to act impulsively, and more likely to improve life skills. Ms. Morrow left the Committee with some takeaways that could help Extraordinary Ventures. One of their biggest barriers is in support staff. Extraordinary Ventures does not provide job coaches; employees come with them individually. The organization has to take a step backwards every time there is turnover, but having consistent, trained staff would help grow the businesses. Ms. Morrow felt that overcoming this challenge would eventually help double the size of the organization.

Committee Discussion

Dr. Gordon thanked the speakers and welcomed the Committee to ask the panel questions. He said he especially appreciated how well these programs addressed the needs of people across the spectrum.

Mr. John Robison thanked the panel for their work on this important issue. He reiterated his belief that people with ASD need to have employment opportunities. He said that it is important to recognize that people with ASD may be sensitive about things people say, such as the suggestion to a person with ASD that they need help with self-assessment. It may be safe to say that all humans need help with self-assessment, not just people with ASD. If they were to ask a group of people on the street if they were a bad driver, for example, he doubts there is anyone who assess themselves accurately. Mr. Robison believes that people with ASD should stand beside those who are working to support these efforts, as they could help identify unintentionally hurtful comments. The goal should be supported employment, doing real work within the community, and making real wages. The government can help by giving tax

credits or other benefits to employers, and not by reducing wages, which is demeaning.

Ms. Ireland agreed with Mr. Robison that there should be self-advocates on the spectrum who participate in these discussions. She said the debate concerning issues from one end of the spectrum versus the other should be stopped, as everyone on the spectrum has different wants and needs. Unfortunately, some people with ASD cannot easily articulate their position. It is important not to forget that there is a wide spectrum of wants and needs, and no one person can speak for everyone.

Mr. Velasco talked about establishing a council of people with ASD from various backgrounds, whether diagnosed late in life or early, and across fields from the arts to technology. These perspectives and feedback can support SAP training programs. They are now on their third version of the program from feedback and are always making incremental changes to improve. They are putting people with ASD at the front and center of the process. Mr. Robison thanked the panel for their commitment to the community and reminded them that the ASD population may feel a lot of pain from having tried so hard without really succeeding to find or maintain employment. Ms. Madfis said their training curriculum includes input from people with ASD. They also have a woman with ASD on their board, and she visits the program and provides a lot of direction.

Dr. Louis Reichardt asked the panel about the presence of implicit bias in job interviews and what steps big companies should take to overcome this bias. Mr. Velasco said SAP tries to share their program model with other companies. In 2016 they launched the Autism and Work Summit, where a lot of large companies and the public sector had a conversation about this type of work. A second Autism at Work Summit was held last year in the Bay Area. This year Microsoft will be holding the summit. Mr. Velasco talks to other companies about bringing people with ASD into jobs that represent core functions, not just charity jobs. He believes there may be a very different world a few years from now because of this direction. Dr. Robertson added that the WIOA will help, but that it passed only four years ago, and it takes time to see effects. ODEP shows employers with hiring initiatives some best hiring practices, and those employers use what they learn. State policy, not just federal policy, needs to ensure that people with disabilities can be trained and included. Ms. Ireland added that they, in conjunction with [Autism Speaks](#), ran town halls in large cities across the U.S., which led to a conference in North Carolina where people attended to hear about the possibilities with small businesses.

Dr. Julie Taylor expressed her enthusiasm for their focus on daily living and job skills, which are not being addressed in schools. People are graduating academically prepared but not otherwise ready, so these efforts are very important. She asked the panel what they think are the key factors to facilitate retention and stability, which are huge issues. Ms. Morrow said that they raised their expectations and standards in the workplace. As their businesses grew, unexpected employee absences caused business to suffer. They decided to hold people responsible. For example, they now require two weeks' notice for time off, and there are consequences, such as losing the job, if an employee doesn't adhere to those expectations. She talked about an individual who did lose his job for deciding to take time off without notice, and was subsequently suspended, but then later came back and was more serious about adhering to policies. Mr. Velasco said that both empathy from people who really understand autism and self-advocacy from the person with ASD are very important. He recognizes that they ask their employees with ASD to act like they are neurotypical, and that can be taxing. It is important to find a middle ground between educating others on the challenges of acting neurotypical and recognizing the positive things that people with ASD can bring.

Ms. Ireland mentioned a 2010 longitudinal study of life outcomes for people with ASD, but these studies are not widely done, and life outcomes need to be studied and better understood. Dr. Geraldine Dawson said she lives in North Carolina and has witnessed the work that Extraordinary Ventures does. She has also worked with SAP through their partnership with Duke University to bring M.B.A. students into the SAP Autism at Work program to educate them. She said it is important to listen to the community and asked if the Committee could bring attention to the need to coordinate government and policy efforts. Dr. Dawson talked about the issues that were brought up by the panel, such as the need for job coaches and losing benefits, and she wondered if the Committee could bring about change.

Ms. Morrow said employees who are able to increase their hours or are eligible for a raise may reach the threshold for receiving social security benefits. The gap between the threshold and a real living wage is too large, and they sometimes have to help employees decide if it is worth giving up their benefits in order to increase their hours or wages. She would like to see that threshold raised. Dr. Gordon asked about federal caps on benefits for Social Security and Medicaid. Ms. Ireland talked about how Medicare waivers are different in each state and are difficult to navigate, as well as the challenges of applying for grants and benefits. Ms. Melissa Spencer said she knows the issues of cash benefit caps is a big consideration and wondered if Extraordinary Venture's employees have worked long enough to be covered by Title II Social Security benefits. She acknowledged that there is a cap on earnings, but that there are creative strategies to retain those benefits. The Social Security Administration makes these rules in terms of earning caps, who is considered disabled, and what is considered work activity. She said that she understands that navigating those rules are the challenge.

Dr. Robertson encouraged the Committee to review a [report from the advisory committee](#) for the WIOA. Some of the recommendations in this report align well with the challenges that are being brought up today. There is a lot of focus on benefits and hurdles. Ms. Ireland talked about her own son who is considered 100 percent disabled and lives on a very small amount in Social Security income. She talked about the challenge of engaging with the social security representative, where they must make hard decisions such as choosing between making him eligible for an extra \$200 a month or providing him with adequate housing. Mr. Velasco said varying policies in different countries create very different levels of support. He said Germany provides two job coaches for five years and it was very helpful. The fear of the unknown from the hiring manager can be substantially reduced with a conversation with the job coach. Some companies are able to self-sustain such programs, but scaling up and retainment requires better public and private partnerships. Some laws provide a job coach for only 90 days, but life continues after that. Taking people off the government payroll and into a job where they become taxpayers would have a positive impact on the government. The amount of money saved would allow companies to hire and retain job coaches.

Ms. Alison Singer reiterated that the government can hinder and not help. She thanked the panel for presenting an opportunity for the Committee to make a difference. She suggested that the Committee create a list of laws and policies that inhibit the ability of people with ASD to expand job opportunities that can be presented to the HHS Secretary.

Ms. Samantha Crane liked how seriously these groups were taking the match between skills and the work. She said that sometimes people with ASD are held to a different standard in job stability. It is normal for a young person to try many different things before settling on a career, but that a person with ASD who is seen to have had many different jobs may be perceived negatively. She hopes that if people are successfully working at jobs, if they are doing well and the business is profitable, that they

could eventually move to a regular business. Ms. Ireland said that they are working under a non-profit umbrella, and that anytime they make a profit, they start a new business. They do all the same things that a regular business does, and people can move to a regular business at any time. Ms. Morrow said that their businesses do not undercut quality, and in some instances, they beat competitors in terms of quality. The difference is that they breakdown tasks, such as one person being in charge of folding clothes rather than washing from start to finish, which is how they are able to accommodate creative job solutions for someone lower on the spectrum. She said that individual skills can also be transferable to a regular business; for instance, they use the same equipment that other businesses use.

Dr. Walter Koroshetz reiterated the need for change and that this need may apply to a wider community than those with ASD. He asked if there are other organizations for developmental disorders where they could go to get stronger attention. Dr. Robertson talked about ODEP's partnership with the [U.S. Business Leadership Network](#) that has about 130 employers who have a strong interest in hiring people with disabilities, not just developmental disabilities. There is also a resource called the [Employer Assistance and Resources Network on Disability Inclusion](#) that provides employer assistance. Some things that are learned with the ASD community can be applied to other communities too because there are a lot of similar challenges, and this can bolster resources and outcomes. A two-way communication stream where resources and lessons learned are shared between autism and broader disability would be extremely beneficial. Ms. Ireland said Extraordinary Ventures does not know anyone's diagnosis, but because they are in Chapel Hill, NC, where the [TEACCH Autism Program](#) is located, they have a disproportionate number of people with ASD.

Dr. Linda Birnbaum asked Mr. Velasco about what SAP does as a business. Mr. Velasco said SAP is a large enterprise software company with 300,000 employees who provide business solutions for medium- to Fortune 500-sized businesses. They provide software solutions that help run an enterprise from A to Z.

Committee Business

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

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

Dr. Daniels thanked the OARC staff for their hard work for Autism Awareness Month and acknowledged the many federal activities around the country. The NIMH hosted an event with the OARC on [The Story Behind Julia](#), who is the Sesame Street character with Autism. Other events included the [Autism Awareness Interagency Roundtable](#) held by the IHS, the United Nations event [Empowering Women and Girls with Autism](#), and [Developing Individuals Who Have Different Kinds of Minds](#) with Temple Grandin at NIEHS.

Dr. Daniels told the Committee that the [2017 Summary of Advances](#) has been published and includes lay friendly summaries of top 20 most significant advances in ASD biomedical and services research. Dr. Daniels invited the Committee to read this publication.

The OARC and their partners in the UK and Canada will be co-presenting the 2016 International ASD Research Portfolio Analysis report at the [International Society for Autism Research](#) meeting in Rotterdam, Netherlands in May and will also present the report to the Committee at the October meeting.

Dr. Daniels said that the Autism CARES Act Report to Congress is due in September 2018, which will cover activities related to ASD and developmental disabilities across the federal government. The OARC's requests for data have been received from all agencies, and they are currently compiling the report. They anticipate it will be completed on time in the fall and will be shared with the Committee.

Dr. Daniels reviewed the progress of the Improving Health Outcomes for Individuals on the Autism Spectrum Working Group, who recently met by phone and is working on selecting working group members. The next step will be to conduct a workshop in the summer that would replace the IACC meeting that normally occurs in July. Dr. Gordon asked for Committee input on a few topics that might be covered in the workshop. Mr. Robison agreed that the workshop should replace the regular meeting because the issues are important and deserve a full day. Dr. Daniels said that they have a list of nominees for the workshop and will finalize the agenda and date for the workshop. Dr. Larry Wexler asked what might be lost if the regular IACC meeting is not held. Dr. Gordon said that the Committee is required to have two meetings, which is doubled with the normal schedule of four meetings. Because they have already decided to minimally revise the Strategic Plan since a major revision was just completed, they felt that this would be a better use of the time. Dr. Daniels talked about Public Comment section of the meetings, and that the public could specifically input their comments on this subject for the workshop.

Dr. David Mandell asked that mortality be addressed along with the other health issues, and Mr. Robison agreed. Ms. Crane also agreed on including the subject of mortality and added a suggestion to include patient-provider interactions. Dr. Edlyn Peña added that practitioner training would also help with those interactions. Dr. Dawson asked if including a discussion on quality of life would provide a positive balance the serious issue of mortality, since quality of life is embedded in that goal. Dr. Koroshetz agreed that mortality is something they want to reduce, but it should be actionable. Dr. Gordon suggested that the mortality issue is focused on the more severe aspects of co-morbidity such as epilepsy, suicide, and chronic health conditions, and that it is important to maintain that focus. He suggested adding a second part on patient-provider interactions to promote prevention and wellness. Dr. Mandell said that the other topic should be something like quality of life, but things can be missed if mortality is not discussed directly. Dr. Peña asked if the working group will be in person or online. Dr. Daniels said that it will be in person, with some conference calls, and that they will take these suggestions and provide the date and agenda very soon. She said if the Committee is interested in submitting a letter to the Secretary on the employment between now and October, they could arrange a phone call to work on that.

Summary of Advances Discussion

Nominations for the 2018 Summary of Advances were reviewed. For [Question 1](#), Dr. Mandell talked about his nomination of a study about a high-risk sample of young children with ASD, who were missed even with standardized measures. For [Question 2](#), Dr. Gordon talked about Dr. David Amaral's nomination of a postmortem study that showed an over-exuberance of neuronal growth in early childhood that declines later. The other nominated study compared differences between ASD and ADHD. For [Question 3](#), Dr. Gordon and Ms. Singer nominated a study on postmortem data across different diagnoses, which showed that there are shared molecular similarities across major disorders, including autism spectrum, schizophrenia, bipolar, major depression, and alcoholism. There is also potentially a generic risk and a generic resilience state. Dr. Linda Birnbaum talked about the environmental role and the complexity of associations in terms of a gene by environment association. A

recent study showed an association of ozone with copy number variation (CNV) and another showing an association of components of air pollution such as volatile organic compounds. Dr. Birnbaum suggested that the environmental component will be very important in terms of association with specific genes.

For [Question 4](#), Dr. Mandell talked about his nomination for a meta-analysis of parent-mediated interventions for young children that showed a small effect size, which suggests either that they don't know how to train parents to provide interventions, or that the training is not feasible within the context of daily life. For [Question 5](#), he nominated a study on the effect of autism on insurance mandates and that showed that age caps matter. States that have lower age caps show a significant drop in services received. This finding is important for advocates to consider. Dr. Gordon said that it is important to recognize the challenge of putting an age cap on care for individuals who have a lifelong disorder. Dr. Mandell talked about his third nomination, which is from the CDC, that looked at eight-year-olds who met research criteria for autism and should be in special education but are not. It is important to determine why they are not receiving services and if there are disparities to consider. Ms. Singer reviewed her nomination on mortality that showed that, despite research showing no relationship between vaccines and autism, parents of children with autism are still withholding life-saving vaccines from their children and their siblings.

Dr. Gordon reiterated that any member of the Committee is welcome to the workshop in July and that it will also be open for public comment.

Summary of Oral Public Comments

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

Dr. Gordon introduced the [Oral Public Comments](#) presentations. There were many public commenters this time, and as a result there will be an extended time to account for all the comments and Committee discussion.

Ms. Deb Cordone is the mother of a 12-year-old son with severe autism and came to address the protection of parents and their autistic children from self-injurious behaviors. She showed the Committee the tools that she uses to protect herself from her son's injurious behaviors, including a baseball cap to keep her hair from being pulled and arm guards to protect herself from bites. She said that there are times her child requires four trained adults to contain him. She wants the Committee to understand these challenges and that lack of provider training makes taking her son to the hospital difficult. Many of the inpatient clinics have waitlists for several weeks. Sometimes there is no trained staff and the only thing the hospital can do is mechanically restrain and sedate her son. She suggested that while one mother might be looking for a sensory friendly restaurant, there is another mother who is restraining her child from putting his head through a wall. These children and their families are being left behind. These issues are not being addressed by national autism agencies

Ms. Susan Jennings is the mother of a young man with ASD, intellectual disabilities, and schizoaffective disorders. She is the founding member of [KIIDS](#) – Keeping Individuals with Intellectual Disabilities Safe – which is an organization that includes families of residents within the Intermediate Care Facilities of Pennsylvania's State Developmental Centers. She would like to keep these facilities open and eliminate the waitlist to serve families who are dealing with aggressive and self-injurious behaviors. Her son was offered a community group home because of an anti-institutional bias, and in that home he was very

restricted and put on several medications. The community group home staff is poorly trained and paid. Often their only recourse is to dial 911. They were able to get him admitted in the intermediate care facility, which has safety measures, is structured, offers social events, and most importantly the staff is well-paid and supported. There are clinicians and specialists on the premise. A person does not get these benefits at the community group home. She implored the Committee to advocate for a spectrum of residential options. She talked about how research shows that young people with ASD were four times as likely to go to a hospital, where they often languish because they have no other place to go.

Ms. Cheryl Smith has a non-profit called the Autism Council of Utah and is a mother to a child with ASD. She came to talk about the people with ASD who need significant support. Every day there are people who may self-injure, injure others, or damage property due to episodes of explosive emotional overload. Parents don't openly talk about this, so people don't always know the extent of these problems. Funding sources don't consider immediate needs of a family dealing with violent behaviors and services are hard to find. Frustration and sensory overload may contribute to these aggressive behaviors. Her son has severe meltdowns and self-injury, he bites himself and her, but she was reluctant to take him to the hospital because she was afraid of what they might say. He hits, pinches, bites, and destroys property but it is clear to her that he doesn't want to behave this way. Their family has PTSD and lives in fear of law enforcement being called. She would like to create a program for quality-of-life skills and behavioral supports that will help these children go into the community.

Mr. Joe Joyce introduced his wife, Elise, and their son, David Joyce. He thanked the Committee for the opportunity to tell David's story. David has severe, self-injurious behaviors but has become an ambassador for individuals with ASD. They have learned how to communicate as a family, and he is here because he fully believes that David wants him to tell his story. Too many people fail to acknowledge him even though he respects when people are patient and understanding. When David was very young, he displayed a lot of self-injurious behavior, to the point that they were concerned about permanent brain damage. The behaviors averaged in the number of 8,000 per day. He and Elise would also become injured if they tried to stop him. Before assistive technology, David communicated with them through facial expressions and his eyes. They began working with the Kennedy Krieger Institute and would drive David 180 miles roundtrip for treatment. At one point, David was in an inpatient unit and their family began to use strategies that were taught by the Kennedy Krieger Institute. Those strategies helped David and reduced his self-injurious behaviors to almost zero. David now communicates using an iPad and his self-injurious behaviors average less than 100 a day. Mr. Joyce is a volunteer on the board of the Autism Center of America, which has a mission to improve quality of life for all people with ASD.

Dr. Dan Fairbanks is the Dean of Science and geneticist at Utah University. His wife is a professor and a violinist. They have a severely autistic son who is 26 years old. He would like to focus on the challenges they have faced when dealing with career, family, and the care of their son. There is a lack of resources for those on the severe end of the spectrum. There are services for those who are higher functioning, and those that are available for lower functioning are so expensive that they can be unattainable. There are often contradictory requirements in getting governmental resources, both federal and state. It was so difficult that they hired attorneys to help them navigate. They lost their home equity and life savings through attempts to obtain care and were fortunate to have the means to recover, but many families are not. As a scientist, he is optimistic for scientific advances as well as the establishment of centers for autism at his university.

Ms. Jalynn Prince is with the [Madison House Autism Foundation](#), which focuses on the issues in adults with autism. They declared April 21 to be Autism after 21 Day. They are hoping this effort will expand

across the country. They became aware of the need for this to be a national day because they often hear two phrases: “what will happen to my child when we are no longer around?” and “I’ve never thought about adults as having autism.” They are staging events to bring together and engage legislators and employers, not just for awareness but also for action. Ms. Prince showed the Committee a brief video about the Madison House Autism Foundation. A child with autism becomes an adult with autism every ten minutes. At age 21, supports that they’ve relied on in the past become unavailable. Adults with autism often go unnoticed. Madison House Autism Foundation raises awareness of the needs of adults with autism.

Ms. Danielle Augustino spoke on behalf of her brother, James, and their family. She is a sibling of a person with ASD. The past few years of life have been overwhelming for her family, and there are many others who are barely making it through the day. Years after adopting James, the self-injurious behaviors became a part of their daily life. She said her parents are now prisoners in their home, and they cannot join family holidays or have their grandchildren visit because it is too dangerous. It is heartbreaking for her to see bruises and teeth marks on her parents, and there is nothing she can do. She is fearful that her parents may sustain a major injury. The most devastating moment for their family was on Christmas Eve, when James required five adults to restrain him, and eventually the only option was to call an ambulance. First responders should be trained to handle children and adults with severe autism and self-injurious behavior. When he was a child, James waited in the hospital for seven weeks while waiting for a spot at Kennedy Krieger. There are not nearly enough beds for these children. Everyone deserves services, trained professionals, and a bed if needed.

Ms. Ann Strober represented Ms. Lisa Wiederlight, who is the executive director of [SafeMinds](#), which is a national non-profit that promotes preventing and curing autism through environmental research and effective treatments. The problems facing the autism community are very serious, and autism prevalence has increased with no widely recognized cause. The Committee should focus on urgency and accountability. She was dismayed to discover that the strategic plan was for the years 2016 to 2017, and asked if there was not a plan for the current year. There are 23 new objectives in the new strategic plan, which also supports an increased budget, but there is no justification for that amount. She asked why there were no measurements of how much change the research objectives aimed for, and as an example asked how much the objectives aimed to reduce disparities and over what time period. She suggested that some terms used in the research plan, such as “understand” and “explore” or “supporting research,” are not measurable. If the Committee instead coordinated research that supported the strategic plan or goals of participating agencies, there would be significant changes, for instance, reducing mortality by a certain amount by five years. Then the agencies responsible could measure the effect of programs over time. The same could be said about autism related prevalence data. She said there needs to be a measurable goal to inform policy. For instance, they don’t know how many people with autism are employed or what should those percentages be. The Committee should create policy, programs, and metrics towards stated goals. This is a necessity, as people with autism suffer from gastrointestinal disease, seizures, suicide ideation, and unemployment. Autism is costing our country \$500 billion.

Ms. Tara McMillian has a son who is impacted by autism. She said he developed encephalitis at 17-months-old after receiving vaccinations. It was not treated as an emergency and her son suffered brain damage. He is now 12 years old and cannot speak. There was a recent Time magazine article that suggested that children with autism were unprotected from vaccine preventable diseases, but this is because children with autism were vaccine injured. Parents of children with autism will not go back to the guidelines that injured their children in the first place. Cause and effect in science can be

documented. Thousands of children have been injured by vaccines. Ms. McMillian implores the Committee to determine why vaccines cause harm. There is no data to support safety of vaccines in newborns. Parents are smart and will follow what other parents will tell them. It is a failure of the CDC and all those that follow their agenda that this problem is not addressed. If the CDC continues to state that vaccines do not cause autism, parents will continue to not vaccinate their children.

Summary of Written Public Comments

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

Dr. Oni Celestin reviewed the [Written Public Comments](#) from 33 commenters, organized into seven broad topics. The first topic is individuals with self-injurious behaviors, with 13 comments received requesting increased awareness and funding for research, treatments, and resources. The second topic was vitamin B12 deficiency, with six comments regarding dietary recommendations, screening, and research. The third topic was the role of the IACC, with four comments about coordination, research focus, and interaction with the autism community. The fourth topic was medical practices with four comments discussing medical causes and treatments of autism. The fifth topic was service needs, resources, and supports with four comments addressing the need for increased funding. The sixth topic was vaccines, with three comments expressing frustration and requesting further investigation. The seventh topic was autism research priorities, with two comments requesting research into co-occurring issues.

IACC Committee Member Discussion of Public Comments

Dr. Gordon opened the Committee discussion about the public comments.

Ms. Crane highlighted the comment about the importance of assistive communication. A lot of people who self-injure struggle with communication, and, in terms of planning a future, this may be of particular concern for a person of color whose expression may sometimes be misinterpreted. Self-injury can often be a result of difficulty with communication. Ms. Crane suggested the Committee should focus research efforts on this.

Ms. Singer expressed her thanks to the parents and sibling who spoke and said that it was brave to tell the stories and highlight very important issues. She suggested that the Committee needs to take note that parents and siblings are here begging for help. This is a segment of the population that is left behind. There are not enough services, and this needs to be addressed so that more options are available for these families. Ms. Singer said that it is unlikely that there is anyone in the room who didn't have a profound reaction to their stories.

Dr. Reichardt also thanked the families for the charge – not just as a Committee, but as individuals – to seek federal and state support to make their lives better.

Dr. Dawson echoed the previous comments of gratitude to the families. Other than the lack of available resources, she had three takeaways: making sure they focus on this as a high priority research area to better understand the cause and interventions, working with ER professionals to improve the handling of kids who come in (as it can be a horrible experience for families), and that informing law enforcement can make an immediate impact on families who are in crisis.

Mr. Robison reiterated gratitude to the families. He pointed out that the solution to self-injurious behavior in people who are severely impacted may lie in technology, whether or not their self-injurious behaviors comes from an inability to communicate or something else, and even though this is described as a medical problem. He is concerned that the NIH is not adequately resourced to address this technology need. It is not just communication technology for autistic people but also technology that can summon help. A traditional LifeLock button does not help if you can't communicate. Mr. Robison said that this is technology that can be developed now and he urges that the Committee begin looking into funding this.

Dr. Alice Kau echoed the thanks to the families. She is reminded of her time as a staff psychologist at Kennedy Krieger, remembers the struggles that families face, and feels that it hasn't changed. The service need is great, and they need to also help the parents. Parents worry so much about what will happen to their children when they no longer can take care of them.

Dr. Nina Schor suggested they need to think about the environment created in emergency rooms and clinics. These spaces are designed for neurotypical children, who may feel comforted by large numbers of people and camaraderie, and colorful things to play with on the floor. But this environment can be frightening for a person who suffers from sensory overload. It may help children to come into an environment that caters to their needs.

Ms. Singer asked the Committee to focus on what they are able to do, such as identifying self-injury as a high priority research area. There is no research that ties self-injurious behaviors to a lack of communication, and they don't know what causes it. The Committee could also work to remedy policies that are hurting this segment of the population. While policies can be positive for some percentage of the autism community, they may also cause harm to those who others. The Committee could make policy recommendations related to employment and other issues they heard. She added that the [Autism Science Foundation](#) will convene a research meeting in the fall to look at research for underserved populations, particularly for people on the severe end of the spectrum and also those with self-injurious behaviors. She invited the Committee and those who made comments who want to be part of the conversation to get in touch with them.

Mr. Robison responded to Ms. Singer by saying she knows she supports evidence and the scientific method, but people with ASD have been talking for years about how they injure themselves out of frustration, and because they can't communicate. Mr. Robison suggested they don't need a research study to tell them this. A research study could quantify the issue, but it feels outrageous to not be able to say that communication difficulties causes those problems. Ms. Crane said that when researchers design these studies they should first consult with people who do self-injure. There are a lot of different kinds of motivation to self-injure. They do need better research, but that research needs to take into account the stories of people with ASD who self-injure.

Dr. Gordon said that there are many reasons for self-injurious behavior, but a legitimate question to ask would be how much of a reduction in self-injury could there be in a person without communication if those problems are solved. This is an empirical question, but there must be a way to facilitate communication with someone who can't communicate in order to find an answer. The NIH does conduct research in terms of understanding why communication is disrupted and how to enhance it, and also with assistive devices. Others are conducting similar work. The NIDCD, the National Science

Foundation, and the Brain Initiative at the NIH also focuses on device development for communication enhancement. He hopes that these efforts will help reduce self-injurious behaviors in the future.

Ms. Melissa Harris addressed a few references about Medicaid funding and intermediate care facilities. She acknowledges that these programs are run out of her office and she is happy to discuss the issues about those services. There is a lot of concern about the regulation of services and how it impacts individuals. Intermediate care facilities are reimbursed and can be recognized as necessary depending on the person and the support they need. It is important to make people aware of the options available, and she would like to further this conversation in the future. Ms. Singer suggested that Ms. Harris could present on these options at a future Committee meeting because the experience on the ground is that there is a lack of preferred options for people who need 24/7 care. Ms. Harris said that she would be happy to do so and that they are working on some guidance documents that would clarify some of these points. A presentation would be most valuable after this document is released, which is targeted for this summer. Dr. Gordon suggested that this topic go on the schedule for the October meeting. Ms. Crane said that it is very important to understand that people across the board experience limited choices and challenges in getting these services, especially those with significant support needs.

Aggression and Self-Injury: Research Needs for the Severely Affected End of the Spectrum

Matthew Siegel, M.D., Director, Autism & Developmental Disorders Inpatient Research Collaborative (AADIRC), Maine Medical Research Institute, Vice President Medical Affairs Developmental Disorders Service, Maine Behavioral Healthcare

Dr. Gordon introduced this presentation as a topic of interest that had been addressed in past Committee meetings and that was also discussed today in the public comments.

Dr. Matthew Siegel said that he felt humbled to hear the stories from the families in such a concentrated dose. There was a lot of discussion about self-injurious behaviors and aggression. His talk focused more on aggression and, although there are similarities between the two, there are actually significant differences in the way they are treated. He heard the frustration in the room about the challenges and reassured the audience that research does not put off solving the problem, but helps to understand the neurobiology and underlying mechanisms of SIB and aggression. He receives several emails every week that are similar to the stories heard by the public commenters, where a child who is severely autistic is displaying self-injurious behavior and aggression and the family is desperate for help.

Up to two-thirds of youth with ASD will show aggression at some point in their development, and this is a primary reason for behavioral healthcare services. Some families suggest that the aggressive behaviors are more distressing and difficult to address than the core social and communication issues of autism itself. This is a particular problem for people with ASD who are minimally verbal, who may be unable to report distress, making it seem that the aggression comes from out of the blue. The unpredictability that the families talked about results in exclusion or restrictions in educational settings. If the behavior could be predicted, then the educational approach could be different. There is a window of intervention in the moments before the aggressive behavior, but this window is missed with limited communication. There is a real, unmeasured effect of this behavior as it can alter an individual's developmental trajectory if they cannot participate in educational programs and services that can promote positive outcomes.

Aggression is not a disorder or a diagnosis, but a symptom. If they think of it this way, then they can ask what is causing this symptom. There may be psychiatric co-morbidity, behavioral function and

reinforcement, functional communication deficits, medication side effects, dysregulated sensory system, mismatch in abilities to demands, family changes, or medical issues that lead to aggression.

Dr. Siegel talked about their treatment program. The foundation of their treatment plan is highly individualized: it uses applied behavioral analysis, a multidisciplinary approach, and the transfer of management skills to the parents or other caregivers. Some of the major therapeutic approaches may include psychotropic medication, communication strategies, medical treatment, family work and parent training, sensory regulation strategies, social skills, social cognitive strategies, and psychotherapy strategies. The best research evidence is for applied behavioral analysis and for medication, but there are issues with both. There can be challenges in administering applied behavioral analysis, and it doesn't solve everything. Dr. Siegel said that medication is his least preferred modality, but it's important to recognize that there are benefits and side effects for everything. In their inpatient program, there have been some published outcomes showing improvement on the Aberrant Behavior Checklist Irritability subscale after participation in the program. They followed up two months later and the improvement was maintained.

They recognize that there is limited research on severely affected individuals, so they developed a research network with other specialty inpatient units to strengthen this. They have currently enrolled over 1,000 individuals with autism and their parents, conducted a core assessment battery, and in the future will include a genetic data collection on the more severely affected population. The phenotypic data is already available through [SFARI Base](#), a database supported by the [Simons Foundation](#). Dr. Siegel talked about a series of papers on phenotypic data and reviewed some of the results. One study looked at risk factors for psychiatric hospitalization and discovered that sleep problems are prominent and independent of autism severity. Another study did not show an association between challenging behaviors and verbal ability, but found that challenging behaviors had a relationship with impaired coping and adaptive abilities

Although there has been some research on aggression and self-injury and his organization's typical approaches, it is clear that they still don't understand the "why" that may explain these behaviors. As an example, Dr. Siegel talked about one of his patients, a boy who was challenging but manageable until about the age of 14, when he developed aggressive behaviors such as biting his hand. At that point, the family experienced a lot of challenges, and he was hospitalized. Over his stay, he improved, but within the next year, and for years after, the family would return. As a young adult, he continues to have these challenging behaviors, and when they happen, they are very severe. He lives by himself, but he is dependent on care. His mother described the behaviors as unpredictable, with very little warning.

There is physiological arousal before, during, and after a challenging behavior, and it has been shown that typically developing individuals who can modulate this arousal have a reduction in the problem behavior. In people with ASD, there is also an association between physiological arousal and problem behaviors, and they hypothesize that the individual is engaging in the problem behavior as an attempt to alleviate stress and manage their psychological state. Dr. Siegel presented an illustration of how heart rate and motor activity change in the time surrounding a challenging behavior. The association of escalation and de-escalation in arousal can be seen. He presented a conceptual model of how distress could affect physiological arousal resulting in a behavior – either coping non-aggressively or aggressively. If there is aggression, there can then be a loop of increasing physiological arousal. They are conducting studies to predict the challenging behavior by monitoring physiological activity through a biosensor, similar to Fitbit, that measures the sympathetic nervous system. This information could then be sent to the parent or caregiver as an alert to an impending behavior. They were able to look about 60

seconds out into the future, and predict a challenging behavior with about 71 percent accuracy. There is still a long way to go, but it is a novel approach towards addressing these challenging behaviors. Ultimately, perhaps five years down the road, there could be a concept where there is a display on the wall alerting the family or a self-monitoring feature using a screen that engages the child to alert him as to what may be coming. Dr. Siegel agreed that there are critical, unmet research needs for those who are severely affected. Technologies and other novel approaches can also support better data collection. In addition, they also need to understand the natural history of these behaviors across the lifespan, and to create better diagnostic tools for psychiatric co-morbidity. They need to conduct studies of emotional regulation and sleep and to compare the effectiveness of treatment between outpatients and those in residential facilities. Billions of dollars are spent on these settings, with almost no research conducted.

Dr. Siegel thanked his research team and collaborators for their work.

Committee Discussion

Dr. Mandell thanked Dr. Siegel for his exciting work and mentioned that Dr. Siegel's team published a review on policy implications. Dr. Mandell suggested that their program is better than what is available to most people and wondered about the potential for scaling up these models and which of the federal agencies at the table could support the costs. Dr. Siegel thanked Dr. Mandell for the recommendation and talked about how the whole continuum of care needs support and research, as well as a coordination of inpatient units.

Dr. Gordon asked Dr. Siegel to talk about recent advances in knowledge about the neurobiology of aggression in animal models (for example, findings about circuits involving the hypothalamus) and how these could be applied to autism in beneficial ways. Dr. Siegel agreed that this knowledge about aggression in other systems and populations is important and did explain why his team went towards physiological issues, but he said that knowledge about aggression does not answer questions specifically about autism. If there is a replicable signal, it may look different in the non-communicative population, and they try to approach it without making too many assumptions.

Dr. Reichardt asked if the role of hypersensitivities were characterized in the individuals and if Dr. Siegel thought they played a role in aggression or self-injury. Dr. Siegel said that not a lot is known about sensory issues, they are typically addressed by occupational therapy, and there are not very good measures for sensory difficulties. It may be easy to hypothesize that sensory overload could lead to aggressive behaviors. The system they use is somewhat agnostic to the triggering stimulus, and they spend a lot of time looking at antecedents and triggers. He suggested it may be valuable if it didn't matter what the trigger is, if it produces arousal or some other marker it could be a very generalizable and powerful tool. He believes further research into sensory sensitivity would be good.

Ms. Crane said that most people experience a rise heart rate in the moment before an aggressive behavior, excepting people with antisocial personality disorder. If heart rate could provide warning, it could be useful for people with ASD who have difficulty recognizing their own mental state and may enable them to do something about it. Ms. Crane was considered aggressive when she was a teenager, but those behaviors went away when she became an adult and was allowed to leave a situation if she needed instead of being redirected. She said that it can be helpful when people are able to both be in control of and recognize their emotions. Helping people identify their own arousal would be actively empowering to those people. Dr. Siegel agreed and said that this is an approach that they are striving

towards, where a cue could open the potential for self-intervention. For instance, part of the treatment for panic disorder is to recognize the markers of arousal so that the person could stop themselves from going into a full panic attack. His program focuses on coping and adapting skills.

Mr. Robison said that perhaps it's time for the Committee to strategically re-think how they present their research strategy. Not too long ago, Congress thought that the problem was how to detect it early enough so that autistic people could be fixed. People don't talk like that anymore. Now people are talking about what can be done about self-injurious behaviors or gastrointestinal issues. It may be time to consider if the Committee needs to re-think their strategy towards what their constituents ask for. This may also more effectively communicate needs both to NIH leadership and to government leadership who read the strategic plan. This could be responsive to the people who spoke and provide constructive guidance. Ms. Crane said that she doesn't have a problem with how the Committee categorizes the questions, but that all of the issues they are hearing about fall under Questions 5, 6 and 7, which are under-addressed by research funding. There is no research on the life course of aggressive behaviors, and the Committee should re-prioritize that.

Dr. Gordon responded that there is research being conducted on these issues, however this research may not be complete yet. If they are looking for urgent answers about issues across the lifespan, it's important to realize that it takes a long time to conduct that research. Reorganizing the research strategy around specific issues may be a subject to revisit. It is challenging to imagine how they could take one piece of a complex and heterogeneous symptom, such as aggression, and sort out the risk factors and causes. The distribution of causes is not a one-to-one or even a many-to-one mapping. Dr. Gordon does agree that there is much more research on Question 3 than others, and they should acknowledge that part of the reason is because some questions are easier to answer than others. Ms. Crane said sometimes the necessary research is messy, and that perhaps this research could start with adults rather than starting with kids. This research could be completed more quickly and produce something faster than following a child across their lifespan. She suggested that if a question came in for a study that looks important but perhaps is not well designed, the Committee could work with those people to improve the study approach.

Dr. Dawson asked about psychiatric co-morbidities and what the role those may have in challenging behavior. Dr. Siegel answered that psychiatric co-morbidities are important and that they may not have good, validated diagnostic tools to assess psychiatric co-morbidities in autism. They do have research tools, clinical experience, and judgement, but it would be good to back those up with clinical tools. Research shows that when people try to adapt assessment tools for co-morbidities to autism, they result in anxiety as most prevalent and depression as second-most prevalent, which is the same as the rest of child mental health.

Dr. Dawson talked about the NIH research study for psychiatric co-morbidity of ADHD in autism. It turns out that a child with both ADHD and ASD will not only show poorer outcomes, but also is 30 times more likely to get a diagnosis of autism after age 6. It may sound strange to address aggression in a 2- or 3-year old, but if you can start working on some of these skills earlier, you can avoid some of the challenging behaviors later down the road. Dr. Julie Taylor talked about the possibility of adding an extra section at the end of the strategic plan to discuss issues that have come up over the past year rather than restructuring the entire plan. Dr. Gordon agreed this could be a good approach for the update this year. Dr. Koroshetz gave an anecdote about treating Huntington's patients, where they recognized that aggressive behaviors were occurring about half an hour before mealtime, and they found that frequent feeding had the biggest effect on decreasing the aggression. Dr. Koroshetz remarked that when they

started to write Question 2 they made a list of things that are really disturbing for patients and families and the potential approaches for addressing them. The list got very long and much of it was cut out. It may be good to show that instead of solving autism all at once, they could address the really important aspects that affect the life of the individual and their family.

Dr. Koroshetz asked Dr. Siegel if it was possible for the consortium to look at different therapies within the inpatient setting to see which work. Dr. Siegel said that it would be a challenge to conduct a controlled trial, but they could conduct a comparative effectiveness trial. The ethical and design issues may be a challenge but not insurmountable in the inpatient setting. Ms. Crane suggested that another challenge with randomized control trials and residential care is that parents are especially concerned about the use of seclusion and restraint in these settings. Dr. Siegel responded that, at least in some settings, those are considered to be emergency safety responses rather than treatment. They could legislate that seclusion and restraints do not happen, which might not be the best approach, or they could produce alternatives. This is the approach that they are taking to address the problem.

Dr. Schor said a lot of time is spent looking for a core cause rather than at the symptomatic treatments. She said that both should be addressed, and there could be synergy in effort. There has been the idea that basic science could inform treatment approaches. They have gotten better at collecting and analyzing data without a hypothesis rather than having to go on a fishing expedition due to lack of analytic tools, but they need to take the data and complete the loop. For example, if you treat a group with the same drug and only some show improvement it is necessary to study what is different about those populations. If you look at the translational curve as bidirectional, they are currently doing one direction better and more frequently than the other.

Round Robin

Dr. Gordon invited the Committee to speak about their current efforts. Dr. Mandell talked about the passage of the [Kevin and Avonte's Law](#) that addresses wandering and allows the Department of Justice department to give grants to local law enforcement agencies to prevent wandering and other related behaviors. The law has received good support, but Congress has not yet provided funding. There may be existing funds already available, but the Committee does not have representation from the Department of Justice. He believes it would important to have representation from the Department of Justice and also for IACC leadership to reach out in advocating for this law. It would be helpful to craft a letter talking about why this law is important. Dr. Daniels said that they can invite the Department of Justice to attend and that it is up to agencies to approach the Committee if they want to join. Ms. Singer clarified that there is nothing in Congress standing in the way of funding, but that it is about the timing of the appropriation, as the bill passed with the appropriation process was over. Writing a letter is more an act of expedience toward getting the funding sooner. She would be willing to take the lead in drafting a letter to the Department of Justice. The wandering issue is one that the Committee has been focused on for years. There has been a lot of progress, and this is one of the last steps towards helping first responders. Dr. Gordon reminded the Committee that they are not allowed to lobby Congress for an appropriation, but suggested they could look into how much they are able to ask the Department of Justice to do.

Dr. Dawson talked about an [event](#) she attended at the U.N. this year and the luncheon for [Autism Advantage](#). She said there was a number of companies that were presented, and that it was heartening to see the number of businesses engaged. She said there will be a lot of NIH-funded research will be

presented at the [International Society for Autism Research](#) conference in Rotterdam on May 9-12.

Dr. Shapira talked about the CDC report on the [Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years](#) and announced that they strive to publish the report early during Autism Awareness month every other year. It is a complex report to develop, but it will be released next Friday, April 27th. Dr. Shapira also announced that the CDC has a new director, Dr. Robert Redfield. He is a public health leader and actively engaged in clinical research and care of chronic diseases. They look forward to briefing him on the Committee's work. Dr. Shapira talked about presenting the [Study to Explore Early Development \(SEED\)](#) last October and said that SEED Teen, the follow-up study, will be launched this May. The [Learn the Signs, Act Early](#) program will now have a mobile app in Spanish and they hope it will be launched this summer.

Dr. Taylor talked about her involvement with a committee on interventions for the transition to adulthood, and on April 20, the grantees will come together for a working group to discuss scaling up research efforts. This may help speed up progress towards helping this population.

Dr. Koroshetz reported that their two studies on regression and Fragile X are still progressing.

Ms. Crane talked about [ASAN's](#) activities for Autism Awareness month. The FDA has yet to finalize a proposal to ban the use of electric skin shock devices on children with disabilities, which is a serious human rights and malpractice concern. The FDA issued a proposed rule in 2016 but still has not finalized it.

Dr. Cruz introduced herself as participating on behalf of Dr. Jennifer Johnson of the Administration on Disabilities.

Ms. Kavanagh said that there will be new data to report from the [National Survey of Children's Health](#) at the meeting in October, as well as the results of their grants competition.

Dr. Yao shared that they awarded a supplemental funding for the [Autism Centers of Excellence at Duke University](#) to address research gaps identified by the U.S. Preventative Services Task Force, specifically to examine the burden and emotional harm of ASD screening when there are no other previous concerns identified by the parent.

Dr. Nicole Williams talked about completing their [Autism Research Program](#) for the FY17 under the Department of Defense and they are in process of making 11 awards. They received a \$7.5 million appropriation and should have solicitations out in the next few weeks.

Ms. Singer talked about the [Autism Science Foundation](#) funding their pre- and post-doctoral grants this month. They also published their annual [Autism TED Talks](#), which included presentations on medical marijuana, diet, pain response, and sleep. And she hopes everyone will look at the videos.

Dr. Gordon talked about the [NIMH Director's Message](#) on Autism Awareness month which is on the NIMH website and will also be up on the IACC website.

Closing Remarks and Adjournment

Dr. Gordon thanked the Committee and adjourned the meeting at 4:34 PM.

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