



## **Minutes of the Interagency Autism Coordinating Committee Full Committee Meeting**

**April 19, 2016**

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Tuesday, April 19, 2016, from 9:00 a.m. to 4:48 p.m. in Building 31 on the main National Institutes of Health (NIH) campus in Bethesda, Maryland.

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

### ***Participants:***

**Bruce Cuthbert**, Ph.D., *Chair*, IACC, National Institute of Mental Health (NIMH); **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), NIMH; **David Amaral**, Ph.D., University of California (UC) Davis MIND Institute; **James Ball**, Ed.D., B.C.B.A.-D., President and CEO, JB Autism Consulting; **James F. Battey**, M.D., Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD); **Josie Briggs**, M.D., Director, National Center for Complementary and Alternative Medicine, NIH (representing Francis S. Collins, M.D., Ph.D.); **Deborah (Daisy) Christensen**, Ph.D., Centers for Disease Control and Prevention (CDC) (representing Cynthia Moore, M.D., Ph.D.); **Samantha Crane**, J.D., Autistic Self Advocacy Network (ASAN); **Geraldine Dawson**, Ph.D., Duke University; **Tiffany Farchione**, M.D., U.S. Food and Drug Administration (FDA); **Amy Goodman**, M.A.; **Melissa Harris**, Centers for Medicare & Medicaid Services (CMS); **Shannon Haworth**, M.A., Association of University Centers on Disabilities (AUCD); **Jennifer Johnson**, Ed.D.; Deputy Director, Administration on Intellectual and Developmental Disabilities, ACL (representing Commissioner Aaron Bishop, M.S.S.W.); **Laura Kavanagh**, M.P.P., Health Resources and Services Administration (HRSA); **Walter J. Koroshetz**, M.D., National Institute of Neurological Disorders and Stroke (NINDS); **Cindy Lawler**, Ph.D., Chief, Genes, Environment and Health Branch, National Institute of Environmental Health Sciences, NIH (representing Linda Birnbaum, Ph.D.); **David Mandell**, Sc.D., University of Pennsylvania; **Brian Parnell**, M.S.W., C.S.W., Utah Department of Human Services; **Kevin Pelphrey**, Ph.D., Yale University (attended by phone); **Edlyn Peña**, Ph.D., California Lutheran University; **Louis Reichardt**, Ph.D., Simons Foundation Autism Research Initiative; **Robert H. Ring**, Ph.D., Autism Speaks; **John Elder Robison**, College of William and Mary; **Stuart K. Shapira**, M.D., Ph.D., Chief Medical Officer and Associate Director for Science, Centers for Disease

Control and Prevention (CDC) (representing Cynthia Moore, M.D., Ph.D.); **Alison Tepper Singer**, M.B.A., Autism Science Foundation (ASF); **Catherine Spong**, M.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD); **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD).

### **Call to Order and Roll Call**

The Interagency Autism Coordinating Committee (IACC) convened on April 19, 2016. Dr. Susan Daniels called the meeting to order at 9:00 a.m. and took roll call.

### **Welcome and Opening Remarks**

Dr. Bruce Cuthbert, Acting Director, NIMH, and Chair, IACC, welcomed those present and said he was looking forward to the day's discussion and debate.

Dr. Cuthbert introduced Dr. Thomas Novotny, who joined HHS recently as the Deputy Assistant Secretary for Health in the areas of science and medicine and was recently appointed as the HHS National Autism Coordinator.

### **Update from HHS Office of the Assistant Secretary for Health**

#### **Thomas E. Novotny, M.D., M.P.H.**

Dr. Novotny opened his remarks by noting that April 2 had been proclaimed World Autism Day by President Barack Obama and observed that April was National Autism Month. He said there was a great deal of activity related to ASD taking place within the federal government, presenting many funding priorities and challenges. He stated that the IACC, with its new leadership, was making good progress. In his role as the National Autism Coordinator under the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (the CARES Act), he is responsible for ensuring implementation of Autism Spectrum Disorder (ASD) activities across the Department and ensuring that HHS is coordinating with other federal agencies. Although not a subject matter expert, Dr. Novotny is a designated public health official who will ensure internal coordination within HHS agencies and identify areas in which the agencies can work collaboratively, as well as ensure that HHS is in compliance with relevant statutory requirements. He also will serve as an HHS liaison with external groups on matters pertaining to autism.

Reporting on initiatives in federal agencies, Dr. Novotny stated that he was impressed with DoD's Carolina Autism Transition Study (CATS). It is a population-based study on the longitudinal outcomes of individuals identified with ASD, beginning at age 8 and continuing through ages 16 to 22. It will be used to identify the predictors of specific outcomes. He noted that ED supports collaborative work on enhancing education for children and youth with ASD and other disabilities. In addition, ED's PROMISE program is a randomized clinical trial examining the impacts of interventions for those eligible for Social Security disability benefits (SSI); 700 to 800 individuals with ASD are included in the sample. HRSA's Innovation in Care

Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program aims to reduce barriers to screening and diagnosis. The CDC published a surveillance report based on the Autism and Developmental Disabilities Monitoring (ADDM) Network, indicating that ASD prevalence continues to be 1 in 68. CDC also has developed an innovation grant to expand their ability to monitor prevalence and risk factors for ASD across the nation. NIH funds a broad portfolio of biomedical research on the underlying biology of autism, its risk factors, diagnosis, interventions, and services for individuals on the autism spectrum. The National Science Foundation funds basic research on cognition, neural networks, and innovative technologies that can be used to develop novel interventions to support people with autism.

Dr. Novotny stated that a large part of his role is to focus on the area of transition, i.e., the time between youth and adulthood, where the fewest ASD research and interventions have taken place. The Autism CARES Act requires submission of a report on youth and young adults with ASD who face challenges related to the transition from school-based services to those needed in adulthood. He said was in the process of engaging a group of federal experts from HHS to begin work on the project and would report on progress at future meetings.

He also recently collaborated with Aaron Bishop, the head of HHS' Administration on Disabilities (AoD), to write a [blog](#) on the HHS website that recognized and emphasized HHS commitments to ASD activities. It stated that they want to move beyond awareness that ASD exists to real acceptance and expectations for improved care and support for people with ASD. Dr. Novotny closed by reiterating his commitment to expanded support for ASD research and services portfolios within the government.

Dr. Cuthbert said the IACC had eagerly awaited appointment of the HHS Autism Coordinator and he asked each participant to introduce themselves to Dr. Novotny and describe their autism-related work.

### **Questions for Dr. Novotny**

Mr. John Robison asked what the government would do to help build leadership positions for individuals with autism to help ensure that they receive the informed guidance necessary to oversee their own destinies. Dr. Novotny acknowledged this challenge and said he would be speaking with leaders of Congress about the need for more inclusion. Ms. Samantha Crane noted that the Autistic Self-Advocacy Network advocates for the LEND programs to actively seek out and enroll autistic individuals. LEND programs are authorized by the CARES Act to create interdisciplinary centers in universities to study autism. She said LEND programs would be a useful mechanism for developing leadership. Ms. Laura Kavanagh said HRSA actively supports self-advocates as trainees and faculty in the LEND programs and asked for advice on providing better clarity about this in their communications.

Dr. Geraldine Dawson mentioned a report from the U.S. Preventive Services Task Force (USPTF) that concluded there isn't enough evidence either for or against universal autism screening. She said the scientific and clinical community is concerned that the effect will be fewer screenings

by busy general pediatricians, even though screening leads to earlier diagnosis and intervention. Dr. Novotny was familiar with the USPTF recommendations and said there is broad agreement that early intervention is indicated and that screening mechanisms need to improve. The Task Force has not yet taken a specific position on universal autism screening and there is a strict process used for its recommendations. He believed the recommendations would change going forward based on the evidence. Ms. Shannon Haworth made a final comment, noting that she is the mother of a child with autism who struggles to obtain services and support.

Dr. Cuthbert provided an overview of the agenda and introduced speaker Stuart Spielman from Autism Speaks.

**Update on the ABLÉ Act, Avonte’s Law, and the Federal Employee Health Benefits Program  
Stuart Spielman, J.D., Senior Policy Advisor and Counsel, Autism Speaks**

Mr. Spielman stated that the Stephen Beck, Jr., Achieving a Better Life Experience (ABLE) Act, which became law on December 19, 2014, creates a new option for some people with disabilities and their families to save for the future while protecting eligibility for public benefits. The ABLE Act authorizes states to establish a qualifying program under which an account may be created by or for an individual with autism or another disability. Modeled after college savings accounts, ABLE accounts help people save for disability-related expenses on a tax-preferred basis. Assets in ABLE accounts will be generally disregarded by means-tested federal programs, such as SSI and Medicaid, so a choice does not have to be made between saving money and participating in these programs.

Federal law determines who is eligible for an ABLE account. An individual must be disabled before age 26 and be entitled to benefits under Title II (SSI) or title XVI (SSDI) of the Social Security Act, or must file a “disability certification” under guidance provided by the Internal Revenue Service (IRS). The funds from an ABLE account can be used for qualified disability expenses related to the individual’s disability or blindness. Examples of qualifying expenses include education, housing, transportation, employment, training, and assistive technology and personal support services. The legal infrastructure for this option has been built most places in the country; more states are planning participation.

**Avonte’s Law**

Following the death of 14-year old Avonte Oquendo in 2014, Senator Chuck Schumer of New York introduced legislation to safeguard children with autism who wander. Although the legislation did not pass the 113th Congress, Senator Schumer reintroduced Avonte’s Law in the 114th and in the current Congress. The legislation has since changed and been reintroduced by Senators Chuck Grassley, Thom Tillis, and Senator Schumer as Kevin and Avonte’s Law of 2016 (S. 2614). Kevin Curtis Wills was a 9-year old boy who drowned while wandering in 2008.

The law reauthorizes the expired Missing Alzheimer’s Disease Patient Alert Program (renaming it the Missing Americans Alert Program) and includes new provisions to support people with

autism and other developmental disabilities. The bill allows Justice Department grants to be used by law enforcement agencies and nonprofits for education and training programs to prevent wandering. The grants will facilitate training and emergency protocols for school personnel, supply first responders with additional information and resources, and make local tracking technology programs available for individuals who wander from a safe environment. The bill includes privacy protections for the civil rights of children who use tracking devices. On April 14th, the Senate Judiciary Committee reported out Kevin and Avonte's Law by a vote of 15-5. The bill has been placed on the Senate legislative calendar. H.R. 4919, a companion to the Senate bill, was introduced in the House the previous week by Representative Chris Smith and Representatives Maxine Waters and Mike Doyle.

### **Federal Employee Health Benefits Program**

The Federal Employees Health Benefits Program (FEHB) is the largest employer-sponsored health insurance program in the country, covering about 8.2 million enrollees. The program allows competing private insurers to offer plans within broad federal guidelines. There are typically more than 250 different health plans to choose from, generally, either fee-for-service (FFS) or health maintenance organizations (HMOs). The federal jobs share is about 2 percent of the workforce, with federal employees concentrated in the District of Columbia (27%), Hawaii (6%), Maryland (6%), and Virginia (5%). However, there is a mismatch between where employees live and where they are covered. Although close to 15% of the federal workforce lives near the nation's capital, only one area health plan offers coverage. Major metropolitan areas such as Boston, Charlotte, and Nashville also lack coverage.

In 2012, the Office of Personnel Management (OPM) re-categorized applied behavior analysis (ABA) as a medical benefit and allowed plans to propose benefit packages that included ABA for 2013. Despite encouragement from OPM, coverage of ABA changed little from 2013 through 2016. There are significant gaps in ABA coverage, and none of the 15 nationwide health plans cover ABA. However, a carrier letter announced a new policy for 2017. OPM announced that carriers may no longer exclude ABA for the treatment of autism, stating, "We expect all carriers to offer clinically appropriate and medically necessary treatment for children diagnosed with ASD."

### ***Questions for Mr. Spielman***

Dr. Cuthbert asked if there is a defined period for ABA treatment, as the allowable time frames varied at one time. Mr. Spielman said this varies by policy, as well as by federal and state laws. However, he noted that carriers have been told to offer clinically appropriate and medically necessary treatment without limitations for children diagnosed with ASD.

Mr. Brian Parnell asked about federal insurance coverage in the state. He noted that in 2013, House bill 57 was passed, which mandated that private insurance carriers cover ABA. Mr. Spielman acknowledged that federal civilian employees in some areas have been at a disadvantage compared to individuals with a different employer. Dr. David Mandell asked if an effort had been made to examine the cost effects of laws that increase coverage to allay the

concerns of insurers. Mr. Spielman replied that studies in Missouri indicate that increased costs in the state have been minimal, on the order of pennies to the dollar. All the data he had seen indicated that concerns about costs have been overblown.

Dr. Cuthbert introduced Dr. Scott Robertson, who presented by phone.

**Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities  
Scott Robertson, Ph.D., Policy Advisor, U.S. Department of Labor, Office of Disability  
Employment Policy**

Dr. Scott Robertson described an ongoing DOL initiative for strengthening access to employment for people with significant disabilities, including autistic people. The literature indicates that underemployment and unemployment for autistic people might be as high as 80 to 90 percent. In 2014, Congress passed the Workforce Innovation Opportunity Act (WIOA), which superseded the Workforce Investment Act of 1998 and reauthorized federally funded initiatives supporting workforce development. WIOA made significant changes to federal law to improve employment access for people with disabilities, for example, by strengthening the requirements of the Rehabilitation Act. It also established the [Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities \(ACIEID\)](#).

Since 2015, the Office of Disability Employment Policy (ODEP) has provided support for ACIEID in its ongoing work, meetings by webinar, and in-person meetings. ACIEID was charged with developing findings, recommendations, and conclusions on competitive integrated employment for people with disabilities. ACIEID also was charged with developing recommendations related to Section 14(c) certificate programs co-administered by DOL's Wage and Hour Division under the Fair Labor Standards Act. Since 1938, that Section has permitted organizations to hold certificates allowing the operation of programs that pay subminimum wage to people with disabilities. In some cases, 14(c) programs have gone by the name of sheltered workshops because they operate as disability-centered settings. In 2015, New Hampshire became the first state to disallow use of the 14(c) certificate for subminimum wages. In 2016, Maryland passed similar legislation, although it was not yet signed into law. Rhode Island and Oregon had reached consent agreements with DOJ regarding their operation of sheltered workshops.

Dr. Robertson reported that on March 16th, the federal [AbilityOne](#) agency declared support for the practice of qualified nonprofit agencies that participate in AbilityOne contracts to begin paying at least the federal minimum wage or state minimum wage (if higher) to all employees with significant disabilities. AbilityOne is the largest single source of employment in the U.S. for people who are blind or have other significant disabilities.

ACIEID is currently engaged in discussions about the possibility of a long-term phase-out of 14(c) nationally. Members of the public have expressed different perspectives on existing and long-term use of 14(c) certificates for paying subminimum wage. Public comments often emphasize the need for sufficient infrastructure so that people with significant disabilities have

enough support. A bill in Congress called the Time Act could phase out 14(c) certificate programs. ACIEID is therefore focusing on improving infrastructure and support for competitive integrated employment for people with intellectual or developmental disabilities and other significant disabilities. Committee members are serving on four subcommittees to develop recommendations on competitive integrated employment, including the Transition Subcommittee, which focuses on youth and young adult issues; the Marketplace Subcommittee, which focuses on employer resources and school supports, as well as employment-related issues; the Complexity Subcommittee, which looks at cross-cutting issues involving the complexity of systems supports and resources; and the Capacity Subcommittee, which overlaps to a certain extent with the Complexity Subcommittee. Issues concerning 14(c) have fallen within the scope of all four subcommittees. An [interim report](#) was released in September 2015 and is posted on their website, part of DOL's main website. A final report will be issued to Labor Secretary Perez and Congress in the fall. Dr. Robertson stated that ACIEID planned to meet face to face on [April 27<sup>th</sup> and 28<sup>th</sup>](#).

### ***Questions for Dr. Robertson***

Mr. Robison thanked Dr. Robertson for the presentation, noting that Dr. Robertson is an autistic adult and a former member of the IACC. Dr. Julie Taylor asked about WIOA's provisions for preparing people with disabilities for employment while they are still in high school. Dr. Robertson clarified that Section 501 of WIOA includes support for pre-employment services for the transition from high school to vocational rehabilitation, as well as to the American job centers, and to have better coordination across the workforce systems, the vocational rehabilitation system, and education. Dr. Cuthbert asked if other members of ACIEID are on the autism spectrum and whether that influences decisions. Dr. Robertson said the committee is free-standing, i.e., not part of DOL, and there are several members with developmental disabilities, including another former IACC member, Mr. Ari Ne'eman. The advocacy perspective is therefore represented in discussions. Dr. Cuthbert thanked Dr. Robertson for his report.

Dr. Cuthbert turned the meeting over to Dr. Daniels, who presented on IACC Committee Business.

### **Committee Business**

Dr. Daniels greeted the group on behalf of the Office of Autism Research Coordination (OARC). She acknowledged National Autism Awareness Month and described relevant events, including lectures and videos available on the IACC website. Recent OARC activities included the [NIMH Seminar Series: New Discoveries in Mental Health Research: Pathways to New Treatments in Autism Spectrum Disorder](#). Dr. Jeremy Veenstra VanderWeele presented on new treatments for ASD on April 13. On February 19, an NIMH workshop was held on [Loss of Skills and Onset Patterns in Neurodevelopmental Disorders: Understanding the Neurobiological Mechanisms](#). Dr. Daniels also introduced the new IACC website, featuring a fresh, streamlined layout; simple navigation; and new features, including more autism and disability news and reports, funding opportunities, and resources. She said it is also mobile-friendly.

## **IACC Responsibilities**

Dr. Daniels recapped IACC responsibilities, including developing and annually updating a Strategic Plan for ASD, developing and annually updating a Summary of Advances in ASD research, monitoring federal activities with respect to ASD, and making recommendations to the HHS Secretary on research or public participation in decisions regarding ASD.

## **Summary of Advances**

Dr. Daniels presented to the committee the 2014 and 2015 Summary of Advances that were recently completed by the committee and OARC, and available on the IACC website. The IACC Summary of Advances is an annual publication, and the committee published two volumes in one year to catch up after the committee's hiatus during 2014. These lay-friendly publications provide short summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC for that year. They address topics including prevalence, diagnosis, biology, risk factors, interventions, and lifespan issues.

## **2011-2012 IACC Portfolio Analysis Report**

The [2011-2012 IACC Portfolio Analysis Report](#) is a follow-up comprehensive report on the data from the 2011 and 2012 Portfolio Analysis. Overview data from this analysis was published originally published in the [2013 IACC Strategic Plan Update](#). The report assists the IACC in fulfilling the CAA requirement to monitor federal activities related to ASD, provides detailed analysis of the ASD research portfolio across federal agencies and private organizations, informs the IACC and stakeholders about the funding landscape and current directions in ASD research, and helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan. Dr. Daniels said the data sets were available in the [Portfolio Analysis Web Tool](#). Dr. Daniels stated that analysis of the 2013 data set was planned for publication within the 2016 calendar year.

## **IACC Strategic Plan Update**

IACC members had volunteered to serve on seven working groups to cover each of the Strategic Plan Questions and had nominated external experts to serve on the working groups. They were in the process of confirming external expert membership. Dr. Daniels asked that volunteers confirm their participation. She said a series of calls would be scheduled to develop updates for each of the seven Question areas, as well as the introduction and conclusion to the report. She recommended that each person sign up for no more than two working groups.

Dr. Daniels listed the seven consumer-based Questions around which the Strategic Plan is framed:

**Question 1: When Should I Be Concerned?**

**Question 2: How Can I Understand What is Happening?**

**Question 3: What Caused this to Happen and Can it Be Prevented?**

**Question 4: Which Treatments and Interventions Will Help?**

**Question 5: Where Can I Turn for Services?**

**Question 6: What Does the Future Hold, Particularly for Adults?**

**Question 7: What Other Infrastructure and Surveillance Needs Must Be Met?**

She recapped the decisions about the structure of the Strategic Plan made at the previous meeting. There will be an introduction and Question description with an aspirational goal, similar to the previous Strategic Plan update. The section on progress toward the Strategic Plan objectives for each of the Questions will provide an overview of progress in the field. The research update will contain information about research and practice to research and will identify gaps, opportunities, and needs. The services/policy update will describe new programs and policies, new research evidence that can inform policy, and services needs/gaps and needed policy changes. The section that follows will describe progress toward the aspirational goal. Dr. Daniels explained the recommendations to assure non-duplication, as one of the requirements of the Autism CARES Act is non-duplication of effort across the portfolio. One proposal was to have three broad objectives per Question, for a total of approximately 21 for the Strategic Plan, accompanied by examples of responsive research and services projects/programs. She listed examples of objectives for Question 1, e.g., "Increase early detection of ASD."

Dr. Louis Reichardt endorsed reducing the number of Questions. Dr. David Amaral agreed that Questions 2 and 3 and Questions 5 and 6 are related and could be consolidated, but the Committee would then not be able to track across years, as in the past. Dr. Amaral said he was not aware that nominations for external working group members had already been collected and he asked for an extension to allow for additional nominations. It was suggested that the working group chairs provide input on the composition of the working groups. Dr. Daniels said she would extend the deadline for nominations, thus pushing back the date when the working groups would be finalized.

Dr. Daniels continued reviewing the structure of the Strategic Plan, noting that budgetary requirements for each Question would follow the Question's broad objectives, followed by a summary or conclusion. Each of the seven working groups will follow the same structure. Members of the working groups would be asked to help write and edit; the chairs will ensure that the content reflects the literature in each area and that all relevant areas are covered. The Strategic Plan would also have an introduction and conclusion. The resources available to the working groups for the 2016 Strategic Plan include: data from the 2013 Portfolio Analysis, IACC Science Updates and the Summary of Advances, other supporting literature, external experts, a Request for Public Comment from the public (if the Committee decided to do this), other public comments received for meetings, 2012 services and research information from the Report to Congress on ASD activities, and policy information from IACC members and policy experts.

With regard to Dr. Daniels' proposal of a Request for Public Comment to assist with development of the new Strategic Plan, Mr. Robison expressed concern about the likely dominance of vaccine questions from the public. Dr. Daniels explained that there would be a

character limit on the comments to ensure that the comments are concise, but that the public would be free to comment on any topic they wish. The Committee voted to move forward with a Request for Public Comment.

The Strategic Plan next steps included confirming external experts after receiving more suggestions from the Committee, scheduling and holding working group conference calls, and reviewing progress at the next full committee meeting in July. The goal is to complete the update during the 2016 calendar year.

### **Topical Working Groups**

In January, the IACC voted to form a housing working group. Dr. Daniels said she would send out a list of IACC member volunteers and nominations for external experts. Volunteers to date included Alison Singer, Melissa Harris, Jim Ball, Amy Goodman, David Mandell, Brian Parnell, Kevin Pelphrey, and Julie Taylor. Additional volunteers were welcome. Dr. Daniels asked for suggestions for external experts. The housing working group would begin work when the meetings for the Strategic Plan were finished.

Dr. Daniels led discussion on the possibility of a safety working group. Dr. Wexler noted that a variety of issues related to safety could be addressed, including wandering, self-injurious behavior, and seclusion and restraint. Ms. Alison Singer, Mr. Robison, and Ms. Crane expressed support for a safety working group and the Committee voted their agreement.

Dr. Daniels stated that Dr. Amaral had raised the idea of a co-occurring conditions working group. She noted that the IACC previously had a working group on this topic and held a workshop that is available on the website. Dr. Amaral felt the Committee could address co-occurring conditions to improve the quality of life of people on the autism spectrum. Some physicians are unaware that co-occurring conditions are not simply part of autism, but should be treated medically, as for any other individual. He said it would be interesting to have both basic scientists and clinicians on the working group. For example, they might find that aspects of the biology leading to the core features of autism, such as an abnormal activity in the amygdala, might also be leading to gastric acid secretion and gastrointestinal problems. Those linkages have not been well-investigated. Dr. Dawson agreed, stating that the focus of the working group could be on ‘improving the health outcomes of individuals with autism.’ The working group could look at medical comorbidities and consider preventive approaches for conditions such as obesity. She emphasized that there is not just a lack of knowledge on the part of physicians, but not enough community doctors are willing to provide medical care for adults with autism. This is a significant issue in her clinic. Ms. Haworth supported the formation of this working group and suggested including co-occurring mental health conditions and parental mental health. Dr. Amaral moved that a working group be formed on improving health outcomes. It was seconded and it passed with a unanimous vote.

### **2015 Summary of Advances Process**

Dr. Daniels led a discussion of the Summary of Advances process and the development of future products. Dr. Reichardt stated that many important papers published in journals were not included in the 2014 report. He suggested reviewing the procedure by which papers are selected. He and Ms. Crane noted that two out of three papers in the services area were on the economic burden of autism across the lifespan, rather than on issues that are beneficial to the autism community. Dr. Amaral agreed that the process should be changed, stating that it is difficult to review 100 papers and make suggestions on the top 20 within a 2-week time frame. He recommended that papers be nominated over the course of the year, rather than at the end. Since the number of publications on autism has increased dramatically over the last 5 to 10 years, he said a more systematic way of reviewing them was needed. Ms. Crane suggested a system that highlights the research related to a Question that is dramatically underfunded and understudied, such as areas of Question 6. Dr. Cuthbert explained that the Committee had been on a very tight timeframe to select the papers for both 2014 and 2015. After additional discussion of possible approaches to nominating papers, Dr. Daniels planned to schedule monthly data calls to collect nominations from committee members on a rolling process throughout the year. Dr. Amaral suggested that nominations include a short narrative justification to explain why the paper is relevant or notable. Dr. Daniels said she would go back to the OARC to come up with strategies to implementing some of the ideas suggested and revisit any remaining issues in July.

### **Oral Public Comment Session**

**Mr. Nathan Olson** was diagnosed with autism in 2011 at the age of 22. He was dually diagnosed with ADHD and a nonverbal learning disability disorder. Prior to his diagnosis, he experienced academic failure. His subsequent academic success was due to the Autism Spectrum Navigators (ASN) Program at Bellevue College in Washington. Central Washington University in Ellensburg later implemented the program on their campus. ASN is one of the most unique programs serving students with autism in the U.S. It focuses on four areas: self-advocacy, self-regulation, executive functioning, and social interaction; quarterly classes in these areas are required. Participating in the ASN program helped him find the calling to advocate for those with disabilities or autism. He now serves as the Strategic Access Network Development Program (SAND) assistant in the Office of Disability Support Services at Pacific Lutheran University. SAND is a new program modeled on ASN; it will be launched in September 2016. He closed with a motto that he lives by: "All it takes is five minutes of your compassion to understand us, and that could transform your life."

**Dr. Dorothy Strickland** stated that 4 years ago, with funding from NIH, her organization ([do2learn.com](http://do2learn.com)) videotaped 68 of the behaviors listed in the DSM-5 that are required for a diagnosis of autism. They developed a website ("Diagnose First") to help school psychologists and other clinicians recognize the symptoms of ASD. The website shows the behaviors in short video clips, indicating what they look like from ages 6 months to 55 years. The website also addresses factors that cause diversity in the diagnosis, such as IQ, age, socioeconomic background, and location. . A study with 120 graduate students indicated that the site was helpful in training them to diagnose. Dr. Strickland asked for help from the Committee in

determining how to best use this resource. She said that by contacting her at do2learn.com, Committee members could receive a login for the site to view the videos and make suggestions on dissemination. She clarified that the website isn't available to the general public due to Institutional Review Board (IRB) protections.

**Dr. Karen Heffler** is the parent of a 24-year-old son with ASD. She stated that researchers have overlooked the effects of early screen viewing on the developing brain. She had reviewed the literature on screen viewing and autism, early brain development, and neuroplasticity, and co-authored an article proposing the theory that the brain and behavior in autism is altered from typical in the exact ways that would be expected from extensive auditory and visual exposure that lacks a social context. This is the type of dose-related environmental stimuli that infants and young children receive from TV, videos, and other screen media exposure. She stated that her scientific review explains virtually all of the findings in ASD. She was aware of local children who were improving with the removal of TV and other screen viewing, in addition to teaching the families strategies to promote prosocial behavior. She believes this may be the only example of removing a risk factor and altering the developmental trajectory of young children with ASD. She believes screen viewing at a young age may be altering early brain development to affect attentional mechanisms; this may explain why children with ASD do not orient to people, faces, eyes, and the social activity around them, but, rather, to non-social auditory and visual contingencies. She said more research is needed in this area, as it has tremendous potential for both prevention and intervention in ASD. She asked IACC members to direct national attention to this area of research.

**Ms. Lisa Wiederlight** is the mother of a 15-year-old boy with autism and epilepsy and is the Executive Director of SafeMinds. She stated that the CDC's National Center for Birth Defects and Developmental Disabilities, led by Dr. Colleen Boyle, released a report in March indicating that autism prevalence has stayed the same as in 2012 (1 in 68 American children). She said this defies human observation and is confusing to special education administrators and medical professionals. She believes this data underestimates autism prevalence and undermines support for autism research and services, resulting in less funding than what is needed federal and state agencies to address autism. She cited methodological reasons why the report underestimates the rate of autism to improve long-term outcomes and receive the best return on taxpayer investment, SafeMinds recommends moving autism surveillance to the National Center for Health Statistics.

**Mr. Brian Parnell** said the IACC received seven written public comments from parents and self-advocates on five broad topics: expansion of adult service needs after graduation from school, including appropriate housing options; wandering and elopement; pre- and perinatal causes of autism, such as complications at birth that result in brain damage; improving interactions in social settings using video games; and vaccines and autism.

#### **IACC Committee Member Discussion of Public Comments**

Mr. Robison stated that there is no need for disagreement about where autistic people can live just because they need supports. Freedom of choice should be the norm. He also commented on autistic mortality statistics, which are not always accurate. He urged the committee to shift its focus to research on quality of life. Ms. Singer agreed with freedom in housing choices, but didn't feel that parents who were advocating for choice were trying to force everyone with autism to live in planned communities. She commented that it seemed as if CMS was focused on preventing use of congregate settings and group-oriented options, rather than focusing on outcomes.

Ms. Harris said CMS had issued a regulation in 2014 and it was in a transition period until 2019, giving state Medicaid agencies time to work with their operating agencies to assess the settings in their state that receive Medicaid-funded home- and community-based services. Until 2019, they will continue to reimburse settings that meet a minimum floor of criteria (e.g., new buildings are not isolating, people are being treated with respect and dignity, and they are free from restraints). They are not trying to reduce individual choice, but ensure that minimum criteria are met. Some of the criteria can be modified based on a person-centered plan specific to the individual. Ms. Harris said the well being of the individual is at the heart of all of care planning. She noted that Tennessee received approval of their statewide transition plan. FAQ guidance and the Tennessee plan are available on the [Medicaid.gov/hcbs](https://www.Medicaid.gov/hcbs) website.

Ms. Singer asked how CMS was measuring the states' efforts to serve people with the most severe needs. Ms. Harris said that as they approve a waiver program, they ensure that the services offered are commensurate with the needs of the population and that the state is maintaining the health and welfare of the waiver participants. Ms. Crane pointed out that level of care and level of integration are different issues. They cannot afford to have states put all new funding toward very segregated planned communities; they should be working toward options for community living at the same level of care. People who are more connected to their communities are less lonely and have higher quality-of-life outcomes. She stated that more funding is needed for research on housing models/outcomes, including quality-of-life.

Mr. Robison said the CMS options and requirements were difficult to understand. He asked what justification existed for a federal agency to put up barriers to housing choice – that autistic people should have free choice just like everyone else.

### **Science Update** **Bruce Cuthbert, Ph.D.**

Dr. Cuthbert presented the science update, addressing each Question in the Strategic Plan.

#### **Question 1: When should I be concerned?**

An article on parent-reported and clinician-observed ASD symptoms in children with attention deficit/hyperactivity disorder (ADHD)<sup>1</sup> highlighted the challenges clinicians and researchers often face when trying to distinguish ASD from other disorders.

A complicated evaluation of a large sample of predictors of age of diagnosis for children with ASD<sup>2</sup> indicated that having a consistent source of care predicted earlier diagnosis for Caucasian, but not African American children. The complex findings bear further exploration.

The USPTF report on screening for autism spectrum disorder in young children<sup>3</sup> was mentioned earlier and would be addressed in further discussions.

A study of the feasibility and effectiveness of an advocacy program for Latino families of children with ASD<sup>4</sup> showed that they were able to achieve consistent attendance, low attrition, and high participant satisfaction.

### **Question 2. How can I understand what is happening?**

One study looked at a large number of gastrointestinal (GI) measures to evaluate intestinal function in children with autism and GI symptoms<sup>5</sup> found only mild levels of mucosal inflammation, similar to children without autism. It leaves open the question of the origin of GI complaints in children with autism.

A small study of 81 children with ASD sleep and behavioral problems<sup>6</sup> observed that sleep problems were significantly associated with physical aggression, irritability, inattention, and hyperactivity. In particular, sleep disturbances associated with behavioral dysregulation among children with ASD, especially nighttime awakenings, had the most consistent association with daytime behavior problems.

A large sample of over 1,200 participants from the Autism Speaks treatment network were divided into those with a lifetime history of depression and non-depressed children to observe medical and behavioral correlates of depression history in children and adolescents with ASD.<sup>7</sup> The children with ASD and a history of depression were more likely to have co-occurring medical problems, including seizure disorders and GI problems, although the direction of causality was not clear.

### **Question 3. What caused this to happen and can it be prevented?**

A study of 2,700 children, including 100 children that were a subset of the Boston birth cohort, looked at the association of maternal obesity and diabetes with autism.<sup>8</sup> They found that the combination of maternal obesity and diabetes was associated with greater risk of ASD than either obesity or diabetes alone, particularly when ASD co-occurred with intellectual disability.

A review of over 1 million children on birth spacing<sup>9</sup> found an increased risk of association between short interpregnancy intervals and an increased risk of ASD. The hazard ratio was about 2 to 1, which was strongly associated. Shorter intervals were also associated with a significantly increased risk of developmental delay and cerebral palsy.

### **Question 4. Which treatments and interventions will help?**

A small study was conducted on the evidence-based preschool social communication intervention<sup>10</sup> called JASPER (Joint Attention, Symbolic Play, Engagement, and Regulation), which was delivered by teachers in preschool classrooms for 3 months, with a 1-month follow-

up. Measures of core deficits, such as initiations of joint engagement, joint attention adjustors, language and play skills, and standard cognitive measures demonstrated the feasibility of this type of intervention when delivered by preschool teachers.

A pilot study promoting participation of families with limited resources in an early autism intervention<sup>11</sup> showed modest feasibility. Treatment attrition was calculated at 62 percent; more work is needed to determine how to engage these families.

#### **Question 5. Where can I turn for services?**

A national survey of children with special health care needs in a very large sample examined differences in perceived need for medical, therapeutic, and family support services among children with ASD.<sup>12</sup> Compared with caregivers of white, non-Hispanic children with ASD, the caregivers of Hispanic children reported less need for prescription medications. Caregivers of black, non-Hispanic children also reported less need for prescription medications and for child and family mental health services. Both English-speaking Hispanic caregivers and black non-Hispanic caregivers reported greater need for occupational, speech, and physical therapy than white non-Hispanic caregivers. There were no differences among races or ethnic groups for perceived need for specialty medical care or respite care. This issue requires health diversity research; the needs perceived by these communities may be somewhat different.

A national survey of children with special health care needs looked at health insurance, including private only, Medicaid only, and combined private and wraparound Medicaid. It examined parent insurance ratings, child expenditures, and financial burden among children with autism.<sup>13</sup> It was found that having Medicaid doubled the odds of reporting adequate insurance compared with private insurance alone. Children from Medicaid families had the lowest out-of-pocket costs, at only \$150. On the other hand, children covered by combined private and wraparound Medicaid insurance had the highest total expenditures, at nearly \$12,000 a year. There was a mismatch between the parents' ratings of their insurance adequacy, the child expenditure, and the relative financial burden. Strategies for new policies in this area are needed.

A study on improving access to care at autism treatment centers<sup>14</sup> took place in two hospitals in Cincinnati. One hospital focused on reducing the number of patients with ASD waiting for follow-up appointments; the other focused on reducing delays to new diagnosis. In both hospitals and both areas, they reduced the problem by about 94 percent through a systems analysis approach, i.e., analyzing the delays in the system.

A study of prevalence and correlates of elopement in a nationally representative sample of children with developmental disabilities<sup>15</sup> used data from CDC's Pathways survey. This is a telephone survey of 4,000 children with a developmental condition; over 3,500 had ASD. In this sample, over 26 percent of the children had reportedly eloped within the previous year, most from public places. Children with ASD, either ASD only or ASD plus an intellectual or developmental delay, were more likely to have eloped than those with an intellectual disability or developmental delay only. The children who did elope were more likely to not realize when

there is danger, to have difficulty distinguishing between strangers and familiar people, to show sudden mood changes, to overreact to everything and everyone, to get angry quickly, to get lost easily, and to panic in new situations or if change occurs.

#### **Question 6. What does the future hold, particularly for adults?**

A large sample of 27,000 people in a Scandinavian or northern European birth cohort looked at premature mortality in ASD.<sup>16</sup> The odds ratio was about 2.0 for more frequent death among people with ASD than non-ASD. The highest risk was among females who had low-functioning ASD. There was an increased vulnerability to premature mortality across the board.

A study of factors associated with subjective quality of life of adults with ASD<sup>17</sup> looked at reports from the adults themselves, from maternal proxy reports, and from the actual maternal reports. Subjective factors, such as perceived stress and having been bullied frequently, were associated with quality of life based on the adult self-reports. In contrast, the level of independence in daily activities and physical health were significant predictors of maternal reports of a son or daughter's quality of life.

A large Danish sample of almost 2 million people looked at the association of psychiatric and neurologic comorbidity with mortality among persons with ASD.<sup>18</sup> The hazard ratio was about 2.0 for greater death among people with ASD. However, there was no difference as a function of whether there were comorbid neurological or behavioral mental disorders. This suggests that these factors operate as a single risk factor for mortality, rather than being differentiated.

#### **Question 7. What other infrastructure and surveillance needs must be met?**

The CDC, reporting on prevalence and characteristics of ASD,<sup>19</sup> found that the prevalence of autism was higher among boys to age 8 years than among girls to age 8 years for children in the Autism and Developmental Disabilities Monitoring (ADDM) Network. In addition, estimated ASD prevalence was significantly higher among non-Hispanic white children (15.5 per 1,000) compared with non-Hispanic black children (13.2 per 1,000) and Hispanic children (10.1 per 1,000). These new data continue to raise the question of whether the differences are due to differences in ascertainment or actual differences.

In a study of 4-year-old children in the ADDM Network, researchers found that the prevalence of ASD was slightly lower among 4-year-old children than among 8-year-old children.<sup>20</sup> It was 13.4 per 1,000, 30 percent lower than for the 8-year-olds. This suggests that identification increases as children age, and that many children are identified after the age of four. The results of this study suggest that monitoring in a younger population may be feasible for the ADDM Network in the future.

The final article addressed schizophrenia populations and was included as a prelude to the upcoming presentation on auditory hypersensitivity and wandering.<sup>21</sup> The subjects had a DSM diagnosis of schizophrenia, schizoaffective disorder, or psychotic bipolar disorder. The investigators performed cluster analyses using a large number of measures, including cognitive ability and sensorimotor reactivity. They found three clusters they called biotypes. Biotype 1

had very blunted reactivity and were very nonresponsive, with poor cognitive functioning. Biotype 2 had poor cognitive functioning, but extremely exaggerated sensorimotor reactivity. Biotype 3 had essentially normal reactivity. The findings were that patients from any of the three traditional categories of diagnosis (schizophrenia, schizoaffective disorder, and psychotic bipolar disorder) were scattered throughout the three biotypes. Dr. Cuthbert remarked that, given the many genetic and phenotypic overlaps between schizophrenia and ASD, the data might be somewhat comparable and bear consideration when trying to understand what the deficits mean and how they reflect etiology in various kinds of impaired functioning. For example, within ASD, there may be subpopulations with normal, hypersensitive and hyposensitive sensory sensitivities. Being able to distinguish these groups may be helpful in identifying individuals at risk for wandering.

### **Auditory Sensitivity and Safety in Children with ASD**

**Paul Lipkin, M.D. and Kiely Law, M.D., Interactive Autism Network**

Dr. Lipkin of the [Interactive Autism Network \(IAN\)](#), described a recently completed a [study of auditory hypersensitivity](#). As background information, he noted a 2011 study on wandering and elopement.<sup>22</sup> It indicated that 30 percent of parents said they felt children's elopement was an effort to escape an uncomfortable sensory stimulus, such as a loud noise. That finding led to the Auditory Sensitivity and Child Safety Study current study. It was launched in 2015 to characterize auditory hyper- and hyposensitivity in children with ASD, determine the relationship between auditory hypersensitivity and potentially unsafe behaviors, and assess use and satisfaction of interventions for auditory hypersensitivity. Previous research on auditory sensitivity indicates that anywhere from 30 to 50 percent of children with ASD have auditory hypersensitivity.

Dr. Law stated that 814 parents completed the survey, "Characteristics of Children with Autism." Consistent with the known autism gender ratio, 82 percent were male. The median age of the child at the time of survey completion was 10 years old. Preliminary results for hypersensitivity indicated that three-quarters of families had current issues related to auditory hypersensitivity. The median age of onset was 2 years of age, with the worst symptoms between the ages of 4 and 5. The top three characteristics defining the child's emotional state were scared, irritable, and stressed. A physical response of "tries to run away" was over 40 percent; "tries to hide" was at 25 percent. A third of children tried to stop the sound. These children were more likely to have a history of epilepsy and seizure disorders and 30 percent of families reported that their child had seizures provoked by auditory triggers. Over 40 percent of families said the hypersensitivity of their child led to unsafe situations. Concerning interventions, about half of families tried earmuffs or ear plugs; 24 percent were very satisfied. However, 20 percent were very unsatisfied with ear muffs; 45 percent were very unsatisfied with ear buds. Other common interventions were taking quiet breaks and avoiding trigger sounds.

Dr. Law addressed questions about hyposensitivity asked of the same families. Over half had never experienced this issue, with 30 percent currently having problems. The median ages were younger for onset, resolution, and worst symptoms. Families reported a higher percentage of

safety concerns, with 52 percent having been in an unsafe situation. Dr. Law closed by thanking her team members and contributors.

### **Autism and Wandering: The Road to Prevention**

#### **Wendy Fournier, President, National Autism Association**

Ms. Fournier stated that data collected by the [National Autism Association \(NAA\)](#) over the previous 5 years indicates that wandering cases involving children aged 9 and under ended in death 44 percent of the time. Cases involving children age 13 and under ended in death 31 percent of the time. Children die quickly; usually within minutes, so prevention is critical. By far, the most common cause of death is drowning, followed by those hit by vehicles. Since 2011, NAA has provided [Big Red Safety Boxes](#) as a prevention effort, with 23,000 boxes shipped. These toolkits contain a booklet of educational information, prevention strategies, door and window alarms, a personalized ID tag, and other items. Dr. Fournier remarked that construction headphones pose secondary safety risks and may impede language development. Children don't like wearing them and they are often teased. There is a need for discreet technology that is customizable to the wearer and that does not impair hearing or compromise safety. She stated that research is needed on the root cause of wandering, which she believes is a non-verbal form of communication that states: "I want, I need, or I don't want." In many cases, there is an acute stress response and loss of control. Auditory hypersensitivity is painful and can trigger a fight or flight/acute stress response.

Needs include the development of effective, safe technology in the short-term, research on the link between seizures and auditory triggers, research on the fight or flight mechanism, research on the sympathetic nervous system (Does the TRPV1 protein affect fight or flight?), and effective treatment of the acute stress response, which could be the ultimate wandering prevention strategy. She closed by thanking the IACC for forming the Safety Working Group and offered assistance from NAA.

### **Questions and Comments**

Ms. Crane confirmed that parents and self-advocates report that auditory seizures occur. She emphasized the lack of research on the safety consequences of elopement and the need for representative statistics, not just the cases reported in the media. Dr. Larry Wexler observed that wandering and elopement isn't exclusive to the autism community and is not represented by the Department of Education as a disability issue, because elopement is also a problem among children without disabilities. He said every preschool has a wandering/elopement issue. He felt that research will likely lead to common sense approaches to prevent wandering/elopement. He said the Big Red Safety Box program should be in every kindergarten and preschool in the country. With regard to auditory hypersensitivity, Dr. Kevin Pelphrey said his daughter has seizures when she hears the birthday song, which is problematic in restaurants. He wrote an [op-ed piece for SpectrumNews.org](#) about how restaurants are designed to adversely affect the nervous system. The noise makes people as hungry as possible and more likely to eat and to drink alcohol. This is a particularly vulnerable situation for children with autism. He hoped for attention on this issue to help change the public's perception. Dr. Geri Dawson noted two ongoing research projects of interest in this area. The first is funded by

NIH: [a randomized clinical trial looking at a behavioral intervention for wandering](#). Also, the DoD funded their team at Duke to validate a very early biomarker of auditory hypersensitivity. It is an electrophysiological marker that measures how the brain habituates to auditory information. So far, the work is very promising. It addresses some of the underlying mechanisms that could account for a child's response to auditory information.

## **Panel on Adult Therapies for ASD**

### **Cognitive Enhancement Therapy (CET) for Adults with Autism Spectrum Disorder Shaun M. Eack, Ph.D., Associate Professor, School of Social Work and Department of Psychiatry, University of Pittsburg**

Dr. Eack stated that his team is concluding the first preliminary clinical trial on cognitive enhancement therapy (CET) for adults on the autism spectrum. He remarked that while some adults with autism do well, many struggle, with difficulty forming significant relationships or maintaining and holding a job. There is limited information available about what can help; only 14 therapy studies for adults have taken place since 1960. One third of these studies are single-case trials. In comparison, there have been 38 randomized, controlled studies of cognitive remediation as a therapy for schizophrenia. Dr. Eack noted that there is a known services and policy "cliff" for autism that might be related to the lack of evidence.

Investigators at the Autism Center at Pittsburgh have proposed that there are repeated, clear biological signatures suggesting that this condition is a brain disorder characterized by challenges in brain communication, giving rise to information-processing problems, including social information processing. Dr. Eack noted that a suite of interventions that fall under the category of cognitive remediation have been available since the 1980s. They address challenges in particular areas of information processing using exercises to strengthen those skills. Although they are beneficial for Parkinson's disease, schizophrenia, and eating disorders, these interventions had not been used for autism. CET, originally developed for schizophrenia, has a neurocognitive training component (playing computer games) and a social-cognitive training component (group therapy). In this study, the CET intervention was provided over an 18-month period. The neurocognitive training component uses the game "Shapes and Locations," which is a basic memory exercise. The social-cognitive group sessions consisted of small groups of six to eight members with coaches, rather than therapists. The content focus was on understanding others, social cognition, and picking up social cues.

The investigators started by running a series of trials to determine whether schizophrenia could be substantially improved by CET and whether some of the neuromechanisms associated with that condition overlap with ASD. CET was shown to enhance the structural integrity of the amygdala and fusiform gyrus in early form schizophrenia; those two areas of the brain have been repeatedly implicated in autism. The approach converged around neuromechanisms that seemed to overlap between the two conditions. Based on preliminary pilot data funded by NIMH, the researchers embarked on the first trial. The population studied included verbal adults without intellectual disability. Participants were randomized to either CET or an enriched supportive therapy control condition. Dr. Eack reported that the final 18-month assessment had

been recently completed. The preliminary data indicated that CET significantly improved neurocognition and social cognition. The neuropsychological test battery indicated highly significant functional improvement in CET over the course of the trial. The supportive therapy in the control condition was also helpful; results were comparable with CET by 18 months. Dr. Eack noted that there was an interesting and dramatic increase in employment as adults went through CET, perhaps indicating the importance of addressing cognitive challenges to remove barriers to employment.

A secondary aim of the effort was to understand the degree to which the adult brain in autism is plastic and amenable to change. If CET is affecting cognition, they should be able to detect a neural signature. He reported that people treated with CET showed a gradual increase in activity in the medial prefrontal cortex over the course of treatment. As individuals go through CET, the synchrony between the prefrontal cortex, particularly the dorsal lateral prefrontal cortex and the amygdala, couples and grows over time. That increase in connectivity was not shown with enriched supportive therapy. Dr. Eack stated that the results were preliminary and included only half of the trial sample. However, they suggest that the brain may be far more plastic and amenable to change in adult autism than was previously appreciated. These areas of the brain may be particularly malleable and could be ideal targets for interventions. He concluded by stating that these cognitive training programs have strong synergy with other types of treatments already available and with those coming to market.

**John E. Robison**

**Self-Advocate and Parent, Neurodiversity Scholar in Residence, College of William and Mary, IACC Member**

Mr. John Robison had volunteered as the first subject in a study at Harvard Medical School's Beth Israel Hospital on using transcranial magnetic stimulation (TMS) to change emotional insight in autistic people. He explained that TMS uses high-powered pulses of electromagnetic energy to induce tiny electrical signals in the brain. By focusing those electromagnetic fields, energy can be induced in areas of the brain as small as 1 or 2 percent of the brain mass. The researchers hoped to suppress an overactive mechanism in the brain that might affect the ability to read social cues. Mr. Robison read the results in the article published about this study, "Brain stimulation over Broca's area differentially modulates naming skills in neurotypical adults and individuals with Asperger's syndrome," which indicated minimal changes in the researchers' areas of focus. However, he wrote the book "Switched On," to focus on the side effects of his treatments, which were significant.

Mr. Robison told the Committee that after his first TMS session, listening to music in his car brought back vivid memories—akin to flashbacks involving all of his senses— of previous times that he listened to live musical performances. The next two treatments had no effects or minor effects. The fourth treatment caused hallucinations and what he referred to as a "tsunami of emotions" that he could feel from other people, as well as from reading written documents. Prior to the study, his autism had made him unaware of the emotions of others and less aware of his own emotions, but the treatment flooded him with an enormous amount of new emotional stimuli that he found overwhelming. Another study participant told him he had the

same types of experiences, to the extent that he would be overcome with emotion from ordinary activities such as reading a magazine. Mr. Robison said the side effects of the treatments were life-changing, but not in a uniformly good way. Emotional overload cost him his friends and his marriage and brought him to the brink of suicide. A short period of brain stimulation changed his world forever and similar experiences are shared by others. He told the Committee that journal articles in psychiatric and psychological research do not necessarily report the full picture of a study's effects, and that in some cases, researchers are focusing on the wrong or an incomplete set of outcomes. They often ignore the impact on quality of life for study participants. In his case, the treatment significantly enhanced his emotional awareness, but had some negative impacts on his quality of life because in the absence of additional supports to assist with the change in perspective, the new insights were overwhelming. He challenged researchers need to take into account a more holistic set of possible outcomes when assessing the impact of interventions and publishing results. He concluded by stating that on the positive side, the treatment provided him with new abilities to understand and work collaboratively with others, and now he is described as an agent who brings people together. He thanked the Committee for listening to his story.

### **Questions and Comments**

Dr. Cuthbert thanked Mr. Robison, and Ms. Crane said his remarks were a sobering reminder that researchers need to take into consideration the long-term effects of treatment for people with autism. She noted that there are many interventions for people on the autism spectrum for which there is no long-term, quality-of-life research, including early childhood interventions. Post-traumatic stress disorder can occur, as well as vulnerability that can be dangerous. Researchers should listen to the feedback of those who receive interventions.

Dr. Julie Taylor asked Dr. Eack to discuss the effectiveness of the control group therapy in his study. He said it is one-on-one individual therapy versus group therapy. The content of the control therapy does not involve cognitive training, social cognition, or neurocognitive issues. It is given for the same amount of time and number of sessions, providing basic psychoeducation on autism and individual support to reduce stress. He described it as standard cognitive behavioral therapy. Dr. Cuthbert addressed Dr. Eack, noting that, under Dr. Thomas Insel's leadership at NIMH, they revised the approach to clinical trials, with an emphasis on fast-fail experimental medicine trials. The idea is to specify a particular target toward which the therapy is intended and demonstrate that one has achieved target engagement. The target does not have to be biological; it could be a mode of cognition or interpersonal processing. The conditions they study are very broad, heterogeneous syndromes and not specific disease entities. He asked Dr. Eack to comment on how his therapy fits with that new approach. Dr. Eack replied that the target engagement for which they are trying to show movement is behavioral measures of cognition. The two primary targets are neurocognitive and social cognitive treatment engagement; the secondary target is functional outcome. They saw the first study as an opportunity to push on these two cognitive treatment targets to see if there would be downstream functional change and to back up and see any underlying neurosignature so they could start specifying biological targets in the future.

## Round Robin

### **Prevalence and Characteristics of Autism Spectrum Disorder among 8-Year-Old Children Daisy Christensen, Ph.D., Centers for Disease Control and Prevention**

Dr. Christensen stated that the Autism and Developmental Disabilities Monitoring (ADDM) Network recently released their latest numbers. ADDM is an active, population-based biannual surveillance of ASD and other developmental disabilities. It is based on multiple source record review in the community, including health and education sources. It is based on expert clinician review of the developmental evaluations contained in these records. The goals are to estimate prevalence and characteristics of ASD, estimate prevalence trends of ASD, and understand the impact of ASD in U.S. communities. She indicated that the overall pool of ASD prevalence was 14.6 per 1,000 in 2012, which was about the same as the 2010 prevalence of 14.7 per 1,000, or 1 in 68 children. The sites that reviewed education and health records had a substantially higher prevalence, at about 17 per 1,000, compared to sites that reviewed health records only, at just under 11 per 1,000. There has been a consistent male-to-female prevalence ratio of about 4.5 since 2000. There are concerning disparities by race/ethnicity. Non-Hispanic white children had about a 20 percent greater prevalence of autism compared to non-Hispanic black children, but more concerning is that non-Hispanic white children had a 50 percent higher prevalence compared to Hispanic children, suggesting under-ascertainment in minority populations.

An important metric for ADDM is the age at earliest evaluation. This informs the Healthy People 2020 goal, which is to increase the percentage of children that are first evaluation by 36 months. Dr. Christensen remarked that despite the fact that nearly 90 percent of children had developmental concerns by age 36 months noted in their records, only 43 percent had a first evaluation by that age. Nearly 40 percent were not evaluated until 48 months or greater. She noted that non-Hispanic white children were a bit more likely to have a first evaluation by 36 months compared with non-Hispanic black and Hispanic children. They want to see additional data points before stating that prevalence is stabilizing. Surveillance for 2014 was continuing; this is the first year for which they will report prevalence estimates using the DSM-5 criteria.

### **Questions and Comments**

Mr. Robison asked if some of the sites use only the educational versus the medical autism diagnosis, and whether some of the sites use both. Dr. Christensen said most, but not all sites have access to education or special education records. They are able to account for more children in the sites that have access to education records, which illustrates the important role that schools play in the evaluation and servicing of children who have ASD. Mr. Robison asked why the published number was 10 percent lower than education-medical combined. Dr. Christensen stated that they publish the numbers based on the ADDM Network data results. Dr. Wexler asked if they take into account that, using educational records in the 3 to 5 age group, many children with autism are not reported under autism. They might be reported as developmentally delayed or having speech and language concerns. He also asked if they address the early intervention program of Birth to Three. Dr. Christensen said that in their surveillance for 4-year-olds, they look at the EI data if they are able to access those records. She said they are not looking at autism eligibility, although they take that into consideration. They

look at the evaluations to determine any eligibility, based on the behaviors described in the evaluation. Dr. Ring noted that Autism Speaks helped fund a collaborative study that involved a South Carolina site and an ADDM site, and also looked at 8,500 children born in 2004 using a direct screening approach. They compared DSM-4 versus DSM-5. Those data might be available and could add to the conversation. They would help address the records-based approach versus a direct population screening approach. Both have value, but address different questions.

Dr. Amaral commented on the public and a private enterprise underway to reach out to families across the country so they are made aware that there is a need for postmortem brain donations to understand the neurobiology of ASD. The NIH NeuroBioBank and Autism BrainNet met in the fall and came to an agreement that there would be one national, collaborative outreach effort. Another meeting was held the previous day to determine the best way to distribute the donations that were coming in at a greater pace. Dr. Amaral said one consolidated process would allow researchers the materials to carry out this research. He said it is turning out to be a successful public-private enterprise supported by NIH, the Simons Foundation, Autism Speaks, and the Autism Science Foundation.

Dr. Walter Koroshetz noted that the National Institute of Neurological Diseases and Stroke (NINDS) was conducting a clinical trial that might be of interest. He stated that in Fragile X, about 50 percent of patients develop or are diagnosed with autism. The trial will use an mGluR5 allosteric modulator, which has been tested in older adults with Fragile X without benefit. The new study is more focused on cognitive learning in children ages 3 to 6. The hypothesis is that perhaps the drug will be more effective when provided earlier in development. A second NINDS trial is being conducted in tuberous sclerosis (TSC); about 50 percent of people with this disorder are diagnosed with ASD. Many TSC patients develop a severe seizure disorder; a previous study indicated that by checking EEGs, one can predict with 100 percent specificity who will develop seizures. The trial will start treatment as soon as the EEG abnormality is detected. The investigators will look not only at preventing seizures, but helping cognition. These two trials can be conducted because of the ability to identify particular subgroups of patients with highly penetrant autism disorders.

### **Closing Remarks**

Dr. Daniels said she would be in touch regarding the working groups and would follow up at the next meeting with a plan for the Summary of Advances. She thanked meeting participants for thoughtful and stimulating discussions on all topics. Dr. Cuthbert added his thanks for a very productive meeting. The next meeting will be held on July 19<sup>th</sup> 2016.

### **Adjournment**

The meeting was adjourned at 4:48 p.m.

## **Certification**

These minutes of the Interagency Autism Coordinating Committee (IACC) were approved by the Committee on July 19, 2016.

I hereby certify that this meeting summary is accurate and complete.

/Bruce Cuthbert/

Bruce Cuthbert, Ph.D.

Chair, Interagency Autism Coordinating Committee

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<sup>1</sup> Grzadzinski R, Dick C, Lord C, Bishop S. Parent-Reported and clinician-observed autism spectrum disorder (ASD) symptoms in children with attention deficit/hyperactivity disorder (ADHD): implications for practice under DSM-5. *Molecular Autism: Brain, Cognition, and Behavior*, January 16, 2016.

<sup>2</sup> Emerson ND, Morrell HE, Neece C. Predictors of Age of Diagnosis for Children with Autism Spectrum Disorder: The Role of Consistent Source of Medical Care, Race, and Condition Severity. *Journal of Autism and Developmental Disorders*, January 2016.

<sup>3</sup> McPheeters ML, Weitlauf AS, Vehorn A, Taylor C, Sathe NA, Krishnaswami S, Fonnesebeck C, Warren ZE. Screening for Autism Spectrum Disorder in Young Children: A Systematic Evidence Review for the U.S. Preventive Services Task Force. AHRQ, February 2016.

<sup>4</sup> Burke MM, Magaña S, Garcia M, Mello MP Brief Report: The Feasibility and Effectiveness of an Advocacy Program for Latino Families of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, March 2016.

<sup>5</sup> Kushak RI, Buie TM, Murray KF, Newburg DS, Chen C, Nestoridi. Evaluation of Intestinal Function in Children with Autism and Gastrointestinal Symptoms. *Journal of Pediatric Gastroenterology and Nutrition*. February 20, 2016.

<sup>6</sup> Mazurek MO, Sohl K. Sleep and Behavioral Problems in Children with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders*, January 28, 2016.

<sup>7</sup> Greenlee JL, Mosley AS, Shui AM, Veenstra-VanderWeele J, Gotham KO. Medical and Behavioral Correlates of Depression History in Children and Adolescents with Autism Spectrum Disorder. *Pediatrics* February 2016

<sup>8</sup> Li M, Fallin MD, Riley A, Landa R, Walker SO, Silverstein M, Caruso D, Pearson C, Kiang S, Dahm JL, Hong X, Wang G, Wang MC, Zuckerman B, Wang X. The Association of Maternal Obesity and Diabetes with Autism and Other Developmental Disabilities. *Pediatrics* February 2016

<sup>9</sup> Conde-Agudelo A, Rosas-Bermudez A, Norton M. Birth Spacing and Risk of Autism and Other Neurodevelopmental Disabilities: A Systematic Review. *Pediatrics* May 2016

<sup>10</sup> Chang YC, Shire SY, Shih W, Gelfand C, Kasari C. Preschool Deployment of Evidence-Based Social Communication Intervention: JASPER in the Classroom. *Journal of Autism and Developmental Disorders*, March 3, 2016

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- <sup>11</sup> Carr T, Lord C. A Pilot Study Promoting Participation of Families with Limited Resources in Early Autism Intervention. *Research in Autism Spectrum Disorders* May 2016
- <sup>12</sup> Benevides TW, Carretta HJ, Mandell DS. Differences in Perceived Need for Medical, Therapeutic, and Family Support Services Among Children with ASD. *Pediatrics* 2016
- <sup>13</sup> Thomas KC, Williams CS, deJong N, Morrissey JP. Examination of Parent Insurance Ratings, Child Expenditures, and Financial Burden among Children With Autism: A Mismatch Suggests New Hypotheses to Test. *Pediatrics* 2016
- <sup>14</sup> Austin J, Manning-Courtney P, Johnson ML, Weber R, Johnson H, Murray D, Ratliff-Schaub K, Tadlock AM, Murray M.. Improving Access to Care at Autism Treatment Centers: A System Analysis Approach. *Pediatrics* 2016
- <sup>15</sup> Kiely B, Migdal TR, Vettam S, Adesman A. Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States. *PLOS One* February 4, 2016
- <sup>16</sup> Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. *BJ Psych* March 2016
- <sup>17</sup> Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JS, Mailick MR. Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report Versus Maternal Reports. *Journal of Autism and Developmental Disorders* April 2016
- <sup>18</sup> Schendel DE, Overgaard M, Christensen J, Hjort L, Jørgensen M, Vestergaard M, Parner ET Association of Psychiatric and Neurologic Comorbidity With Mortality Among Persons With Autism Spectrum Disorder in a Danish Population. *JAMA Pediatrics* March 2016
- <sup>19</sup> Christensen DL, Baio J, Braun KV, Bilder D, Charles J, Constantino JN, Daniels J, Durkin MS, Fitzgerald RT, Kurzius-Spencer M, Lee LC, Pettygrove S, Robinson C, Schulz E, Wells C, Wingate MS, Zahorodny W, Yeargin-Allsopp M. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly* April 2016
- <sup>20</sup> Christensen DL, Bilder DA, Zahorodny W, Pettygrove S, Durkin MS, Fitzgerald RT, Rice C, Kurzius-Spencer M, Baio J, Yeargin-Allsopp M. Prevalence and Characteristics of Autism Spectrum Disorder among 4-Year-Old Children in the Autism and Developmental Disabilities Monitoring Network. *Developmental and Behavioral Pediatrics* January 2016
- <sup>21</sup> Clementz & Tamminga. BSNIP "Biotypes:" (1) Cognitive Control, (2) Sensorimotor Reactivity *Am J Psychiatry*, in press.
- <sup>22</sup> Anderson, C., Law, J.K., Daniels, A., Rice, C., Mandell, D.S., Hagopian, L. & Law, P.A. (2012) Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics*, 130(5): 870-877.