



## Minutes of the Interagency Autism Coordinating Committee

### Full Committee Meeting

July 24, 2019

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The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a meeting on Wednesday, July 24, 2019, from 9:08 a.m. to 5:05 p.m. at the Rockville Hotel and Executive Meeting Center in Rockville, Maryland.

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

### Participants

**Joshua Gordon**, M.D., Ph.D., *Chair*, IACC, NIMH; **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), NIMH; **David Amaral**, Ph.D., University of California, Davis (UC Davis) MIND Institute; **Melinda Baldwin**, Ph.D., L.C.S.W., Administration for Children and Families (ACF); **James Ball**, Ed.D., B.C.B.A.-D., JB Autism Consulting; **Diana Bianchi**, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD); **Samantha Crane**, J.D., Autistic Self Advocacy Network; **Geraldine Dawson**, Ph.D., Duke University School of Medicine; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA) (representing Ruth Etzel, M.D., Ph.D.; attended by phone); **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., NICHD (representing Diana Bianchi, M.D.); **Laura Kavanagh**, M.P.P., Health Resources and Services Administration (HRSA); **Cindy Lawler**, Ph.D., National Institute of Environmental and Health Sciences (NIEHS; representing Linda Birnbaum, Ph.D.); **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; **Marcella Ronyak**, Ph.D., L.C.S.W., C.D.P., Indian Health Service (IHS) Headquarters; **Nina Schor**, M.D., Ph.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, Ph.D.); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC); **Alison Tepper Singer**, M.B.A., Autism Science Foundation; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Cheryl Williams**, Social Security Administration (SSA); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD).

### 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 9:08 a.m. and Dr. Susan Daniels took roll call. Dr. Daniels made a motion to accept the minutes for the last Committee meeting. There was a unanimous move to accept the minutes.

## **Welcome and Introductions**

Dr. Gordon began by announcing that this is the last meeting of the current iteration of the Committee under [The Autism CARES Act of 2014](#). They expect that the House will vote to reauthorize the legislation and with it a new Committee and a new mission. Dr. Gordon thanked the Committee members for their public service and expressed his gratitude for the opportunity to work with them, as well as with experts around the world. He said that it has been remarkable for him to see how the Committee's focus on autism-related topics has raised awareness for and motivated action related to future research and care. Dr. Daniels also thanked the Committee for their important work and contribution.

Dr. Gordon said that Dr. Ann Wagner was not available to present and would update the Committee by email.

## **Panel Presentation: Using Innovation and Collaboration to Develop a Community Continuum of Care Model—Baton Rouge, Louisiana**

**Representative Franklin Foil**, Louisiana House of Representatives, Louisiana State Legislature

Rep. Franklin Foil described his history working with children with disabilities, including his sister, who has Down syndrome, and his third child, who is on the autism spectrum. As a result, he has prioritized children with disabilities throughout his political career. Specifically, Rep. Foil has worked to improve insurance coverage for Applied Behavior Analysis (ABA) therapy by encouraging families of children with disabilities to testify about the importance of this intervention at the state capital, and eventually passing legislation to cover ABA therapy in Louisiana. He has also worked to increase the number of ABA therapists in the state.

Rep. Foil explained that education is another critical element of improving quality of life for children with disabilities and their families. Many schools in Louisiana would not accommodate these children's needs, preferring to push children to self-contained classrooms rather than working to mainstream them. To address this issue, Rep. Foil passed legislation to provide tuition assistance to parents with special needs children for specialized education.

As his own child got older, he began to consider the need for job training. He worked with [Baton Rouge Area Foundation](#) (BRAAF) and Baton Rouge Community College to develop a year-long program to provide life skills and job training to high-performing children with intellectual disabilities. The program identifies partners in the community who will employ transitioning adults as interns. While the participants are employed through the program, the school provides job coaching and services to help them successfully maintain full-time work.

Rep. Foil has also worked to improve housing opportunities for children with intellectual disabilities. He

noted that all parents want safe, independent living conditions for their children, but there are no options for children with intellectual disabilities in Baton Rouge. Rep. Foil and other stakeholders are working on the issue with goal of safeguarding children's futures when their parents are no longer able to provide care. To this end, they contacted OARC to learn more about federal activities and invited them to tour their programs in Baton Rouge. Rep. Foil expressed his hope that the Committee and advocates in Baton Rouge can form an ongoing collaboration to improve quality of care for children and adults with intellectual disabilities in Louisiana.

**Lauren Crapanzano Jumonville, M.B.A.**, Director, Civic Leadership Initiatives, Baton Rouge Area Foundation

Ms. Lauren Jumonville provided an overview of the BRAF. They are a community foundation that provides philanthropic support for quality-of-life issues in Baton Rouge. Currently, the BRAF manages, advises, and directs the interests of several hundred donors with donor funds. Their grants tend to be multiyear, multimillion-dollar efforts that require partnerships with the public sector, nonprofit organizations, the business community, and area stakeholders.

A few years ago, executives at BRAF recognized the need to fund initiatives to fill the significant gaps in lifespan services for individuals on the autism spectrum. After compiling [a comprehensive report](#) that covers 25 recommendations across the life cycle, they decided to create a network of key community organizations who meaningfully, consistently engage with autism spectrum disorder (ASD)-related issues. The resultant Capital Area Autism Network (CAAN) is composed of three of these key organizations: the [Emerge Center](#), [Our Lady of the Lake Pediatric Development and Therapy Center](#), and [Families Helping Families](#). Embedded within the Network are additional task forces that focus on topics such as family support, transition and workforce opportunities, workforce development for employers who work with adults with ASD, and advancement of educational opportunities.

Ms. Jumonville explained that they began to face challenges in distributing this information to families, and they created a website through an online platform called [Exceptional Lives](#). This website offers action guides that help Louisiana families navigate critical decision points across their child's lifespan; for example, how to complete a complicated Medicaid waiver for access to additional resources. They also offer a resource directory that helps families track statewide organizations, such as therapists, dentists, and other providers, who have experience working with children with ASD. Finally, Exceptional Lives offers live support through a helpline, a chat feature, and additional support via an email address.

Ms. Jumonville concluded by noting that BRAF engaged nearly 300 families while working on this report, recognizing that loved ones are some of the most valuable experts about ASD services across the lifespan. They developed these resources to reduce community burdens and to provide families with comprehensive, reliable resources.

**Traci Olivier, Psy.D.**, Pediatric Neuropsychologist, Our Lady of the Lake Physician Group

Dr. Traci Olivier provided background about the [Our Lady of the Lake Children's Health program](#), which is part of the larger [Our Lady of the Lake](#) health system, which is one of Louisiana's largest health organizations. She also described their current partnerships and future directions. She recognized the ongoing need to expand services to accommodate children with disabilities, most of whom have complex medical and psychological needs.

Within their health system, the [Pediatric Development and Therapy Center](#) is an interdisciplinary team focused on diagnosis and treatment of children with developmental disabilities. The majority of children they see have ASD, but many have other global developmental delays or mental health concerns. Their [Social Engagement Clinic](#) consists of a team of professionals specializing in developmental medicine, psychology, speech-language pathology, and occupational therapy. These specialists work together to develop coordinated treatment plans and to provide ongoing follow-ups.

Dr. Olivier explained that Louisiana is a low-resource, high-need area. As a result, provider collaborations and community partnerships are critical for helping families in need. Our Lady of the Lake works to fill some of these gaps with telemedicine, health agency partnerships, and referrals to local health centers. One of these partnerships was with the CAAN Implementation Committee, where they collaborated to set goals and priorities to guide the activities of five task forces. These efforts resulted in the creation of an Autism Stakeholders Group, consisting of 65 participants who attend semi-annual meetings to review initiatives and attend town hall meetings to inform the community of their activities.

Finally, Dr. Olivier reviewed some of the organization's recent successes and future directions. Our Lady of the Lake has successfully fostered team collaboration and worked to decrease siloed work environments, enabling them to develop the [Office for Citizens with Developmental Disabilities](#) Waiver Program. They have increased police awareness and safety related to ASD issues and have improved Louisiana driver's license identification for individuals with ASD. They also partner with the Franciscan University Board Certified Assistant Behavior Analyst program, which has help expand ABA services and foster ongoing collaborations among community groups.

Despite these successes, there is still more work to do. Future initiatives include refining goals, furthering partnerships, working with public authorities to improve reimbursement for care, and establishing CAAN as an independent 501(c)(3) organization.

**Melissa Juneau, CCC-SLP**, Former CEO, The Emerge Center for Communication, Behavior, and Development

Ms. Melissa Juneau discussed the mission and vision of the [Emerge Center](#), an early intervention pediatric care center that supports the individual needs of individuals and families who are challenged with communication, behavioral, and developmental issues. They provide audiology, occupational therapy, therapeutic classrooms, ABA, behavioral health services, and family support. They provide autism programming and services for children from ages 18 months to 7 years, and provide a variety of services for older children and teens. Adults also use their audiology program. Currently, their team consists of 75 professionals and 30 university students who are training to respond to the needs of these families and individuals.

The program is child-centered, ensuring that each child receives an individual plan and case management services within a fun, comforting environment. The Center provides activities such as book fairs, sensory-friendly movie days, and a Mardi Gras parade for the nearly 900 children they engage with each year.

Future activities of the Emerge Center include continued advocacy, research and data collection, mentorship, community partnerships, and regional expansion. Additionally, they have launched the

[Emerge School for Autism](#), which they hope will eventually serve 140 school-age children with ASD. It is the first charter school for children with ASD in Louisiana, and they aim to provide kids with the tools they need to be successful in a general education environment. Last year, they successfully transitioned seven children to general education, and next year, they will enroll 32 students. Both the Emerge Center and the Emerge School for Autism rely on philanthropic investment. The Emerge Center's participation in CAAN helps ensure a continuum of care for individuals with ASD and provides a forum of collaboration for ongoing community assessment of needs and services.

**Stephen Whitlow, J.D.**, Executive Director of Transition Services, Merakey Gateway

Mr. Stephen Whitlow shifted the focus of the panel discussion towards the barriers to providing transition services, transportation, and housing to individuals with ASD. He explained that he and his wife established their own transition program when they discovered a lack of services for their son with ASD. After meeting with the Baton Rouge Area Foundation and the [Wilson Foundation](#) to discuss ideas, they found that community stakeholders do not effectively communicate and collaborate about available services.

To address this gap, the Whitlows developed a task force for programs related to transition services for individuals with ASD, including housing, employment, and transportation. They collaborated with developers and donors to expand housing opportunities and they have worked to expand ride-sharing opportunities. Mr. Whitlow explained that employer education can be an essential way to increase awareness about the issues and reduce their hesitation to hire individuals with ASD.

Their CAAN partners include Baton Rouge Community College, [The Arc of Baton Rouge](#), [Capital Area Transit Services](#), the [Governor's Office of Disability Affairs](#), and [Moran Construction](#). They have learned that a common mission and frank communication are an essential component of agency collaboration, and that programs need to be willing to challenge the status quo in order to meet families' needs.

The [Merakey Gateway Transition Services](#) programs aim to honor the inherent dignity of every individual with ASD by enriching and empowering their lives. One of their main goals is to enhance employment opportunities for people with autism. They build pathways for families by providing education, a group skills program, independence coaching, and community outings. The program also operates a customized t-shirt shop called [Gateway Ink](#), which provides job training and employment for young adults with ASD, with a goal of transitioning them to full-time work. The Residential Training Program is under development and will teach practical independent living skills for young adults with ASD between the ages of 21 and 35. Finally, Mr. Whitlow said that they are working to collaborate with the Employment Coalition to create a database of available jobs, create training plans for employers, and identify champions. Dr. Whitlow concluded that these collaborations help organizations to stay informed, understand the marketplace, form partnerships, and, most importantly, help families.

## **Committee Discussion**

Dr. Daniels thanked the Panel and expressed appreciation for her visit to these programs in Baton Rouge. She encouraged committee members and listeners to reach out to them to develop future collaborations.

Dr. Diana Bianchi pointed out that adult transition is a gap area in the Committee and across all centers

at NIH, posing an issue for all children with disabilities and other medical or psychological problems. She expressed hope that the day's discussion will inform future research areas to improve transition-related issues.

Dr. Geraldine Dawson asked if there are any broad, systemic plans to improve ASD medical care as it relates to common co-morbid conditions, such as gastrointestinal disorders and seizures. She also wondered what experts are doing to address anticipated care-related needs as young people with autism begin to age. Dr. Olivier responded that the Our Lady of the Lake clinic has faced significant challenges in lack of awareness and education for these issues. They are hoping to connect parents with education advocates who will help them navigate medical issues and services.

Ms. Jumonville added that they are developing a coordinated system of care where various pediatric specialists would come to one place, allowing individuals and their families to schedule one full-day of appointments. Dr. Dawson expressed concern that people with ASD, especially children, struggle to complete basic medical evaluations because of sensory and communication issues. Ms. Juneau said that Emerge Center addresses this concern by sending its pediatric residents to observe the child in a naturalistic environment over an eight-hour day. They have also partnered with local dentists to support long-term prevention and care for young children with ASD.

Mr. Whitlow addressed Dr. Dawson's comment about aging, he acknowledged that they will have to face challenges as both the clients and caregivers get older. Dr. Olivier agreed that this is already a significant issue, as literature suggests that many caregivers are burned out. She said that there needs to be a focus on caring for the caregivers, both in the present and in the future as they begin to age.

Dr. Nina Schor wondered how Our Lady of the Lake considered the specific sensory and environmental needs of children with ASD in the construction of the children's hospital. Dr. Olivier answered that they created special sensory rooms and theme-based decorations, and that the building committee carefully considered aesthetics with a focus on visual and auditory stimulation.

Dr. Julie Lounds Taylor spoke about a program at Vanderbilt that fosters collaboration among adult service providers. She said that families experience challenges navigating Medicaid and other programs, so they are developing relevant guidance resources. Rep. Foil agreed that the process can be challenging for families, and he hopes Congress will address this issue.

Dr. Stuart Shapira asked if they are working to reduce waitlists for diagnoses and intervention services. Ms. Jumonville and Dr. Olivier replied that although they have reduced their waitlists, the wait times are still long. Dr. Olivier said that they are further addressing this issue by advocating to fund more providers. Ms. Jumonville added that long waitlists can be exacerbated because many providers do not accept Medicaid patients. As a result, reimbursement is a significant barrier to receiving services. Mr. Whitlow agreed that it is a serious problem in Louisiana.

Dr. Gordon thanked the panelists for their presentations and expressed appreciation for the depth and breadth of their services. He encouraged the Committee to consider that such community-based programs are an essential way to provide families and individuals with the ASD services they need.

## Committee Business

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

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

Dr. Daniels acknowledged the OARC staff for their work and reviewed some of their recent activities. They have been working on the [2016 International Portfolio Analysis Report](#), which engaged 34 government and private collaborators to collect ASD research funding data from the United States, the United Kingdom, Canada, and Australia. Projects were aligned with the seven research priority areas identified in the [IACC Strategic Plan](#), and the portfolio showed large investments in the areas of underlying biology, treatments, and interventions for ASD. The full report details further information about the size and composition of each country's portfolio. This information will be included under the new "international" tab of the [Autism Research Database](#). Finally, Dr. Daniels noted that the 2018-2019 IACC Strategic Plan Update will include summaries from the recent Working Group meetings and workshops. They will provide the draft update to the Committee via email for approval.

Dr. Daniels asked the Chairs of the two Working Groups to provide updates on their activities. Dr. David Amaral and Dr. Julie Taylor co-Chair the Health Outcomes Working Group. Recently, they have held two conference calls and two in-person workshops. The first workshop addressed physical health, including epilepsy, sleep, and gastrointestinal disorders, as well as healthcare access. The second workshop addressed mental health issues such as depression, suicidality, self-injurious behaviors, and accessing services. Dr. Amaral hopes that their written document, a policy brief, will promote awareness of topics such as risk of drowning or suicide, particularly among groups such as higher-functioning girls with ASD. Dr. Taylor said that they are struggling to disseminate their important findings to service providers and families, and she hopes the document will present the information in a useful, accessible way. They aim to circulate the document before the end of the current iteration of the Committee.

Ms. Alison Singer is the Chair of the Housing Working Group. Their most recent conference call and workshop included experts from across the nation, and summaries will soon be available online. Ms. Singer thanked the workshop participants and reviewed the takeaways from the meeting, including the need to balance autonomy and supportive services in housing options for people with ASD. She recognized that the diversity within the ASD population necessitates diverse housing options, and the workshop participants reviewed a number of models that could be replicated in other areas.

During these discussions, they learned that cost differences across models are driven by specialized services and supports rather than by differences in brick and mortar costs. Some participants noted that retrofitting existing structures is not the best way to accommodate people with ASD, who often have specific sensory needs. They also found that existing state policies and laws may prevent people from getting the funding they need to access these housing options, leaving individuals with ASD at high risk for homelessness when their aging caregivers pass away. The Housing Working Group concluded that the Committee needs to focus on outcomes rather than settings, as there is very little research in this area. Significant improvements in research and data collection are necessary to affect policy change. The participants created a list of actionable steps for the next iteration of the Committee to consider.

Ms. Samantha Crane respectfully disagreed with some of the ideas, such as that retrofitting existing housing is not effective. She agreed that such decisions are typically based on values rather than data. However, she noted that values play a role in determining which variables to measure.

Dr. Daniels said that many federal agencies were represented in the Working Groups, and that their work will continue during the interim between committees. The next iteration of the Committee may choose to continue this work building on the information gathered by the current committee. She updated the Committee on the authorization of the Autism CARES Act and the terms of the current Committee members. The Secretary of the U.S. Department of Health and Human Services (HHS) will request nominations, and that call will be posted in the Federal Register. The current legislation limits membership to two terms, which means that those who have already served two terms may not be considered eligible. The Health Subcommittee of the House Energy and Commerce Committee voted to send the bill to full committee, which they passed on July 17, 2019 with some amendments. The full House of Representatives was set to consider the bill later that day.

Dr. Daniels reviewed the accomplishments of the 2014-2019 iteration of the Committee. These included the 2016-2017 Strategic Plan (and its 2018-2019 Update), the four Portfolio Analysis Reports covering six years of data, one International Research Portfolio Report, and five Summary of Advances reports. They have held 15 full Committee meetings and 9 Working Groups, comprising 24 phone calls and 3 full-day workshops. They have addressed many important topics in autism, including early detection, interventions, health issues, behavioral concerns, premature mortality, suicide, legislation, advocacy, and financial planning. She concluded by thanking the Committee for their service.

## **Public Comment Session**

### **Summary of Oral Public Comments**

Mr. James Williams addressed common misconceptions about ASD disability benefits. Many people rely on disability benefits as their main income, and some may wonder why people choose benefits over having a job or another sources of income. Mr. Williams suggested that in some states, having disability benefits is a prerequisite for accessing other services. He provided a case study of an adult with ASD who worked a full-time job for only \$1,000 a month, half of which she paid out in rent. After leaving her job and receiving disability benefits, she now pays only \$333 per month for HUD housing and reports that her standard of living is safer, more supported, and overall better. Mr. Williams urged the public not to think of people with disabilities as “system abusers” for receiving disability benefits, and he asked the Committee to consider the various reasons people decide to go on benefits.

Dr. Eileen Nicole Simon talked about the history, uses, and clinical evolution of umbilical cord clamps, which she said may be related to biological or developmental challenges. She suggested that families should have access to information about clamping so that they can make informed decisions about using this tool during childbirth.

### **Summary of Written Public Comments**

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

Dr. Oni Celestin summarized the six written public comments.

The first commenter urged the Committee to consider researching probiotics as a treatment for high-



functioning autism.

Another commenter expressed concern about the practice of active management during labor and early umbilical cord clamping. She believes that this practice puts babies at risk and may be a cause of autism.

A comment from a mother of an adult autistic son urged the Committee to provide employment services for those with high-functioning autism. She also wrote about the possible roles of metabolic disorders, brain injuries at birth, language disorders, and hearing disorders in ASD. Finally, she submitted a summary of a grant proposal she has written and asks for advice for receiving funding.

Another comment expressed concern about previous comments at a Committee meeting regarding wandering behavior in autistic people.

One commenter believed that, given the heterogeneity of ASD, autistic people can only speak for themselves and their own experiences. She requests that the Committee continue to include parents of autistic individuals who are unable to advocate for themselves, as well as self-advocates. She believes that this will be vital for increasing representation of more severely impacted individuals in autism research.

Finally, a commenter suggested that her autistic son needs structured, one-on-one activities, as well as a sensory diet.

Full length comments can be viewed on the IACC website.

## **Summary of Live Feed Public Comments**

There were no live feedback comments for this session.

## **Committee Discussion of Public Comments**

Ms. Crane acknowledged Mr. Williams' comment about access to benefits and the challenges that people with ASD experience in accessing affordable housing. She said that many people wait years to receive benefits or are not eligible because of restrictions, and that housing programs will not be productive if they are not available to the population. Ms. Crane also noted that many people with autism do want to have meaningful work, but they experience challenges when receiving social security or other disability benefits results in a better quality of life. Disabled people should not have to choose between meaningful employment and benefits.

Dr. Dawson pointed out the irony of the situation, where employment often improves quality of life for people with ASD, but unemployment and disability benefits may be the only way for them to survive and thrive. Dr. Gordon suggested that issues like these are often solved by policymakers who are concerned about the cost of expansions, although there may be significant cost benefits. He wondered if there are any cost data comparisons across states that would enable policymakers to understand the implications of changing these policies.

Dr. Jennifer Johnson added that the [Administration for Community Living \(ACL\)](#), works in the area of

employment for people with intellectual and developmental disabilities. Their [Partnership for Employment Systems Change Grants](#) is designed to unite state entities to address some of these policy barriers. She also noted that the 2014 reauthorization of the Workforce in Innovation and Opportunity Act helped to facilitate some of these changes at the federal level.

Dr. Scott Robertson said that his office would be happy to share their data on employment, benefits, and work incentives. They have also partnered with the Social Security Administration, the ACL, and other federal agencies on this topic. Dr. Gordon acknowledged that federal employees cannot lobby at the state or national level, but he asked that the Committee provide guidance to advocates and self-advocates about how to communicate to local, state, and national legislatures about these issues. Dr. Robertson added that the [Office of Disability Employment Policy](#) supports the State Exchange on Employment and Disability. They collaborate through intermediate organizations, such as the National Governor's Association, the Council of State Governments, and the National Council of State Legislatures to provide technical assistance collaboration on policy change. In 2018 their task force on Workforce Development for People with Disabilities produced a report, [Work Matters](#).

Dr. Gordon addressed Dr. Simon's housing-related suggestion to work with hotel chains to offer combined housing and employment. He also noted the comment about asphyxia at birth as a potential cause of brain systems and hearing damage. In response to the question about funding for this hypothesis, Dr. Gordon reiterated that there are more research ideas than can be funded, and that grant submissions to the NIMH are vetted rigorously for a basis in evidence before they can receive funding. Finally, Dr. Gordon addressed the written comment regarding an objection to comments about wandering made by a Committee member. He would like entered for the record that he disagreed with the comment and that he believes the Committee member to be a valuable and credible participant with a unique and valuable perspective.

## **Panel Presentation: Racial and Ethnic Disparities in Autism**

### **Presentation: Detecting, Understanding, and Addressing Racial and Ethnic Disparities Among Children with ASD**

**Sandy Magaña, Ph.D., M.S.W.**, Professor in Autism and Neurodevelopmental Disabilities, Steve Hicks School of Social Work, University of Texas at Austin

Dr. Sandy Magaña presented an overview of her research about the relationship between race and ASD. She began by defining two important terms in the field: *health disparities* and *health equity*. Health disparities are health differences that are closely linked with economic, social, or environmental disadvantages. The term often refers to trends of poor health outcomes among groups who face systematic discrimination or identity issues. Health equity aims to reduce and eliminate these health disparities, particularly among those who are vulnerable or who experience disparities because of economic or social disadvantage.

People with intellectual or developmental disabilities are typically considered one of these vulnerable groups. Among people on the autism spectrum, there is a growing need for diagnosis, treatment, and other services, but many individuals and families are unable to access these supports due to entrenched social inequities.

Dr. Magaña then provided a framework of her research, including her efforts to detect disparities, to understand why they occur, and ultimately to reduce them. She explained that existing research efforts have found that race-related health disparities play a significant role in neurodevelopmental disorders. Data from the CDC's [Autism and Developmental Disabilities Monitoring](#) (ADDM) program indicate that Latinx children are consistently undercounted, and that both Latinx and black children tend to receive other diagnoses before receiving an ASD diagnosis, resulting in late access to interventions. Asian American children also show some health disparities compared to other groups. Dr. Magaña pointed out that although researchers do not know all of the exact causes of these data differences among racial groups, these trends indicate a need to further investigate the role of racial disparities in neurodevelopmental disorders.

She talked about one of her research studies, which used the National Survey of Children with Special Needs to compare white and Latinx children's access and utilization of general health care services. They found that the Latinx children were less likely to have access to insurance, less likely to have a usual source of health care, and overall more likely to face barriers to using services and getting referrals. Dr. Magaña said that a previous study by Dr. Katie Zuckerman found that some pediatricians even admit to under-referring Latinx children. Another study looked at quality of health care. Dr. Magaña said that they found significant disparities between white and black children, and between white and Latinx children. These differences persisted from the 2006 data set to the 2010 data set, despite legislation and policy changes to reduce health disparities.

In terms of autism-specific research, Dr. Magaña explained that data indicate that Latinx and black children receive fewer ABA services and other evidence-based treatment approaches than white children. She also reviewed a study about the autism diagnostic interview schedule, including the Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) instruments. They found that although the ADI-R has been directly translated into Spanish (and 16 other languages), it was never validated for culture. Spanish-speaking Latinx families in the United States had significantly different scores in social reciprocity and other social domains. The language translation barrier presents a significant issue for diagnostic parity, especially if the parents primarily speak Spanish and their children primarily speak English.

Approaches to addressing health disparities include adapting culturally tailored interventions and training providers to recognize and reduce disparities. For example, the [Parents Taking Action program](#) provides Latinx families, in their own language, with general psychoeducation to understand what autism is, which evidence-based interventions are available, and how to support and advocate for their children. They found that after completing the Parents Taking Action program, parents felt more confident using the strategies they learned to help their child. The parents also showed increased use of evidence-based health services for their child after finishing the program. In general, parents felt more empowered, used more evidence-based strategies, and reduced social communication issues, indicating that the initiative was at least somewhat successful at moderating health disparities.

Magaña believes that promising future directions for research in this area include detecting disparities, understanding barriers, and developing culturally tailored interventions.

## **Presentation: Disparity Up Close: Centering the Diverse Voices of the Autism Community in a Research Framework**

**Temple Lovelace, Ph.D., B.C.B.A.-D.**, Associate Professor of Special Education, Department of Counseling, Psychology, and Special Education, Duquesne University

Dr. Temple Lovelace provided a qualitative view of what health disparities look like in the African American community. She explained that much of existing autism research is quantitative, but qualitative and participatory research is necessary to better understand what drives and perpetuates disparities among families. She reviewed the System Dynamics model, a behavioral analysis theory that aims to understand how all the parts of the system relate to each other and influence the behavior of the system over time. The model allows researchers to understand disparities at the systems level, and to correlate these disparities with desirable changes at the individual level.

Dr. Lovelace uses this model to understand the Autism Disparity Causal Loop. Her goal is to examine how health disparities in autism can begin with one variable, how that relates to other variables, which together might impact funding and access to services in particular communities. Her research team also collaborates with families and individuals to identify the systems-level causes of disparities.

For example, they determined they needed operationalized best practices to examine cultural and linguistic diversity in children with autism. Using the causal loop model, they were able to look at the impact of variables such as parent training, policies, and school drop-out. Policy loops in particular can help researchers understand the areas where funding will have the greatest impact. In this case, Dr. Lovelace found that culturally and linguistically diverse children with autism benefit when they receive early diagnosis using culturally sustaining research methods. This knowledge helps them to develop reliable and valid ASD-focused interventions for these students.

They used these models to conduct a study of African American mothers who have sons with ASD. They found that these families often do not receive an autism diagnosis from their family doctor. Instead, daycare and education providers are usually the first to suggest to parents that their young child could be on the autism spectrum. As a result, these children often take longer (up to two years) to receive a diagnosis, missing a critical early intervention window that could have improved their outcomes over the lifespan. Their mothers also typically report negative experiences during the diagnosis process. Although the presence of a therapeutic support specialist was sometimes associated with more positive interactions, mothers still experienced significant stressors and barriers to locating services, accessing insurance, and finding providers who are a good cultural fit.

As they gained a better understanding of mothers' experiences, Dr. Lovelace's team also began to look at their collaborations with school personnel. One mother felt she needed to take on a more formal role of parent advocate, not only for her own family but for others. Mothers in this study also felt that they struggled to receive accommodations through the IEP process, which is in place to ensure that children receive the services they need in school. Additionally, they faced challenges collaborating with school personnel because staff were not trained in evidence-based practices, and there was difficulty identifying if the barrier was the result of prejudice or a lack of knowledge about autism.

Dr. Lovelace reiterated that families need educational materials to better understand autism and how it affects behavior. The [National African American Autism Community Network](#) (NAAACN) organizes national town hall events to foster autism education and awareness in communities that report needing more information about early intervention, ABA therapy, school-based services, transition, advocacy,

and independent living.

Dr. Lovelace ended her presentation with recommendations for future actions. These included increasing the use of qualitative and mixed methods studies to better understand the experiences of ethnically diverse individuals and their families. She said that there is a need to increase multi-disciplinary collaborations, and advocates should aim to support evidence-based practices for both individuals with ASD and their caregivers.

## **Presentation: Using Community-Based Autism Research to Tackle Racial and Ethnic Disparities**

**Sarah Dababnah, Ph.D., M.P.H., M.S.W.**, Assistant Professor, University of Maryland, Baltimore

Dr. Sarah Dababnah emphasized the importance of families in autism research, as they are often the case managers and experience high levels of stress and financial burden. It is also well understood that parental stress and well-being is correlated with child outcomes, therefore her research focuses on the well-being of both the child and the parents. For example, she studied a group-based intervention for parents of two- to six-year-olds with autism. Dr. Dababnah found that the program significantly reduced parents' stress and that the children's behavior improved. However, she considered those parents who never joined or were unable to complete the intervention, noting that low-income families, single parents, and black families were significantly underrepresented in the program. She began to wonder how to foster inclusivity in their research.

She clarified that although racial disparities often involve poverty and limited education, health care barriers still exist even for families of color who reach higher income and education thresholds. She has found that black families often encounter racial prejudice from providers and assumptions about their access to service. Other studies have looked at related experiences among Latinx, Korean-American, and Arab-American families, all of whom face unique challenges.

Dr. Dababnah's team is building community partnerships to help document and address these health disparities in autism services. One of their goals was to increase involvement of black families in autism research. They found that common barriers include autism-related embarrassment and shame, distrust of the research process, a lack of time or interest, and literacy challenges. Providers can facilitate the health care process by offering information and supports for the children and families, highlighting the importance of inclusive research, and engaging with research teams from local communities. The research team also considered how to reach black families earlier. They used the 14-week Parents Taking Action program, which was specifically adapted for the African American community in Baltimore by adding photos of black children, recording new narrations in English (from their original Spanish), and including resources on police interactions. The study is still in the trial stage, but preliminary results already indicate barriers to recruitment and program delivery.

Dr. Dababnah has used global autism research from low- and middle-income countries and hard-to-reach populations to inform their local program development. Key takeaways from global research include engaging community liaisons to tailor interventions, training parents, and recruiting non-specialist workers. She also highlighted the importance of measuring the time needed to ensure positive to potentially shorten parent-training or offer different formats. Finally, Dr. Dababnah recommended incorporating content on trauma and stigma in the program materials.

She ended by conveying the need for future research that is inclusive of all families, culturally relevant, multilevel, and multidisciplinary. Community partnerships are essential for reaching underserved populations. It takes time to build trust in communities, to hire and train staff, and to reach those who are not already connected to services. In order to effectively pool resources and reduce redundant research efforts, there is a critical need to collaboratively support local autism research consortiums.

### **Presentation: The Color of Autism**

**Camille Proctor**, Founder, The Color of Autism Foundation; Founding Member, National African American Autism Community Network

Ms. Camille Proctor talked about her son, who was diagnosed with ASD at age 2. She found that her family's race complicated the process at every turn and that support groups did not understand the significant disparities and barriers she faced as a person of color. In response to these complex challenges, she founded [the Color of Autism Foundation](#) in 2009 to raise awareness in the African American community, erase stigma, and to help families of color navigate early intervention and services.

Ms. Proctor is careful to warn families about the importance of overcoming the community stigma of having a child with developmental disabilities. She underscores the need to fiercely advocate for their children and to provide them with the best supports and services possible. Unfortunately, autistic children of color are at perilously high risk of involvement with the criminal justice system, and Ms. Proctor highlights the importance of early advocacy and intervention for reducing these children's chances of arrest or imprisonment.

Throughout the years, she has been contacted by other advocates who want to know how they can do similar work. She formed NAAACN with the mission to support African American families who are affected by ASD. The network of community partners helps to increase awareness, screening, and treatment of autism in underserved communities.

Ms. Proctor concluded by suggesting that organizations that work with underserved communities need more funding. Researchers also need to include more people of color to help recruit for studies that directly support the African American community. Overall, the community needs a strong infrastructure of support, training, and education, with a robust investment of public funds towards resources that improve healthy, equitable communities.

### **Presentation: Addressing Disparities for Latino Families**

**Matiana M. Ovalle**, Grupo SALTO

**Jose Luis Ovalle**, Regional Coordinator Region 1, The Autism Program of Illinois (TAP) Senior Advisor, Grupo Salto

Ms. Matiana Ovalle introduced [Grupo SALTO](#), which was founded in Chicago in 2003 to increase equity in health care access for primarily Spanish-speaking Latino families who have children with disabilities. Mr. Jose Luis Ovalle added that Grupo SALTO receives support from other organizations, such as the

University of Illinois and [The Autism Program of Illinois](#) (TAP), that provide services, information, and resources.

He said that the program aims to equally educate every family member of a child with autism, including their grandparents, aunts and uncles, and cousins. Ms. Ovalle added that in 2018, there were 600 families registered with Grupo SALTO. The organization provides families with educational meetings while placing their children in art programs, music programs, childcare, and social groups.

Every month, they host culturally sensitive sessions for family members to learn about leadership and self-care. One of their most popular and cherished programs is Parents Taking Action, which was discussed earlier by Dr. Magaña. Other programs include Tu y Yo, a young adult peer mentorship program composed of college graduate self-advocates with autism. These peer mentors help adolescents and children by sharing their own experiences with autism-related issues, including bullying, misconceptions, and invisible differences. Grupo SALTO also collaborates with the Parent Leadership Support Project, which provides parents with leadership skills and self-advocacy tools. Parents can also sign up for a leadership retreat, the Growing and Looking Forward with Hope program.

Grupo SALTO also works with families at home and hold ASD-friendly monthly events such as picnics, parties, arts and crafts programs, and music events. The organization also provides semiannual autism screening events. Ms. Ovalle said that they rely on fundraising activities, donations, grants, and TAP to provide these services. With this support, they can fulfill their ongoing mission to create opportunities for families of children with ASD, provide leadership and advocacy, and ensure that young adults with autism have a voice of their own.

## **Invited Public Comment**

**Yetta Myrick**, President and Founder, DC Autism Parents, CDC's Act Early Ambassador to the District of Columbia

Ms. Yetta Myrick is a parent of a child with ASD, and she began participating in research after his diagnosis. Because her son has low verbal ability and IQ, Ms. Myrick has faced challenges participating in research. A recent analysis showed that eleven percent of research participants with ASD had an IQ below 85, and even fewer were minimally verbal. She said these disparities can be addressed by involving stakeholders whose lived experiences can inform research projects. She said that involving stakeholders at every step of the research process will ensure that autism research is accessible and integrated in the community. Ms. Myrick suggested that researchers should establish relationships with the community, attend events, connect with local support groups, and establish local advisory boards to identify each community's unique needs. She concluded that community-guided projects founded on mutual respect are the best way to ensure inclusivity and parity in autism research.

## **Committee Discussion**

Dr. Louis Reichardt pointed out that some studies, such as the [Simons Foundation SPARK cohort](#), already adequately represent Hispanic families. He said there are ongoing grant-related efforts to increase representation of other underrepresented minority groups. He also asked how, if at all, the national organizations for autism have contributed to these efforts. Ms. Proctor responded that large organizations tend to remain outsiders and they lack inclusivity. Dr. Magaña added that many autism



societies tend to be willing to work on diversity issues, but they lack the staffing capacity because they are often volunteer-based. Ms. Proctor pointed out that merely hiring people of color is not sufficient—they need to be given the voice and the platform to successfully advocate.

Dr. Elaine Hubal commented that she was especially interested in Dr. Lovelace’s presentation about the System Dynamics model. She said that this study added rigor to complex social and environmental systems, and she hopes to see similar research in the future.

Dr. Johnson provided information about the ACL’s ongoing efforts to address health disparities. They fund a national network of 67 university centers, including the University of Illinois, where she said she has heard positive remarks about Grupo SALTO. She added that they fund minority partnership grants to promote equal partnerships and build cultural competence in university centers. [The National Center on Cultural Competence](#), funded through Georgetown University, is affiliated with their network. Dr. Johnson said that they have also partnered extensively with Ms. Laura Kavanagh and HRSA to promote cultural competence and diversity training.

Dr. Schor wondered if there are any ongoing efforts to promote diversity in Ph.D. programs and to tap into this expanding talent pool. She said that some students and graduates may be interested in activities that give back to their community and wondered how they can help foster this interest. Ms. Myrick suggested that organizations could bring in community stakeholders to talk to students to raise awareness and interest about these issues. Mr. Ovalle added that Grupo SALTO has had 15 Ph.D. students return to assist their organization. Dr. Dababnah said that medical students at the University of Maryland are trained on autism, and she has been working to include further education about racial disparities in ASD. Ms. Proctor suggested that the Committee reach out to Dr. Leslie Rubin, a developmental pediatrician who volunteers to provide services to underserved communities and historically black universities.

Dr. Gordon announced that the House had just passed the Autism CARES Act reauthorization.

## **Department of Labor Apprenticeship Initiative**

**Scott Robertson, Ph.D.**, Office of Disability Employment Policy, U.S. Department of Labor

Dr. Scott Robertson co-presented with Ms. Carolyn Jones, a senior policy advisor from the Youth Policy Team at the [Office of Disability Employment Policy \(ODEP\)](#). ODEP is a non-regulatory, non-enforcement agency in the Department of Labor that seeks to promote policies and coordinate with employers to increase competitive integrated employment and workplace success for people with disabilities, including people with ASD. At its core, ODEP wants all people to have the same opportunities for access and self-sufficiency.

Ms. Jones reviewed ODEP’s [Apprenticeship Initiative](#). In general, apprenticeship combines classroom learning, on-the-job training, and credentialing processes. ODEP sees apprenticeship as a way to support people with and without disabilities, especially in times of shifting technology and job opportunities. The Apprenticeship Inclusion Models (AIM) initiative is focused on researching, testing, evaluating, and expanding inclusive apprenticeships and integrated apprenticeship training. It has received \$2 million over the last two years and works closely with emerging industries that pay a livable, sustainable wage (including Microsoft, Amazon, and the Industry Manufacturing Technician program).



Two of their pilot programs focus exclusively on youth with ASD. Dr. Robertson discussed the [Apprenti](#) program, which supports technology apprenticeships in collaboration with [PEAT](#), ODEP's technical assistance initiative. The program focuses specifically on increasing technology skills and jobs—including software development and IT positions at Microsoft and Amazon—for people with disabilities. The second program is a [Healthcare Career Advancement Program \(H-CAP\)](#), which focuses on jobs related to medical coding, community health work, and central sterile processing. These apprenticeships provide pathways for individuals with disabilities who want gainful employment but struggled to obtain post-secondary education.

ODEP also has a Technical Assistance Center specifically for employers, called [EARN](#). They provide resources that help employers connect and ensure that their workplaces are accessible for people with disabilities. They also have available resources on autism-specific information, neurodiversity, and neurodivergence. The [Job Accommodation Network \(JAN\)](#) offers free, confidential conversations with experts and provides resources for anyone who wants to help people with disabilities attain employment. They focus on include accommodative, assistive technologies that help people with disabilities maintain their jobs and achieve success in the workplace. Finally, the [Workforce Recruitment Program](#) is a collaboration with the DoD to increase student access to jobs with the federal government.

## Committee Discussion

Ms. Crane expressed concerns about disability minimum wages, and she wondered if the participants earn more than the minimum wage. Ms. Jones confirmed that all programs adhered to the Mavis Beacon Act, which requires them to pay at least minimum wage.

## Summary of Advances Discussion

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

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

Dr. Daniels provided a brief overview of what will happen with the 2019 Summary of Advances as the Committee will be going out of session. Current Committee members may continue to nominate articles by email through September 30, 2019, and members of the next iteration of the Committee will be able to nominate any other articles published in 2019.

Ms. Singer suggested that the current Committee vote for a 2019 Summary of Advances through September as a placeholder, in case there is a hiatus and the new Committee is not appointed in 2020. Dr. Daniels clarified that in this approach, the 2019 Summary of Advances would only include nine months' worth of research, while the 2020 Summary of Advances would comprise five quarters' worth of research (beginning in the last quarter of 2019 and spanning all of 2020). Dr. Gordon agreed and said he would open a discussion and a vote on this matter over email.

The Committee reviewed their [current nominations](#). [Question 1](#) deals with Screening and Diagnosis. Dr. Schor commented on a study that followed phenotypic characteristics of individuals who received an early tentative autism diagnosis, 98 to 99 percent of whom received a formal, definitive diagnosis down the road.

[Question 2](#) examines the Underlying Biology of ASD. Dr. Reichardt talked about a paper that showed that a gene deletion in the cell nucleus affects production of certain proteins, which can cause relevant autism phenotypes in rodents. Dr. Schor discussed a study about disruptions in the Shank3 gene, which may be a common etiology of autism. She also commented on Dr. Walter Koroshetz's nominated article, which uses a mouse model to compare gut microbiota from individuals with and without autism. They found that mice who received microbiota from individuals with autism began to show certain behavioral characteristic related to ASD. Finally, Dr. Gordon reviewed a study about gene expression within single brain cells. Even when obtained from postmortem tissue, two types of cells—neurons in the cortex and immune-related cells called *microglia*—show promise in helping researchers understand the origins of autism.

[Question 3](#) aims to determine Risk Factors for autism. Dr. Alice Kau reviewed a study of from five countries of the Multigenerational Familial and Environmental Risk for Autism (MINERVA) Network, which compiles the largest family-based database for autism research. The authors of this study used genetic data from more than two million individuals to estimate that the heritability of ASD is about 80 percent. The study is important for its large sample size and because previous estimates were based primarily on twin studies, therefore the findings of this study more accurately represent the general population. Dr. Cindy Lawler agreed that this is a strong study that demonstrates the challenge of communicating complex scientific findings.

[Question 4](#) targets Treatments and Interventions. Ms. Singer suggested a study that demonstrates differences between lab settings and naturalistic environments. The study showed that the same intervention had significantly different outcomes when it was implemented in a research setting versus a community setting. She discussed a second study that worked to deliver behavioral interventions in a school setting.

[Question 5](#) examines Services in ASD. Dr. Gordon reviewed two NIMH studies related to state differences in service provision and disparities. One looked at spending based on high-deductible insurance plans, while the other focused on racial disparities in access to Medicaid waivers. When Home and Community Based Services (HCBS) waivers are made more available throughout the state, there is a decrease in existing disparities between white and black Americans. Furthermore, unmet needs of black children with ASD are cut in half.

[Question 6](#) focuses on Lifespan Issues among people with autism. Dr. Taylor reviewed a study of 200 young adults on the autism spectrum and their experience with the “services slope.” The study found that rather than ending service access abruptly after leaving high school, service use began to drop off gradually in the years before high school exit. However, young adults with intellectual disability were more likely to retain services throughout high school and suddenly drop them immediately after leaving high school. For all young adults with ASD, with or without intellectual disability, service use continues to decline after high school.

Finally, [Question 7](#) deals with Infrastructure and Surveillance. Ms. Singer talked about a meta-analysis that shows that although the CDC reports that half of people with autism also have intellectual disability, only 6 percent of participants in autism research are identified as having an intellectual disability. As a result, researchers need to find new ways to broaden inclusion criteria to ensure that adults with more severe forms of autism and intellectual disability are represented in the research.

## Round Robin

Ms. Singer discussed a survey from the [Autism Science Foundation](#) and the University of Pennsylvania. The [Experience of People Enrolled in Clinical Trials \(EXPECT\) Survey](#) aims to understand the factors that motivate people to participate in autism research and, on the other hand, what drives them to quit. The goal is to help scientists develop more positive, inclusive studies with practical outcomes. Dr. Daniels confirmed that an accessible weblink is posted on the IACC website and was included in the last OARC newsletter. Ms. Singer added that they also have two upcoming stakeholder events. They are running two Autism TED Talks in San Francisco and New York City in October 2019 and March 2020, with keynote addresses from Dr. Tom Insel and Dr. Louis Reichardt.

Dr. Marcy Ronyak announced that the [Indian Health Service \(IHS\)](#) recently hired a Maternal-Child Health Consultant, Dr. Sharon McKernan, who will conduct site visits and talk about screening for autism. Dr. Ronyak added that IHS has also partnered with Autism Speaks to develop their own ECHO [Environmental influences on Child Health Outcomes] project for autism.

Dr. Kau reiterated that [NICHD](#) has ongoing interest in supporting research that involves individuals with intellectual disabilities.

Dr. Johnson updated the Committee about new funding opportunities. One is called [Human Dignity and Civil Rights for People with Disabilities](#), a three-year cooperative agreement that will focus on disparities in access to health care, transplants, mental health referrals, prenatal counseling, and other issues that affect people with intellectual and developmental disabilities. The second opportunity is a planned grant to support decision-making across the lifespan. They are collaborating with the Administration on Aging to identify gaps in policies that promote decision-making and self-determination in communities of aging disability groups.

Dr. Nicole Williams briefly talked about the Autism Research Program. They are finalizing their [awards from fiscal year 2018](#) and will continue to accept grant award applications for the next few weeks.

Dr. Schor said that the [National Institute of Neurological Disorders and Stroke \(NINDS\)](#) is involved in strategic planning for the next five years with a general goal of promoting partnerships with other institutions and organizations for intellectual disabilities and autism.

Dr. Lawler announced two recent grant awards from the [National Institute of Environmental Health Sciences \(NIEHS\)](#). One is a study of the association between air pollution and autism risk with a focus on health outcomes and susceptible windows during gestation. The other is an eight-year project that aims in part to address the time-intensive nature of grant writing. She mentioned that one investigator under this project is currently developing methods to identify environmental use of chemicals that interact with molecular pathways that may have genetic implications for autism.

Dr. Shapira announced that the [National Center on Birth Defects and Developmental Disabilities \(NCBDDD\)](#) is undergoing reorganization, to be implemented October 1, 2019. Their goal is to align similar topic areas in two divisions of the National Center (the Division of Congenital and Developmental Disorders and the Division of Human Development and Disability), poising them to leverage scientific and administrative expertise to maximize program activities and resource management.

Dr. Reichardt talked about ongoing activities at [the Simons Foundation](#). The [SPARK recruitment project](#) has enrolled nearly 200,000 individuals (about half of whom have autism). He also noted that their ResearchNet program, which helps scientists apply for research studies, has had a very high response rate. They have signed contracts for early phase studies of R-Baclofen. Finally, [Autism Brain Net](#) has begun the process of distributing tissue for neuroimaging.

Ms. Crane said that the [Autistic Self Advocacy Network \(ASAN\)](#) recently published a community living [toolkit](#) based on a summit that included self-advocates with a variety of support needs. The toolkit is a recommendation for future research on community living, and two more are being produced by the National Council on Disability. One examines the role of quality-adjusted life-years in treatment decision-making, and the other examines discrimination in organ transplantation decisions.

Dr. Gordon again thanked the Committee for their service over the years, and also thanked Dr. Daniels and the OARC staff for their work.

Dr. Daniels thanked the Committee members. She noted that if the new bill as currently written passes the Senate, four new departments may join the IACC: the Department of Labor, the Department of Housing and Urban Development, the Department of Justice, and the Department of Veterans Affairs. As always, they are committed to securing inclusive representation across the United States and across the entire autism spectrum, including stakeholder, community, and professional groups.

## **Closing Remarks and Adjournment**

Dr. Gordon thanked the Committee and adjourned the meeting at 5:05 PM.