U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, APRIL 19, 2016

The full Interagency Autism Coordinating Committee (IACC) convened in Bethesda, Maryland, at the National Institutes of Health (NIH), Building 31, C Wing, 6th Floor, 31 Center Drive, Conference Room 10, at 9:02 a.m., Bruce Cuthbert, Ph.D., Chair, presiding.

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., JB Autism Consulting

JAMES BATTEY, M.D., Ph.D., National Institute on Deafness and Other Communications Disorders (NIDCD)

JOSIE BRIGGS, M.D.(for Francis S. Collins, M.D., Ph.D.), National Center for Complementary and Alternative Medicine

SAMANTHA CRANE, J.D., Autistic Self Advocacy Network

GERALDINE DAWSON, Ph.D., Duke University

RUTH ETZEL, M.D., Ph.D., Environmental Protection Agency (EPA)

TIFFANY FARCHIONE, M.D., U.S. Food and Drug Administration (FDA)

AMY GOODMAN, M.A., Self-Advocate

MELISSA HARRIS, Centers for Medicare and Medicaid Services (CMS)

SHANNON HAWORTH, M.A., Association of University Centers on Disabilities (AUCD)

JENNIFER JOHNSON, Ed.D. (for Commissioner Aaron Bishop, M.S.S.W.), Administration for Community Living

LAURA KAVANAUGH, M.P.P., Health Resources and Services Administration (HRSA)

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

CINDY LAWLER, Ph.D. (for Linda Birnbaum, Ph.D.), National Institute of Environmental Health Sciences

DAVID MANDELL, Sc.D., University of Pennsylvania

BRIAN PARNELL, M.S.W., C.S.W, Utah Department of Human Services

KEVIN PELPHREY, Ph.D., George Washington University and Children's National Medical Center

EDLYN PENA, Ph.D., California Lutheran University

LOUIS REICHARDT, Ph.D., Simons Foundation Autism Research Initiative

ROBERT RING, Ph.D., Autism Speaks

JOHN ELDER ROBISON, College of William and Mary

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)

STUART K. SHAPIRA, M.D., Ph.D. (for Cynthia Moore, M.D., Ph.D.), Centers for Disease Control and Prevention, Atlanta, Georgia

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

LARRY WEXLER, Ed.D., Department of Education

NICOLE WILLIAMS, Ph.D., Department of Defense (DoD) (attended by phone)

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PROCEEDINGS

DR. CUTHBERT: Good morning, everyone. I think we are ready to get started. Welcome to the second meeting of the IACC for calendar year 2016. I am Bruce Cuthbert, the Acting Director of the National Institute of Mental Health. Welcome to all of you.

We have a very full and packed and productive agenda today. And I really look forward to these discussions. I want to thank our IACC committee, our office chair at NIMH, Dr. Susan Daniels, for all of her work to put this agenda together. And I simply have the luxury of chairing this meeting, which is a pleasure and a privilege.

So I think we will just get started right away. And our first activity is, in fact, to call the roll to make sure we are all here. So, Susan, I will turn that over to you for that.

DR. DANIELS: Good morning. So we are ready to take the roll. Bruce Cuthbert --

DR. CUTHBERT: Here.

DR. DANIELS: -- is here. Jim Battey or Judith

Cooper?

DR. BATTEY: I am here.

DR. DANIELS: Jim, hi. Cindy Lawler?

DR. LAWLER: I am here.

DR. DANIELS: Jennifer Johnson?

DR. JOHNSON: Here.

DR. DANIELS: Josie Briggs?

DR. BRIGGS: I am here.

DR. DANIELS: Ruth Etzel will not be joining us today, I believe. Tiffany Farchione?

(No response.)

DR. DANIELS: Melissa Harris?

(No response.)

DR. DANIELS: Elisabeth Kato?

(No response.)

DR. DANIELS: Laura Kavanagh?

DR. KAVANAGH: Here.

DR. DANIELS: Walter Koroshetz?

(No response.)

DR. DANIELS: Stuart Shapira --

DR. SHAPIRA: Here.

DR. DANIELS: -- for Cindy Moore? Linda Smith or Shantel Meek?

(No response.)

DR. DANIELS: Cathy Spong?

DR. SPONG: Here.

DR. DANIELS: Larry Wexler?

DR. WEXLER: Here.

DR. DANIELS: And Nicole Williams?

DR. WILLIAMS: Here.

DR. DANIELS: For the Federal members. For public members, David Amaral?

DR. AMARAL: Here.

DR. DANIELS: Jim Ball?

DR. BALL: Here.

DR. DANIELS: Samantha Crane?

(No response.)

DR. DANIELS: Geri Dawson?

DR. DAWSON: Yes.

DR. DANIELS: Amy Goodman?

MS. GOODMAN: Here.

DR. DANIELS: Shannon Haworth?

MS. HAWORTH: Here.

DR. DANIELS: David Mandell?

DR. MANDELL: Present.

DR. DANIELS: Brian Parnell?

MR. PARNELL: I am here.

DR. DANIELS: Kevin Pelphrey might be joining us by phone. Edlyn Peña?

DR. PENA: Here.

DR. DANIELS: Louis Reichardt?

DR. REICHARDT: Here.

DR. DANIELS: Rob Ring?

DR. RING: Here.

DR. DANIELS: John Robison?

MR. ROBISON: Yep.

DR. DANIELS: Alison Singer?

MS. SINGER: Here.

DR. DANIELS: Julie Taylor?

DR. TAYLOR: Here.

DR. DANIELS: Do we have anybody on the phone?

(No response.)

DR. DANIELS: Maybe not right now. And some of these other folks may join us a little bit later. Thank you.

Actually, the next order of business that maybe I will take you through is just the approval of the minutes. I sent out draft minutes to the Committee. Does anyone have any discussion of the minutes that needs to take place before we look to approve?

(No response.)

DR. DANIELS: Hearing none, can we get a vote on how many people would like to approve the minutes? All in favor?

(Ayes.)

DR. DANIELS: Any opposed?

(No response.)

DR. DANIELS: Any abstaining?

(No response.)

DR. DANIELS: So the minutes are approved and will be posted to the IACC website shortly. Thank you.

DR. CUTHBERT: Thank you, Susan.

I just want one reminder whenever you have something to say, please remember to turn on your microphone and then turn it off again afterwards so we don’t get microphone overload. Our transcribers having difficulty seeing everyone around the table. And, of course, as usual, all of our activities are transcribed for the minutes. So please remember to do that. Thank you.

So now it is my distinct pleasure to introduce Dr. Thomas Novotny, who has joined HHS relatively recently as the deputy assistant secretary for health in the particular areas of science and medicine.

We have had several conversations already about his activities with respect to ASD. And we are delighted to have him with us this morning. So we are going to give him a chance to make a few introductory remarks. We will go around and let you all introduce yourselves a little bit more extensively to Dr. Novotny. And then we can have a brief Q&A with the Committee after that.

So, Dr. Novotny, welcome. We are glad to have you here.

DR. NOVOTNY: Thank you, Bruce and Susan. And good morning, everybody. I am delighted to be here. And though I rejoined HHS just recently, in

January, I was here 15 years ago and had a 23-year history of work in the Federal Government. And so I am delighted to be back, actually. It is an honor to be a part of the Obama administration here again. Even though it is only going to last another nine months or so, it is truly an honor for me to be back in Government.

In fact, President Obama proclaimed April 2nd as World Autism Day, as you know. And in that proclamation, he encouraged all of us to support people with ASD and their families and to help shape a world in which all people are able to lead lives filled with opportunity and are accepted for who they are. So I am delighted to be a part of this activity.

I am pleased to be here with you just a couple of weeks after that proclamation and let you know a little bit about my new role and to hear more about what the work of the IACC is and to recognize National Autism Month.

So let me first say that there is an awful lot of Government activity related to Autism Spectrum

Disorder. It’s ongoing and robust. I have really learned a lot over the last, oh, two months or so talking with many of my colleagues across the department and other departments as well. And, in particular, this Committee with its new leadership, Dr. Cuthbert, and exceptional stewardship by Susan Daniels -- I think you will all agree with that -- there has just been a lot of good progress, not just in research but in other areas as well.

So in preparation for this meeting, I’ve come to appreciate again the breadth of ongoing ASD work, activities as well as funding challenges and program priorities and some of the challenges in the gaps that you all have become aware of.

So, in addition to being the deputy assistant secretary for health with the subtitle “Science and Medicine,” I have also been designated as the national autism coordinator. So this appointment was recently announced; in fact, just last Friday at 5:00 p.m. And that doesn’t get a lot of press detection usually at that time of the day, but this is in response to the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014. This is otherwise known as the Autism CARES Act. This is in order to enhance, this appointment was made to enhance, coordination efforts across HHS and with other departments as well to better address the needs of people on the autism spectrum and their families across U.S. Government activities.

So the coordinator is responsible to be an existing Federal official to implement ASD activities and to ensure that the efforts of HHS and other Federal agencies are coordinated and not necessarily duplicative. This rule is not again necessarily one of a subject matter expert. And I will be the first to admit that I am not such an expert but, rather, a designated public health official to address this coordination challenge and the collaboration that is necessary within HHS and across Government and nongovernmental partners. So it will not supersede but, rather, complement the work of the IACC in many ways; so, for example, ensuring internal coordination within HHS.

We have got a lot of agencies working on Autism Spectrum Disorder issues from HRSA to NIMH to ACLA, you know, all of this alphabet soup of Government agencies that, even for someone like myself, it is a challenge to remember what they mean. But, nonetheless, there is just an awful lot of diversity among these agencies in the work that they do.

So I will be working with the IACC staff, Susan and others, to track progress on the seven priority areas identified in your strategic plan. I will be trying to identify areas where HHS and other Federal departments, projects, and programs can intersect. It is kind of gluing things together. And I see my role more as a facilitator than a coordinator in so many ways. I will try to assure that HHS is in compliance with the relevant statutory requirements, such as a report that I will mention in a moment here related to the Autism Spectrum Disorder work.

As appropriate, I will serve as a liaison with external groups on matters pertaining to autism, but, of course, this will not be superseding the work that individual departments and agencies work with nongovernmental partners.

As I mentioned, there is just an awful lot of work going on within the Federal Government. I don’t want to go into a great deal of detail. I know you will be hearing more about that as the day progresses. But, for instance, some of the things that I have been particularly impressed with, for instance, is the Department of Defense. One project there is the Carolina Autism Transition Study, or CATS, which is a population-based study on longitudinal outcomes of individuals identified with ASD beginning at age 8 and continuing through youth ranging in age from 16 to 22. This is going to be used to identify the predictors of specific outcomes. And this is again this transition issue that I know you are aware of and what we will be focusing on in this report that I will mention.

The Department of Education supports a lot of collaborative work on enhancing education for children and youth with ASD and other disabilities. And I was just recently informed about the Promise program, which is an evaluation project involving a randomized clinical trial to show what the impacts of interventions are on those who are eligible for SSI. It’s not just autism but the whole spectrum of the disability. But at least I think Dr. Wexler mentioned to me that seven or eight hundred individuals with ASD may be included in that sample. So that is important.

The Department of Health and Human Services has a number of programs involved. For instance, the health resources and service administration, otherwise known as HRSA, has the innovation and care integration for children and youth with Autism Spectrum Disorders and other developmental disabilities.

So this project aims to reduce barriers to screening and diagnosis. An important early intervention possibility, it will promote evidence-based guidelines on the development of these interventions and trained professionals to utilize screening tools that can diagnose and provide early evidence-based interventions.

The CDC, as you know, just published its recent surveillance report, indicating that the Autism Spectrum Disorder prevalence is 1 in 68, which is what it has been in the past. The ADDM, or A-D-D-M, Autism and Developmental Disabilities Monitoring network is the source of that information. And it monitors the prevalence of ASD across several research sites in the U.S. and supports a large study in the U.S. to help identify factors that may put children at risk for ASDs and other developmental disabilities.

We have just recently learned about an innovation grant that CDC has developed for itself, actually, to extend surveillance using technology and algorithms to expand their ability to monitor the prevalence and risk factors for ASD across the nation.

The NIH funds a broad portfolio of biomedical research to better understand the underlying biology of autism, its risk factors, diagnosis, interventions, and services for individuals on the autism spectrum. And you will hear much more about that today, I know.

The National Science Foundation also funds a lot of basic research on cognition, neuro networks, and innovative technologies, including computing, robotics, wearable sensors, and artificial intelligence that can be used to develop novel interventions that support people with autism.

So I have spent a lot of time already trying to get up to speed on autism efforts within HHS and with those of our other Federal partners, such as in the Department of Education, Department of Defense. And I'm very impressed with this range of activities and the extensive body of work focused on ASD, particularly since funding for this issue is not excessive and has not recently increased.

I see a number of folks here whom I've

recently met in person or by phone. I want to thank you for all of the time and effort that you’ve put into that provision of information. And for those of you I have not yet met, you can expect my call.

Although there are a number of pressing issues facing the autism community, everything from availability of services and insurance coverage to the very troubling issues of wandering and seclusion and restraint, a large part of my role is to focus on the area of transition, the time between youth and adulthood where the least research and interventions have yet been reported.

In fact, the CARES Act requires production of a report on youth and young adults with Autism Spectrum Disorder who face challenges related to the transition, from school-based services to those needed during adulthood. I know that most of you or many of you are very, very interested in this particular aspect of autism.

Unfortunately, that report requirement is no accompanied by funding from Congress. That said, I am now engaging a group of Federal experts from across HHS particularly to produce an interim document that will not only emphasize what we are already doing to address the needs of this population but to identify areas, whether policy-related, programmatic, or research-based, that need further attention. So we are going to do our best on this report with the resources that we have in-house.

For now, let me just say how truly honored I am that Secretary Burwell has charged me with this important responsibility. And I am particularly happy that the appointment coincides with National Autism Awareness Month.

And on Friday last week, Aaron Bishop, the head of HHS's Administration for Community Living, where much autism work is being done, and I wrote a blog on the HHS website to recognize and emphasize HHS commitments on ASD activities. In that blog, we reflect on how we want to move beyond simply being aware that ASD exists but to create real acceptance and raise expectations for improved care and support for people with ASD.

Aaron and I agree, as I am sure all of you do in this room, that the time is right to strengthen efforts to ensure that people with autism are integrated into every aspect of community life and are appreciated for all of their contributions.

As a society, we are all better off when everyone is given such opportunities. That sentiment is being echoed in some unexpected places. Last week, I read an article in the Economist that was entitled "Beautiful Minds Wasted: How Not to Squander the Potential of Autistic People." This article supported what you already know, that the significant economic cost and social cost associated with autism might be mitigated with wide-ranging strategies from early screening, diagnosis, appropriate treatment, and intervention and ultimately to independent living and job placement.

So this task is not an impossible one, but it certainly is a tough one. Much work is already being done, and much is left to do. However, through this IACC and the Federal agencies that are working diligently on Autism Spectrum Disorder and the nongovernmental organizations with whom we partner, we can, in fact, strive to not only increase awareness, which was done very specifically by the CDC last week with the accompanying press releases, but to expand support for ASD research and services portfolios within the Government.

So I want to thank you for allowing me to come this morning and introduce myself. And I look forward to meeting many of you as we go forward over this next year and beyond, I hope. So I thank you very much. And I look forward to hearing much more about ASD from this Committee. Thank you.

DR. CUTHBERT: Thank you very much for that succinct and thoughtful summary of some of the many activities going on across the Government, Tom. And, again, welcome.

I think you can tell, those of you who have not met Dr. Novotny, just from his speech how very approachable he is. We have waited a long time for an autism coordinator to be named. And I think you'll agree with me that we can feel very fortunate that Dr. Novotny was the person who was, in fact, nominated and assigned to this position.

So, again, we are very glad to have you here.

DR. NOVOTNY: Thank you very much.

DR. CUTHBERT: We are happy to have you.

So, as I mentioned, now I would like to have us just go around the table and introduce each of you to Dr. Novotny. I know some of you had met him already. If you could just briefly state your name, where you are from, and the nature of your connection with ASD and with this Committee? And that would be useful.

And, Ms. Haworth, we will start with you. And, again, thank you for remembering to turn on your microphone.

MS. HAWORTH: Good morning. I am Shannon Haworth. I am a public health program manager at the Association of University Centers on Disabilities. And my connection to autism is I have a young child with autism and some comorbid mental health issues. And I also have a spouse with autism.

DR. WEXLER: Good morning. Larry Wexler from U.S. Department of Education, the Office of Special Education. I direct the Research to Practice Division, which has oversight over all of the discretionary grants in special education and early intervention. Thank you.

DR. LAWLER: Hi. I am Cindy Lawler, here representing National Institute of Environmental Health Sciences. Our institute funds research that looks at the contribution of environmental risk and protective factors for autism. So I manage a portfolio of grants in this area as well.

DR. MANDELL: Hi. I am David Mandell. I am at the University of Pennsylvania, where I study the organization financing and delivery of care to people with autism.

DR. TAYLOR: Hi. My name is Julie Taylor from Vanderbilt University. And my research is focused on the transition to adulthood for people with Autism Spectrum Disorders, not only how they are affected by this transition, and their families, but also how do we promote more positive transition outcomes.

DR. NOVOTNY: We will be in touch.

DR. TAYLOR: All right. We have a lot of overlapping interests, I think.

DR. FARCHIONE: Hi. I am Tiffany Farchione. I am the Deputy Director of the Division of Psychiatry Products at FDA. And if there were to be any medications approved for the treatment of autism or its symptoms, it would go through me.

DR. PENA: Good morning. I am Edlyn Peña from California Lutheran University. And my research focuses on the transition from high school to college for students on the spectrum and outcomes in college and how to support them.

MS. CRANE: Hello. My name is Samantha Crane. I am the Director of Public Policy at the Autistic Self Advocacy Network. We focus on advocacy for greater research and supports, especially for long-term services and supports, inclusion in the community, and the transition to adulthood.

DR. BALL: Good morning. My name is Jim Ball. I am the President and CEO of JB Autism Consulting. I work with individuals, agencies, schools, and clinics that provide services for people on the spectrum. And I am also the Executive Chair of the National Autism Society's Board of Directors.

DR. KAVANAGH: Good morning and welcome, Dr. Novotny. I am Laura Kavanagh. I am with the Health Resources and Services Administration. You met with several of my colleagues already. We support interprofessional education, autism intervention research, and states' grants to develop systems of care.

DR. AMARAL: Good morning. David Amaral. I am a neuroscientist and professor at the University of California, Davis. I am also the Research Director of the MIND Institute, a center dedicated to studying autism and neurodevelopmental disorders. My own research is interested in examining longitudinal studies of biological, behavioral features and outcome measures of individuals with autism spectrum.

DR. WILLIAMS: Hi. Nicole Williams. I am the Program Manager with the Autism Research Program within the Department of Defense.

DR. BRIGGS: Hello, Dr. Novotny. My name is Josie Briggs. I am the Director of the National Center for Complementary and Integrated Health here at the NIH and the Interim Director of the Precision Medicine Initiative. And I have the honor of representing Dr. Collins on this Committee.

DR. SHAPIRA: Good morning. I am Stuart Shapira. I am representing the National Center on Birth Defects and Developmental Disabilities at the CDC. I serve as the Associate Director for Science and the Chief Medical Officer for the center. And I am trained as a pediatrician and as a clinical geneticist.

DR. RING: Good morning. I am Rob Ring, most recently the Chief Science Officer at Autism Speaks but also served as the head of the Autism Research Unit at Pfizer Global Research and Development before that, that position.

MS. HARRIS: Good morning. I am Melissa Harris from the Centers for Medicare and Medicaid Services. And I am a senior policy adviser in this context focusing on the provision of Medicaid-funded services to individuals with autism. Thanks.

DR. REICHARDT: Yes. Louis Reichardt. I direct the Simons Foundation's Autism Research Initiative, which the focus is to support science that will increase our understanding of both the risk and causes and eventually treatment of autism. My background is in molecular neuroscience. I was many years at UC-SF.

MS. SINGER: I am Alison Singer. I am the co-founder and President of the Autism Science Foundation. I also have a 19-year-old daughter with autism as well as an older brother with autism. Both my daughter and my brother are severely affected by their autism. My daughter is minimally verbal. My brother is nonverbal. They both have aggressive and self-injurious behaviors and also both have intellectual disability. So our foundation raises money to fund research, but we are focusing on those individuals with autism who are most severely affected by their autism who are not able to come to meetings like this and advocate on their own behalf but who rely on their family members and parents to speak on their behalf.

MR. ROBISON: I am John Elder Robison. I am an autistic adult. And I am the parent of a 26-year-old autistic son. I guess sitting here beside Alison, I represent the other end of the autism spectrum, but I share, Alison, in some of your concerns about the fact that people who are not able to speak for themselves in our community tends to be overlooked and marginalized. But I certainly am keenly aware of the need for support.

I teach neurodiversity at William and Mary. Where many of my colleagues here on IACC work in medical research in autism, we have the first program to teach neurodiversity, really, in a major American university.

And one of the things I kind of stand for her at IACC is the idea that we autistic people should be taking charge of our destiny, you know. And to the extent the Government is here to help, I believe it is our role to provide guidance and oversight because we are the population that ultimately will benefit from this and that is seeking help. And I guess I point you to some of my younger autistic colleagues that I hope are going to do that because I am kind of the old dog of this now, you know. I am the oldest autistic one of us.

(Laughter.)

DR. NOVOTNY: Welcome to the club. Thank you.

DR. DAWSON: Well, welcome. It is a pleasure to meet you. I am Geri Dawson. I am both a scientist as well as a practicing licensed clinical psychologist and see people with autism in the clinic every week. I have been in the field a long time. My own research is in the area of early detection, early intervention, and brain development and function. And I am the Director of the Duke Center for Autism and Brain Development and a professor at Duke. I am also President of the International Society for Autism Research.

DR. JOHNSON: Good morning. I am Jennifer Johnson with the Administration for Community Living, Administration on Disabilities and we spoke on the phone a few weeks ago. ACL is focused on long-term services and supports that support community living for people who are aging and people with disabilities. So, broadly, our agency focuses on that. And our work has an impact on people with autism.

MR. PARNELL: Good morning. I am Brian Parnell. I am with the Utah Department of Human Services in the Division of Services for People with Disabilities. I oversee programs that offer supports for people with intellectual disabilities and related conditions, including autism. We provide supports to about 6,000 people who live throughout Utah and are operating in home and community-based supports.

DR. BATTEY: Good morning. I am Jim Battey. I am the Director of the National Institute on

Deafness and Other Communication Disorders. And we support a portfolio of grants that focuses on autism as a communication disorder.

MS. GOODMAN: Hello. I am Amy Goodman. I am a self-advocate from West Virginia. I was the Director of Autism Now, but, unfortunately, I am now looking for a new job. I am in the process of looking for employment and finding it very discouraging. Being on the spectrum myself, it is difficult to find work.

DR. SPONG: I am Cathy Spong. I am the Acting Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development here at the NIH.

DR. CUTHBERT: Okay. Thank you, everyone. Dr. Novotny, I am sure you can see the breadth of expertise and interest and experiences on this Committee. So it is really a very integrated body.

DR. NOVOTNY: Thank you, everyone.

DR. CUTHBERT: So we have time now for questions for Dr. Novotny. He obviously indicated a lot of interest in the areas, and I know many of you have comments and questions. So we will open the floor.

MR. ROBISON: One thing I guess I would like to speak to as a representative of Health and Human Services, if we had a problem that was of great concern to the Jewish community in this country, I don’t think there is any question that we would look to the Jewish leadership in America for guidance as to how the U.S. Government should act to resolve the problem. I think that if you agree with that thinking, which I would like to think everyone in this room would subscribe to, that the Jewish leadership should oversee Jewish destiny here, I think the argument that autistic people should oversee autistic destiny is exactly the same.

One thing that concerns me is that we don’t have any good mechanism for identifying and developing autistic leadership to facilitate that. If I ask any of you in this room, who are the Jewish leaders in your community, even if you don’t know who they are, you can quickly look them up. You can determine. You can determine that in a moment. If I ask you who the autistic leaders are, no one knows. And, yet, the population of autistic people and Jewish people is roughly the same in the United States.

I guess I wonder what you might see the Government as being able to do to help build this leadership, encourage it, and bring them into positions in Government, where we can provide the sort of guidance for our population that other groups, like Jewish folks, do today.

DR. NOVOTNY: Well, that is a challenging question and one that I don’t have a quick answer for, but I do know that the U.S. Government does, in fact, guarantee the rights of access to employment for those with disabilities. And I would assume that this would apply in the case of Autism Spectrum Disorder as well.

But I think what really is at the heart of your question is how best to get the ear of those who could make decisions and provide programmatic support. You know, I know I am going to be asked to speak with members of Congress. And I know that they have ears that must listen and provide sort of encouragement to those of us in the administration to do what we can to involve those with the issues that we are dealing with.

ASD is perhaps under-served, as you point out, but is something that I think we can look to improve if we have the administrative mechanisms to do so. And that means funding at times. But I do think that the CARES Act intends for us to have more of a role in coordinating this response.

So all I can say is that we will give it a try to see if we can't do a better job on this and appreciate the astute finding that you reported here today about the sort of need for direct involvement of those affected by the policies that we have.

So I just want you to know that we will be listening and that I would be honored to have a longer conversation with you about how this might work. So let's open that up for the future as well. Okay?

MR. ROBISON: Thank you.

MS. CRANE: Actually, John’s comment is a good segue into one of the things that we have been advocating on, which is the LEND programs. These are great programs that are authorized by the Autism CARES Act to create interdisciplinary centers in universities to study autism. And they include people who are training to be occupational therapists, educators, psychologists, neurologists, really anyone who could be connected to the autism spectrum.

We have in the Autism CARES Act a requirement that these LEND programs engage in active efforts to improve the cultural diversity and cultural competency of the LEND programs. And we would like to and we have been advocating for interpretation of that that includes an active effort to make sure that the LEND programs enroll autistic individuals. And that includes people across the spectrum who are either studying for a degree or in any kind of undergraduate program that could participate in the LEND program.

We think that would actually be very useful to developing autistic leadership. And we would love if we could get further guidance explaining that the LEND program should be engaging in active efforts to recruit autistic.

PARTICIPANT: And who are you?

MS. CRANE: Oh. I am Samantha Crane from the Autistic Self-Advocacy Network.

DR. CUTHBERT: Tom, did you want to reply to that? We have another comment from --

DR. NOVOTNY: No. Again, it is another one of these efforts that I would like to learn a bit more about. So I would appreciate any inputs on that as possible.

DR. CUTHBERT: Okay. Dr. Kavanagh?

DR. KAVANAGH: Samantha, as the head of the agency that funds the LEND programs --

DR. CUTHBERT: Again, sorry. Can you mention your name? Oh, okay. Can you just mention your name again, Laura?

DR. KAVANAGH: This is Laura Kavanagh.

We actively support having both the self-advocates as trainees and faculty in our LEND programs as well. And let me know how we can better provide clarity about that in our communications as well.

One of the project officers for LEND is also here, Robin Schulhof.

DR. DAWSON: So I want to just briefly mention --

DR. CUTHBERT: Sorry. If you can state your name for --

DR. DAWSON: Oh, I am sorry. This is Geri Dawson. I wanted to briefly mention a report that came out a few months ago from the U.S. Preventative Services Task Force that pertained to whether there is benefit in providing universal autism screening. As you may know, that task force concluded that there wasn't enough evidence to support either for or against universal autism screening.

I wanted to convey sort of on behalf of the International Society for Autism Research, if I may, that the scientific and clinical community, many disagree with that conclusion. And we are very concerned that the effect of this will be that, particularly for the general pediatrician who is very busy, that this will be a reason not to provide universal autism screening, which we have been able to show through research does lead to earlier diagnosis and also earlier access to intervention. And we know that early intervention improves outcome.

Then one other point, which I made in an editorial I wrote in JAMA in response to this, is that universal screening also effectively reduces disparities in access based on racial and ethnic background. So I would just like to make that point. And I would hope that your department would seriously look at those recommendations and think about how we might counteract the negative impact that they might have.

DR. NOVOTNY: Right. I am very aware of the controversy in the impacts if they stem from U.S. Preventative Services Task Force, but at the same time, you know, there was not an attempt to say that screening is not worthwhile, that it is not something that is done. I know what the impact of a lukewarm recommendation might be, but at the same time, I think that there is plenty of agreement that early intervention is completely indicated and that we need to improve our screening mechanisms perhaps further.

I know that there are tested screening tools that the American Academy of Pediatrics recommends. And these things are certainly I think going to be used and should be used, but as the strict sort of approach that the U.S. Preventative Services Task Forces uses, Clinical Preventative Services Task Forces uses, we have to respect that as well, but it is something that will change over time. And with evidence, that is what is important for us to continue to support.

So I think the common sense approach is something that is also something that can be supported, but we have an obligation to review the evidence and coldly and as calmly as possible but also to do it is the right thing at the same time.

So I don’t think it is going to be exclusive of recommendations going forward, and I am sure things are going to change as time goes on. It is a dynamic process.

DR. CUTHBERT: Okay. One more question. Ms. Haworth?

MS. HAWORTH: It is more of a comment than a question. I know that you are aware, but I just wanted to bring up that I have a child with autism. And I would like him to grow up to be an independent adult, and like the self-advocates on this panel, but families are struggling to have services for their children and support for themselves. I just really want to make you aware of that.

Also, with the LEND program, I am a former LEND trainee in the family discipline. It really was a great program to help me to learn how to advocate for my child as a professional and as a family member. I just wanted to make you aware, you know, especially with mental health challenges and wandering and things of that nature, parents are really struggling.

We don’t want to, I don’t want to, have a guardianship of my child. I want him to be an independent adult and to be able to work because I believe that he can do that, but we need supports as families to be able to get to that point.

DR. NOVOTNY: I hear you. Thank you very much for that comment. Just, again, my background is that of a family physician. I took care of lots of families. And several of them had people on the Autism Spectrum Disorder. So I understand what you are saying. It is not that distant from my background and interest as well. So thank you very much for that comment.

DR. CUTHBERT: Thank you, all. You can see that we can look forward to an engaging dialogue with Dr. Novotny in the months ahead on a wide range of issues relevant to the spectrum.

So we are ready to start for our formal presentations today. I just wanted to give you a little highlight of what is ahead. First of all, up next will be Stuart Spielman from Autism Speaks giving us an update on several new laws and administrative policies. After that, we will have Scott Robertson, a policy advisor from the U.S. Department of Labor, talking about integrated employment for individuals with disabilities, clearly very relevant to many of the concerns that we have and have already been expressed today. Then after lunch, we will, in fact, have an update on wandering research, also an important topic that has been mentioned, with Wendy Fournier from the National Autism Association; Paul Lipkin from the Interactive Autism Network; and Kiely Law, also from the Interactive Autism Network. And, finally, at 2:50, we will have a panel on adult therapies for ASD, which will include Shaun Eack from Pittsburgh and our own John Robison from William and Mary. And that should be a very interesting discussion as well. So you can see we have really made a focused effort this year with Susan's leadership to address some of these concerns about adults on the spectrum in our deliberations. So that continues today.

So, with that, I am pleased to introduce Stuart Spielman from Autism Speaks. He will be giving us an update on the ABLE Act, Avonte’s law, and some new information about the Federal Employees Health Benefits Program. So, Stuart, welcome.

MR. SPIELMAN: Thank you, Bruce.

I am Stuart Spielman. I am Senior Policy Advisor and counsel for Autism Speaks, but my most important position is that I am the father of a 21-year-old son on the spectrum who is nonverbal and has an intellectual disability. That is my primary source of information about autism.

I am going to be speaking about a law, a bill, and an administrative policy change. Let me start with the law.

So, to pivot from some comments before, people and families on the spectrum are often struggling financially and in other ways. One of the interests that I have -- I am a tax lawyer by training -- is the issue of poverty and the economic struggles that individuals with autism and their families face.

I am not sure if we had very good metrics for these struggles. We have some studies. We have some data that applies generally to the disability population. We know from the Census Bureau, for instance, that the income poverty rate; that is, one measure of poverty, income poverty rate for people with a disability is about twice that, more than twice that, of individuals without a disability.

We also know that a lot of programs are means-tested, acid-tested programs, like SSI. A lot of people in the autism community rely on SSI, and SSI has a $2,000 resource limit. This obviously can discourage individuals from getting jobs and fully participating in the community.

So this brings me to the ABLE Act. Again, I think it is important to frame the ABLE Act and to look at the context in which the ABLE Act and what a lot of the advocates were thinking.

We know that individuals who are college-bound have a way of providing for their futures for that important transition period. But for people with disabilities, this has been a real challenge. We know that there is a very strong resource base for college-bound kids. College savings programs nationwide, the accumulated assets in these programs is over a quarter trillion dollars. This is an enormous sum of money that has changed the college landscape, but until recently, we really haven’t had anything for the disability community that is like college savings accounts. This changed a couple of years ago when the Stephen Beck, Jr. Achieving a Better Life Experience Act, known as the ABLE Act, became law.

So what do ABLE accounts do? What does the act do? The act allows states to establish programs under which an account may be created by or for an individual with autism or another disability. As I said, these accounts are modeled after college savings accounts, and they allow people to save for disability-related expenses.

The critical feature about these accounts is that they do not interfere with means-tested

Federal programs like SSI and Medicaid. They don’t force a choice on individuals between these programs and saving money. They allow an individual to do both.

So who is eligible for an ABLE account? An individual must be disabled before age 26. The age of diagnosis is irrelevant. The disability must be before age 26. An individual must be entitled to benefits under Title II, SSI or Title XVI, SSDI, or the Social Security Act, or file a disability certification under guidance provided by the IRS. These two portals are essentially the same as far as standards of the severity of disability.

So there are many, many rules on these accounts, not surprising given that the ABLE accounts are tax provisions. An eligible individual may have only one ABLE account. This is different than in the college savings landscape.

The beneficiary of an ABLE account owns the account. Again this is different than the college landscape, where there can be different owners.

Total annual contributions may not exceed the

Federal gift tax exclusion, which is currently $14,000. Again this is a difference from the college savings landscape.

Aggregate contributions may not exceed the state limit for college savings accounts. Those limits are fairly high. They can range up to I believe $400,000 in a state like Alaska.

When an ABLE account beneficiary who receives Medicaid benefits dies, amounts remaining in the account may be subject to a claim for medical assistance paid on behalf of the beneficiary.

So ABLE accounts are focused on individual needs. Wealth transmission, generational of wealth transmission may not be the primary focus of ABLE accounts.

Now, the last rule is actually a new rule. A resident of one state can open an ABLE account in the resident’s home state or any other state. So this is much like the landscape for college savings accounts, where there is no restriction, where individuals can shop around, find the account that is best for them.

The one thing that may -- well, there may be several reasons why an individual may want to have an ABLE account in his or her own state. One of the reasons may be that we have seen tax incentives develop around ABLE accounts, state tax incentives. So there are any number of reasons why an individual may choose to have an account in his or her home state or in another state.

So ABLE accounts can be used for many, many different disability-related expenses. Here is a listing. You can see how broad this is. They can be used for education, just like college savings accounts can be used, but they can also be used for other things that may be needed by a person with autism or another disability. The Internal Revenue Service has put out some proposed guidance, and they have given some indication of what is permissible. So a device like the one I have in my pocket, called an iPhone, might be permissible if that device was, let’s say, a communications tool for an individual with a disability.

So where are we on implementation of ABLE? As you can see from the map, most states have actually gone ahead and authorized state ABLE programs. This is rather remarkable when you consider that it is April 2016, the Federal Government approved ABLE, ABLE became law in December of 2014. In just a period of months, really, we have had the legal infrastructure built virtually, well, not everywhere but close to everywhere, in the country.

So, you know, all of this is nice, but when are these accounts going to become available? What we are seeing now is a change from building legal infrastructure to opening businesses. This is, you know, what we would see in any other area. First comes the legal infrastructure. Then comes the business development. And we are going to see ABLE accounts very, very soon.

On the left I have listed some of the leaders here, actually underscored one of the leaders, Nebraska, because they have some wonderful nice videos and material. Ohio is probably ahead of the pack, but we have a number of states that have shown a very strong interest in this program. Illinois is leading a consortium, a multi-state consortium, working on things like reducing program costs and sharing common obligations, such as providing information.

So where is all of this going? Well, you know, first and foremost, we are going to be seeing some accounts available pretty soon, and programs are going to be gearing up. Congress obviously likes ABLE as a platform. There are three bills pending in Congress. One bill would allow working individuals to save more money for ABLE accounts. A second bill would allow rollovers to ABLE accounts and from ABLE accounts and college savings accounts.

Probably the most common question I get from individuals, from families, is “Can I roll over the funds that I put into the college savings account that I established for my child into an ABLE account?” So the Financial Planning Act would allow that.

The third bill that is pending is an age adjustment act. As I mentioned before, the eligibility age for onset of the disability is 26 currently. This would raise that eligibility age to 46.

So I want to move on to something that is very different than financial services and financial planning. I want to move on to wandering, which is a huge issue facing many of us in the community.

So it is a horrible thing, but tragedy often brings attention to incidents that affect all of us. And one of the great tragedies was the death of Avonte Oquendo in 2014. Following Avonte’s death -- this is a young child who left his school in Queens, New York and wound up drowning -- Senator Chuck Schumer of New York introduced legislation to safeguard children with autism who wander. The legislation did not pass the 113th Congress.

Now, Senator Schumer reintroduced the bill in the 114th Congress, the current Congress. And the legislation has since been modified. It has been reintroduced by Senators Grassley, Tillis, and Schumer as Kevin and Avonte's Law of 2016. Kevin Curtis Willis was a 9-year-old boy who drowned in the Raccoon River in Iowa.

So what would this law do? What would this bill do if enacted into law? Well, it reauthorizes the expired missing Alzheimer's disease patient alert program, renames it 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 programs for education, training, to prevent wandering. It will facilitate emergency protocols, supply the first responders with additional resources, and make local tracking technology programs available for individuals. The bill also includes privacy protections to respect the civil rights of children who are wearing these devices.

So there has been a lot of recent activity on Kevin and Avonte's Law. Just last week, the Senate Judiciary Committee reported out the bill by a vote of 15 to 5. And we have companion legislation now in the House, H.R. 4919. It was introduced last week by Representative Chris Smith and Representatives Maxine Waters and Mike Doyle.

I am going to move on to another topic, which is the Federal Employees Health Benefits Program. This is the largest employer-sponsored health insurance program in the country. It is about split between dependents and employees and retirees.

So this is an insurance marketplace. There are literally hundreds of plans to choose from nationwide. Each state offers certain plans. Many of those plans are geographically restricted. Plans generally fall into two categories: fee-for-service and HMO plans. This is a stratified marketplace. BC/BS has a two-thirds market share. And the top 10 carriers cover 94 percent of the market.

So I think it is also important to look at who is in the Federal workforce. The Federal civilian workforce is about 2 percent of the entire workforce, a little less than 2 percent. And, of course, the Federal workforce is concentrated in certain areas, D.C., Hawaii, Maryland, and Virginia. I tried to reproduce a map, but due to the limitations of my technical skills, the map may not be all that visible. But you can see from the dark areas in the map where Federal employees are concentrated. They are concentrated in areas like Maryland, Virginia, some other places. And I think that is important for some of the subsequent slides.

So in 2012, OPM, which manages the Federal Employees Health Benefits Program, recategorized applied behavioral analysis as medical benefit and allowed plans to propose benefit packages that included ABA for 2013. OPM encouraged plans to cover ABA, but there was actually little coverage in 2013 through 2016.

So this is the current coverage map. And I hope you have a little bit of a mental picture of the prior map. You can see here that there is actually an obvious mismatch between where Federal employees are concentrated and the ABA coverage in 2016. There are no plans available to Federal civilian employees in Maryland that cover ABA, and this map actually -- it is blue to indicate a state where there is one or more plans that cover ABA.

Virginia has one plan that covers ABA, even though there are a lot of Federal workers in Virginia. That plan is restricted to northern Virginia. You know, we have a lot of Federal employees in places like Hampton Roads. There is no coverage available there. So there was quite a bit of a mismatch or has been quite a mismatch between availability of coverage and where Federal employees live.

So here is some more on the mismatch. None of the 15 nationwide health plans cover ABA. We have only one health plan in the Washington, D.C. area that covers ABA, even though 15 percent of the Federal workforce lives around the nation’s capital. We have large cities lacking coverage. In 2016, some states gain coverage, but a couple of states actually lost coverage from 2015.

Now, there is good news here. It is always nice ending on some good news. OPM has announced that for 2017, carriers may no longer exclude ABA for the treatment of autism. They put out a carrier letter at the end of February which announced this new policy, and the letter states, “We expect all carriers to offer clinically appropriate medical necessary treatment for children diagnosed with ASD. Benefits may be managed, but there must be no exclusion of benefits.” So this is a positive administrative development, and that is my summary of what has been going on at the agencies and in Congress.

DR. CUTHBERT: Thank you very much for the summary, Stuart. These are all very interesting. If I may take the Chair’s prerogative to start with one question about this one because we have a few minutes for questions and comments? Is there generally now a defined period for ABA treatment? You know, I know these have varied at one time. Some states offered virtually unlimited periods of time, and then as research showed that if you didn’t see much improvement in about a year --

MR. SPIELMAN: Right.

DR. CUTHBERT: -- you know, there is a point of diminishing returns.

MR. SPIELMAN: Right.

DR. CUTHBERT: And just practically they stopped that. So would you know the state of that?

MR. SPIELMAN: So this is going to vary by policy. And I do not have specific information on particular policies. I think there is going to be a divergence between, there very well may be a divergence between, what we see under state law and what we will see under the Federal, under the new Federal policy. But I am cheered by the language that carriers are to offer clinically appropriate and medically necessary treatment for children diagnosed with ASD. There was no limitation in the carrier letter, nothing that suggested that age would be an appropriate way to cut off benefits.

DR. CUTHBERT: Thank you.

Other comments and questions?

MR. PARNELL: I am Brian Parnell. I am with the Department of Human Services in Utah. In your slide that showed what states provide insurance coverage, is that only for Federal employees? That one.

MR. SPIELMAN: So this is a slide for the FEHB. And you can see there was no coverage in Utah.

MR. PARNELL: Okay . But that is just through FEHB?

MR. SPIELMAN: Correct.

MR. PARNELL: Okay. I wanted to clarify that because in 2013 --

MR. SPIELMAN: Right.

MR. PARNELL: -- our legislature passed --

MR. SPIELMAN: Yes.

MR. PARNELL: -- through House bill 57 the autism mandate for private insurance carriers --

MR. SPIELMAN: Right.

MR. PARNELL: -- to cover ABA.

MR. SPIELMAN: And I think you bring up an interesting point that Federal civilian employees in some areas actually were at a disadvantage to individuals who had a different employer. And we would see this strange pattern where healthcare, the availability of healthcare, would depend on a parent's employment, you know, which would be a -- that is a strange way of allocating healthcare but, in fact, that is the system. That has been the system.

DR. DAWSON: I was just going to make the comment that states do vary in terms of the amount and the ages. So, for example, North Carolina, where I am located, we just passed a bill last year that provides $40,000 of insurance coverage for behavioral health interventions from point of diagnosis through age 18. This is every year annually.

And I also want just to make the point that, you know, we used to think about that the period between infancy and age 5 was the period where most of the change in things like IQ occurred and it maps onto our notions about brain plasticity. And then what happened was that there were longitudinal studies published where we actually followed people with autism into adulthood, and they found that there was as much change in IQ in the elementary school period as that there was in the preschool period and, furthermore, that many people with autism actually developed language for the first time during the elementary period. So our notions about brain plasticity and when intervention is effective have really changed based on these longitudinal studies.

DR. MANDELL: David Mandell. Stuart, this is very exciting that these changes are happening, and I know that insurers have expressed a lot of concern about the potential increase in cost and, therefore, increase in premiums that might occur. I think most of the data from larger plans suggests that that is not happening the way that insurance companies feared it would, but these are smaller plans and they cover, you know, smaller groups of people. And I wonder if there is any effort to examine what the effect of these laws are on cost in a way that could allay concerns or help tweak the benefit.

MR. SPIELMAN: So I know that Missouri annually puts out studies regarding costs. And the costs in Missouri have been minimal, you know, on the order of pennies to the dollar. So I think that there is some data out there on the costs. And all of the data that I have seen indicates that the concerns about costs have been overblown. And so I think that there is a growing acceptance, you know. And this decision by OPM reflects that, that this is a good healthcare decision, that the benefits outweigh the minimal costs.

DR. CUTHBERT: Okay. Thank you again very much, Stuart, for those interesting updates.

MR. SPIELMAN: Thank you.

DR. CUTHBERT: Appreciate it.

So, moving right along, our next speaker will reflect again the wide range of activities across the Federal Government. We are pleased to welcome next Dr. Scott Robertson, who is a policy advisor with the U.S. Department of Labor in the Office of Disability Employment Policy. He will be speaking to us about the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities.

Dr. Robertson is going to be joining us by phone. So, Dr. Robertson, can you hear us okay?

(No response.)

DR. CUTHBERT: Not yet. Are you perhaps muted? Yes. Okay. We will see what we can do.

DR. DANIELS: Yes. Dr. Robertson wasn't able to be here in person due to a last-minute urgent situation. So he asked if he could do this by phone. We will see if we can get him on the phone.

MR. ROBISON: Should we

Should we just do the morning break and if he calls in during the break, we can take him in right after?

DR. CUTHBERT: That is a good idea. Does that sound good to everybody?

DR. ROBERTSON: I am on the phone right now.

(Laughter.)

DR. CUTHBERT: Good idea, John, but --

DR. ROBERTSON: Does this still work? I mean, I can do it later if needed.

DR. CUTHBERT: He didn’t want to lose us all right away.

Okay. Dr. Robertson?

DR. ROBERTSON: Yes, yes. Speaking. And my glasses had broken is what happened. So if I am reading a little bit slowly on what I have got to talk about, bear with me a little bit.

DR. CUTHBERT: Okay. Thanks. We do have your slides here. So maybe you can just let us know when you want us to change the slides here in the room?

DR. ROBERTSON: I didn’t --

DR. CUTHBERT: Oh, it is just a title slide. Sorry. There was a title slide up. So I thought there was an actual presentation.

DR. ROBERTSON: Oh, okay. Yes. I just have some talking points here.

DR. CUTHBERT: Okay. The only other thing I would say is that you are coming through a little bit soft for volume in the room. So if you can either turn up your microphone volume or just speak a little bit more loudly, that would help.

DR. ROBERTSON: Is this better?

DR. DANIELS: Yes.

DR. CUTHBERT: Much better, yes.

DR. ROBERTSON: Okay.

DR. CUTHBERT: So thank you. Please go ahead.

DR. ROBERTSON:

DR. ROBERTSON: Thank you, Dr. Daniels and the members of the Interagency Autism Coordinating Committee for letting me speak to you all today. I am delighted to speak with you about an ongoing initiative for strengthening access to employment for people with significant disabilities, including autistic people.

I work as a policy advisor in the U.S. Department of Labor's Office of Disability Employment Policy here in D.C. I serve on our youth policy team and as a liaison to a workforce systems policy and employment-related supports policy team.

As many of you know, people with significant disabilities, including autistic people, face significant challenges in obtaining and maintaining employment. Many people with significant disabilities, including autistic people, want to work but often lack needed supports and services. Plus, the employment rate and the labor force participation rate for people with significant disabilities, including autistic people, remains far too low than should be the case. Many people with significant disabilities are also forced into much higher underemployment; in other words, doing jobs not commensurate with knowledge, skills, and abilities because of the lack of sufficient support. Some articles in the research literature have indicated that underemployment, unemployment for autistic people might be potentially as high as maybe even 80 to 90 percent when you count for underemployment and unemployment. In other words, in some cases, folks, for instance, having higher education training and not having employment, that meshes with that.

So the subject for employment access remains the major focus right now. In 2014, Congress passed the Workforce Innovation Opportunity Act, WIOA. And President Obama then signed the bill into law on July 22nd of that year. I happened to be working on the Hill at the time for Senator Harkin in the Senate Health Education, Labor and Pensions Committee when that law passed, which is a major guiding force of what we are working on now in the department, U.S. Department of Labor.

WIOA superseded the Workforce Investment Act of 1998 and reauthorized federally funded initiatives supporting workforce development across the U.S. These initiatives, including the natural network of nearly 2,500 American job centers, which were previously known as the one-stop career centers, these initiatives also include the network of workforce development boards as well as programs like Youth Build. DOL's Employment Training Administration oversees this federally funded workforce development system.

WIOA also made significant changes to Federal law to improve employment access for people with disabilities, particularly for making amendments to the Rehabilitation Act. For instance, section 511 of the Rehabilitation Act maintains to strengthen access to employment for youth and young adults with disabilities age 24 and younger. Section 511 established requirements for the roles and responsibilities of vocational rehabilitation and education agencies. Youth with disabilities must have opportunities to access employment for these services before consideration of subminimum wage placement under the Fair Labor Standards Act section 14C.

Section 461 of WIOA also amended the Rehabilitation Act, section 609 of the Rehab Act, and established the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, which I am just going to report to you as the committee here because the abbreviation is actually ACIEID, which is a little bit of a mouthful.

Since 2015, ODEP, the Office of Disability Employment Policy that I work in, has provided support for the committee to assist its ongoing work and organization of in-person meetings and meetings by webinar. And the committee has met in person to U.S. access force in 2015.

WIOA has charged this committee with developing findings, recommendations, and conclusions concerning access to competitive integrated employment for people with disabilities, particularly people with significant disabilities.

WIOA also charged the committee with examining, discussing, and developing recommendations around the 14 fee certificate programs co-administered by DOL's Wage and Hour Division under the Fair Labor Standards Act. This also includes discussions of the development of infrastructure and approaches, such as customized employment necessary to support better employment access for people with disabilities, who in some cases may currently be in placement under section 14C of the Fair Labor Standards Act; in other words, organizations that have 14C certificates.

Since 1938, that section has permitted organizations to hold certificates enabling operation of programs that pay subminimum wage to people with disabilities. These programs are in exception to the Federal requirement for paying minimum wage, which currently is $7.25 an hour, to all people, including people with disabilities. And in some cases, 14C programs have commonly gone by the name of sheltered workshops because they frequently operate as disability-centered settings.

States currently have the authority to regulate and enforce additional requirements, in addition to Federal requirements on these programs. In 2015, New Hampshire became the first state to disallow use of the 14C certificate for subminimum wage within its borders. In 2016, Maryland has also passed similar legislation as New Hampshire, although that has not yet been signed into law. And then there are two other states, Rhode Island and Oregon, that have reached consent agreements with the U.S. Department of

Justice regarding their own operation of sheltered workshops.

On March 16th of this year, the Federal AbilityOne agency declared its support that all qualified nonprofit agencies participating in the AbilityOne program commit to and begin, if not maintain, paying at least the Federal minimum wage or state minimum wage if higher to all employees who are blind or have significant disabilities working on AbilityOne contracts. And that declaration is online. AbilityOne is the largest single source of employment in the U.S. For people who are blind and have other significant disabilities. More than 550 nonprofit organizations employ people with disabilities and provide services to the Federal government through that AbilityOne program.

The committee -- so, as you might imagine, 14C is a major focus of that committee, which is engaged in discussions about possibilities regarding potential long-term phase-out of 14C nationally, which is obviously a very complex topic and focus because 14C has been around since the 1930s, as I mentioned.

Many members of the public have expressed different perspectives on the existing and long-term use of 14C certificates for paying subminimum wage. Public comments have usually emphasized ensuring that sufficient infrastructure goes into place so that people with significant disabilities have sufficient support. Right now there is also a bill in Congress that might potentially phase out 14C certificate programs called the Time Act.

So this and other focuses around improving infrastructure, improving support and everything that is needed to improve competitive integrated employment for people with intellectual or developmental disabilities and other significant disabilities, has been a major focus of the committee.

The committee’s membership includes 18 representatives from 7 groups, self-advocates for individuals with intellectual or developmental disabilities. There are three of those individuals on the committee. Providers of employment services, including those who employ individuals with intellectual and developmental disabilities and competitive integrated employment. Folks in that category are on the committee, representatives of national advocacy organizations for adults with intellectual and developmental disabilities, experts with backgrounds in academia, research, and expertise in employment at which policy issues, representatives from the employer community or national employer organizations, other individuals or representatives of organizations with expertise on increasing opportunities for competitive integrated employment for individuals with disabilities, and several Federal officials as well, including the Office of Disability Employment Policy through our secretary, the Employment Training Administration through their assistant secretary, the administrator of the Wage and Hour Division at the Department of Labor, the commissioner of the Administration on the

Intellectual and Developmental Disabilities at Health and Human Services or their designee, the director of the Centers for Medicare and Medicaid Services, Health and Human Services, the commissioner of Social Security, and the commissioner of the Rehabilitation Services Administration at the Department of Education or their designee. And these members have been serving on four subcommittees which are supporting their development of findings, conclusions, or recommendation around increasing support for competitive integrated employment, including the Transition Subcommittee, which is focusing on youth and young adult issues, including Indicator 14 under the Individuals with Disabilities Education Act, capacity, improving opportunities and systems capacities, including coordination across Federal agencies on employment and coordination with state agencies; the marketplace Subcommittee, which is focusing on employer resources and school supports as well as employment-related issues, such as transportation access; and the Complexity Subcommittee, which is looking at high-level cross-cutting issues involving complexity of systems supports and resources and overlaps to a certain extent with the Capacity Subcommittee.

As you might expect, issues concerning 14C under the Federal Labor Standards Act have fallen under all four of these committees. And they have approached and discussed it in many different ways, in addition to discussing many other focuses that are currently in their interim report, which was released last September and is posted online on their website, which is a page off of the Department of Labor’s main website.

The committee has thus far met 7 times since 2015, including in 2015 January and March and May, July, August and October of that year, and January of this year by webinar and will be meeting very soon, later this month, on April 27th and 28th. The agenda, again, is posted online. And this meeting is open to the public. It is going to be held at the U.S. Access Board, which is 1331 F

Street, Northwest. And, again, any members of the public are welcome to join that meeting. The committee will be discussing updates in January on how they have been working on approaching their recommendations on improving access to the integrated competitive employment.

As I shared earlier, the committee had previously prepared and submitted an interim report last September 15th of 2015 through Secretary of Labor Thomas Perez and Congress, as required by WIOA. This interim report appears online on the committee’s website on DOL’s main website, and discusses the preliminary findings, conclusions, and recommendations for increasing competitive integrated employment for people with intellectual and developmental disabilities and other significant disabilities.

And, as required by WIOA, the committee is in the process of developing its recommendations, conclusions, and findings for a final report that would be issued to Labor Secretary Perez and Congress this coming fall. The statute specifies that the committee should be submitting this final report by September 14th of this year, so in a few more months.

So I know that was a complex bit of information, and I was wondering. I wanted to check if anybody has any questions from members of the -- if any members of the IACC have any questions about the committee and its current work.

Now, note that I can’t share any specific state on recommendations because it is being driven by the committee itself. So the Office of Disability Employment Policy, ODEP, is only in a support role. The actual work is driven by all these public members on there. So I can only share what is already publicly out there in terms of what the committee has currently been focusing on.

DR. CUTHBERT: Okay. Thank you very much, Dr. Robertson.

Are there any questions or comments? And would you please just let Dr. Robertson know your name and the nature of your involvement with the committee so he knows, you know, kind of your perspective on these things? Yes, Dr. Robison?

MR. ROBISON: I would like to just thank Scott for the presentation. And for Dr. Novotny, who is new to our committee. Scott is also an autistic adult, and he is a former member of our committee.

DR. ROBERTSON: Thank you.

DR. TAYLOR: Hi, Dr. Robertson.

DR. ROBERTSON: Yes?

DR. TAYLOR: This is Julie Taylor from Vanderbilt.

DR. ROBERTSON: Yes.

DR. TAYLOR: My research is focused on the transition to adulthood for people with autism.

DR. ROBERTSON: Yes.

DR. TAYLOR: It is my understanding -- and I don’t know a ton about WIOA --

DR. ROBERTSON: Yes.

DR. TAYLOR: -- but it is my understanding that in this act, part of voc rehab’s budget needs to go towards preparing people with disabilities for employment while they are still in high school.

DR. ROBERTSON: Yes.

DR. TAYLOR: Is that true?

DR. ROBERTSON: Yes. Part of WIOA, especially in section 501, includes support for pre-employment services to be assisting the transition from that gap from high school and to having better connection, not only with vocational rehabilitation but also the American job centers as well, and to have better coordination across both the workforce systems and the vocational rehabilitation system and education. And, of course, this is also major focus of the Transition Subcommittee right now.

You may want to particularly check out in the interim report the section on transition that was generated by the Transition Subcommittee, which is exploring all issues around that intersection of youth and young adults as they are growing up, going through school, and then trying to navigate that connection back out to employment options.

But is that helpful for your question?

DR. TAYLOR: Very helpful. I am really excited about that piece of it because, at least in Tennessee, where I am from, there is a complete disconnect between voc rehab and what is happening in the high schools.

DR. ROBERTSON: Yes.

DR. TAYLOR: So I think this is a real step forward.

DR. ROBERTSON: Yes. And I would agree that nationally it looks different I think in systems around the country, but that was one of the main purposes on WIOA, is to emphasize that coordination between systems, which hasn’t always operated that well, particularly many, many youth. And I have been looking at some research lately on how a lot -- in practice, for instance, we are supposed to be there, for instance, at IAP meetings and participating in the transition planning, but in practice, that hasn’t always happened. So I think that is something that will likely be changing as the coordination improves.

DR. CUTHBERT: Okay. Thank you.

Other questions and comments?

(No response.)

DR. CUTHBERT: I had one just question. And thank you again. This is Bruce Cuthbert --

DR. ROBERTSON: Yes.

DR. CUTHBERT: -- the chair of the IACC.

DR. ROBERTSON: Yes.

DR. CUTHBERT: I know that you were, as -- John, thank you for mentioning that, Dr. Robertson, you are a former IACC member.

DR. ROBERTSON: Yes.

DR. CUTHBERT: Are there any other members of your committee who are on the autism spectrum? And does that influence the kinds of specific policies and deliberations that you have? Obviously for people on the spectrum, there may be a somewhat different palate of services that are needed, perhaps compared to other individuals --

DR. ROBERTSON: Yes, yes.

DR. CUTHBERT: -- with other kinds of disabilities.

DR. ROBERTSON: Yes, yes. So, in addition to other folks with developmental disability on that committee -- and I should clarify that it is not Department of Labor’s committee as much as it is more of a freestanding committee that we support and provide assistance to, but, as I say, the members of the committee are driving it independently in terms of their focuses and their discussions.

Another former IACC member, Ari Ne’eman, is on that committee. So the perspective of autistic people has been represented in the discussions of that advisory committee on increasing competitive integrated employment for individuals with disabilities.

So does that help kind of answer your question?

DR. CUTHBERT: Yes. Thank you.

DR. ROBERTSON: Okay. You are welcome.

DR. CUTHBERT: So it looks as there are no more questions or comments at this time, but we are very happy to hear from you. And I am sure we will want some follow-ups. Clearly from this discussion, this area of both the school-to-work transitions, which is a really critical period, and also just finding more employment and employment supports for individuals on the spectrum are going to be things we want to continue our emphasis on.

DR. ROBERTSON: Yes.

DR. CUTHBERT: So this is very timely. Thank you again for joining us this morning.

DR. ROBERTSON: Yes. Thank you. And I would be happy to share any updates in the future if so requested.

DR. CUTHBERT: Okay. Thank you very much.

DR. ROBERTSON: Thank you. Okay.

DR. CUTHBERT: We will take you up on that.

DR. ROBERTSON: Okay. Okay. Bye.

DR. CUTHBERT: Okay. Thanks for joining us.

DR. ROBERTSON: Okay. Bye.

DR. CUTHBERT: Okay. Bye-bye. So we actually finished a little bit early. And that is probably good because Dr. Daniels has a full plate of activities for our Committee business. So I would propose that we move into our break now and reconvene at 10:45. That will give us the full time of our break. And I am sure that we can use the time for all the activities we have going on. So we will see you in 15 minutes. Thanks.

(Recess taken.)

DR. CUTHBERT: We can gather. We enjoyed a 20-minute break. One does sometimes wonder if a useful experiment might be to see if the meeting is not more productive if it is just one eight-hour break and everybody can chat, catch up, exchange ideas. So thanks for gathering.

Next, as I mentioned, up we have our Committee business. There is a great deal of work to be done, as you know. So I am going to turn the microphone over to Susan Daniels now, who will lead us through, as you can see on the agenda, the summary of advances, the strategic plan update, and the working groups, all of which will be significant topics. So, Susan, take it away.

DR. DANIELS: Thank you, Bruce. So I heard that there were some problems with the slides advancing. Hopefully it will work out for me.

So I want to go through the IACC Committee business with you. I want to give you all greetings from the Office of Autism Research Coordination for National Autism Awareness Month. We have been working visibly in the office trying to prepare materials. And I know that many of you saw emails that have gone out in the last couple of days and tweets about some of the new products that we have put out.

Recently, on April 11th, we hosted a special lecture for Autism Awareness Month that was organized by the office. John Donvan and Caren Zucker talked about the history of autism. And it was an interesting lecture. It is available on the website, the video. So please visit if you are interested and you weren’t able to come or watch the original webcast.

We also had a couple of other events. These were both sponsored by NIMH, but OARC provided the webcast and the funding support for one of these meetings. So the NIMH seminar series, we had Dr. Jeremy Veenstra VanderWeele present on April 13th about new treatments in Autism Spectrum Disorder. And back in February, there was an NIMH workshop on loss of skills and onset patterns in neurodevelopmental disorders: understanding the neurobiological mechanisms. Both of these videos are also available through the IACC website. So you are welcome to view those.

So yesterday we announced that the IACC has a new website. I hope that many of you had a chance to click through it, but if you haven’t yet, it is there. So we welcome you to check out the new website. It has a fresh, new look; a streamlined layout; simpler navigation. And there are several new features, including some autism and disability news & reports that are new. We also have a page with funding opportunities, not only from the Government but from several of the other private funders of autism research. And if there is anyone out there who has funding opportunities that you don’t see listed on our site, please alert us so that we can also feature your funding opportunities. And we have some new resources on a resources page that we will be building out, but for now, we have information about some of the other Federal advisory committees that work on autism and other disabilities, information about the state interagency autism coordinating councils that are diverse across the country. And we are trying to accumulate more information about those, about several of the other private organizations and Federal agencies that work on autism. And we will be continuing to add information. And our new site is mobile-friendly.

We have a small feedback box on each page. So if you have feedback on our website, features that you would like to see or things that you like or would like to see improved, let us know. We would love to hear your feedback.

So, just to recap this information, which I know that we have talked about in previous IACC meetings, IACC responsibilities include developing and annually updating a strategic plan for ASD, developing and annually updating a summary of advances for ASD research, monitoring Federal activities with respect to ASD, and making recommendations to the HHS Secretary regarding research or public participation in decisions regarding ASD.

So the work that we have done toward meeting these responsibilities includes the production of the 2015 IACC summary of advances that was just published and is available on our website. And so this publication represents the 20 top, most significant advances in ASD biomedical and services research that were selected by members of the IACC. And it covers a number of topics that roughly span the same types of topics covered in our strategic plan. And the advances are broken down into those strategic plan categories in the document. So we welcome you to have a look at this document.

I have provided a hard copy version that is available to you at your place. And we have a few copies at the publications desk outside. And we welcome people to pick them up. This is a pre-publication copy. The final publication copy will be a little bit nicer quality of paper. But, anyway, it gives you an idea of how the publication looks.

We also went ahead and produced the 2014 IACC summary of advances. This is available on the website, but we weren’t able to get it to print production quite quickly enough to have it at the meeting in hard copy. So those hard copies will be printed after the meeting. But the publication is available on the website.

So now we are caught up on the summary of advances. So congratulations to the Committee on completing that task.

I also wanted to bring to your attention that the OARC has provided a follow-up comprehensive report of the data from 2011 and ‘12’s portfolio analysis. We provided this data originally to the Committee back in 2013, as you were working on the 2013 strategic plan update. An overview of the data was provided in the update publication, but this is a more comprehensive analysis. And I think that you may find some of the information interesting. We did quite a few new things in this research report compared to the previous report. And now we have a great template for going forward with doing more analysis across the years of what has been happening in the portfolio.

So the data sets are also available in the portfolio analysis web tool. So we will be planning to publish the 2013 data set and update within this calendar year. So you will probably be hearing about that in the fall.

The next item that we have on the agenda is to discuss our IACC strategic plan update, which we talked about at the last meeting. So IACC members have volunteered to serve on seven working groups to cover the seven strategic plan question areas. And members nominated several external experts to serve on the working groups.

So I just recently sent out a list to all of you of who volunteered for each of these seven working groups and just request that you confirm that we have the list correct.

I would recommend that each member sign up for one to at the maximum probably two working groups because each will have a series of calls. And I think it will get very confusing for you if you are starting to receive the emails for three or more groups. I think it will be a challenge to manage, although if you can manage it, you are welcome to do that.

I am in the process of confirming the external members based on your nominations. So we will begin scheduling a series of calls to develop the updates for each of the seven question areas as well as the introduction and conclusion of the report. So the strategic plan is based around the seven consumer-based questions. And we decided at the last meeting, we are keeping that structure in general.

And, just to recap the structure based on the discussion we had at the last meeting, we are going to have an introduction and then a question description with the aspirational goal, which would be similar to the previous strategic plan update. And then the progress section for each of the questions will contain information about research. So that would encompass advances that have been made in science.

The Committee wanted to make sure that we do some work in the area of practice to research and talk about where we can learn from what is going on in the field to inform research opportunities; and then to identify gaps, opportunities, and needs, as we have in the past; and then to talk in more detail about services and policy. And this section can encompass description of new programs and policies or existing programs and policies affecting people with autism, new research evidence that can inform policy, which is part of that loop that you all said that you wanted to see, and then services, needs, and gaps and needed policy changes.

The next section would be progress toward the aspirational goal. The following would be recommendations to assure non-duplication, which will help meet one of the requirements of the Autism CARES Act that the Committee consider efforts to ensure that there is not duplication of effort across the portfolio.

We talked about how many objectives we want to have in this new plan. The current strategic plan has 78 objectives, and I think the Committee agreed that we don't want 78 or more next time. And so this is something that I just wanted to confirm with you all before we start working on the phone calls, is that one proposal would be to have approximately three broad objectives per question. That would give us 21 total for the strategic plan and that what we could do is have very broad-based objectives.

I have given a couple of examples of what kinds of objectives we could have. For example, increase early detection of ASD could be a type of objective we would have for question 1 but then under that to provide examples of what you are looking for, what types of projects would meet this requirement. And you could make that list hopefully not overly long just because it would be difficult to read if it became 25 different suggestions. But if you had a few examples? And that I think would enable us to appropriately analyze the portfolio for what is meeting that objective.

So with the Committee, do you have any feedback on that suggestion to go with something of that type of a number for objectives? So Louis?

DR. REICHARDT: I strongly endorse reducing the number of questions. I mean, I think that, in fact, I would also endorse reducing the number of seven over -- I mean, when I just looked at what was put in summary of advances, there was considerable overlap where things were listed, for example, no genetics and understanding why something had happened. It was in a different section and stuff. I mean, I think we simply have to reduce the numbers to be general and, frankly, questions that we all can remember. None of us can remember 78 different things.

DR. DANIELS: David?

DR. AMARAL: Susan, I wanted to go back to an earlier slide just to bring up a point. That is that I guess I missed that all of the external Committee members were already nominated and maybe others have as well. So I wonder if we could extend the period of time, you know, for nominations of external members to the Committees for a couple of weeks maybe, just so that we can -- now that we are primed, we can actually think about who would constitute the best possible Committee.

DR. DANIELS: Sure. And I should have mentioned that. In the email I sent you, I actually gave you a deadline of next Wednesday. But if you want it to be longer, that would be fine. Do you want more than a week to come up with more external members?

DR. REICHARDT: I mean, do you think there could be feedback on the external members? Perhaps the Committee chairs could have some discretion in this. I mean, we don't want this to be too large, I just say.

DR. DANIELS: Right. So we agreed to keep a manageable number. Obviously if we have 50 people on a phone call, it is not going to be productive.

And we are looking for balance. So we are putting together people based on the nominations. Obviously every person who is nominated can’t serve but looking for balance among those. And we are going to be coming up with a slate of people for each group and certainly can run that by the chairs. We will try to, like I said, keep it balanced and keep it manageable. But we do plan to do all of these meetings by phone. So we won’t have travel costs involved.

So in terms of the seven questions, at the last meeting, we decided we were going to keep the seven questions for this year and try to just work with a number of objectives in terms of reducing so that we have the ability to continue translating across from previous years of portfolio analysis. So I think that that is what we are going to do unless the Committee feels that you right now want to reduce the number of questions. For example, questions 2 and 3 and questions 5 and 6 are related, certainly could be consolidated, but then you won’t be able to track across years the same way as we have done previously.

DR. WEXLER: Susan, will there be any FACA limitations on the operations of these committees?

DR. DANIELS: So --

DR. WEXLER: These aren't public meetings?

DR. DANIELS: These are all public meetings. Every meeting of the IACC and every phone call, we have been committed to keeping them --

DR. WEXLER: I am talking about the subcommittees.

DR. DANIELS: Yes. The working groups', all working group, phone calls are open to the public. We provide summaries of those calls, although the summaries aren't always as quick. When we are doing a set of 20-some calls, it is pretty tough to produce those summaries really quickly, but we do try to keep it to the same standards. Under FACA, we are not necessarily required to do that, but we do.

DR. WEXLER: Is there some public notice that we have to give that we are having a committee meeting?

DR. DANIELS: So because these are working group meetings, we are not bound by FACA to put this in the Federal Register, but we do try to give adequate notice by our website and listserv and tweets that these meetings are coming up and to post a listing on our website so that everybody knows that the meetings are coming up. But we don’t necessarily announce them as far in advance as we do the regular meetings. It is not a requirement. But I think from the past few times that we have done this, the way we have run with working groups in announcing things to the public, I think the public has had adequate notice and access to the meetings. And we try to ensure that everyone can listen to the proceedings and participate.

So any further feedback regarding is approximately three broad objectives per question reasonable? Is that what we will try to go for? And, like I said, it is approximately three. So if it is, you know, slightly more, slightly less, we can roll with that and try to work with you.

So the next section will be we will have to include budgetary requirements in some way, shape, or form because that is in the law. And how we will do that, what I suggest is that we come back to that after we have written the text and we have come up with our objectives and then determined how we are going to do those budgetary requirements. Especially if we are doing such broad objectives, it may be a little bit more challenging. So I think that we will probably put our heads together and try to think of a good way to do the budgetary requirements to meet that requirement in the law.

And we will repeat this formula seven times with each of the working -- or once with each working group out of seven working group and then prepare a summary and conclusion. So that is the structure that we are planning on doing. And so we will divide the working group meetings to address these sections in reasonable chunks so that you can work on them. And members of the working groups will contribute, can volunteer to help write, help edit. And the chairs will be responsible for ensuring the content is reflective of the proceedings and of the literature in each area, et cetera, but, of course, depending on the help of everybody that is serving on the working group.

There is still opportunity if you -- as I mentioned in response to David's question, if you want to change working groups, join, hopefully not join too many because I just -- for your sake, you probably want to stick to one or maybe two. And if you want to nominate additional external working group members, I will extend that deadline to two weeks from now. So I will send you a follow-up email with a deadline. And the deadline will just help us to be able to cut off the nominations and just get people invited and so we can get started on those meetings.

So the resources that you will have available to you for the strategic plan update include data from the 2013 portfolio analysis that our office has already been working on. And we have already prepared the data for you. So that will be available. It will be a subset of the kind of data that you see in this portfolio analysis report. It won’t be all 150 pages worth, but I think it will be adequate for you to be able to go through in reasonable detail what is in each of the question areas. And it will be some new information to add to what you have from this recent report that we just put out.

We will also be providing you with the IACC science updates and summary of advances that are recent. And then the Committee or the working group members can help identify other literature that you want to use to support the material you will be writing in the strategic plan update.

We will have external experts who can weigh in on some of these issues. I wanted to ask the Committee if you would like us to run a request for information from the public to really solicit specific public comment about the strategic plan. If you would like that, that is something that we can do. You do receive normal public comment through the Committee process. And so you have that available to you. And we have it archived on the website.

John?

MR. ROBISON: Susan, if we are going to solicit public comment for the strategic plan, how are we going to address the likely dominance of vaccine questions, which is still the dominant thread in our written commentary? Shouldn’t we probably have to say something about that because if we don’t, we then end up how we incorporate that in there. I don’t, frankly, think it has a place in these questions.

DR. DANIELS: So what we have done in the past when we do an RFI, we put out a really general set of and that we don’t even really phrase it as questions, but we ask for input on each of the seven areas. And we would do a word limit so that we don’t get tomes of information because if the Committee is just bombarded with a huge volume, which, actually, the first time we did it, we did bombard the Committee with a huge volume of public comments. And it was really challenging for everyone to get through all of that information. So we would try to keep the word count short, keep it divided according to the seven areas, but it would be open to anyone to provide whatever type of comment they want. And we would be able to have staff here categorize it for you so that you would be able to focus on the areas that you are interested in. But we wouldn’t, for example, tell people they can’t comment on an issue that is important to them.

MR. ROBISON: Yes. I agree that we couldn’t say that they couldn’t comment on the issue. I guess I would be concerned that if we solicited commentary and then we ignored it, that that would itself create an issue.

And I think that if we are going to solicit public comment, that, at least in my opinion, means that we might want to have a paragraph or two in the strategic plan that says that the IACC supports the idea of the public health benefits of vaccination and that we hope, whatever people’s opinion on that topic is, they will join with us in supporting the IACC’s mission to maximize the quality of life and success of autistic people, which is the major problem facing us and is independent of those concerns.

DR. DANIELS: I think if any statements are going to be crafted, that would be a part of the process that the working groups can go through. And so there have been -- in fact, our first strategic plan did have a section that was on some of those environmental concerns. And so that would be handled by the individual working group. But it doesn’t really need to be spelled out in the RFI if we do an RFI.

So I just wanted to get a temperature read from you about whether you want to have us specifically solicit public comment, if you want us to do that, or if you would like to just go forward with the kinds of public comments we normally get for the meetings. David?

DR. AMARAL: So I do think it is helpful to solicit public comment. Even in the case that John brings up, you know, if there is a preponderance of feedback that deals with that particular issue, the Committee can acknowledge that this may be a lingering issue in the public’s mind, but that, in fact, John, I think, you know, what to do is actually to then cite the published literature showing that the evidence is really against this link between vaccines and the etiology of autism. So, I mean, we can address it and not have to thwart, not ignore it but actually address it, which I think would be a more reasonable way and more effective way of dealing with any input that we got in.

So, you know, I think the Committee should be as inclusive as possible of advice from the general public.

DR. DANIELS: Right. And one of the disclaimers on any request for information or public comments, I think the Committee is very open to hearing what the public feels and wants to say about autism, but the Committee is not always able to translate every individual suggestion into text or other projects. But these things help inform the Committee, which helps them with their deliberations and recommendations. And I think it is all helpful. We all want to be aware of what is happening on the ground with people that are dealing with various issues in the autism arena. So we really are open to what the public has to say and want to keep everything as open as possible.

So Sam?

MS. CRANE: I have a quick comment, both on the public comment issue and on the research portfolio analysis. So one thing that we have been hearing from the public very consistently is that we really need a lot more research into the transition to adulthood and long-term services and supports.

Right now according to the most recent portfolio analysis, we have actually seen even less funding for these types of projects on questions 5 and 6 than we did in the 2010 analysis. And so I think that is going to be something that I hope the public might be able to comment on and guide us on this.

One thing, though, that I am a little bit concerned about is that in the research portfolio analysis, the LEND programs and other kinds of practitioner training activities that are funded through the Department of Education are being counted as research. And, in fact, they are making up over two-thirds in 2011 and about exactly two-thirds in 2012 of all of the services research that is being counted by the portfolio analysis, which I think is going to be a little bit misleading to the public because these programs are not primarily research programs. They are training programs.

Since the Autism CARES Act authorizes the IACC to separately monitor both research and other programs in the Federal Government and because we are separating those out for a strategic plan as well, I would propose that we take these types of programs and separate them out into a different kind of portfolio analysis and have the research portfolio analysis solely consistent of activities that are primarily research-focused.

DR. DANIELS: So, to address that question, back in 2010, this issue was raised. And we tried to be clear as much as we could in the portfolio analysis report that we did provide additional guidance to funders that were working, especially in question 5 areas, that the information that we were requesting from them was funding information about projects that if they worked on training, that it was on development of training modules, evaluation, things that would be considered within our definition of research. And so that is what is represented in this report. The areas that are just delivery of training, general delivery of services, were not counted in this report. So that issue has already been addressed.

Going forward, if we do collect information about services activities and try to do analysis with those kinds of activities for the activities that cover both services and research activities, we will have to make a determination of how to work with those, probably counting the larger portion. For example, if it is a LEND program that is mostly about delivering services and has a tiny component of research, it is counted as services so that we don’t double count things, which is always a perennial problem, even with NIH projects, trying to count multiple categories. If you really want to count it as a separate project in every category, you are just going to be multiply counting the same project. So usually the best way to get a more accurate read on the funding is to count it in one category, whichever is the greatest, but that is something we can address later.

So, anyway, I just wanted to address your concern that the research that is presented in the portfolio analysis does meet the definition of research that the Committee agreed on back when we presented the 2010 portfolio analysis. And we worked with all of the funders on this.

So are we in support of -- do you want to have an RFI or not or do you feel like what we have already with just regular public comment is sufficient? Geri?

DR. DAWSON: I would like to propose that we do have an RFI. I think that would be really helpful.

PARTICIPANT: Second.

MR. ROBISON: I would second or she seconded it, and I would third it. Okay.

DR. DANIELS: Maybe not as an official vote, but can you just give me a show of hands for who would be in favor just so I can get a sense of how interested you are?

(Show of hands.)

DR. MANDELL: May I ask for a point of clarification?

DR. DANIELS: Sure.

DR. MANDELL: When is the RFI? Is the RFI in advance of any documents from the subcommittees being available or is the RFI in response to drafts of materials from the different working groups?

DR. DANIELS: So what I was thinking about was going ahead and doing an RFI, starting it as soon as possible, so that we can just get general input from the public. If you wanted to do something more to collect specific input on drafts, that is really a different process. I would suggest that in order to keep things more timely -- and I think that most of the public already knows what their concerns are. And they probably don't need to see your draft to figure out what they want to say to us or to the Committee. So probably we can go ahead and just collect information. By the time we get the RFI set up, all of the information collected, broken down into something usable for you, it is going to take us a little bit of time. So hopefully that input will come to you. It might come to you a little bit later in your process as you are working on the drafts, but you can use it to refine your drafts. So if that sounds reasonable, that is what we would go with. So it sounds like you want to do that. So we will work on that in the OARC.

You have this portfolio analysis report. And, oh, there is the report to Congress from 2012 that you also will have available to you for information to inform the strategic plan update. And you will have policy information from IACC members and policy experts, like what we had presented to us this morning, that can help you with your strategic plan update.

So the next steps are confirming the working group members. So over the next couple of weeks, then, we will confirm who you would like for external experts. I had begun already extending some invitations, but we can also wait to get a few more suggestions from the group. And hopefully I will hear from all of you about your membership on the working groups to make sure that you have the working groups that you want to be on.

Via email, we will brainstorm some topics to include under the questions just so we can assure that the working groups are addressing questions that you all think are important. And we will, of course, bring this up for public discussion in the working group calls so that everyone can hear what was suggested.

So the set of working group meeting calls will happen in May and June. And then at the July meeting, we will review progress on how the draft is coming. And we must complete this update during the calendar year, and I think that we should have more than enough time to be able to do that.

So that’s what I have for you in terms of the strategic plan update. So I will follow up with you after this meeting to begin working on all of those working groups.

The next order of business that we have is some topical working groups that the Committee was interested in having. So in January, the IACC voted to form a housing working group, and I will be sending you the list of IACC members who have already volunteered. Actually, I put that right on the slide. Those are volunteers that had emailed me specifically saying they wanted to be on the working group, but it is still open. So anyone else who would like to join the working group is more than welcome. And we also will be -- I will ask you to provide me with some suggestions of external experts who might be able to help work with that working group. And we would start work with that as soon as we are finished with the working group meetings for the strategic plan.

So up for discussion today are the possibility of having a safety working group. This was brought forward to me by Larry Wexler as something that he had heard in the Committee. And I am sure some of the others of you were also interested in this. So I wanted to give you a chance to discuss the possibility of having a working group on this topic.

Larry, do you want to start discussion?

DR. WEXLER: Sure. I think it is a good idea.

(Laughter.)

DR. WEXLER: I mean, we have talked about a variety of issues related to safety, from wandering to self-injurious behavior to restraint, seclusion. And I am sure we could go on. It seems like a really important issue, and it is not something we have -- I think there used to be a safety committee years ago. So it is just a suggestion.

DR. DANIELS: Alison?

MS. SINGER: So I used to be the co-chair of the Safety Subcommittee on the previous IACC. And I would strongly support a subcommittee to look at issues of safety. I think that the work that that subcommittee did was very valuable. I think it has informed some of what we are seeing today in terms of wandering legislation, as well as policy regarding restraint and seclusion. I think the letters that we sent to the Secretary were an important output of that committee, and I would strongly urge that that subcommittee be resurrected.

DR. DANIELS: John?

MR. ROBISON: I, first of all, support the safety subcommittee idea, but I think that it is time for the IACC to specifically address the question of autistic suicide, now, whether you think that is part of the safety committee or you think suicide is a separate question. But I think that is really an important thing, and it seems to me that it would fit in safety.

DR. DANIELS: Shannon?

MS. HAWORTH: I know we haven’t gotten to it yet, but that could also fit under co-occurring conditions with mental health as well. Suicide could fit under there.

MR. ROBISON: You are suggesting suicide?

MS. HAWORTH: Mental health. Mental health issues. Yes, suicide is a product of mental health and could also go under co-occurring conditions.

DR. DANIELS: Certainly there is also the issue of premature mortality among people with autism and that, again, co-occurring conditions and safety, I think it can overlap there. We would probably want to try not to have too much overlap so that we are having two sets of meetings that are talking about the same thing and coming up with different conclusions, although if maybe there are specific aspects that you want to cover in two different working groups, that would be fine.

Samantha?

MS. CRANE: Yes. I would second or third or fourth the safety subcommittee but also add that when we have been looking at safety at ASAN, one of the things that we are very seriously looking at -- and it does overlap somewhat with suicide -- is police interactions with people with disabilities, which have been really making the news quite a lot lately, especially police interactions with people of color who have disabilities.

When people have a behavioral health crisis or a mental health crisis and their safety is in doubt, a lot of people will call 911. And that will lead to a police interaction that will have its own safety concerns to make.

So I think if people have information on strategies to address crises in a way that minimizes the likelihood that someone with a gun will show up to the situation and potentially escalate that, I think that would be extremely helpful.

DR. DANIELS: Thank you. I think all of these concerns that you have brought up seem like they would be appropriate.

Do we need further discussion or do you want to move to -- would someone like to put a motion on the floor?

PARTICIPANT: So moved.

MR. ROBISON: Second.

DR. DANIELS: All in favor of forming a safety working group for the committee?

(Show of hands.)

DR. DANIELS: Anyone opposed?

(No response.)

DR. DANIELS: Anyone abstaining?

(No response.)

DR. DANIELS: It looks like the motion carries. So we can form a safety working group. Oh.

MS. SINGER: Can we extend the RFI and collect public input for the Safety Subcommittee as well as the Strategic Plan Subcommittees?

DR. DANIELS: I think trying to expand further on the same RFI, it might slow things down for us.

Let me give some thought to how we might be able to do that. So I will give it some thought and see if there is a way to roll that together. With RFIs, if they get overly huge, sometimes people aren't as responsive. If it is more clear what the goal is, sometimes you get better responses. So we will think about that and see what might be the best way to do that.

Anything else for that?

(No response.)

DR. DANIELS: Okay. So the next issue that David Amaral brought up at the last meeting was a request to discuss the possibility of a co-occurring conditions working group. And we previously did have a working group on this topic with the last Committee and did a workshop on the subject of co-occurring conditions. That is available on our website.

So, David, would you like to talk about that a little bit?

DR. AMARAL: Sure. Thanks.

So at our last Committee meeting, I think you prefaced or maybe it was Bruce prefaced the whole meeting saying that one of our goals should be looking for low-hanging fruit of bringing benefit to the community. And I do think that we are getting new information now that mortality is increased with autism.

There is data coming from Lisa Croen that is a whole bevy of illnesses that are more common in individuals with autism, although we have very little understanding of why that is. Is it because they are not getting adequate health care initially or is it because the biology of autism leads to other disorders as well?

I think, you know, this is an area where, even though it may take us longer to deal with the core features of autism, maybe we could do something medically to treat some of these co-occurring conditions, at least improve the quality of life of people on the spectrum.

And I do think that there is a dissemination issue as well because I think physicians in the United States still are, in part, unaware that these co-occurring conditions are not simply part of the autism but they should actually be treated medically just like any other individual.

I think a final point is that, you know, I think if this co-occurring committee or subcommittee goes forward, it would actually be interesting to have both some basic scientists and some clinicians because, you know, I think we might ultimately find that some of the biology leading to the core features of autism, like an abnormal activity in the amygdala, might also be leading to gastric acid secretion and leading to some of the GI problems. But those linkages have actually not been really well-investigated.

So I do think that there is a whole host of issues that are very troubling to families who have children with autism and adults with autism. And I think it would be helpful for this Committee to really explore those and actually try and develop a program of dissemination of that information out to the nation.

DR. DANIELS: Geri?

DR. DAWSON: Yes. To follow up on David’s comments, you know, it might be helpful to have this working group be something like improving the health of, you know, or health outcomes of individuals with autism, which would really look at, you know, these medical comorbidities but also, you know, consider preventive approaches. For example, obesity is a real issue, understanding the risk factors that contribute to obesity and what might be done in terms of anticipatory guidance around issues like that but then also have a section that really does address this issue of -- you know, I think it is not just lack of knowledge by, say, an internal medicine physician but, really, it is the lack of people that are willing to provide medical care for adults with autism.

It is just a huge issue. We face it clinically every day at our own clinic in trying to find physicians out in the community for people with autism.

So I think this whole workforce issue could be kind of a piece of that with this broader idea of improving health outcomes.

DR. DANIELS: Shannon?

MS. HAWORTH: I just wanted to give my support for that working group. And hopefully we would also work on mental health. It is definitely -- I mean, 70 percent of our kids with autism are going to have a co-occurring mental health condition -- and also to look at the parental mental health as well. So if we are talking about dissemination, definitely making people aware of that as a separate issue that needs to be treated under the autism spectrum and also its research out there on parental mental health and how it affects their children. So I am hoping that we can also talk about that as well in that working group.

DR. DANIELS: Other comments?

DR. RING: I just wanted to add my support for this, this particular workgroup, nothing to add there but just maybe a question for those in the room who might be asking it in their head as well as me. Can you remind me what the scope of these workgroups are, what their charter is, what they would be delivering as a product of their activities and how that informs the other activities along the strategic plan?

DR. DANIELS: Sure. So with forming these working groups, I think that because we have limited time here in the Committee to discuss details, it is best to just if we decide that this is an issue we want to work on, get the people together who want to work on it and to come up with a list of priorities they want to work on.

And so some of the outputs of previous working groups have been workshops, where we have a big public discussion covering important topics. We have had letters to the Secretary. A working group could put together a white paper or a report if they wanted to. We have never done that before, but it is -- well, we have a DSM, which is kind of -- it wasn't quite a letter. It was more of a report, maybe not like a full-length long report but a recommendation.

So, you know, the working groups do have flexibility to do various kinds of activities. So you might want to determine based on the topic, the issue that you are working on, what would be the most effective way to be influential, whether it would be issuing a statement, issuing a letter, creating a white paper or any of those types of activities. So I think that right now we probably couldn’t make a decision on that, but the working groups could decide what they want to do.

Alison?

MS. SINGER: I would just add that there are also some policy implications that the working groups have been able to accomplish. So one specifically was in the Safety Subcommittee, by working with the CDC, we were able to create an ICD-9 code specifically for wandering with autism. And that led us to be able to get insurance coverage for anticipatory guidance from pediatricians and family practitioners so that parents were advised of the possibility and potential for wandering and they were able to be aware. Most parents weren’t even aware that wandering would be an issue.

And I think that has led to many lives saved because, of course, we want to prevent wandering. We don’t want to have to go out and find the kid. So I think there are definitely some policy focuses as well.

DR. DANIELS: Yes. So we need further discussion on this topic. So it sounds like we have a proposal to have a working group on improving health outcomes as a title. How does that sound to folks at the table? So if we are done with discussion, are we ready to put a motion on the floor. David Amaral?

DR. AMARAL: So moved.

DR. DANIELS: Louis Reichardt?

DR. REICHARDT: Second.

DR. DANIELS: All in favor?

(Show of hands.)

DR. DANIELS: It looks pretty unanimous. Anyone opposed?

(No response.)

DR. DANIELS: And any abstaining?

(No response.)

DR. DANIELS: So it looks like that motion carries with a unanimous vote. So we will have a new working group on improving health outcomes. So we have never had one of those before. It sounds like a good plan. So we will again start that working group after we are done with the strategic plan working groups.

The last item -- actually, we are doing really well on time -- that I wanted to bring up, there were a couple IACC members who brought up some issues about the summary of advances. And I wanted to provide a little bit of time for discussion about this, perhaps starting with if there are concerns with the summary of advances, how do you feel about the products that you have in front of you and the product for the 2014 that you have seen? And if you would like to have it different, how would you like to have it different? I think that starting with talking about what the product is, is informative for deciding process questions. So let's start there. Louis?

DR. REICHARDT: Well, I just say that I find the list of what are important papers somewhat bizarre frankly. I mean, there are so many important papers that were published in important journals that are not in this report. I realize that vaccines, you know, is like a hydrid, has endless heads, but to have two out of the three publications that are featured on vaccines, it seems to me is just wrong. So I think the procedure by which we select these papers perhaps needs some review that the -- I mean, I don’t believe all of the important papers were included in the list. I realize there were some changes, but, in fact, this simply is not very good at collating the most important papers in the field. And I just cite that by many of the journals. I mean, you know, there were things that were simply missing.

DR. DANIELS: David?

DR. AMARAL: So I would rather address the process than the product. And I think, you know, first of all, I know it is a really hard job to do this, to try and -- you know, there is a couple thousand papers a year, I think, on autism or related topics. So just trying to go through all of that and come up with the top 20 is a daunting task. So I appreciate that.

Given that it is so complicated, you know, I think a different process has to be pursued because I think when we as a Committee get, you know, the 100 candidates and we are asked in a couple weeks, you know, to review them and make our suggestions, it just is impossible. Nobody has the time to look at all of the papers in a really comprehensive way. So what you do is you pick off, you know, a couple of papers that you think you know something about and hope everybody is doing that, but it is not really a comprehensive systematic process.

And so what I would recommend is that, rather than trying to do it at the end of the year, there be a process put in place where nominated papers could be submitted in some way. The committee could be made aware of them. And then we can, you know, in real time sort of try and take a look at those papers. And maybe there is even a voting process so at the end of the year we have a much smaller set that are the candidates.

And even, you know, the process for nomination of the papers wasn’t crystal clear to me. I mean, I understand where some of the sources for the papers came from, the Simons Foundation, for example, the top 10 from the Simons Foundation was in, which I -- you know, they were vetted. And that was fine, and those were some of the better papers. But then there were other papers that I had no idea how they got into the category of like, you know, the best papers in autism.

So I think that this is really important. And I think that we want the product to be the best representation of what is going on in autism research. And because that is what we want the product to be, the process has to be able to be better in order to lead to better nominations, a more systematic review and then ultimately a product that reflects what is the best in the science of autism.

So, you know, again, this is not intended as a criticism because I know what a huge amount of work this is. But I think with the numbers of publications in autism increasing so dramatically over the last, you know, 5 to 10 years, some other more systematic way of trying to review this is going to have to be put in place. Otherwise it is going to be an impossible task.

DR. DANIELS: Samantha?

MS. CRANE: I mean, I would also like to suggest that in the future we have some process to ensure that when these things are voted on, they end up sort of covering a more broad range of topics. So one of the things that I was rather disappointed about in terms of the finalists here was that both papers for 2014’s question 6 were on the economic burden of autism across a lifespan, rather than on, you know, things that are beneficial to our community, like the supported employment or community integration research papers that had also been nominated in that category. I am not sure, you know, how this ended up happening, whether it is partly because people were sort of just going through the list and voting on something that they felt most familiar with, but I would want to try and get a system where we can accurately reflect the diversity of research in a particular question, especially in a question that is already really dramatically underfunded and under-studied so that we actually get some papers on improving services for question 6.

DR. CUTHBERT: Can I just jump in? Thank you. I hope we can take these suggestions and fairly rapidly put them into an efficient process. I think it is useful just to provide context for how this went this year.

Just so everybody recalls, that this Committee was not reconstituted until November of last year. You know, we sort of heard it about over the summer, but, of course, we did not have the first meeting until November. And, as you see on the slide at the front there, the final documents had to be completed in April. So there was obviously no chance, say, to nominate papers going along through the year because we were already pretty much at the end of the year. And we were working on a very tight timeframe. And we had to produce two years’ worth of papers in that same timeframe, 2014 and ‘15.

So that is not at all to be defensive -- and, David, you know, I hear your point that you are not being critical -- but, rather, just to say, you know, we can see the shortcomings of having to do it in such a compressed timeframe and the concerns that have been expressed.

So this is our opportunity to kind of get it right in a proactive way and so I hope, you know, that with this discussion can lead to our deciding that we are going to do it like this and we can move forward because, for instance, if we want to be nominating papers, then we can start 7 o’clock tonight and the plane is back home or whatever. We can do that right away.

DR. DANIELS: Sure. Just to briefly comment on what Bruce said, just to put that in perspective with the past of the Committee, the process wasn’t terribly different this time from the past, even though the Committee only started its work in November. The main difference would have been that the Committee didn’t hear science updates throughout the year before starting the process. But in the past, we have always done this project on this type of a timeframe where we start the voting process in January, February, and we have these documents produced by April.

And so, actually, in January’s meeting, I promised you the documents by July. And we did manage to get them done by April to try to keep on our timeframe to have it available for autism awareness month.

But, of course, it is optional. It doesn’t have to happen that way. It doesn’t have to be done on such a short timeframe. You could take longer. However, if it is the previous year’s summary, the later in the year that you present it, the more outdated it seems by the time you are done.

So okay. Let’s have a comment from Geri.

DR. DAWSON: So I just wanted to point out that -- and this is a little bit in response to Louis’ comments, which is that the -- you know, the voting process is really reflecting the broad perspectives that this Committee brings. Right? So if you were to bring, you know, a group of purely scientists, right, in the field, to do this task, they would come up with a different list. If you were to bring a group of all self-advocates to the task, right, they would come up with a different list or, say, people who are involved in advocacy, you know, and science funding and government officials. Right?

So I do think that, you know, probably what is reflected does reflect the broad perspectives that this Committee brings, rather than, say, what a group of scientists would, you know, say, “This is the top scientific breakthroughs of the year.”

And maybe someone else would say, “Well, that may be a top scientific breakthrough, but I am not sure that that has relevance to the things that I care about. And so I am voting for something else."

So I do think that has to be kind of figured into the way that we view this document.

DR. DANIELS: David?

DR. MANDELL: I think the IACC has an opportunity with this that maybe some other places don't. That is, if we think about a summary of advances, we have established as a group the areas in which we think advances need to be made and that are important. This speaks to Sam's point that, rather than having a best of list without comment, we have an opportunity to look at where we have made advances in the areas that we think are important to make advances because we established them as goals and objectives.

And I wonder if there is a more narrative way to do this that, rather than says -- because I agree with you. And I am the author of one of those cost papers, but I am embarrassed to see that all there is in services are two cost papers.

And why aren’t we talking more about, you know, what meaningful improvements we are making in the area of services research, for example, that is represented by a broader swath of literature? Because there are more services papers, not many more services papers and certainly not enough, that were published in those two years.

So is there a different way to configure this that we are not another top list like Autism Speaks puts out or like the Simons Foundation puts out but we are providing a more thoughtful collation of the research that has been done in a particular area?

DR. DANIELS: Louis, did you have another comment?

DR. REICHARDT: Yes. I just want to say I certainly don’t claim expertise in all areas, but, for example, we all acknowledge that genetics is a major risk factor. And there is not a single genetics paper on what caused this to happen and how can it be prevented. I mean, this is a significant oversight. And I think, frankly, Geri, you are wrong on this.

I mean, I think there needs to be -- you know, as one suggestion, I would just say let the committees at least provide some comments. Then let everybody vote. You know, very few of us on this Committee are really qualified to vote intelligently on all seven topics, honestly, at least myself.

DR. DANIELS: Can I share a comment regarding this process? In the law, the Committee was charged with this, producing this document. I think that it was Congress' intent for every person on the Committee to have a voice in the document, regardless of the diverse backgrounds --

DR. REICHARDT: That is fine.

DR. DANIELS: -- or, actually, inclusive of the diverse backgrounds and that if Congress had wanted, say, a blue ribbon panel of experts to be put together by NIH to come up with a list, they would have put that in the law. So I do think that they really do want it to be reflective of your entire group, but how you do that is another matter. And there are different ways to get to something that reflects the group thought process.

Who was next? John?

MR. ROBISON: I think that we have a kind of a philosophical thing that is missing from this. David raised the objection to our putting two studies that don't show a vaccine connection kind of front and center in our report, but, of course, we all know that that question dominates the commentary we receive, even if it is not a principal public health concern.

I am concerned that what we have done by doing that hasn't really accomplished anything. Those two studies that we publish in our summary of advances are not going to change one single mind of a person who believes that there is a government-pharmaceutical conspiracy here.

What I think we could do is we could construct a portion of our IACC website. And we could make a constructive series of statements, "This is why we believe in vaccination for the public health benefits. These are studies that tell us that there is not the connection that is suspected," but I think that then we have to express where do we think this autism comes from.

And I think one thing we tiptoe around here but we don't straight-up confront is the reality that -- and I think it is more and more recognized that there is some amount of autism which is simply naturally occurring. Whether you want to think it came from God, it came from evolution, there are people like me who were just born the way we are.

And when we look at the population who is intellectually disabled, we don't say, "Those people are a blight on society. They are the products of disease," "conspiracy," whatever. We accept that that's a part of humanity. And what are we going to do to have the best quality of life?

And I think that for us to kind of say that here in the IACC, that would be a major step towards moving towards constructive quality-of-life focus for autistic people who both are like me and who are really severely impaired.

And I think we might also say that we have reason to believe that there are environmental and genetic factors that could be pathways into particularly debilitating and crippling forms of autism and we hope that we can find ways to help that in the future.

But “autism” as a word refers to such a wide range of things. And I think that we do a disservice to our community by not recognizing that in our plan. And I think that we should speak to that exactly and how did we come to be in this place. And anyway, that is --

DR. REICHARDT: Very well said.

DR. DANIELS: Thank you.

David?

DR. AMARAL: So just a short comment that I am not sure how to pick the best papers. Maybe, you know, we try and use some information like metrics, like how many times a paper is cited or something, something that gives an indication of its impact on the scientific community. But I think I also like David Mandell’s idea of adding a narrative. So if this comes across as not, you know, the best science because -- we are going to miss a huge amount of the best science, right? You can’t just have 20 or 30 papers and have all of the best science out of the thousands of papers that are published. But sort of addressing both what David said and I think what John was saying, sort of have a narrative that says, you know, let’s push the needle a little bit in these areas.

And then having papers -- I wasn’t actually the one who was against the vaccine papers because I think in a sense, that does provide again additional assurance to those who may be wavering there really isn’t any evidence and that we can say, “Consistent with all of the data that has come in the past, you know, here are some new papers that show the same thing.” Hopefully eventually that will not be necessary but that the narrative would be saying, “Where has there been significant push in certain areas?” and not portray these as like the best science but science that has been influential in one way or another.

DR. DANIELS: Julie?

DR. TAYLOR: I have maybe a concrete suggestion that wouldn't change the process that much. So when I was reviewing the papers, I am sure everybody had this experience, but there were some papers that were so far outside of my area of expertise, right, that I looked at where they were published and I read them over. And I thought, "Well, this seems like it is a good paper, and it seems like it is important." But it was hard to really judge.

I wonder if maybe we could come up with a list, just like we always have, of the 20 papers and then bring them to the Committee and let people -- I mean, this is about let people advocate for the papers that were not included, that maybe somebody who has some expertise says, "Actually, this wasn't on here, but this was a breakthrough in this way" that I may not know as somebody who is not in that specific area or if there is a paper on the list that somebody says, “You know, I know a little bit more about this. And this methodology really is suspect” or there are certain things like that. We could maybe have some discussion around the 20 papers and perhaps come up with a list that incorporates people’s expertise in different areas in a little bit more thorough way would be one way to not change things too much but just maybe still end up with papers that are a bit more representative.

DR. DANIELS: David?

DR. MANDELL: I come up -- I was thinking about those same issues I think that Julie was. And the potential solution that had come to me is what if -- because the chapters that each subcommittee writes are then subject to a vote and approval from the whole IACC. What if we thought about the summary of advances in the same way, that the subcommittees, which have representation from hopefully a lot of different constituencies within the IACC, could make recommendations to the IACC along with a narrative about why they think those papers are the important papers? And the rest of the IACC could make additions or talk about why they don't think that one of the papers are appropriate but that -- and then when the summary of advances is published, it would be both with those papers but also with that narrative so that a more naïve audience and people who are outside of these walls could also understand why people thought that these papers were important, rather than just listing them.

DR. DANIELS: Samantha?

MS. CRANE: I was actually going to make a very similar suggestion. And I think we could actually also try and do it in a sort of an iterative process so that, you know, first the subcommittee comes up with maybe not just two but maybe its top five papers in that topic, writes a narrative for each of them, then has an opportunity for people to add in, but the narrative would be very rough, not the final narrative. That way we can more efficiently sort of incorporate input from the rest of the Committee, taking into account the fact that, you know, many people are not going to

-- because of the amount of work that goes into a subcommittee, people might have strong views on subcommittees that they are not actually on, even though they are not on the subcommittee because people are only allowed to get one or two. And then we could have an opportunity for people to vote on that final list and pick the top two in each topic.

DR. DANIELS: John?

MR. ROBISON: I think that we have two things that are sort of being discussed here. I think we have the consensus among the scientists here that somehow our collective choice of papers sucks.

(Laughter.)

MR. ROBISON: And --

MS. CRANE: I am not a scientist.

MR. ROBISON: And then I think we have also the philosophical issue that I have raised, which is that where did we come from? How did autistic people come to be here, how did we come to exist? That is I think a fundamental philosophical question. It is not a component of question 4 or question 6 within the thing.

And I guess I would say to those of you in the Committee, you know, if you think that that is a pertinent, well-spoken thing, should we perhaps then address that question, which I think kind of rides above the quality of the papers? Maybe it should be addressed in the introduction to the strategic plan, which I already volunteered to write something on and have so far not been clever enough to think up, but should it be part of that? Should we address it in some other way?

I think this is a really fundamental thing because I think what we are seeing in our Committee is we are seeing a recognition that we need to move our focus towards what are we going to do for the quality of life for all of us autistic people as we get older?

We have Alison’s family, who has significant challenges that are different from my own and they are very real. Where are they going to live? We have challenges for people like me. Why do we kill ourselves? That should be the primary focus. And I guess maybe it is time to say that. We have never done that in any of our publications. Don’t you folks agree that this is about quality of life for our people?

DR. DANIELS: The strategic plan, of course, help that you gave us on the last strategic plan update, you put some of that information in. And we will have an opportunity in the next strategic plan update also to have an introductory section and a conclusion that certainly can reflect some of those types of ideas that members on the Committee have.

So I think, hearing this discussion, it sounds like one possibility would be to keep the working groups alive after the strategic plan update is over. If you wanted to try to keep those working groups working and use them to also produce the summary of advances, do you think that the working groups would be able to manage in one meeting to make decisions about, for example, like one phone call, to make decisions about the summary of advances, or do you think that they would need multiple phone calls to be able to do that?

Of course, I am thinking about the management problem. I was hoping the seven working groups would be done. Then we could start the next three working groups. But then if we have to run all 10 working groups, if it is just one call for the 7, that is one thing, but if it is a series of multiple calls for the 7 plus the 3, I mean, at least for the OARC, it is a significant challenge.

David?

DR. MANDELL: Here is how you could do it in one call, I think, is that the Committee members would have to commit to sending around to each other the articles that they would propose that might be considered and to read them ahead of time. The meeting would have to come to consensus. This is not necessarily always a consensus-building group but would be to come to consensus on those articles. And then they would have to agree to follow up by email to come up with the proposed narrative that then would be sent around to the IACC members.

I think that is a reasonable plan, but I know on question 5, that we are not dealing with the same volume of work that some of the other questions are dealing with.

DR. DANIELS: Geri?

DR. DAWSON: So I wonder if, for one thing, we could start collecting these articles throughout the year, right; so, in other words, so that we are not this huge task suddenly, you know? And so as we, I mean, the updates, right, are an aspect of that, but we could -- in this meeting if we thought there was a particularly important breakthrough that had occurred, you know, we could do that in a round robin or something or just send it to you. But, anyway, so you would have sort of a collection going on.

Then I think if we could in -- I guess it is the January meeting, right?

DR. DANIELS: Usually we discuss it in the January meeting.

DR. DAWSON: Yes. In the January meeting if we could have a discussion among our group about the papers and that we think are the most important, we could actually give people maybe an individual time just to discuss that. And then we would have the voting process. I am worried that consensus is going to be really, really hard, honestly, on 20 things among this group. And I also worry just about the time, but I do think that if we had an opportunity to talk face to face about important breakthroughs around certain papers that had, had occurred and people that have a specific area would have a vested interest in having followed that literature and know that literature, could present it to the Committee. Then we would go into that voting process much more informed, I think, by, you know, a much deeper sort of perspective on the literature.

DR. DANIELS: So do you think you would necessarily need a voting process if you have the working groups, well, more than just an approval? So if, say, the working groups are coming up with their list and they are going to present you with what they think are the top three advances for question 1 and then you are going to have this discussion in the Committee, do you think the decision could be made there or do you think you need additional voting?

DR. DAWSON: Yes. I was suggesting not even having working groups, right, that literally people in this group who have the expertise in different areas would be submitting different -- you know, I sometimes if I was in a working group, I am probably aware of other really important, you know, papers along and I could submit them to you and that at a meeting, we discuss what we think are some of the most important breakthroughs of the year without this, you know, more intensive working group process. And then we vote about we have had a discussion of that.

I mean, I think that if we had an hour-long discussion, for example, about advances and people could all present different papers and points of view, we’d have a pretty rich I think discussion and ability to vote without working groups.

DR. DANIELS: I am in favor of, of course, trying to make a simple process. I am trying to understand. So in one hour, we would be able to present? For example, say throughout the year we send out an email from the OARC every month to you saying, “Please submit your papers” and we just collect all of that. You will end up with the big list that we had. And so then how would we get to a narrower list to talk about at the meeting?

DR. DAWSON: I am suggesting that we have that list, right? We are all looking it over, just like we did, right? And we also had the ability, everyone, to add to that list because Susan requested that, and numbers of people sent in more things. And there was a lot of genetics paper on that list, by the way, because I voted for them, by the way.

But, anyway, but what would happen is at the discussion, we would go through each of the areas. And we would say, “Let’s open it for discussion on what people feel were the most important papers on, you know, “why did this happen?,” and people could talk about them, right, in the group and say, you know, “There was a major genetics paper that was published in Nature. And this is what it found. And I want people to be aware of it” and why it is important for the field, right? And then we would go on to the next area. And so then when we would go into the voting process, people could just be better informed.

DR. DANIELS: Louis?

DR. REICHARDT: I support something very similar. And I would say the --

DR. DANIELS: Microphone.

DR. REICHARDT: Oh, sorry. Excuse me.

The other thing that I think would be important in terms of the working groups’ recommendations would be the issue of breadth, I mean of covering the different areas. And so I certainly wasn’t advocating that every paper should be genetics, but I thought there should have been at least one, And, similarly, I heard very much what Samantha said, for example.

So the committee could make recommendations. I mean, the whole Committee doesn’t have to accept it. Everybody would vote, but at least they would hear a rationale for both the importance of individual papers and making sure the breadth of the areas under a question were covered, you know.

DR. DANIELS: Rob?

DR. RING: Yes. I would like to support Geri's idea for -- however it emerges in detail, I don't want to encumber this with any further detail but a running tracking of the advances as they are occurring over the year. And without adding another detail, I really do think it should be something beyond just submitting an abstract, that whoever does submit that provide a lay abstract, if you will, explaining, interpreting why this is an advance or why we should be paying attention to this.

And whether or not that is immortalized in the minutes of meetings or it could be run as a tally on this new website of ours, I think, you know, providing the narrative in real time. As David says, that narrative is critical in putting the onus on those who submit the abstracts to provide the interpretation would be incredibly important so that we are not playing catch-up at the end of the year, when we get the bolus of papers. And anyone else who is enlisted into the process of supporting that decision-making, however, whatever form it takes place, they are already on that story because it really is science. And these advances are a story that plays out and will play out over the coming year. It would be great to have a running narrative of why this is important.

DR. DANIELS: Jim, last comment?

DR. BALL: Yes. Having listened to all of this and processed it and taken it in, I totally agree with Geri. And I would even say that we should take an entire meeting and discuss it, not just an hour. I think the thing that we produce that is the most beneficial to everybody is this document. And we should spend that entire time talking about it and then having really open, meaningful discussions around it.

DR. DANIELS: So based on what I have heard here, now, with that comment and Geri’s comment, too, I do have my doubts about whether we would be able to have the thorough kind of discussion you seem to want in an hour. It sounds like an all-day meeting to me. Would you want to devote an entire one of your four meetings a year to discussing the summary of advances or would you want to just have an all-day phone call, which all-day phone calls are grueling? All right. Well, I got a clear answer on that.

(Laughter.)

DR. DANIELS: No all-day phone calls. Maybe without making it a series of seven two-hour phone calls, maybe we could find some kind of a phone call schedule to have discussions.

In terms of every member submitting a lay summary of every paper they want to submit, I would say that sounds kind of unrealistic unless each member was only going to submit maybe one thing or two things. I know how busy you all are and I know how much work it takes to put together a lay summary. I think that that would be a tall order.

So I see there are a couple of more hands. We are like running into our lunch time. And we haven’t really come up with a clear decision yet. David?

DR. AMARAL: Well, I just want to say I don’t think it is such a big deal to write a four or five lines lay summary. You know, I think the diversity of backgrounds of this Committee would actually benefit from having somebody else who proposes a paper say, “This is important because” boom, boom, boom, I mean, 300 words or less, right? And, you know, everybody can do that in 10 minutes. So I don’t think that that is a huge onus. Come on.

DR. RING: It was intended to be as we roll through the year, rather than at the end of the year, you submit your bolus of papers and why. I was supporting Geri’s idea for keeping this as a process throughout the year. If you want to submit a paper, why? Help people understand why you think that is important.

DR. DANIELS: It would certainly set a high bar. I think that it would discourage you from submitting 50 papers. You probably would try to submit a few, maybe a handful, and really think them through carefully.

Do most people feel like they would want to do that, to provide basically a justification for why they are submitting particular papers? It sounds like people are okay with that suggestion.

Doing a data call monthly is fine with us. I mean, it is really more for you. You would be getting emails from me saying, "Please submit your information." And then, of course, you would need to respond if you want to submit things. But it would be rolling throughout the year.

Okay. Larry?

DR. WEXLER: Yes. Two things. One, if the calls could be focused on topical areas, you might get the people who actually are -- you know, if you are talking, you know, the genetics area, you are going to get the genetics people who understand the science, if you are talking services and so forth while still inviting anyone who wants to participate.

The other thing -- and I don’t want to start a whole major discussion here, but I think, you know, you mentioned the why. I think the why is really important. There is a difference I think between advance and impact, and to me, the value of this would be, what are the studies that have had the greatest impact in those areas? Because something can be an incredible advance but be in such a narrow area that it doesn’t yet have a massive impact. Others really get people’s attention. So that is it.

DR. DANIELS: Julie, we have really got to move on. So let’s have this be the last.

DR. TAYLOR: I will be fast.

DR. DANIELS: I want to reach out.

DR. TAYLOR: I think when we are thinking about breadth, we should also keep in mind that there are I think lots of really important -- I am thinking about question 6 now, adults, right? There are lots of really important areas of research that we just don’t have good studies in.

And so they are not going to be reflected here. And we are going to see probably more of the same type of studies because that is what a lot of people are doing, myself included to some extent.

So I don't know if we could ever use this document as a way to say, "Here are some other things that we would like to see happen. And it is not in here because it is not happening now." Maybe that happens more in the strategic plan but --

DR. DANIELS: Strategic plan is really the place for that.

So I think that we have had a really rich discussion. I think that certainly if you want to do monthly data calls, I can start sending monthly data calls right away. I think that I would like to come back to the OARC to discuss with the team how we could potentially implement some of these ideas and probably could have a discussion about this again in July, when we have refined it a little bit more, but at least we will be collecting the data already.

So be expecting a data call. It will be requiring you to provide a justification for any nominations, and we will try to work with you. I mean, it is great to have the Committee so interested and dedicated to this project. So we will be working with you on that.

Thank you for your time. We have lunch scheduled now. There is a cafeteria on the bottom floor. I would like the Committee to stay for just a couple of minutes to get a group photo with our photographer before you leave. And we will reconvene at 1:15. Thank you.

(Whereupon, at 12:15 p.m., a luncheon recess was taken.)

DR. DANIELS: Hello, everybody. We are going to reconvene. I apologize that we are a little bit behind schedule here. Hopefully everyone that wanted to give oral public comment is in the room and is going to be able to do so.

So Bruce had to step away for an emergency, but I will be acting chair for now.

So let’s go through the oral public comments.

We have four commenters today. And we’re going to start with Nathan Olson. Would you like to use the podium or -- oh, you want to sit in the chair? Fine. Thank you.

MR. OLSON: Hopefully everybody can hear me. I appreciate the accommodation. I get much less nervous when I sit down and speak in environments. I really appreciate it.

Madam Chair, members of the Committee, I am honored to appear before you here today as we commemorate Autism Awareness Month across the country and around the world.

I am a junior undergraduate at Pacific Lutheran University studying cultural anthropology with a minor in sociology. I was a late diagnosis of autism at 22 years old, in 2011, as an adult. And that diagnosis changed the course of my life and transformed the perception of self. I posed the question, how could I ask you to accept me if I didn’t have the courage to accept myself? I am also dually diagnosed with ADHD and nonverbal learning disability disorder as well as of last summer.

In terms of disability advocacy, I have kind of since that point made it kind of the cause of my adult life. I didn’t expect it to turn out that way, but over time, it just kind of fell into it.

So, in the interest of time, I am going to kind of skip down to the second paragraph talking about my experience in higher education. In my journey, in my journey in higher education, I have experienced tremendous academic failure at prior schools attended, prior to the diagnosis. When the diagnosis came, it helped fuel a sense of academic vitality I never knew I was capable of achieving.

I owe my success academically to the Autism Spectrum Navigators Program at Bellevue College in Washington, which I was part of in my two years there. This is a program designed and directed by our program director and professor, Sara Gardner, a person who I owe my success to greatly for creating a program that gave me the opportunity to graduate successfully from college. What she has done with the ASN program, as it is known, profoundly inspires or, I should say, profoundly inspired me. And her leadership led to our Central Washington University in Ellensburg to adopt and implement our program on their campus as ongoing.

The program focuses on four areas, self-advocacy, self-regulation, executive functioning, and social interaction, and has quarterly classes required of students in these areas and is one of the most unique programs serving students with autism in the United States. I am proud to say that I had the privilege to be part of it.

The experience to take classes with those like me was a powerful opportunity. The program encouraged me to wake up believing that I am worthy of myself. And I owe that mindset to our program director, Sara Gardner, a person who greatly inspires me for what she has achieved with our program over the last five years, since its inception. I am one of many students who has graduated from Bellevue College because an institution had the courage to believe in what it means to learn differently and take the opportunity to transform lives.

Being part of the Autism Spectrum Navigators Program helped me find that calling in life to advocate for all of those with disabilities or autism and disabilities all over the world.

The Bellevue College ASN Program led to my current institution reach out to them and seek to create our own version of this transformational program, molded for the PLU community here on our campus.

Since January 2016, I have served as the SAND assistant in our Office of Disability Support Services at Pacific Lutheran University. The Strategic Access Network Development Program, SAND, is a new program which is in the process of being designed and will be launched this September at the start of the 2016-17 academic year. This new PLU program will focus on eh same four areas: self-regulation; executive functioning; self-advocacy; and social interaction, or socialization. And I am honored to have even given the opportunity to utilize my personal experience in higher education as a student who has autism to help my campus community understand life in my shoes. Education and awareness are how we breaks down those barriers together.

Real briefly I will conclude with this thought, which is a motto, a personal motto, that I kind of adopted five years ago and I have lived by, essentially lived by, ever since in any advocacy effort I am ever part of. It is kind of more the definition, what I tell them, you know, "Here is how." And that is I quote "All it takes is five minutes of your compassion to understand us, and that could transform your life."

And so, in closing, really, my first time I've been to this Committee, although I have heard many things about it. And so I hope at least in the future enjoy the discussion but especially focus on higher education. So I hope this is kind of at least a start to that. Thank you.

(Applause.)

DR. DANIELS: Thank you very much, Mr. Olson.

Next I would like to call up Dr. Dorothy

Strickland, who will be sharing some comments with us and a video.

DR. STRICKLAND: Not that exciting a video after lunch.

I am sure this Committee is very aware of the issues with diagnosis. And I think the speaker before me indicated that often now we are seeing more lay diagnosis than we did before.

We had noticed a while back that the -- because the spectrum is so broad, that the variations in the behaviors defined by the DSM ranged across our different users. We have a website, “Do 2 Learn,” which has lots of, 12 million, hits a month. And we are seeing a lot of variations in when people are diagnosed and what they are being diagnosed as.

So with the generous support of NIH, about four years ago, we went to experts around the country. We took the DSM-5, and we tried to break it down into behaviors that we could clearly video, and I think this has been done before. We came up with 68 behaviors. We developed a website that shows the 68 behaviors with short video clips of what they look like from ages about 6 months to 55 years. And we mixed it with the things that we know cause diversity in the diagnosis, such as IQ, age, socioeconomic background, location, I mean, the things that those of you in the field are well-aware of.

We put those together. And we put it on a website called “Diagnose First.” And then we added a lot of other things that experts have said they wanted to help; for example, feedback on how to tell parents, a complete diagnosis by the experts when they look at a child for an hour and tell you what they are seeing. In this website, we have the ability to take your PowerPoint course, put it on with our videos, add your videos, have student logins where you can come in and do training on how to diagnose and how to assess using actual video clips showing the behaviors.

And, in fact, let me run this short video, which is at YouTube under “Diagnose First” if you want to see it again.

(Video shown.)

DR. STRICKLAND: Okay. What I really need help with with this Committee is figuring out what to do with this resource. We have it sitting out there --

(Video interruption.)

DR. STRICKLAND: Oops. And on another topic that is long obsolete, which was, by the way, the last time I was before this Committee was on JobTIPS, which was about four years ago. Anyway, we did have to try to measure the effectiveness of Diagnose First. We did a study with 120 graduate students from universities across the country to see if they are actually seeing guided descriptions of what to look for on the DSM-5 markers were better at helping university students training to diagnose actually see the behaviors and understand them.

And we found, as you might expect, that, actually, a practicum experience, where you can see hundreds of children with different behaviors across different issues does help you understand what you are looking for in the DSM-5.

So what I asked this Committee to do is to contact me or contact Do 2 Learn at do2learn.com and let me send you a login and look over the site, see if you can think of what we should be doing to get this out there, how we could help disseminate it in the community that actually could possibly use these thousands of videos to understand what the experts are seeing because, interestingly enough, despite the fact that the diagnosis does vary a lot, even depending on what center you are in, what city you are in, a whole range of issues, the experts -- and the experts that helped us lay this out were from autism centers across the country. They do agree in statistical significance with what they are seeing.

So after they have been in the field a while and they have done a lot of diagnosis, they know exactly what the DSM-5 behaviors look like. However, when you first start, our studies indicate you don’t know.

And so, you know, the goal is to get out this expert advice that the experts have put together with this video in a way that it is available to people in training.

Now, the only caveat is that it isn’t available to the general public. And that is because of the IRB protections. A lot of subjects are adults and teens and so protecting them. It is really only for school psychologists, professionals who really understand the subtleties of what they are looking for and could use the tools in their training.

I have a million cards if anybody wants one, rather than look me up on the website.

DR. DANIELS: Thank you very much, Dr. Strickland.

Next we have Dr. Karen Heffler.

DR. HEFFLER: Hi. Thank you for having me here this afternoon. I am delighted to be here speaking with you this afternoon. I am a parent of a 24-year-old son with ASD.

Dr. Waldman and his research associates at

Cornell University 10 years ago found an association between early television viewing and autism and proposed television viewing as a possible trigger for the development in autism in those with a genetic risk.

In the 10 years since this research, autism has increased more than 100 percent. Non-hereditary factors are now known to contribute to at least 50 percent of causation in autism.

We have overlooked the effects of early screen viewing on the developing brain. Early screen viewing is associated with ASD, ADHD, language delay, and behavioral problems. Why are we not devoting more attention to researching screen viewing as a possible trigger for ASD?

Extensive research in neuroplasticity involving animals and humans definitively shows that a young brain develops connectivity according to what the animal or baby sees, hears, feels, and experiences. And this determines behavior.

I am an ophthalmologist. I reviewed the literature in autism, early brain development, and neuroplasticity. And what I found was astounding. The brain and behavior in autism is altered from typical in the exact ways that we would expect from extensive auditory and visual exposure that lacks a social context, the type of dose-related environmental stimuli that infants and young children receive from TV, video, and other screen media exposure. The theory I wrote with my co-author based on this scientific review explains virtually all of the findings in ASD. Please read the article.

I am now aware of local children who are improving with the removal of TV and other screen viewing, in addition to teaching the families strategies to promote pro-social behavior. These children appear to be losing the core deficits of ASD. This is not a prospective study, but the experience of a community provider, Lori Frome.

Research is desperately needed in this area. I believe this may be the only example of removing a risk factor and altering developmental trajectory of young children with ASD. The response of these children is consistent with the research of Dr. Chonchaiya’s group, which shows that earlier screen viewing, beginning at six months, as opposed to a year, and more hours of screen viewing are associated with developing an ASD diagnosis.

The opposite was found with regard to the time that children spent engaging in social interaction and the time they spent being spoken to. All of these findings suggest that early experience matters, and interactive social experiences affect the brain very differently from TV and video watching. 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. The research shows that children with ASD have auditory and visual hyper-connectivity. And this appears to interfere with social function and attentional mechanisms. More research is needed in this area.

I am an associate professor at Drexel. However, research can move very slowly without an urgent national focus. Removing screen viewing and promoting pro-social behavior is inexpensive and readily available. This has tremendous potential for both prevention and intervention in ASD.

As of 2010, ASD affects 1 in 68 children and 1 in 42 males. I am speaking with deep concern and compassion for young children with ASD and those at risk. Together, we can help children to develop to their full potential. We cannot afford to wait another 10 years.

The American Academy of Pediatrics recommends that children under the age of two avoid screen viewing, but this recommendation is seldom followed.

Who is advocating for future generations of children at risk of developing ASD? It is not their parents, as they do not yet know that their children may be affected. The IACC members must serve in this role. I am asking you, the members of the IACC, to direct national attention to this area of research, which offers real hope in ASD.

I am happy to answer any questions at any time regarding this. Please take a look at the article and direct your attention to this.

Thank you.

DR. DANIELS: Thank you, Dr. Heffler.

Our next comment is going to be from Lisa Wiederlight.

MS. WIEDERLIGHT: Good afternoon. I am a mother to a 15-year-old boy with autism and now epilepsy and the Executive Director of SafeMinds.

On March 31st, the CDC announced that autism prevalence has stayed the same as in 2012 at 1 in 68 American children. This defies human observation and befuddles special education administrators and medical professionals. The data comes from the CDC’s National Center for Birth Defects and Developmental Disabilities, which is led by Dr. Colleen Boyle. The negative implications of using this faulty data when more people are diagnosed than ever before and cost is estimated to be $268 billion annually cannot be overstated. The NCB’s DDD data underestimates autism prevalence, which continues to result in unfunded mandates for the agencies represented in this very room and does a disservice to those facing autism and to the American taxpayers.

Specific problems include, but are not limited to, the March 2016 prevalence estimate represents children who were born in 2004 who were diagnosed with autism by age 8 in 2012. That data is, therefore, four years old. And it is based on children born 12 years ago. How can this be considered acceptable? Where is the urgency that this crisis so obviously demands?

Next, New Jersey, which has kept the most rigorous and consistent case ascertainment practices since its inclusion in the ADDM, has the highest prevalence of all sites. The state continues to see an increase in prevalence, rising 12 percent in 2 years from 1 in 45 in the 2010 report to 1 in 41 in the latest report.

Next, the ADDM report chronically

underestimates the rate of autism by allowing sites to use only medical records, rather than both medical and educational records. Medical records miss a high percentage of autism cases. 17.1 per 1,000 are ascertained using both sources versus 10.7 per 1,000 using medical records alone.

Next, variability in case ascertainment methodology among catchment areas also threatens the integrity of the data. This includes how sites access records, how medical records are kept, and the quality of the investigators assigned to the site.

SafeMinds is also concerned about the Utah court case which will be brought by the former principal investigator for the Utah ADDM site. Dr. Judith Zimmerman is alleging that the CDC's ADDM network allowed research misconduct and persistent data errors in their autism prevalence reports and that she alerted the CDC to these allegations.

In contrast to the ADDM, the national health interview study puts autism prevalence at 1 in 45. This estimate is based on data from 2014, 2 years more current than the ADDM compilation. This research is coordinated by the National Center for Health Statistics. To quote the 2015 national health statistics report, "Children diagnosed with developmental disabilities typically require a substantial number of services and treatment to address both behavioral and developmental challenges. Measuring the prevalence of these conditions in children aids in assessing the adequacy of available services and interventions that may improve long-term outcomes."

Improving long-term outcomes and getting the best return on the taxpayers' investment is what is really most important. Therefore, SafeMinds suggests moving autism surveillance to the National Center for Health Statistics to improve quality of this critical research. Given NCB DDD's track record, this reassignment has a better chance of providing the most accurate and strongly supported estimate available to the decision-makers here at IACC and elsewhere in the Federal Government for appropriate resource allocation and better long-term results.

Thank you.

DR. DANIELS: Thank you Ms. Wiederlight.

Now we have an opportunity to hear from Brian Parnell about our written comments that we received. These, in addition to the statements that go with the oral comments, are posted on the IACC website for public access. And Brian will be giving us a summary of the written public comments.

MR. PARNELL: The IACC received seven written public comments from parents and self-advocates on five broad topics. Topic one was issues related to adult service needs. The commenters who provided input on this topic were Dr. Eileen Nicole Simon, Shannon Rosa, Matt Carey, and Gizelle Tolbert. Their comments made the following key points. After graduation from school, there are not enough resources to facilitate higher educational trade or vocational schools.

Adult services need to be expanded. Currently the wait lists for services are extremely long.

And this creates significant stress for families. Parents of adults with ASD with significant support needs are faced with difficult experiences, including identifying appropriate housing options that allow them to receive the supports they need while also being able to live in a manner that allows them to be a part of the larger community. Special communities that segregate people with autism from the rest of the community should not be the only option for those with high support needs.

Recent research findings published by a Swedish research group in the British Journal of Psychiatry showed alarming rates of premature mortality in adults with autism, particularly those with intellectual disability. Suicide was one of the causes listed. This is of great concern. Understanding mortality and improving life, life expectancy for people on the autism spectrum should be a high priority for research and needs to be included in the next update of the IACC's strategic plan.

Topic number two was wandering and elopement. Commenters included Kerry Lehr and Gizelle Tolbert. Their comments made the following key points. Safety issues, such as those associated with wandering and elopement, remain a concern. And, therefore, they would like to see the IACC take this issue up by forming a subcommittee or workgroup focused on safety issues. Support for Avonte's law and training for law enforcement during interactions with autistic individuals is very important to prevent tragic outcomes.

Topic number three was pre- and perinatal causes of autism. Commenter was Dr. Eileen Nicole Simon. Her comments made the following key point. The IACC should consider complications at birth, resulting in brain damage, such as asphyxia, umbilical cord clamping, and disruptions during development when investigating causes of autism.

Topic four, improving interactions in social settings. The lone commenter was James Williams. And his comment made the following key points. The anime subculture and conventions can provide an example for promoting and improving social skills and interactions for individuals with autism by incorporating explicit rules for expected behavior. This can reduce uncertainty for individuals with autism as well as prevent harassment from their peers. Video games can provide training in social skills and behaviors through visual, novel-style games that reward players for appropriate social decisions.

Finally, topic five was vaccines and autism. The commenter was Ann Jaykus. Her comment made the following key points. The IACC should urge Congress to hold a hearing on the CDC whistleblower, and the IACC should support a proper study of vaccinated versus unvaccinated children to determine if vaccines increased the risk of autism.

DR. DANIELS: Thank you, Brian.

So we now have a few minutes to have a discussion among Committee members of the public comments. So, John, would you like to start?

MR. ROBISON: Yes. I would like to address two of the comments. The first was a comment from Shannon Rosa, who said that she was concerned that her son is growing up and her son will need to be in some kind of supported living environment like Alison’s son, and -- what is that? Daughter. I am sorry. Yes. Anyway. And I guess I have to raise the question. Why is it that we feel that there is a basis to have a fight over where autistic people can live just because they need supports? I mean, for Christ’s sake, you know, the idea that one person might want to live in an apartment and receive supports and another person might want to live on a farm or in a communal setting, and those are two valid points of view for where an autistic person could live, why is that even subject to dispute?

I guess I have a real problem with why we are proposing to take away freedom of choice and just make it for somebody. Why are we saying we are not going to pay for one place or another? I guess I think it is wrong. And I hope that the Committee members could speak out in favor of freedom of choice because we are not talking about taking something away except freedom of choice.

The other thing that I would like to talk about is Matt Carey's comment about autistic mortality. You know, I mentioned suicide earlier. And Matt in his comment suggests that the life expectancy for his son who has intellectual disability and fairly major impairments is 40 years if you read those statistics. My own expiration date passed four years ago by those statistics. It probably shouldn't surprise you that I would be concerned about that.

You know, most of my autistic relatives are dead now. And I grew up with non-speaking cousins and I grew up with cousins with Asperger's, like me. And they are dead today. And they are not dead from any one cause. We are not dead from suicide. They are not dead from freezing to death. We are just dead.

I guess I think that that is a very, very big deal. And I urge the Committee to shift its focus in calling for more research into adult issues and quality of life. I mean, I know I sound like a broken record about quality of life, but as an autistic person, that is foremost to me.

And, frankly, causation, I don’t want to say it is not important, but to those of us who live with autism, what matters is quality of life, not how we got here.

Yes? What?

(Laughter.)

DR. DANIELS: Alison?

MR. ROBISON: Oh. I thought you were about to swat me or something.

(Laughter.)

MS. SINGER: No. Actually, I am about to echo what you just said. I agree that Shannon Rosa’s son deserves, as she says, the choice to live the life he prefers. But I don’t agree with the comment she made later that the parents are trying to force everyone with autism to live in planned communities.

I guess I would pose the question that John raised to Melissa and say it seems like CMS is singling out congregate settings and group-oriented options that best serve people like my daughter, who has very serious needs. And it is serving her very well.

So my understanding was that CMS had said originally the rules would be focused on outcome, but now it seems that the regulations that were issued just earlier this week were focused more on physical setting than outcome. And maybe you could speak to that issue as to why CMS seems to be singling out congregate and group settings that serve people with intellectual disability as well as autism.

MS. HARRIS: Sure. I know this was a big topic at the last meeting. So I was kind of expecting it.

So there are a few things that CMS is issuing. We issued a regulation in 2014, and we are in a transition period that runs until March of 2019 for states, state Medicaid agencies, to work with their operating agencies or other state agencies that administer programs to individuals with a mental illness perhaps or individuals with a developmental or intellectual disability, to do an assessment of all of the settings in their state that currently receive Medicaid-funded home- and community-based services. And by the end of the transition period, which is March of 2019, all of the settings that Medicaid will continue to reimburse as home- and community-based need to meet a set of criteria, a minimum floor of criteria. This is not to, you know, kind of rid the nation of a particular type of provider. It is, instead, to kind of level the playing field of all the choices that individuals have.

I was particularly struck by one of the comments that said that individuals with autism should not have their only choice be a setting that segregates them away from the larger community. I think that is exactly right. We are not trying to reduce individual choice. We are saying that for Medicaid-funded services, there is a set criteria that needs to be met.

And this five-year period that we are two years into is to give the states and the providers time to do an analysis of how they are operating today. And by “providers,” I mean residential providers that could span from group homes to, you know, very large congregate settings and nonresidential providers, which, again, could span across individuals with multiple types of disability and could include day programs with an employment focus, a pre-vocational or competitive employment focus, and those nonresidential settings that are more adult day health center-focused.

So now is the time for all of those providers to be assessing how they operate now and how they facilitate the community integration of individuals who receive services there, not force the community integration but facilitate it. There is no definition of integration or community because that is very much at the individual level.

And so I would say to you, Alison, for your daughter, for anybody, you know, the regulation is not meant to take away choices. It is to say wherever a person who needs home- and community-based services funded by Medicaid is living or receiving services, there should be some basic community integration requirements, like, you know, the setting facilitates the individual engaged in the community as much as he or she wants, the setting facilitates the person being treated with respect and dignity and being free from restraints.

And then as we get further into some subset, a rather large subset, of settings that are provider-owned and -controlled, which could be a group home, which could be another type of intentional community or congregate settings, there are additional criteria like there needs to be a legally enforceable document, like a lease. There needs to be a choice of roommates. If a roommate has to be had, the individual gets to choose roommates. The individual needs to be able to lock their door. Other people could have keys to the door depending on the individual circumstances, but I should be able to lock my room if I would like privacy.

I should be able to have access to food at any time, access to visitors at any time, unless there is a requirement that means one of those criteria is not good for me. If I have got a particular type of an eating disorder or some other kind of health condition where I should not have access to food at any time, that’s fine.

Again, this is not a one size fits all. Any kind of modifications to the criteria should be spelled out in a person-centered plan that is very specific to the individual. So there needs to be an assessment that puts the individual at the heart of all of the care planning and individuals that that person wants to be, you know, part of the decision-making process. And as long as the modifications to our criteria are documented and tied back to an assessed health condition and assessed need, that’s fine, but the goal is to make sure that there are choices of where to reside and where to receive day services to kind of remove as a variable for how you experience life whether or not you are receiving Medicaid-funded services.

So there is so much confusion and, you know, heartache, frankly, about this regulation. And the states are concerned. The providers are concerned. And, above all else, individuals, beneficiaries, and family members are concerned.

We did have one state last week, Tennessee; get approval of their statewide transition plan. That does not mean all work in Tennessee is done. It means Tennessee has laid out a good process for how they are going to use the rest of the transition period to do the assessment of state policies, things at the state level that need to change, how they are going to work with their provider community to make sure that all of the providers are compliant by the end of the transition period and how they are going to involve the public in that.

So I do encourage you. If you look at the Medicaid.gov/hcbs website, it will take you to the link for the approved document in Tennessee and lay out the parameters of what we approved and what we haven’t in Tennessee because, again, the journey is not over in Tennessee, but it does give states the ability to say this regulation, the CMS regulation, is achievable. CMS will, in fact, buy off on efforts a state is doing in the name of complying with the regulation. And we are happy to continue that conversation.

We issued last week a “frequently asked questions” document. And it is also on the Medicaid.gov/hcbs website. The focal point of that guidance was on planned construction because we know that, even though we are in this transition period, new resources are being put into building new capacity for either residential services that will be relying on Medicaid funding or nonresidential services.

That guidance indicated that if there is a new setting that is being built in any of the scenarios that our regulation says are presumed to be institutional, that CMS cannot give preliminary approval of such building as it is being constructed because the regulation really boils down to how individuals living in a particular setting are experiencing the community. We can’t do that. We can’t evaluate that looking at blueprints of a building and, you know, proposed locations of kitchens and beds and things like that. It has to be like, what are the individuals living there experiencing on a day-to-day basis, and how does their experience match up with our criteria? It is not a no. It is a not now kind of thing.

So the regulation has three scenarios that are presumed to be institutional in nature. And those are settings that are on the grounds of a public institution -- and that could be settings that are on a campus maybe with the public ICF -- a setting that is in the same building as the public or private institutional provider -- so that could be a setting that is in the same building as a nursing home, let’s say, so an assisted-living facility wing of a nursing home, let’s say -- or any other type of setting that could be isolating to individuals receiving Medicaid-funded HCBS from the larger community.

And, again, the reg does not say a setting in any of those three scenarios is not home- and community-based. It means that the state needs to assess that setting, in particular, and figure out if, really, the individuals living there are living by our criteria. And the state needs to send information to CMS. CMS needs to take a look at it.

So what our guidance, our FAQ guidance, said was if a state is building a new setting in any of those three scenarios, something new on the grounds of an ICF, something new in the same building as -- something new that could be isolating, we can’t say before that setting is built that it is going to be okay for Medicaid HCBS funding. It doesn’t mean it is not going to be okay. It just means we can’t give any kind of commitment. And so there is risk involved, the point being that everybody as new facilities are being constructed and new resources are being put into crafting capacity, be it residential or nonresidential, community integration is the way to go and to not even trip any of those three scenarios of heightened scrutiny. So if you are going to build new housing, build it smack in the middle of the community. If your community is all the way out in the middle of rural nowhere, you know, that is different. Community, you know, is evaluated within the context of each individual location.

But we really want this regulation to be in the minds of builders, of developers, of states, counties, all funders, you know, as impacting decisions on how new resources are allocated, and really want that, you know, very much in the forefront, but the goal is to not minimize choice but to make sure that people have informed choice about where to be and receive services in settings that are achieving achievable community integration criteria.

DR. DANIELS: So we want to try to wrap up by 5 after. So we have got a couple of minutes. If you can keep your comments very brief and just to the point that would be great.

Alison?

MS. SINGER: I mean, it is all well and good to say you can’t evaluate a blueprint, but the actual effect of that regulation is that no one is going to be able to afford to build not knowing whether it is going to be accepted. So that the real effect is prevention of housing that would serve the most needy population. So let’s just be clear about that.

My question is how CMS is measuring how the states are actually serving people who have the most severe needs. What data are you collecting from the states with regard to home- and community-based services for the most severely affected people? And how is it being monitored?

MS. HARRIS: So let me react to your first point first. The only reason that CMS would get involved in reviewing a particular setting is if, again, a state wants to add a new setting to a location that would tip off heightened scrutiny.

So don’t build on the grounds of a public institution. Don’t build or add onto an existing institutional provider. Don’t build something that is going to be isolating. If you don’t do any of those things, CMS is not involved in your business in terms of adding new resources.

If, for some reason, your only ability to add new capacity is in one of those three, then, again, you have a pathway. It is not an automatic no. It is a we can’t tell you with absolute certainty that this will be eligible for Medicaid funding. It would be a disservice to the whole community integration tenor that we worked so hard to establish with years of public comment.

Your second point, you know, every waiver, every kind of filing that a state puts in front of us is very different. The beauty and the challenge of Medicaid-funded home- and community-based services is that it covers an enormous different spectrum of individuals across the age spectrum, across a disability spectrum. And so we have to evaluate each waiver to see who is the state covering. The state can put limits on individuals in terms of the number of people that they serve, the institutional level of care that the waiver is serving. And states establish that institutional level of care, which can vary widely across the state. So one state serving a waiver that has individuals with an ICF level of care can look very different from the neighboring state, who might have the same waiver with the same level of care associated with it.

So part of the responsibility as we approve any kind of waiver program, this regulation aside, is to make sure that the services that the state is offering are commensurate with the need of the population and that the state is maintaining the health and welfare -- that is a direct quote from our statute; it is a bit outdated, but it is a quote from the statute -- the health and welfare of the waiver participants. That is one of the backbones of the waiver program.

DR. DANIELS: Melissa, can we wrap that up quickly --

MS. HARRIS: Yes.

DR. DANIELS: -- so that John and Samantha can have the last word so we can move on?

MS. CRANE: Can I speak first because --

DR. DANIELS: Yes.

MS. CRANE: -- I have been waiting for a while? So I think it is extremely important that we not lose sight of the fact that level of care and level of integration are completely different questions and that Shannon Rosa’s comment was actually trying to make it fit that explicit. Her son has very high service needs. She wants to have her son be in an integrated environment.

Now, when we do not have people, services available in an integrated setting for high levels of care, we cannot afford to have states be putting all of their new funding for new settings toward planned communities that are very segregated when we don’t have options for community living for the same level of care.

We are particularly concerned with this because when you actually look at the research --

and that is something that Shannon Rosa also noted -- when you adjust, even when you control for level of care, people who are more connected to their communities are much less lonely, are having much higher quality-of-life outcomes. And, as a body that is designed to coordinate research and services, I think we have to keep that in mind as well. This is, again, another reason why we really need to be adjusting our funding for services research to have a lot more funding for research on housing models and outcomes for those housing models, including the quality-of-life outcomes.

DR. DANIELS: Thanks.

And, John, you have the last word.

MR. ROBISON: I don't want to seem disrespectful towards Melissa's comments, but I do feel that I am justified in being critical. I have sat here and listened to 15 minutes of Federal justification for why we are not obstructive in housing operations. And, for Christ's sake, I can't make sense of it. How could somebody who needs to put their child in housing possibly make any sense of it?

The fact is as an autistic adult, I am free to live in an apartment, a home, a group environment of any kind. I can make that choice. Why is it that we debate how we are going to restrict the choice of another autistic person who happens to be more disabled than me who can’t speak out for his own freedom of choice? What possible justification is there for having a Federal agency putting up all kinds of elaborate barriers for how we are going to construct housing when we already have a system in the United States of local building inspectors to ensure buildings and residences are safe? I think it is a terrible misunderstanding of the purpose of government.

DR. DANIELS: Thank you for your comments and, everyone, for a very robust discussion. I am happy that we have a housing working group, where we can have much more lengthy discussions of this topic. So I think that we will wrap this up so that we can move on to the next section, but thank you, everyone, for your participation. And for those of you who came to share comments with us, thank you very much.

Bruce?

DR. CUTHBERT: Thank you.

So we are due for our break at 2:15. So this won’t be a quick run through our science updates. It will be a lightning run through our science updates. So fasten your seatbelts. I will try to be very succinct but at least clear. Okay.

So we will go through these as indicated in the agenda on the questions on the strategic plan. One, when should I be concerned? First, parent-reported and clinician-observed Autism Spectrum Disorder symptoms. This is a relatively unique study from Cathy Lord’s group in which they looked at parents who had children diagnosed with ADHD who came in to an ASD clinic to have their children examined for ASD as well. So of this ADHD sample, 21 percent met ASD cutoffs on the ADOS. And 30 percent made the ASD cutoffs on all of the domains of the four social communications areas: quality of social overtures, unusual eye contact, et cetera. The idea is that these results do highlight the challenges that clinicians and researchers often face when trying to distinguish ASD from other disorders or, indeed, to look at comorbidity.

Second one, predictors of age of diagnosis for children with ASD spectrum. This was a complicated evaluation of a large sample trying to look at age of diagnosis. Overall what they found is that African American children were actually diagnosed earlier than Caucasians, but this interacted with ASD severity and the presence of a consistent source of care. So having a consistent source of care actually predicted earlier diagnosis for Caucasian but not African American children. So it is a very complex finding that bears further exploration.

The third study, the brief report about -- wait a minute. Oh, that one, they are a little out of order from what I had seen before. Okay. Yes. The McPheeters one -- sorry -- is the familiar Preventive Task Service’s report that we discussed extensively the last time and we referred to this morning. So I think we are all very familiar with that, and I am not going to take time to go through that.

And, finally, when should I be concerned? The feasibility and effectiveness and an advocacy program for Latino families. Obviously, this is a particularly significant issue given the potential language barriers. This looked at 40 Latino family members with children with ASD who participated. And they showed that they were able to achieve consistent attendance, low attrition, and high participant satisfaction. So this suggests that, in fact, it is feasible to establish advocacy programs in Latino children.

Okay. Two, question 2, how can I understand what is happening? First, evaluation of intestinal function in children with autism and gastrointestinal symptoms. We know that these are consistent complaints throughout children on the spectrum, but in this study, actually, they looked at a large number of gastrointestinal measures and so forth. The only finding was that some autistic children had mild levels of mucosal inflammation but nothing, you know, really to write home about. So, really, overall, the conclusion was that children with autism who have symptoms of GI disorders have objective findings that are similar to children without autism. And so that leaves open the question of where do these GI complaints come from?

Sorry. The next one is sleep and behavioral problems, again another paper relevant to co-occurring disorders, which we talked about this morning. This is a small study of 81 children with ASD. And, as is often observed, the sleep problems were significantly associated with physical aggression, irritability, inattention, and hyperactivity. And, in particular, sleep disturbances associated with behavioral dysregulation among children with ASD, especially the nighttime awakenings, had the most consistent association with daytime behavior problems.

Finally, another co-occurring report, medical and behavioral correlates of depression history in children, adolescents with ASD. This is from Jeremy Veenstra VanderWeele’s group, from whom, of course, we heard last meeting. This was a large sample of over 1,200 participants from the Autism Speaks treatment network, who were divided into a lifetime history of depression and non-depressed children, only 89 patients in the ever-depressed category.

Overall, 4.8 percent of the children age 6 to 12 showed symptoms of depression or had gotten a diagnosis of depression compared to just over 20 percent of those age 13 to 17 years. A positive history for depression was associated with a greater chronological age, higher IQ, and an Asperger disorder diagnosis from these retrospective data.

Interestingly, the ever-depressed group exhibited significantly greater rates of seizure disorders and also gastrointestinal problems, which might not have been predicted. The groups did not differ in autism severity or repetitive behaviors.

So, overall, the children with ASD and a history of depression are more likely to also have co-occurring medical problems, although the direction of causality is not clear.

Okay. Moving along to -- I think we once again got in the wrong -- so yes. I just looked. The author list looked a little bit different. Association of maternal obesity and diabetes with autism. In this study, they looked at 2,700 children, including 100 children who are a subset of the Boston birth cohort. Essentially what they found, in brief, is that the combination of maternal obesity and diabetes was associated with greater risk of ASD than either obesity or diabetes alone. And this is in particular when ASD co-occurred with intellectual disability.

The authors speculated on that basis that ASD with and without intellectual disability may be etiologically distinct, which, you know, one can discuss whether you can conclude that on the basis of a sample of maternal obesity and diabetes, but that was their interesting conclusion.

The next study in pediatrics, birth spacing and risk of ASD and other neurodevelopmental disabilities, this was a review from over a million children. In this large sample, they did find, as has been reported before, an increased risk of association between short interpregnancy intervals and an increased risk of ASD. And the hazard ratio was about 2 to 1, which was strongly associated. And it was stronger for the somewhat older reporting system for autistic disorder as such in an observation of 2.62 percent.

Three studies also reported a significant association between long interpregnancy intervals and increased risk of ASD. Shorter intervals were also associated with a significantly increased risk of developmental delay and cerebral palsy. So clearly it is a risk for a range of disabilities and not just ASD.

Okay. Moving on to question 4, which treatments and interventions will help? This study from the Chang group and with the senior author there Connie Kasari, who was involved in intervention, this was a small study, with 66 children, of the preschool intervention, of an intervention called JASPER, which stands for Joint Attention, Symbolic Play, Engagement, and Regulation. This was delivered by teachers in the preschool classrooms for three months with a one-month follow-up. Measures of core deficits, such as initiations of joint engagement, joint attention adjustors, and language and play skills, and standard cognitive measures, all approved for the treatment group, thus demonstrating the feasibility of having this kind of intervention delivered by the preschool teachers themselves.

Next, the pilot study promoting participation of families with limited resources. This is from Cathy Lord’s group again. This was, you know, modest feasibility at best. They had 27 families referred to this project, 13 of which did not meet eligibility requirements. And only eight families enrolled. Overall for the project, treatment attrition was calculated at 62 percent. Attrition during treatment was 12 percent. So there is some evidence that this can be done in some families but clearly much more work to figure out how to get these families engaged and staying with it.

Question 5, turning for services, this is from our own member, David Mandell’s group. And I hope I don’t misrepresent these data, David. This is from the national survey of children with special healthcare needs in a very large sample of over 2,000 children then and from an earlier cohort and over 3,000 at a later cohort. Overall compared with caregivers of white, non-Hispanic children with ASD, the caregivers of Hispanic children reported less need for prescription medications on analyses. And, similarly, caregivers of black non-Hispanic children also reported less need for prescription medications and for child and family mental health services.

On the other hand, both English-speaking Hispanic caregivers and black non-Hispanic caregivers reported greater need for occupational, speech, and physical therapy than white non-

Hispanic caregivers. And there were no differences among the races or ethnic groups among perceived need for specialty medical care or respite care. So clearly this is an issue for health diversity research in that the needs perceived by the communities may be somewhat different.

Second, imagined examination of paired insurance ratings, again in the internal pediatrics. In this case, they looked at insurance histories in that same survey, national survey of children with special healthcare needs, and looked at health insurance, including private alone, Medicaid alone, and a combined private and wraparound Medicaid.

Perhaps somewhat expectedly, having Medicaid doubled the odds of reporting adequate insurance compared with private insurance alone. And the children on Medicaid's families had the lowest out-of-pocket costs, at only $150.

On the other hand, children covered by a combined private and wraparound Medicaid had the highest total expenditures, nearly $12,000 a year, and the highest expenditures paid by their insurance. Clearly there is a mismatch between the parent ratings of their insurance adequacy, the child expenditure, and the relative financial burden, which offers strategies for changed policies in this area.

Finally, in terms of improving access to care at autism treatment centers, these are two hospitals in Cincinnati. One hospital focused on reducing the number of patients with ASD waiting for follow-up appointments and the other on reducing delays to new diagnosis.

In both hospitals in both of those areas, time to new diagnosis, and time for follow-up appointments, they reduced the problem by about 94 percent, just through a systems analysis approach, just analyzing all of the delays in the system. So this shows that it is possible to do this if you really do a systematic approach.

And, finally, presence of correlates of elopement. That is, of course, wandering. This is from the CDC's Pathways survey, a telephone survey of 4,000 children with a developmental condition, of whom 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, and children with ASD, either ASD only or ASD plus and intellectual or developmental delay, were more likely to have eloped than those with an intellectual disability or developmental delay only.

And the children who did elope were more likely to have the following characteristics: to not realize when there is danger, to have difficulty distinguishing between strangers and familiar people, to show sudden mood changes, overreact to everything and everyone, to get angry quickly, to get lost easily, and to panic in new situations or if change occurs.

Okay. Question 6, the future for adults. There are two papers, not exactly consecutive but the first, “Premature Mortality in Autism Spectrum Disorder.” This was a large sample of 27,000 people in a Scandinavian or northern European birth cohort. Overall, the odds ratio was about 2.0, slightly over 2.0, for more frequent death among people with ASD than non-ASD. The highest risk was among females who had low-functioning ASD.

Curiously, there was an increased biological vulnerability across the board. This was not due to any one particular area. It was just sort of all-cause mortality, holding true for all causes of death. So this raises the speculation of an increased biological vulnerability overall, generally in ASD. This can be compared with schizophrenia, which seems to have a similar sort of data there with premature mortality, not due to any particular area.

Second study, factors associated with a subjective quality of life in adults with ASD. They looked at reports from the adults themselves, from maternal proxy reports; that is, the mother's report of how she thinks the child would react or report, and from the actual maternal report itself.

So 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, level of independence in daily activities and physical health were significant predictors of maternal reports of their son or daughter’s quality of life. So, interestingly, the children and the mothers reported somewhat different factors in their perceptions, respective perceptions that were associated with quality of life.

And, finally, association of psychiatric and neurologic comorbidity. This is in a large Danish sample of almost two million people. And, again, if you looked at mortality, similar to the prior study, 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, which suggests that in general, these factors operate as a single risk factor for mortality, rather than being differentiated between autism versus other things.

And, finally, we finish again with the future. This is a clinic report. I am actually going to skip these two and go to the end because we are running out of time. Actually, somehow I missed those four. And I didn't look at them. Probably the names got mixed up, but this is -- sorry. Yes. I am hurrying quickly.

So yes. These are the four-year-olds and the eight-year-olds. Okay. So let's do the eight-year-olds first. This is the paper from the CDC reporting the now familiar data that the rate of autism in a large sample was 14.6 per 1,000, or 1 in 68 children aged 8 years. And estimated prevalence was significantly higher among boys to age 8 years than among girls to age 8 years at 23.6 versus 5.3 per 1,000, a very large difference.

Also, estimated ASD prevalence was significantly higher among non-Hispanic white children, 15.5 per 1,000, compared with non-Hispanic black children, 13.2, and Hispanic, 10.1

per 1,000, which, of course, raises the question of whether these are due to differences in access to care and reporting, as opposed to actual differences. And that remains to be seen.

Similarly, in the children aged to four years old, in a similar study from the CDC, here the rate for the children was slightly lower. They were around 13.4 per 1,000, which was 30 percent lower than the 8-year-olds, again at 14.6 per 1,000. So, again, that depends on reporting and perhaps, you know, the nature of the sample as to whether there is -- and when the autism is detected, as opposed to some fundamental difference in when this occurs.

I apologize for rushing through that so much. But we perhaps can take a little break. I think there is one slide, actually. Yes. I wanted to give you one other slide because our next session coming up after the break is a wandering research update about auditory hypersensitivity and safety.

So these are data from schizophrenia. I have mentioned the mortality in schizophrenia. And these are also data that might be interesting.

This is a sample of subjects, as you can see, who are taken from populations with a DSM diagnosis of schizophrenia, schizoaffective disorder, or psychotic bipolar disorder. And in that middle slide there, I don’t know if the pointer will work, but in the middle, you see a big psychosis box. All of the patients were lumped together for analysis. The investigators did cluster analyses using a very large number of measures, of which they called cognitive control, generally cognitive ability; and sensorimotor reactivity, which referred to patients reacting either with an exaggerated response on electrophysiological measures of response to cones and lights and anticipation of tones and lights.

What you can see is that if you look at the bottom, they found three clusters that they called biotypes. You can see them illustrated in the little brain diagram. Over on the left, biotype 1 had patients that if you look at the little box with their EEG, the little squiggly lines there, on the far left, that first biotype had very blunted reactivity. And so they were very nonresponsive, the way we tend to think of schizophrenia patients in state hospitals who are very nonreactive, and also very poor cognitive functioning.

The second group, however, had, similarly, poor cognitive function but extremely exaggerated sensorimotor reactivity. You see how big those squiggly lines are. They overreact to things. And, finally, a third group, the ones with green, had more or less normal reactivity.

So this is really interesting because what the findings were is that patients from any one of those three traditional categories, schizophrenia, schizoaffective, and psychotic bipolar, were scattered throughout those three biotypes. It was completely almost random as to which biotype they wound up in.

So it shows that you can maybe parse this traditional spectrum with these measures in a different way. And, just to anticipate the discussion that we are going to have, perhaps given the many genetic and phenotypic overlaps between schizophrenia and ASD, these data might be somewhat comparable and bear thinking about when we try to understand what these deficits mean and how they reflect etiology in different kinds of impaired functioning.

So, with that little teaser, I hope, we will go to our break. And what do you think, Susan, maybe a 10-minute break, and we will try to recover? Let’s come back at 20 of the hour. And we will look forward to our next session. Thank you.

(Recess taken.)

DR. CUTHBERT: We are ready to proceed. So we are now running about 15 minutes behind schedule, but, on the other hand, we do have some time to give at the end. So we can probably make that up.

So now we are really very pleased to have this group presentation on wandering or elopement, as in the article I cited by Wendy Fournier from the National Autism Association; Dr. Paul Lipkin with the Interactive Autism Network; and, also from that same network, Dr. Kiely Law. So, Dr. Fournier, I think you are going to go first.

MS. FOURNIER: Actually, Paul is going to start.

DR. CUTHBERT: Okay.

MS. FOURNIER: Thank you very much.

DR. CUTHBERT: Whatever order you prefer. That is fine.

MS. FOURNIER: I am just a mom. You don't have to call me "Doctor."

DR. CUTHBERT: Oh, okay.

(Laughter.)

DR. CUTHBERT: Okay. So welcome. We will look forward to this panel.

MS. FOURNIER: I'm just a mom.

MR. LIPKIN: Thank you again for the opportunity to come and speak to the Committee today.

We recently completed a survey on auditory hypersensitivity at the request of the National Autism Association, Wendy's organization. And she will tell you a little bit more about that.

What we would like to do is to present the data that we have today. We think this is interesting and compelling data that will be informative for the community at large.

For those who aren’t familiar with the Interactive Autism Network, we also call ourselves IAN. And we’re an online volunteer research registry of networks and a network of parents and individuals who are affected by autism. We were created with the aim at linking researchers with family members.

We currently have about 54,000 participants. Of those participants, about 15,000 are children with ASD whose parents complete information on them, but we now have actually close to 6,000 adults with Autism Spectrum Disorder who are part of our panels of participants within IAN. This study was conducted by volunteers who are interested in completing this survey.

As a background, important background, here, in 2011, actually, at the request of the IACC Safety Subcommittee at that time, we completed a study on wandering and elopement due to concerns that were voiced and expressed by the autism community at that time of the dangers of this behavior in children.

That study, in fact, if you look at the red line -- the pointer is not working, but if you look at the red line, this was in response to the question "If you are able to, please tell us what you believe causes your child's elopement behavior." And 30 percent of the parents said that they felt that the children's elopement was from trying to escape an uncomfortable sensory stimulus, like a loud noise. And it is that specific finding that has provoked, in fact, this study.

Prior research on auditory sensitivity has shown a really wide range of numbers in terms of how common it is, but, no matter which studies that you look at, it is really a very common problem amongst children of having any type of abnormal sensory experience. Anywhere from 40 to 100 percent have been reported.

In terms of auditory hypersensitivity, the best reports were that it affects 30 to 50 percent of children with ASD.

What seems to be true is that it does not appear to be related to auditory acuity. It is an independent process.

And then parents have voiced a lot of concerns about this reaction because the children often seem in pain or in significant distress. They are often increased in unsafe behaviors and, hence, the concern with safety and elopement. And the children are particularly very difficult to manage with this problem.

There have also been questions brought about -- about the opposite response or high post-sensitivity and whether that represents a safety concern.

And so the leaders of the National Autism Association got in touch with us about funding to support us on a study which would look at auditory sensitivity, both hyper- and hyposensitivity, look at its effect on child safety.

We had a team which included parents, experts on Autism Spectrum Disorders, audiologists, and researchers who helped devise our survey. And we launched it in the spring of 2015, not 2014, as it states on here, with three primary aims: one, we wanted to characterize auditory hyper- and hyposensitivity in children with ASD. We wanted to look at the relationships between hypersensitivity and potentially unsafe behaviors and to assess the use and satisfaction of the interventions that, in fact, have become quite prevalent for use in auditory hypersensitivity.

So I am going to turn it over now to Dr. Law.

DR. LAW: Hello. So I just want to get right into the results. So we had 814 parents complete the survey, "Characteristics of the Children with Autism." Consistent with the known autism gender ratio, 82 percent were male. Consistent with the greater IAN sample or the ethnicity and race of those who participated, the median age of the child at the time of survey completion was 10 years old, with 50 percent of the children being between the ages of 7 and 13. And you also see the distribution of ASD diagnoses that parents reported their child as being given.

So I just want to say that these are preliminary results, sort of a first glance at the data. So of the 814 families that participated, three-quarters of them reported that their child had current issues related to auditory hypersensitivity. Ten percent had said this had been a problem in the past but had since resolved, and 13 percent had never experienced this issue. The median age of onset of the symptoms, parents reported at 2 years of age. For those whose symptoms resolved, the median age was between 7 and 8 years. And for the groups that had experienced the problem, parents reported the worst symptoms between the ages of 4 and 5.

When we asked parents about their child's emotional state, you will see that the top three characteristics are scared, irritable, and stressed. And when we asked parents about the child's physical response at the time of the auditory trigger, I will just point out the "tries to run away," which was a little over 40 percent. And "tries to hide" was at 25 percent, which parents also shared as being a safety-related concern. And, in addition, a third of children tried to stop the sound or noise. And this, again, parents had pointed out in the comments that when the auditory trigger is the TV or the vacuum cleaner, this may not be a problem, but when the trigger is your infant sister or brother, trying to stop the behavior puts other family members at risk.

We did some preliminary comparisons between the two groups. There is a lot left to do here, but just to report, similar to what has been published in the literature about hypersensitivity, these kids were more likely to have more severe autism behaviors, symptoms in general, based on the social responsiveness scale.

Also, probably related to autism severity, they were also more likely to have a history of epilepsy and seizure disorders. What was surprising to us, however, that was shared with us by parents before the survey was that 30 percent of the families had reported that their child had seizures provoked by auditory triggers. And, again, I would just point out that seizure disorders also bring about their own safety-related concerns.

In regards to impact on the child’s participation in activities, as you can see, there was limitation in participation in family and school activities as well as community activities.

In regards to how often children experienced hypersensitivity reactions, over 60 percent of families said it happens weekly with a quarter of families saying this is a daily occurrence. And 50 percent of parents characterized or said that it was moderately or extreme difficult to manage this behavior.

And then we had a particular focus on safety concerns. Just in general, we asked about their child being exposed to unsafe situations as a result of hypersensitivity-related issues. And over 40 percent of families said that their child had been in unsafe situations.

And then also we asked about injury to the child as well as others as a result of these behaviors. You will see that close to 20 percent of children had been either physically injured or harmed and 30 percent of others had been physically injured or harmed. When we asked parents more about this, it was tied to the fact that parents also reported an increase in self-injurious behavior provoked by auditory sensitivity, hypersensitivity, as well as an increase in aggression towards others when the child is exposed to auditory triggers.

We asked families about the most common interventions. This is just the top six. The top three you will see are more behavioral-based approaches; whereas, the other, the bottom three, are sort of mechanisms to block the sound.

Earmuffs, those are the standard sort of ear-covering headphones that you often see or you sometimes see children with autism wearing at community events and that are now being advertised and developed specifically for families with autism. About half of families have tried these. You will see that 24 percent reported that they were very satisfied, but at the other end, you will see that there were 20 percent who said that they were very unsatisfied with this solution.

In discussion with our audiologists, also, there is concern about long-term use of these types of sound-blocking devices because they actually produce a compensatory physiologic response that may actually increase auditory sensitivity after removal of the device.

PARTICIPANT: Why were they unsatisfied?

DR. LAW: I will have to get back to you on that. We haven’t looked through the details.

Then also we just asked a few questions about hyposensitivity from the same 800 families and kind of a very different makeup in that over half had never experienced this issue, with only 30 percent currently having problems. The median ages were all younger, with onset, resolution, as well as worst symptoms. Families did also report safety concerns and actually had reported higher percentage of the child being in unsafe situations as a result of this lack of response. But when you looked at actual harm to the child or harm to others, the percentages were less.

And then I just wasn’t to recognize our other team members and contributors to the survey and to thank the families that continue to participate in IAN. And then also I just want to mention that IAN is a partnership project of the Kennedy Krieger Institute and the Simons Foundation and that we also receive partial funding from the Patient-Centered Outcomes Research Institute.

With that, I am going to turn it over to Wendy.

MS. FOURNIER: We are going to knock this out in 20 minutes, girl, no problem. I told you we could do it, Susan.

Thank you, Paul and Kiely, so much for your help with this study. Thank you, Dr. Daniels, for allowing us to come here and present this compelling update on the wandering issue.

For the new Committee members whom I haven’t yet met, my name is Wendy Fournier. I am the President of the National Autism Association. Our organization has presented to IACC several times on safety issues, especially wandering, since 2010. We are focused on preventing tragic deaths in the autism community.

In data collected by NAA over the last 5 years, we have learned that cases involving children aged 9 and under ended in death 44 percent of the time. Cases involving children aged 13 and under ended in death 31 percent of the time. Two thousand fifteen was the deadliest year that we have on record since we started collecting data. And fatal outcomes last year nearly doubled from 2014. It is a very serious issue affecting our community.

We have also learned that our children die quickly. It is not very often that you will hear a story of a missing child with autism where there is a long-term search and they actually find the child alive. Usually they are dead within minutes.

By far, the number one cause of death from wandering is drowning, followed by getting hit by cars. We had three vehicular accidents just in the last week alone: two children, one adult. Two of them are dead. The adult and one of the children are dead, so three in one week.

So because our kids die, tend to die, very quickly, prevention is the key. Prevention does save lives. We know this because of the families that we serve through our safety programs in NAA. These are some of the adorable kids that have received one of our Big Red Safety Boxes. We received this very sweet note from a mom, who said, "I really believe the door chimes in the Big Red Safety Box saved my son's life when he bolted from the house and onto a busy street a few years ago. Because of that door chime, I was alerted and able to get to him just in time."

These toolkits just contain a booklet of educational information, prevention strategies, door and window alarms, a personalized ID tag, and some other items. They are seemingly simple resources, but they can literally mean the difference between life and death.

We have also provided other items, like tracking technology, distance monitors, safety gates, and those noise-cancelling headphones that many of the families in this auditory hypersensitivity study reported using.

The construction headphones do pose secondary safety risks. Through this study, we now know that we really need to develop some technology that is customized to the individual needs of the person with autism and can address their specific auditory triggers. So for some kids, it may be a certain word. For some, it might be a baby crying. For others, it might be somebody's squealing or just a certain tone of voice. But we have to find better technology to help besides these construction headphones, which look ridiculous and our kids get bullied and parents aren't happy with them. I am sure the kids aren't happy with them. But I found on Kickstarter this campaign of these little wireless ear buds that you can control using a smartphone app. And so you are basically just like a stereo. You are equalizing the sound of your world by making adjustments using the smartphone app. So we could literally get to the point where technology could allow us to filter out the sounds that really bother us on an individual level. So that is the direction that we are hoping that technology can go. And I am hoping that that is something that IACC can help with and possibly coordinate with NIDCD to help us develop that kind of customizable technology.

Items like this and the others that are shown you can be very effective tools in a multilayered approach to wandering safety. But, in reality, they are just Band-Aids. We really need to dig deeper into the root causes of wandering, which is why this study was conducted.

We believe that in almost every case, wandering is a form of communication. With regard to cases involving auditory hypersensitivity, the message is “I need to get out of here right now.”

Most of us in this room have probably experienced some level of auditory hypersensitivity. You may be at a busy restaurant or a public event or even in a relatively quiet setting, but there is one particular noise that is just so irritating to you. It could be the sound of a coworker tapping on their desk or your neighbor’s dog barking incessantly and you get to the point where it is seriously driving you crazy.

Now, you have choices, and you have some control over your own environment. But, most importantly, you are fully aware of how you are feeling. And you have control of your physical response to those sounds that are causing you stress.

We believe that children suffering from auditory hypersensitivity are so affected by sound that they become unable to rationalize that it will eventually stop or that they might be leaving in a few minutes. They will hear a certain sound or in some cases even a certain word. And it causes them pain and a level of distress that can suddenly elicit an abnormal fight-or-flight response as an involuntary physical response to sound. And I relate this to the response that you would have to a phobia. So if I see a tarantula, I am 50 yards away before I even realize that I have left.

Now, in most cases, fight or flight is a really good thing. Of course, it is our way of self-preservation. But if that response is altered to the point that it impairs your own sense of safety and your level of awareness of what is going around you, it could actually pose some serious risks with potentially tragic consequences.

So what we need. In the short term, we need some technology to help relieve these symptoms of auditory hypersensitivity. I would love to know today who can help us with developing that to make our kids more comfortable. We need research on the link between seizures and auditory triggers, which was such a surprise to us it really blew us away that a sound could actually trigger a seizure. But if parents said it, we need to listen to it because it may be anecdotal evidence, but if you want an answer to a question, ask the parents. We know everything. Right?

We need research on fight or flight. What is happening on a biological level? And we have to think outside the box, looking at the sympathetic nervous system. We found an interesting study on TRPV1 protein.

And we need effective treatment. We need to find effective treatment for acute stress response because that could be the ultimate wandering prevention strategy.

So we know that auditory hypersensitivity is a significant cause of elopement and that an impaired fight-or-flight response may be involved in many children, not just those with auditory hypersensitivity. Forty-two percent of the children respond to auditory hypersensitivity by trying to run. Thirty-three percent of elopers overall are trying to escape an anxious situation, indicating an acute stress response. Acute stress response or fight or flight in ASD may go far beyond the elopement issue, contributing to some of the most potentially dangerous symptoms of ASD, including seizures; self-injury; depression; suicidality, which we are learning is the number one cause of death in adults with autism.

The most heartbreaking and challenging problems that our kids and adults with ASD have could be helped with some research around acute stress response and the fight-or-flight response. It could possibly be one of the most important areas of research to increase safety and to improve quality of life for individuals with autism today. So I hope that you guys will think about that when you are developing the strategic plan.

Also, I want to thank you for establishing again the Safety Subcommittee and to offer our assistance from NAA. We work on safety pretty much nonstop, all the time. So we are happy to provide you with any information or resources that you might need.

Thank you.

DR. CUTHBERT: Thank you very much, to all three of you.

We have a minute for one or two questions. Yes?

MS. CRANE: I just have a couple of comments. One, I am really, actually, very excited that people are taking sensory sensitivity seriously and realizing that it is not only a comfort issue, but it can be a safety issue.

I do want to confirm also that not only parents are saying that people can have auditory seizures. It is also self-advocates who say, you know, that sounds can give them seizures. So that is absolutely true.

I do want to caution, though, that one area where we are really lacking rigorous research is on the safety consequences of elopement. So if I am correct because I remember you presenting on this before, the 44 percent figure is based on a review of cases that receive media attention. And so while that is a really sobering statistic based on the cases that can come to advocates' attention, they are not necessarily representative of all wandering incidence. And what we really need is better research on the safety consequences of wandering that is a little bit more focused on getting representative statistics.

DR. CUTHBERT: Thank you.

Larry?

DR. WEXLER: Thank you, Wendy. Thank you. At our Department of Education, we have used your work. It is great work, and we appreciate it.

I would like to, though, comment on the advantages or disadvantages of making this autism-focused, that wandering and elopement isn't owned by the autism community. I think it is really important. And I will go back to what we did with restraint and seclusion. We purposely did not represent it as a disability issue. If you look at the Office of Civil Rights data, you will find that while it predominates disability, it is in no way only a disability issue.

As a result of doing that document where we articulated 15 principles that we thought were principles, it was our best thinking on how a district, a school, or a state should go relative to restraint and seclusion. Thirty-one states have adopted into legislation those 15 principles. We didn’t have the authority to regulate on it, but we had the authority to put something out that we thought made sense. Every preschool in this country, whether it is serving kids with autism or any child, has a wandering and elopement issue. And we can go right down the line with that.

So what I would ask is as you continue to do this research -- and, certainly, you are particularly focused on autism -- that what comes out of it will more than likely be common sense approaches to prevent wandering and elopement from taking place and to remember there is a much wider community.

In my world in special education, frankly, we don’t care what the disability is. We are about what do the individual needs of the child, regardless of disability label, and ensuring that the child gets those services. I think that that is kind of the lens that I look at the world in. And there is a much wider world that even goes beyond disability that we should consider.

So please. Thank you for the work you are doing. It really is terrific work. I love the Red Box. As far as I am concerned, the Red Box should be in every preschool in the United States, every kindergarten, and probably every elementary school. But I would plead that we think of this as a broader problem than just autism. Thanks.

DR. CUTHBERT: Thanks, Larry.

I think we just have time for one more comment. We are running -- like Kevin. You have had your hand up patiently for quite a while.

DR. PELPHREY: Putting on my parent hat and a little bit the scientist hat, so I have a daughter who runs every time she hears the birthday song. She always has. And now she has developed epilepsy. It actually causes a seizure when she hears the birthday song. So restaurants are always a challenging place.

I actually wrote an op-ed piece that will be out soon in SpectrumNews.org about restaurants. So one thing that resonates with this very important work is that you actually might be surprised to know that in schools of architecture, they teach you a course on how to design restaurants that includes several lectures on how to design the sound systems to be maximally efficient at moving through patrons and making them as hungry as possible and as likely to eat and drink alcohol as possible. The way you do that is to maximize audiovisual synchrony and the intensity of noise. So for our families, restaurants are particularly problematic because they are actually designed to, if you will, torture the nervous system that might be particularly vulnerable for children with autism. So, you know, it is like you see these low-hanging fruit.

We have been carrying around headphones, but now it is middle school time. You know, I would challenge someone to tell somebody in a wheelchair they need to just bring the ramp to the restaurant. It is like you really just can't turn down the music, especially if it is designed specifically to increase profits.

I am a strong believer in not just creating laws for every little thing, but I think we as a body can speak quite loudly and maybe change the public perception of this, realizing just how low-hanging of a fruit this is. It is a dial. And turn it down. So my soapbox.

DR. CUTHBERT: Okay. Thanks.

Geri, if you can be brief? We do want to leave time for our next panel.

DR. DAWSON: Sure. So very briefly, I just wanted to let folks know about two research projects that are ongoing that are of interest in this area. One is that Nathan Call at the Markus Autism Center is funded by NIH to conduct a randomized clinical trial that is looking at a behavioral intervention for wandering. I just think that is really great that now we have gotten to the point where we are getting NIH funding in this area.

And then the Department of Defense funded our team at Duke to actually validate a very early biomarker of auditory hypersensitivity that is an electrophysiological marker that actually measures how the brain habituates to auditory information. And so far the work that we have been doing validating it, it is really, really promising. It also gets at what some of the underlying mechanisms might be that would account for why a child is actually responding to the auditory information the way they are.

DR. CUTHBERT: Thank you. It is reminiscent of the classic electrophysiological findings of augmenters versus reducers from the 1960s, which may indeed turn out to be relevant again.

So we will move on. Thank you, everyone, for those comments. Now we have another panel on adult therapies for autism spectrum disorder. This is a mini panel of two people: Dr. Shaun Eack from the University of Pittsburgh, who will discuss his research on cognitive enhancement therapy for adults on the spectrum; and John Robison, our own

John Robison, who is a self-advocate, as we know, and the author of several popular books on autism, including his latest one, “Switched On: A Memoir of Brain Change and Emotional Awakening,” which I think he has generously distributed to us today. And thank you for that, John. So, Dr. Eack, I think we are going to lead off with you.

DR. EACK: Great.

DR. CUTHBERT: So, please, take it away.

DR. EACK: Well, I know the day is getting late. So good afternoon, everyone. I am going to tell you about some work we have been doing in Pittsburgh on cognitive enhancement therapy for adults with autism. This is early work. We are just finishing the first trial, preliminary trial, now. And the data I will show to you is still very much under review.

I don’t have any current financial conflicts of interest, but I am very thankful for the grant support that we have from NIH and Department of Defense and Autism Speaks.

So what do we know about autism in adulthood?

Well, I guess I don’t have to tell this group much. This is a very informed group of individuals. But we know that autism is not a childhood terminal illness. Right? So people grow up with this condition. And some people fare well, and other people fare less well.

The prevalence estimates in adulthood seems to be about the same as it is in childhood. Of course, as you reach the 80s, 90s, and 100s, there is decrease in that prevalence as mortality takes hold.

We also know that outcome in adulthood is variable. So meta-analysis of over 800 patients recently published -- I think it is still in press, in fact -- suggests that somewhere around 45 percent of adults with ASD will have a poor outcome, but some individuals, maybe a quarter, will have fair or good outcome. Unfortunately, I didn’t see excellent represented in the results. So maybe someday we could change that.

To put some context around what do we mean by these types of outcomes because I don’t really know the difference between good, fair, and -- I am pretty sure you don’t want to be in poor, but this is one of Patricia Howlin’s studies. This is her 20-year follow-up study of a modest sample of individuals diagnosed in childhood and examining the different outcomes of major life domains with regard to employment, friendships, and close relationships. And while you can see some individuals are doing well, a lot of individuals are struggling in adulthood. Many individuals are having difficulty making friends, having significant relationships. Even fewer never get married or have a lover or a partner. And many of the people that I work with who are adults want these things, just like everybody else.

In addition, many individuals, although are often incredibly bright and have incredible talents, have a lot of difficulty both maintaining and holding a job. So over 20 years, half of this sample was either never been employed or chronically unemployed. And these were individuals who I believe were verbal yet at childhood. So some might characterize these as among the higher-functioning individuals.

So what do we know? This is what I would consider a pretty bleak situation in terms of adult outcome. So when 75 percent of our adults are not having close partners or relationships and half of them are unable to work, I think that is a lot of talent and a lot of possibility really wasted and squandered.

There is some information available about what can help. Sadly, it is limited. As of 2013, I can fit on this screen all of the therapy studies for adults in existence since 1960. There are 14 of them. That is not exactly a whole lot to guide what we should be doing. You might notice that a third of these studies are single-case trials; that is, *n* equals 1, can't even calculate an effect size in them. There are some of them that are randomized, controlled trials, which is at the standard for evaluating efficacy and interventions.

This is also another interesting fact about this finding is this is not just one type of therapy. These are all of them. Yes.

If you fast forward to schizophrenia and look at just one type of therapy, cognitive remediation, the therapy I am talking about today, we have 38 studies. Not only do we have 38 studies, these are 38 randomized, controlled trials. And so I think compared to some other areas of medicine and some other areas where people live a long part of their lives as an adult and disabled, we have got quite a bit of catching up to do in adult autism.

This would suggest that there is indeed a cliff. We know there is a services and policy cliff. I think this might have something to do with the evidence cliff. So I think there is a lot of excellent work in childhood on early detection and early intervention. And, unfortunately, as individuals grow into adolescents and adulthood, there is just far less research on how to help individuals with these conditions.

So where should you start? Well, I mean, I think this could be very debatable. So I will tell you where we started. Hopefully you will think it is somewhat sensical. And I will give you a sense of what we have been doing with cognitive enhancement therapy and the results of our initial trial.

Well, all of this work really comes out of Nancy Minshew’s Autism Center at Pittsburgh. For those of you who know that center and its history, it has spent the past 25 years trying to understand Autism and the neural basis of this condition. What I think those investigators, including Marcel Just and Nancy, have arrived at is that there are repeated and clear biological signatures to suggest that this condition is a brain disorder. It is a disorder characterized by difficulty and challenges or alterations in brain communication, that those problems with brain communication give rise to information-processing problems, difficulty processing information in the everyday world, whether that is maintaining attention or shifting it to something that maybe you are not interested in but need to attend to, or something more social, social information processing, which we all know is heavily affected in ASD, things like theory of mind or emotion perception.

So these are performance from the first 30 adults we saw in our trial just on a broad cognitive battery. What you can see is individuals performed on about a half a standard deviation below “neurotypical” or healthy volunteers, suggesting that many areas, the brain impairments, the lack of connectivity, the challenges in connectivity that we see in ASD give rise to a broad array of neuropsychological and social cognitive impairments in this condition.

Now, we are really waiting -- oh, this is a .pdf. So my brain is not doing workouts on there. So just you might pretend it is. So now while we are all waiting for a pro-cognitive drug, I have been on some of these panels with industry who is really trying to develop pro-cognitive drugs to address some of these cognitive challenges in many conditions, from Alzheimer’s disease to schizophrenia and even some in autism. Much of the work that has come out of that hasn’t proven to be particularly effective, unfortunately, at the moment, but what we do have that is not new at all that has existed at least since the 1980s is a suite of interventions that broadly fall under the category of cognitive remediation. So people may have heard of this before. The whole idea, very simplistic idea, behind cognitive remediation is that if you have challenges in particular areas of information processing, perhaps if we give you exercises to work out those areas that you have challenges in, maybe that will result in a lasting improvement in these areas.

So this field has actually moved ahead in lots of areas and in some areas with really quite a bit of success. So people have been using this from everything from Parkinson’s disease to schizophrenia to even work on eating disorders. I have only highlighted papers here as their meta-analyses, where they have enough evidence to suggest that there is an overall benefit.

Strangely, autism is not at all represented on here, a condition that we all know is a brain condition and that affects cognition in some interesting but significant ways. So the question that we have is to what degree might we address some of these cognitive challenges that we think stand in the way of adults really making the most out of their adult life? I mean, think about it. If you go to school and you have difficulty paying attention or you have difficulty paying attention to something that is not your special interest, how well are you likely to do at school? Right? So I think you are likely to have significant challenges.

Add that on top of the social challenges adults with ASD have. And you can start to picture the situation that these individuals face.

The work that we are doing is on a particular intervention called cognitive enhancement therapy. There are many cognitive remediation approaches available, not a whole lot with scientific evidence behind them, but there are some.

CET was originally developed for schizophrenia. It wasn’t developed for autism at all originally by Jerry Hogarty from the University of Pittsburgh. It contains two parts. One is a neurocognitive training component, so playing computer games to try and work out your attention, memory, and executive functioning muscles in your brain, if you will. The other is a social-cognitive training component, which is a group-based component.

We feel that using computers is very helpful. And, in fact, both adults with autism and adults with schizophrenia really enjoy that type of modality. It is new. You know, it is a great way to engage. Even if our computer games don’t look like Xbox or some of the other things that they are used to, it is oftentimes a great way to engage individuals in neurocognitive training, basic information-processing training.

Social cognition, we felt a group format was more powerful, something where people could learn from each other, where people could learn from their coaches in the group, where people could take an opportunity to practice in an everyday or unrehearsed social situation.

This intervention is provided over the course of 18 months. So it is a long-term approach. That has been our perspective on how to help people with autism. We feel that many of the issues that adults have are probably not likely to get better in four or five sessions and that ongoing support is needed, at least for a substantial length of time.

This slide won’t work. So this is my backup slide. So you guys might wonder, well, what do some of these exercises look like? As you can see, they are not Xbox or anything like that. Right? So it is kind of like memory games. This is an example memory game, which this is just a static image. I can’t play it for you on this presentation software.

What you can see here is there is a bunch of boxes up here, and there is a bunch of shapes down here. Those of you who heard me say it was a memory exercise can imagine what happens next. Right? So you press START. Shapes flash up here. And then they go away. And then you have to remember where they are, which shape, and which location. It is called Shapes and Locations. It is a very basic memory exercise. It is not one that our adults with ASD struggle too much with, I don't think, actually. We have been learning that they have far more difficulties than sort of cognitive flexibility and processing speed. The idea behind this exercise is as you gradually have to hold more information in your working memory, in your visual spatial memory, that you will start taxing the areas of the brain that support that cognitive function. And gradually over time, you will generate some improvement, and hopefully it will be lasting.

The social-cognitive group session, I don't have a screenshot to show you. They are very dynamic. They are small groups, six to eight members, with coaches, rather than therapists. So the focus in CET is really on empowerment and independence facilitating that. In fact, our group members, our adults run part of the group session, run part of every group session, in fact, with us. And it covers a very structured format to keep things predictable. So we are focused on understanding content in this. The content focus is really on understanding others, social cognition, understanding people, understanding the perspectives of others, picking up social cues, learning how to tell what another person is thinking or feeling based on their nonverbal cues, so on, so forth, domains that we know are really functionally limiting for adults, particularly as they are moving on into adult roles that require the maintenance of ongoing adult relationships.

Ew. That is horrible. Well, there was a beautiful slide up here once upon a time, although, actually, the slide somewhat represents. This is how we got to CET for adults with ASD. And it was ugly. So it actually took a while. It started in schizophrenia. We had run a series of trials to suggest that that condition could be substantially improved by this approach and that some of the neuromechanisms associated with that condition were surprisingly overlapping with ASD. CET was shown to enhance the structural integrity of the amygdala and fusiform gyrus in early form schizophrenia. Those are two areas of the brain that have been repeatedly implicated in autism. They are obviously not the only two areas of the brain implicated in this condition.

It was interesting that this approach has started to converge around neuromechanisms that seem to overlap between these two conditions. And then when you examine the types of cognitive challenges adults have when they come into our study and compare them to adults with schizophrenia, they are almost identical. In fact, the domains if you break out the specific domains of impairment, the most problematic domains that we were able to measure were processing speed. That was most problematic in both schizophrenia and in adult autism and emotion management, both most problematic in both conditions. So not only was the size of the impairment the same, but the qualitative ranking of them was also strikingly similar.

And so, armed with some preliminary pilot data that was generously funded by the NIMH here through an R-21 that showed that this intervention was at least acceptable, that people would stay for 18 months, we embarked on our first trial. It took a family to get this off the ground, and we are so appreciative to NIMH, DOD, Autism Speaks, and ARI for their support for this.

This is some inclusion criteria for the trial. So the population we are focusing on for this trial are verbal adults, adults who can speak in sentence language, and also do not have a comorbid intellectual disability. Okay? So I know that doesn't speak to all of the spectrum. We are very cognizant and aware of that. Individuals who are eligible for the trial are randomized to one of two conditions, either cognitive enhancement therapy or an enriched supportive therapy control condition. They are then treated for 18 months and assessed every 9 months with an extensive battery.

This is an abbreviated consort diagram just to give you a sense of where the study is at at the moment. We just actually finished our last 18-month assessment last week. So things are moving along.

You never know in an 18-month trial how well retention will be. It seemed like it was fairly halfway decent; people in both arms, about a 70 percent retention rate; interestingly, slightly higher retention rate in our control. You will see more information about that control here in a minute.

I should tell you something about what enriched supportive therapy is. This is an individual approach, doesn't focus on treating cognitive impairment at all but does focus on providing individual support, stress management, and psychoeducation about ASD. Okay? We originally had constructed this trial as a CET versus usual care and then quickly realized there was no such thing for adult autism. So EST was what we thought might become someday usual care.

These are some of the characteristics of individuals in the study. So these are young adults, mostly men, mostly boys. So very few are employed. And most are still dependent on their family, as many of you would expect. The only difference between the two trial arms is the control arm seems to have slightly higher proportion of college-educated individuals.

All right. So I have underlined "Preliminary" here. So I tried to come and present the freshest data to all of the agencies who paid for them. So these are effect sizes of cognitive enhancement therapy on the left-hand side and enriched supportive therapy on the right-hand side. These are effect sizes in terms of Cohen's d. And I will orient you to the conventions here in a minute. So what you can see across a number of domains, so I am only listing neurocognition, social cognition, and functional outcome. These are multivariate composite indices of probably 20 measures each. I will spare you of them.

What you can see for the cognitive domains, cognitive enhancement therapy, as we would hypothesize and might expect, significantly improved cognition, both neurocognition and social cognition. These are levels of improvement that Cohen would characterize as large. So an effect size of near one is quite a substantial effect size, something that the untrained eye should be able to detect.

In addition, we were pleased to see that these changes in our neuropsychological test battery translated into something meaningful, like meaningful functional improvement. You can see that there is quite a bit of and highly significant functional improvement in CET over the course of the trial. In addition, it turns out that providing supportive therapy and teaching people a little bit about their condition and how to manage stress isn’t too bad either. So you see enriched supportive therapy actually doing pretty good, not quite as good as cognitive enhancement therapy, but they do catch up by 18 months. Maybe CET gets them a little bit quicker.

If you zoom in on one of my favorite functional domains, employment, you get somewhat of an interesting picture. So, you know, those functional composites have everything in them: social functioning, family functioning, vocational functioning, et cetera, et cetera. So what you can see here is that groups are relatively comparable in the beginning of the trial with regard to their participation in competitive employment. And people in enriched supportive therapy, the adults who were treated in that condition stay at about the same level. There is an interesting and dramatic increase in employment as adults go through CET, which we think is surprising given that CET is not an employment intervention and tells us something perhaps about the importance of addressing some of these cognitive challenges to removing barriers to employment and other functional domains.

A secondary aim of this effort has also been to start understanding the adult brain in autism and particularly to what degree it is neuroplastic and amenable to change. And the degree that cognitive enhancement therapy is truly affecting cognition, it should be we should be able to detect a neural signature.

And so I am showing this is differential brain activity in a subsample of participants. So the people that have cleaned and preprocessed data. During a social cognitive task, a theory of mind task, one of Marcel Just’s theory of mind tasks -- and what you can see is an interesting finding. In the medial prefrontal cortex, an area of the brain that is frequently implicated in the theory of mind, you can see people treated with CET are showing a gradual increase over the course of treatment and activity in that region. And you don’t see that increase in enriched supportive therapy. In fact, there may even be some decrement.

If you try and examine neural signatures of these findings using some connectivity models, which because connectivity is a main issue in ASD, particularly long-range connectivity, this is connectivity affects between prefrontal cortex and the amygdala, so frontal and limbic connections during an emotion regulation task. What we can see is 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; whereas, we don’t see that increase in connectivity as individuals are moving through enriched supportive therapy.

I think these data are incredibly preliminary. You can see they are only on half of the trial sample. I think, you know, the jury is still out about whether they will hold up and whether the regions will be the same and, you know, all of that. I think what they kind of suggest to us is that the brain may be far more plastic and amenable to change in adult autism than maybe was previously appreciated and that these areas of the brain may be particularly neuroplastic and particularly ideal targets for future interventions.

All right. That was quick. So, to conclude, if you take nothing else, if you don’t even remember CET, please remember there is a crisis in treatment development for adults autism. In 2013, we had 14 studies, I know at least added 1 to that list since then. And I hope others are, but we need many more people working on this.

It is taking way too long, just since I am here at NIH, it is taking way too long to get interventions funded and conducted. And I think that is part of the issue. So we don’t have a lot of interventionists who are able to run these trials. And I think building the next set of trainees so that they have the skills to run large-scale randomized, controlled trials is very important.

That said, cognitive remediation seems like it is -- just as it has worked in schizophrenia and some other conditions, it seems like it may be one that could be helpful for adults with autism. It seems like it can result in meaningful cognitive change and also meaningful functional change, also perhaps some changes in the brain, notwithstanding, though, darn it, our control condition is also doing quite well.

Nancy Minshew, who is my mentor, keeps talking me into this, “This isn’t a randomized, controlled trial, Shaun. This is a comparative effectiveness study,” now that both of our interventions are doing well. So she is very hopeful that at the end of this, we might have arrived at not one intervention but two interventions that could be helpful for adults, although for very different things.

In addition and last, but not least, you know, I think these cognitive training programs have incredible synergy with lots of other things that are available and lots of new things that are coming on the market. Almost every pharma company I have been to has wondered whether a pro-cognitive agent needs a cognitive training program paired with it in order to see a benefit, something like taking steroids and sitting on the couch the whole time and not gaining muscle mass. Right? So, I mean, this seems like a logical conclusion and reason to me. You know, I think also with TMS and TDCS, new areas, new ways we are finding to tune the brain to maybe optimize the brain to receive these types of treatments. And perhaps cognitive training might help guide the effects of those types of treatments, which, actually, my good colleague John Robison here is just going to talk about in just a second.

So, with that, I will thank my key collaborators, particularly Nancy Minshew.

And are we holding questions for after the panel?

DR. CUTHBERT: Unless there is just a quick clarifying question, but the general discussion we want to hold, yes. Are there any quick questions about a specific aspect of the results or procedures?

(No response.)

DR. EACK: Great, guys.

DR. CUTHBERT: Okay. It looks like we are straight. So thank you very much. Fascinating data.

DR. EACK: Thank you.

DR. CUTHBERT: We have been interested at NIMH in the compound treatments involving pharmaceutical agents and these kinds of cognitive effective therapies. So we look forward to further discussions about that.

Okay. Now for our very own John Robison. John?

MR. ROBISON: Well, I don't actually have any slides for you. I rely on my ability to speak to you and keep your attention. And I feel like if I can't do that, I have failed.

I do have two papers or two books. I've got the official results of my participation in a study at Harvard Medical School's Beth Israel Hospital on using TMS to change emotional insight in autistic people. It is called "Brain stimulation over Broca's area differentially modulates naming skills in neurotypical adults and individuals with Asperger's syndrome." It is here. And I have got the book I wrote about it here.

Now, if I have not told you that these two things were about the same thing, you would never in a million years guess there was any connection between these two.

You might wonder as a seemingly successful adult, why would I even take part in a study that might alter my brain. And the answer I think came in our previous presentation. And that is that the outcomes for autistic adults are overwhelmingly bad. There are some of us who have obviously bad outcomes because we are in jail, we can’t have jobs, we are disruptive, we are fired from jobs. We fail in very visible ways. And according to the statistics you just saw, that represents 60 to 70 percent of the adult population. But I suggest to you that most of the remaining population is like me, where we might be said to suffer in silence to varying degrees.

You know, we talk about how we can’t read expressions in other people, we can’t read social cues, we can’t do this, we can’t do that. As successful as we look, you know, it hurts. I listen to people in committees like this tell me about their children with real autism. And, you know, my autism is real, too. And I understand that I have done many good things. I understand that my writing and speaking are widely praised, my books are said to have helped many people, and my ideas here are said to help people. But, you know, that just doesn't take away the lifelong hurt of it for some of us. I am sorry if that is not the positive portrayal that, you know, people want to hear, but that is the hard truth of it. And you feel it more as you get older.

So when I wrote my first book and scientists began to approach me, a scientist from Harvard came to one of my talks. And she said she wanted to hand out some flyers that were describing a study they wanted to do that was aimed at changing potentially emotional insight in autistic people. She didn't ask me to join it. She just wanted to leave some flyers.

And I asked her how it worked. And she told me about TMS. I had heard nothing of TMS. For those of you who don’t know, TMS is the idea of using high-powered pulses of electromagnetic energy to induce tiny electrical signals in the brain. And by focusing those electromagnetic fields, you can induce energy in areas of the brain as small as 1 or 2 percent of the brain mass.

I thought, “How cool is that.” Then, of course, I thought, “Shit. I probably know more about that technology than she does.” I mean, what, after all, is a big concert sound system except a bunch of high-powered signal generators firing energy into electromagnets that vibrate speaker cones? What are the power systems that I built that energize lasers? And what are the power-conditioning devices I made for the U.S. Government for nuclear testing?

I couldn’t even have told you guys that I did stuff like that when I was younger because it was all like hidden and you couldn’t say it. But the Discovery Channel did a TV show about me.

(Laughter.)

MR. ROBISON: And they went, and they uncovered it under the Freedom of Information Act. And they put it on TV.

So I did a lot of work in my engineering days on high-powered, pulsed electronic systems. And I felt immediately comfortable with the idea. And I thought, what if that is true? What if they could fire energy into my head and change my ability to see other people, to read signals from other people?

So then I met the scientist Alvaro Pascual-Leone, who was leading the effort. And I asked him how exactly he thought it would work. He said, "Well, the conventional wisdom says that autistic people don't have the wiring to read social cues from other people, but," he said, "I think that is wrong. I think there is a regulatory system for that mechanism in autistic people. And I think perhaps it is overactive. So maybe that system is in you right now but it is suppressing that ability, and our thought is that maybe we can suppress that suppression network."

And I said, "Well, where is it?"

And he said, “Well, I can’t tell you exactly because that is the idea of the study. But,” he said, “we have hypothesized several locations where it might be. And we have got several other locations where it might not be. And we propose to stimulate all of them and see what happened.”

And that is a little bit of a kind of a rolling the dice. Right? But I thought, “How cool is that? What if it works?”

And he said, “You know, it is a safe thing because the stimulation will not last very long. We are going to evaluate you beforehand. Then we will do the stimulation. And then we will evaluate you on a test afterwards. And,” he said, “the evidence we have now says that a single TMS stimulation will have an effect that lasts about half as long as we stimulate you. If we stimulate you for half an hour, it will affect you for 15 minutes.”

And I said, “Well, shit. What good is that?”

And he said, “Everything in medicine has some kind of lifespan. You take a pill. And the pill wears off in time.” And he said, “The value of this is that if we stimulate you once and it lasts 15 minutes, we could do it again tomorrow. And it might be half an hour. And if we stimulated you every day and we did it for a month, it might last five or six months.” That was ultimately the basis for the TMS depression protocol that is FDA-approved now. It was still in the final stages of that when I started the study.

So I volunteered to do it. And when I did, I realized I was the first subject to try this. Then I learned later on that Manny Casanova in Louisville had been doing some similar studies. He, of course, felt sort of miffed that he didn’t I think get to do this one. I kind of like Manny. And if I was nearer him, I would have been a guinea pig for his, too, but I wasn’t.

Anyway, I did this study. And this is what the scientists said. They said, “Object naming was assessed before and after low-frequency RTMS and sham stimulation as guided by each individual’s MRIs. In autistic participants, naming improved after TMS compared with sham stimulation. In healthy subjects, stimulation of parts of Broca's area did not lead to significant changes." It is a kind of a modest statement of success, huh? But the thing is, for those of us in the study, this didn't mean anything. What meant something was the side effects.

And I want to read you my version of what happened from the first pages of my book. The idea of fixing myself with a fancy new treatment, it sounded great in theory, but from what I had seen so far, it hadn't worked. The scientists had proposed using electromagnets to rearrange connections in my head. It seemed like science fiction, and maybe that is all it ever would be.

As I got into my car that evening after four hours at the hospital, I was more exhausted and annoyed than when I had arrived, but otherwise, as far as I could tell, nothing had changed.

The drive to Boston had taken two hours. And now I was facing another two hours to get home. "What was I doing there?" I asked myself. But I knew the answer. I had volunteered for this research study because the scientists had issued a call for autistic adults, and I wanted to make myself better in some ill-defined but powerfully felt way.

Those thoughts and 1,000 others were running through my head when I plugged in my iPod and music filled the car. I had done the same thing 1,000 times before, and heard nothing more than songs on my car stereo. I hadn’t seen anything at all, just the road ahead.

This time, the result was strikingly different. All of a sudden, I wasn’t in my car. I wasn’t even in my body. All my senses had gone back in time, and I stood backstage listening to the Tavares Brothers singing soul music in a dark, smoky club. Years ago, I had stood by those stages as the sound engineer whose job was to make sure the machinery of the show kept running. These days I hung around the stage as a part-time photographer following performers through my camera lens in the hope of catching a magic moment. This was something totally different.

When I had engineered rock and roll shows, all I saw or heard were the little cues that told me everything was okay or not. Now when I work as a photographer, I concentrate so deeply on my subjects that I don’t even hear the sounds of the show. That night in the car, the recorded music captured me and drew me into a world of a long ago performance in a way I had never experienced before.

The transition was instantaneous. One moment I was navigating traffic in my Range Rover, and the next I was watching five singers in a club. Flood lights hung from the ceiling illuminating the stage, and I stood just outside the lit area. To my left on the stage, I saw the Tavares Brothers in sport coats and bowties with a backup band on the side. A flute player stood in the background whispering his contributions to the melody.

Tavares is known to the world for singing “More Than a Woman” from the Saturday Night Fever soundtrack, but they had a long history in New

England before that and a much larger repertoire of songs. Thirty years ago, I had been a part of that world working as a sound engineer and special effects designer. Many of the big Boston venues used my sound and lighting equipment. And I had stood beside countless stages and watched more performances than I could remember.

Was I reliving one of those now or was this a figment of my imagination? I could not tell then, and I still don’t know today. All I can say is that the experience felt incredibly real. I could almost smell the cigarette smoke on my clothes. And, through it all, some separate part of my mind kept driving the car, though I only know that because I didn’t crash.

Later that night, I sent a message to the scientist who was heading the effort. “That is some powerful mojo you have in there,” I told him. And we were just beginning.

After that, after that, the brilliance of the music lasted all night. I stayed up all night listening to music. And it began to fade away by morning, and I went to work.

I went back the next week, and we did a different stimulation. And nothing much happened.

I went back the next week, and we did a different stimulation. And it kind of made me mad and irritable.

And I went back the next week, and I did another stimulation. And nothing seemed to happen on the way home. Then I got home. And I got in bed, and I tried to go to sleep. It was like I was drunk. The world was spinning, and I started having hallucinations. I couldn’t fall asleep until 4 or 5 in the morning. And I got up at noon, and I went to work. And I walked into the back door of my business, and I walked down the corridor. And I looked at one of the guys in the corridor. And this thought hit me: He has the most beautiful brown eyes.

And, you know, that is a thought autistic people like me simply do not have. I don’t have thoughts on people’s eyes, beautiful or otherwise, because I don’t look at people’s eyes. It was the title of my book. And I thought, “What has happened to me?”

And I walked out in the waiting room. There were customers waiting to talk to me about their cars. And I looked at them, and it was like a tsunami of emotions. And then people got up to talk to me about mundane things, like putting water pumping on their cars. I looked at them, and I could see worry and anxiety and fear and all of these things.

And people started talking to me. I said, “Excuse me. I have got to go outside.” I was almost reduced to tears by the ordinary conversation of commerce. Seeing emotion in people was truly devastating for me.

Now, that ultimately kind of faded away, but something else grew in its place. And, you know, the strangest thing happened. first, I realized I was seeing emotion in other people, but I began to see emotion in written documents.

You know, in “Look Me in the Eye,” I had written a story about how sometimes I would go to parties, and people would talk about things like seeing a bus crash on the news in Peru. And they would be crying and wailing about it. I thought, "They must just be making a play for attention. How could they care about somebody in Peru?"

And, yet, today I pick up the New York Times. And I can't always read the stories because sometimes they bring tears to my eyes.

One of the other fellows that did this study with me, he said, "I can't believe that." When he read it, he said, "The same thing happened to me. I can't read magazines anymore because the emotion overwhelms me."

And so we have this situation where there was a paper published about what happened to us, and it said nothing meaningful about what really happened. And the paper said that there might be some benefit from this, it might produce some change.

And then we have the book about the side effects, and the side effects were life-changing. And they weren't life-changing in a uniformly good way. They cost me my friends. It cost me the failure of my marriage. The ups and downs of emotions almost drove me to suicide, to kill myself. It was a powerful, powerful thing.

I think what it shows is a few things that all of you on the Committee should really, really take to heart. First, it shows that we can read all of these journal articles that we want, but very often because of the way scientific papers are put together, there can be effects in psychiatric and psychological research that are totally missed. The whole premise of this thing was we will measure what happens to this guy 15 minutes after we stimulated him. And all of the effects that mattered happened to me days, weeks, months, and years later.

Now, it would be easy to say, “Did Robison just imagine this?” But, as you will see in the book, I didn’t just imagine it. Other participants in the study had similar experiences, though to a lesser degree.

You might ask why did I have more of that experience? And I don’t really know the answer except to say that my life history suggests that I am an outlier in many other ways.

And the previous presenter, of course, from Nancy Minshew’s lab, he is one of those people that characterized me as an outlier with Marcel Just’s brain imaging and everything else. I don’t know why I was more affected, but what I do know is that a short period of brain stimulation changed my world forever.

I have thought for a long, long time -- and, actually, Alvaro Pascual-Leone, who led this research, we are going to go on Public Radio. And we are going to talk about this together, why we think that happened.

The best thing I can say to you about why such a thing might happen from a so-called 15-minute stimulation, first, imagine that we autistic people have more plasticity than other people. So the 15 minutes that applied to a typical person might be hours or days for me, but then consider if you were a person who was colorblind all your life and all you heard about was beautiful reds, greens, blues, and yellows and you saw shades of gray and by the time you were an adult, it became something that made you angry because it was just bullshit. You knew the evidence in your eyes. And one day you go into a lab and the doctors turn on color. All of a sudden, you walk out and you see this was true all along. Now I know beautiful blue sky and green grass and red and green and everything else. And you know what? Even if that color vision fades away tomorrow, your life will never be the same because you will always conduct your affairs with the knowledge that "that's real."

And so what this shows is that technologies like TMS have a transformative power that is potentially far beyond the expectations of the doctors and scientists who use it. TMS also has a tremendous transformative power as a tool to reach into untouchable areas of the brain.

And I ask that those of you who think about this don't think about just Robison's experiment with emotional insight in autism. Frankly, I don't think that matters for the future of TMS. I think you should think about my experience as a metaphor for the transformative power of this technology and imagine that if the power of the experience I had was applied to suppress epilepsy in your child, that's lifesaving. That is not life-changing. Imagine if the power of that was applied to reduce brain plasticity in a person with intellectual disability who couldn't hold a skill in his mind. And then, suddenly, we have raised that person's IQ. Think of its existing power to change lives and depression and anxiety and how we are looking at it now in Parkinson's and addiction and so many other areas.

It is easy to dismiss patient accounts like this as wild imaginings. And they are not wild imaginings. They are backed up by other very, very similar accounts. And when you read about the wildest things in this book, what I discovered, to my amazement, is that you can Google the TMS depression forums, and you will find little vignettes of every bizarre experience that I describe in here described by those depression patients right now. So this technology is having that effect on many, many people. And it is totally ignored in the medical community, and it is totally ignored in papers like this.

So my message is that we really need to rethink how we conduct these studies and how we publish the results. That series of hallucinations and strange visions, its only appearance in here is in the notes at the back that say a couple of patients reported dizziness and vertigo. And, you know, that is all the scientist said because that is all the context of the study called for. And of course, now having gotten into science, I see that that is true.

And another thing I would suggest that you folks think about, those of you who know something of the history of my life from reading "Look Me in the Eye," I grant that I was more successful than most autistic people at many things, but, you know, I succeeded as a loner. I left school, and I engineered things for rock and roll bands by myself. I made my way into companies as an engineer, and I designed things by myself.

In those same companies, I was fired from my jobs because I couldn’t work with other people. I started a car business, and I fixed cars by myself. Then I hired employees. And they either worked for me my way or they hit the road. So again it was by myself.

And then I take part in these TMS experiments. And what happens after that? You guys in the science community, you ask me to join these committees. And what could be more difficult for a person like me to work in but a government bureaucracy? And, yet, you guys describe me as an agent that brings you together. You describe me as a success in the very environment where I have failed all my life before.

Look at the things I do today: teaching neurodiversity, serving on committees like this, representing us on World Health Organization committees, another huge bureaucracy. And ask yourself, is it all in his imagination or did something in him change to connect him with people in those ways?

I can't answer positively about that, but I think what I said to Alvaro the night of the first stimulation sums it up. There is some powerful mojo in this medical technology, and I think we would be wise to pay close attention to the messages. And I hope you will read these two books. And tomorrow if you want to -- I think we are going to be on NPR on Thursday. And what I am going to do is I will send a link to Susan. And she will circulate it to the IACC. And he and I talking about it together I think is going to be a kind of a cool thing.

So I thank you for listening to my story. It is the first time I have ever undertaken to say something like this, but, you know, it really means a lot to me. I believe with all my heart in neurodiversity. I believe that people like me are here for a purpose. I don't believe I am a blighted victim of a pharma conspiracy. I was born naturally, and I serve a purpose.

But at the same time, I believe in making myself the best I can be. And that is why I tried this. I hoped I could make myself better. And I guess I made myself different, but, you know, it is part of what brought me here. It is a powerful thing to me. And I hope you enjoy the story and think about it.

(Applause.)

DR. CUTHBERT: Thank you very much for sharing that very interesting and engaging story with us. And we are glad that you decided to share that with us today. We are privileged to hear that for the first time. So thank you.

MR. ROBISON: You are welcome.

DR. CUTHBERT: We have some minutes for discussion now from both of our presentations. So we have had one, you know, fairly standard scientific presentation and one very engaging individual account of sort of a non-expected perhaps experience outside of the confines of the trial, so lots to discuss.

(No response.)

MR. ROBISON: Did I stun them into submission?

(Laughter.)

DR. CUTHBERT: Yes, Sam?

MS. CRANE: Yes. I really appreciated John sharing his story with us, and I think it is really a sobering reminder that whenever we do research, a lot of the times long-term effects aren't followed up on. And there are actually quite a few interventions for people on the autism spectrum where we have absolutely no long-term quality-of-life research, including early childhood interventions.

So we have a lot of people on the autism spectrum who have experienced early childhood interventions. And they will report both good and bad long-term effects of the interventions that they experienced, some of which can include even, you know, posttraumatic stress disorder or seriously over-generalized things that they learn. Maybe people, for example, will say that if an intervention involved a lot of hand-over-hand touching that wasn't consensual, they learned that people, you know, had a right to touch them when they didn't want them to touch them, and that made them more vulnerable to abuse later on.

These are things that are extremely important for us to actually listen to the people who went through an intervention and really try and see, are we missing something long-term that we can then take into account and change what we are doing and change how we are interacting with especially vulnerable children who can't provide the kind of informed consent that John was able to provide to an intervention?

So I think we really need to be much more mindful about long-term follow-up studies and keep an open mind not just to focus on one particular factor on long-term follow-up but really include -- you know, ask people for feedback on what they perceive as long-term effects because there are a lot of things people might otherwise miss because it is not what they are looking for.

MR. ROBISON: If I could offer just a response to that, what she said there?

DR. CUTHBERT: Sure.

MR. ROBISON: One of the things that came up in the study I took part in was the idea that we participants because of these experiences, like seeing music, we might need some kind of counseling or backup support in the course of the study. And I said to Alvaro “Shouldn’t we be doing this TMS along with therapy from a psychologist to help us integrate it into our lives?”

He explained to me that if the study had been structured that way, it probably wouldn’t have been accepted because people would have said that the benefit came from the therapist and it didn’t come from the TMS. So we actually have a situation where we create potentially hazardous situations by what we think of as good scientific design.

And I understood that, and I thought about that. And I went into it with my eyes open. But I recognize that that and the absence of ability to describe outlier effects, those represent two fundamental failings in how we ask for scientific research to be structured today in medicine.

DR. CUTHBERT: Rob?

DR. RING: John, I was just really impacted by what you have shared. And, you know, I was sort of pivoting back and forth between whether or not I was hearing reporting of psychiatric toxicity with the treatment or benefit. And, clearly, you know, there was both through --

MR. ROBISON: There was both, yes.

DR. RING: There was both. And, you know, having worked in the pharmaceutical industry, you know, I still really firmly believe that we are struggling with the measurement of outcome as a really critical component to paving, you know, a pathway to the future of treatment development, particularly in the medical area.

So if I am, you know, trying to take a new therapeutic to Tiffany, you know, what is it that you have experienced there? How are we measuring outcome through that narrative? I think it is going to be really important to try to capture more of that journey that you have experienced now that we are finding things that are producing efficacy. We may not know whether or not it is beneficial or what is beneficial or not, but it is an incredibly powerful narrative.

That paper just didn’t have the outcome measures informed by the experience that you went through. It is informed by other perspectives that are, you know, equally important, but a lot of them have come from, you know, the clinician perspective and not always from the actual individual who is experiencing the treatment effect, but thank you for sharing that.

MR. ROBISON: You are welcome.

DR. CUTHBERT: Thank you.

Other comments or questions? Yes, Julie?

DR. TAYLOR: I have a question for Dr. Eack, actually. Could you talk a little bit more about your control group therapy? That seemed like that had some effectiveness as well.

DR. EACK: Yes. Should I find a mike?

TRANSCRIPTIONIST: Yes, please.

DR. EACK: It is different than CET in a number of respects. So it is a one-on-one individual therapy versus a group therapy, and the content doesn’t involve any cognitive training, no focus on social cognition or neurocognitive issues. But it is given for the same dosage, amount of time and sessions, and the focus is pretty basic. So it’s can we teach you about this?

So many of the people we see in our adult studies are newly diagnosed. And so they have got a lot to learn about this. And even some of the people that haven’t been newly diagnosed are still learning things about it.

And then psychoeducation seemed to be particularly important and then individual support during times of crisis, right? So people having trouble, people going through things like what John described, we are there to try to help and then proactive kind of stress management, basic behavioral principles, though. I mean, it is pretty garden variety CBT.

DR. TAYLOR: Thanks.

DR. EACK: Yes.

DR. CUTHBERT: Other questions or comments? Actually, I will bring you back to the table. I have a question for you.

As you probably know, at NIMH, under Tom Insel’s leadership, we revised our approach to clinical trials with an emphasis on fast-fail experimental medicine trials, where the idea is to specify a particular target towards which the therapy is intended and to demonstrate that one has, in fact, achieved target engagement.

The target does not have to be a biological target. It could be some mode of cognition or interpersonal processing and so forth. So the idea is that we know that our conditions are very broad heterogeneous syndromes and not specific disease entities.

So I would just be interested that -- you are obviously very familiar with all of this. I would be interested in your thoughts about how your therapy kind of winds up with that new approach that we have and if you are sort of changing and can just think about demonstrating target engagement or how you line that up in accounting for the individual differences that we see in patients.

DR. EACK: Oh, yes. Lots of great questions in that. My last R01 that is the second trial for this, the large confirmatory efficacy trial, went in under the experimental therapeutics in medicine approach. And so our target engagement that we are trying to show movement on is behavioral measures of cognition. Right at the moment, we are not at the point where we know enough about the brain that we can say, “Oh, we are expecting a percent signal change in this area” or something like that, but we are hoping someday we will get there.

And so the two primary targets are neurocognitive and social cognitive treatment engagement. And then the secondary target is functional outcome.

So we have been thinking. I think this is a really exciting way to think about treatment because, you know, you start to push on mechanisms and see where there is change. And so we saw this first study as an opportunity to try and push on these two cognitive treatment targets and to see if there would be downstream functional change and also to kind of back up a little bit and see what neurosignature that might suggest underlies that so we could start specifying biological targets in the future.

So yes. I mean, we have tried to fit this in this window, although I didn’t present it in these terms today. I wasn’t sure they would be as familiar to everybody around the table. I am sorry.

DR. CUTHBERT: Thank you for addressing that, a very thoughtful response. Thank you.

Seeing no further questions, we can move along. We are actually ready to go to our round robin. Thank you again to our two panelists for really interesting conversation, very nice integration of two very different kinds of talks. That was fun.

So now we have the opportunity for members to share brief updates. I know that we have an update on autism prevalence from the CDC. And we may have other important updates, too. So I will open the floor for updates if anyone wants to contribute. Yes, Dr. Shapira?

DR. SHAPIRA: So for the CDC report, I would like to invite my colleague Dr. Daisy Christensen to the table to ask her to introduce herself and to provide a brief presentation.

DR. CHRISTENSEN: Hey. I am Daisy Christensen, as Dr. Shapira said, from the Centers for Disease Control and Prevention.

So, as most of you know, we just released our latest numbers from the Autism and Developmental Disabilities Monitoring network, which is an active population-based biannual surveillance of Autism Spectrum Disorder, ASD, and other developmental disabilities that has been active since 2000. It’s based on multiple source record review in the community, including health sources and education sources. And it’s based on expert clinician review of developmental evaluations that are contained in these records that could be, for example, an evaluation by a developmental psychologist or for education sources would be evaluations that are performed to determine eligibility for special education services.

The goals of the ADDM network are to estimate the prevalence and characteristics of ASD, to look at prevalence trends over time, and because the methodology of the ADDM network has been stable since its inception and we also have a number of areas that have been the same geographically over time. We can control for that so that we can look at trends over time and to understand the impact of ASD in U.S. Communities.

So for the surveillance years 2010 and 2012, this is our map. This is generally the sites that were included in 2012 with the exception of the Alabama site.

I am just going to breeze through this. I think, Bruce, you gave most of the numbers here. So people probably remember that the overall pool of prevalence was 14.6 per 1,000, which was about the same as the 2010 prevalence of 14.7 per 1,000, or 1 in 68 children.

As you can see, for the sites that reviewed education and health records, the prevalence was substantially higher at about 17 per 1,000, compared to the sites that reviewed health records only, at just under 11 per 1,000.

We have seen a very consistent male-to-female prevalence ratio of about 4.5. And that has been absolutely rock solid throughout the years of the prevalence increase that we have seen in ADDM. We still see very concerningly some disparities by race/ethnicity. So what non-Hispanic white children had, about a 20 percent greater prevalence of autism compared to non-Hispanic black children, that has actually come down a little bit over time, but the most concerning disparity that we see is that non-Hispanic white children had a 50 percent higher prevalence compared to Hispanic children. And that really has not changed over time.

So when we look at 2012 compared to 2010, there were some differences in the surveillance areas between the two years. And so we did actually restrict to the sites that were consistent in terms of their geographic area and the types of records that they reviewed, and we actually found that again the prevalence estimates were very similar between the two years.

One of the other really important metrics that we look at in ADDM is the age at the earliest evaluation. This informs the Healthy People 2020 goal. That is related to increasing the percentage of children who have a first evaluation by age 36 months.

So what you will see here is that, in spite of the fact that nearly 90 percent of children had developmental concerns by age 36 months noted in their record, only 43 percent actually had a first evaluation by the age of 36 months. And, you know, a high proportion, nearly 40 percent, were not evaluated until 48 months or greater. So there is some progress to be made to reach the Healthy People 2020 goal of having 47 percent of children have that first evaluation by age 36 months. And, in addition, non-Hispanic white children were actually a little bit more likely to have that first evaluation by 36 months compared with non-Hispanic black and Hispanic children.

In terms of the prevalent similarity, we don’t want to make too much of that. It is two data points. We will want to see additional data points before we feel really comfortable saying that the prevalence is stabilizing. In addition, the fact that there is such variation in prevalence by race, ethnicity, and also by geography sort of suggests to us that there is probably some room for growth in some groups. And there was prevalence change at some sites, particularly prevalence increases in New Jersey and Wisconsin.

As I said, the disparities in prevalence by race/ethnicity suggest to us that there are children who are not actually receiving appropriate support and services. And there is progress needed to lower the age at first evaluation among all children but particularly in non-Hispanic black and Hispanic children.

So we are continuing surveillance for the 2014 surveillance year now. This will be the first year that we will report prevalence estimates using DSM-5 criteria. So this represents -- obviously, this was study year 2012. And so all of these records that were used, all of the evaluations that were used in these findings were generated prior to the publication of DSM-5, but for the 2014 study year, we will have a combination.

Since most of those children will have been identified and evaluated under DSM-4, we will produce prevalence estimates using DSM-4 but also DSM-5.

And so this actually for the ADDM network represents a real opportunity to actually look at the effect of a diagnostic change in the ASD criteria, which we have not had the opportunity to do before.

And I am happy to answer any questions.

DR. CUTHBERT: Thank you.

Are there any questions or comments?

DR. CUTHBERT: Yes?

DR. CHRISTENSEN: Sure, John.

MR. ROBISON: So you separate the educational versus medical autism diagnosis in there. That means that some of the sites only use one and others use both. Is that right?

DR. CHRISTENSEN: So most of the sites have access to education records or special education records at some or all of their area, but not all of them do. And what we found is that we pick up more children for the sites that have access to education records. And that to us really just illustrates the important role that schools play in the evaluation and servicing of children who have ASD.

MR. ROBISON: So why is it, then, that you publish the number that's 10 percent lower than the education-medical combined? Are you saying that you think that that represents a slight overstatement? That is sort of what the lower number implies.

DR. CHRISTENSEN: That's the number that is the ADDM network. And the ADDM network is selected through a competitive process.

MR. ROBISON: I’m not sure I understand that. Could we go back to that slide for a second?

DR. CHRISTENSEN: Sure.

DR. CUTHBERT: While she is going back, John, those data I believe are the same as reported in the paper that I mentioned with Dr. Christensen.

MR. ROBISON: Right. Yes.

DR. CUTHBERT: I didn’t mention that distinction in the data when I went through the --

MR. ROBISON: So yes. I guess my question, though, is if you report overall, why would you report overall, of 14.6 when overall education and health together is 17.1? It seems to me that if you are reporting a lower number than 17.1, it must mean that we believe that the 17.1 is overstated for some reason. And if so, why?

DR. CHRISTENSEN: We report all three numbers. I don’t believe that the 17.1 is overstated.

MR. ROBISON: Okay. Well, I guess that is the answer, then.

DR. CUTHBERT: Yes. Thank you.

DR. WEXLER: Do you take into account that, especially if you are using educational records in the 3 to 5 group, an awful lot of kids with autism are not reported under autism? They are reported either as developmentally delayed if the state opts to do that or they’re reported frequently as speech and language or anything else but autism. It is more of a generic.

And part two is, do you address at all the early intervention program of birth to three?

DR. CHRISTENSEN: So in the eight-year-old data, we don’t because those records typically aren’t available for children age eight. In our surveillance for four-year-olds, we do look at the EI data. Even though those children are four, sometimes we are able to access those records, even though they are typically archived for children who are age four.

Going back to your other question, regardless of whether -- so we are not looking at whether they have an autism eligibility or not, although we do take that into consideration. So we are looking at the evaluations that are conducted to determine what, if any, eligibility they are eligible for. And so we are looking at the behaviors that are described in the evaluation. And our clinician reviewers code those behaviors and determine their case status based on in this report DSM-4 criteria.

DR. WEXLER: So you make a decision? You essentially countermand what the clinician who did the evaluation arrived it? You decide what the behaviors actually mean, as opposed to the clinician? I mean, that is what it sounds like to me.

DR. CHRISTENSEN: Well, I mean, a child with autism might be in an eligibility other than autism if that serves the best interest of the child.

DR. WEXLER: But, again, if the child has communication disorders and the clinicians decide in the evaluation that he is a child with under IDEA a speech/language disorder child, your clinician is then reviewing those records and deciding he is a child with autism?

DR. CHRISTENSEN: If the child meets the case criteria for the ADDM network and they had an eligibility for -- yes, for speech/language, yes, and they meet our case criteria, yes, we would count them as a case.

MR. ROBISON: I think it sounds like you are sort of pressing her on the point of second-guessing the clinicians out there, but, you know, having observed that myself in schools, I guess I have to agree with her. It puts us in a difficult fix when we try and gather the statistics because I do think she is right that people, especially in school diagnosis, will assign the diagnosis that gets the best service. And that doesn’t necessarily tie in with what a medical professional would say. And I guess I think that is just a fact of life in the game of getting services in public schools. And I guess it is a matter for public health statisticians to figure out how to treat it.

DR. WEXLER: You know, John, I would not agree with you. And I wouldn’t agree with you because, again, the focus is on services, but, more importantly, our data, our longitudinal data, show the same increase of school-age kids with autism as CDC shows.

So the folks that are doing the evaluations and the “labeling” of those kids maybe aren’t so off in that sense.

So it is just -- frankly, it doesn’t matter. I mean, this is the way ADDM decides they want to do their business. It is a curiosity to me because what I would say in response to you is, well, then, it sounds like we need a third set of clinicians to validate between the two. What is the real answer? It doesn’t really matter that we know that there has been a geometric progression of autism prevalence.

Our data are complementary to yours in terms of percent of the population that is labeled as autistic. But we really look at it more after the kid gets out of preschool because a lot of, an awful lot of, parents prefer -- you are saying they prefer autism because they get services. I am saying based on our data, they prefer developmentally delayed or speech-language because they don’t want a pejorative label.

It is the same thing with intellectual disabilities. There is not a difference. It tends to over time -- I mean, I supervisor all the data, all the IDEA data. So I have some idea of what goes on with it.

And any time if you all want, I have a data team, if you want them to come. And you want to dissect our data, we would be happy to work with you on that.

MR. ROBISON: Well, Larry, it may be that we got the validation from Bruega because Bruega was a third set of evaluators over in the U.K. with adults. And they backed up your findings, too. And maybe we just -- maybe it does all amount to the same thing.

DR. CUTHBERT: Rob?

DR. RING: I think we all remember the South Korea study that came out a number of years ago that looked at more of a direct population screening method. My recollection is that that study, Autism Speaks, helped fund a collaborative study that involved the South Carolina site, ADDM site, and looked at 8,500 kids born in 2004 using a direct screening approach exactly like South Korea and compared DSM-4 versus DSM-5. My understanding is that was supposed to read out at the end of last year, beginning of this year.

Are you aware of where that is? And if it is, it might be a good set of data to bring into the conversation now at this point.

DR. CHRISTENSEN: We are looking forward to seeing those data as well.

DR. RING: Okay.

DR. CHRISTENSEN: I don’t have any information on when they will be out.

DR. RING: That will help address the records-based approach versus a direct population screening approach, which both have value and address different questions but may bring some additional light to the conversation.

DR. CUTHBERT: Okay. Thank you. That was a very valuable update and a useful discussion.

Other updates? I thought David Amaral might want to give us a brief summary of our conversation yesterday about brain postmortem and brain networks.

DR. AMARAL: Thanks, Bruce.

So, just briefly, there is a public and a private enterprise to try and bring an outreach effort to families across the country who need to know, be made aware, that there is a need for postmortem brain donations in order to understand the neurobiology of Autism Spectrum Disorder. And last fall, the NIH NeuroBioBank and Autism BrainNet had a meeting. And we came to an agreement that there would be one national outreach effort, a collaborative effort.

And we had a meeting yesterday in which we are trying to determine what will be the best possible way to distribute the donations that are now coming in at a greater pace and do it in again a collaborative way, a consolidated way so that researchers will have one source to get materials to carry out this kind of research. So I think the bottom line is that this is I think turning out to be a very successful public-private enterprise that is supported both by the NIH, on the one hand; on the other hand, by Simons Foundation, Autism Speaks, and the Autism Science Foundation as well, so I think a very good collaborative effort overall.

DR. CUTHBERT: Thank you. We are indeed very enthusiastic about this collaboration. And thank you for coming yesterday. It was a very productive discussion. So we are moving forward very well.

Okay. Other updates? Oh, sorry. Yes?

DR. KOROSHETZ: So NINDS has a trial which might be of interest. So people may know in Fragile X, about 50 percent of folks develop or are diagnosed with autism. We have a trial going on in network that will use an mGluR5 allosteric modulator, which has been tested in adults, older folks with Fragile X, without benefit, but we are going to try and go into a study that is much more focused on the cognitive learning in children ages 3 to 6.

We have another trial in tuberous sclerosis, which, again, about 50 percent of people with tuberous sclerosis are diagnosed with Autism Spectrum Disorder. What we have found is that in many tuberous sclerosis patients, they develop a severe seizure disorder. And a study that was already done showed that by just checking EEGs, you can predict with 100 percent specificity who is going to develop the seizures. So the trial is to start treating as soon as you see the EEG abnormality.

And the question is, not only will it help the seizures, maybe prevent the seizures from coming on, but also might help cognition. So two interesting trials that kind of we can do because of the ability to identify particular subgroups of patients with highly penetrant autism disorders.

DR. CUTHBERT: Thank you.

Can I ask the geeky question of, do you know yet exactly what the EEG signature is? Is it an alteration in the rhythm?

DR. KOROSHETZ: No. It is actually epiletiform activity. Yes. So it is a pretty blatant abnormality.

DR. CUTHBERT: Very interesting. Thank you.

Other updates?

MR. ROBISON: I don't have an update, but I will just briefly say that if any of you want me to sign your books or something, I should try and do it before 5 because I am getting picked up and I am happy to do that. Those of who believe in autistic mortality, you should know that the value of authors' signed books always rise when they are dead. So you should hedge your bets and do it now.

(Laughter.)

DR. CUTHBERT: Thanks, John.

If I can go back to Walter one more time, just remind us the status of these trials. Are they in --

DR. KOROSHETZ: Just starting.

DR. CUTHBERT: Just starting up? Okay. Great. Okay. Thank you. We will look forward to progress.

Okay. John’s comment is probably a good note on which to move towards wrapping up the meeting. So, Susan, I will leave it to you to outline the next steps for us.

DR. DANIELS: Well, I think I went over the next steps at the end of the business section, but I will be in touch regarding all of the different kinds of working groups that we are going to be starting and will also be following up on coming up with a strawman for the summary of advances process based on our discussion. And so we will be working on that.

So don’t worry. You will be receiving more emails from me in case you were worried that it was going to go quiet. You will be hearing from us.

So thank you so much for a really thoughtful and stimulating discussion on all of these topics.

DR. CUTHBERT: Let me add my thanks. It was a very productive meeting. It is good to see you all again. And we will look forward to all joining together in July, right?

DR. DANIELS: Yes. The next meeting is July 19th.

DR. CUTHBERT: So wonderful D.C. summertime. It will be fun. Thank you so much, everybody. Safe travels home.

(Whereupon, at 4:48 p.m., the meeting was adjourned.)