

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, NOVEMBER 17, 2015

The full Interagency Autism Coordinating Committee (IACC) convened in Rockville, Maryland, at the National Institute on Alcohol Abuse and Alcoholism (NIAAA), Fishers Lane Conference Center, 5635 Fishers Lane, Room 508/509/510, at 9:36 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

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)

AARON BISHOP, M.S.S.W., Administration for Community Living (ACL)

FRANCIS COLLINS, M.D., Ph.D., National Institutes of Health (NIH)

JUDITH COOPER, Ph.D., NIDCD (representing James Battey, M.D., Ph.D.)

SAMANTHA CRANE, J.D., Autistic Self-Advocacy Network (ASAN)

GERALDINE DAWSON, Ph.D., Duke University

AMY GOODMAN, M.A., Autism Now Center

PARTICIPANTS (continued):

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

JENNIFER JOHNSON, Ed.D., ACL (representing Aaron
Bishop, M.S.S.W.)

ELISABETH KATO, M.D., M.R.P., Agency for
Healthcare Research and Quality (AHRQ)

ALICE KAU, Ph.D., Eunice Kennedy Shriver National
Institute of Child Health and Human
Development (NICHD) (representing Catherine
Spong, M.D.)

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., National Institute of
Environmental Health Sciences (NIEHS)
(representing Linda Birnbaum, Ph.D.)

CYNTHIA MOORE, M.D., Ph.D., Centers for Disease
Control and Prevention (CDC)

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

KEVIN PELPHREY, Ph.D., Yale University

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)

PARTICIPANTS (continued):

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

LARRY WEXLER, Ed.D., Department of Education

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

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PROCEEDINGS:

Dr. Susan Daniels: Good morning. It's my pleasure to welcome you all, members of the IACC and our new chair, Dr. Bruce Cuthbert, and Dr. Francis Collins, Director of NIH, as well as members of the public who might be listening on the phone or in the audience or watching our webcast.

We've been looking forward to this day for a while, and we are excited to be working through a full agenda to talk about updates that have happened in the last several months and to get started on Committee business.

So I'd like to begin by taking a roll call of all the members of the Committee.

Bruce Cuthbert?

Dr. Bruce Cuthbert: Here.

Dr. Daniels: Jim Battey?

Dr. James Battey: Here.

Dr. Daniels: Linda Birnbaum? Oh, Cindy Lawler?

Dr. Cindy Lawler: [Off-mike response.]

Dr. Daniels: Jennifer Johnson for Aaron Bishop?

Dr. Jennifer Johnson: [Off-mike response.]

Dr. Daniels: Francis Collins?

Dr. Francis Collins: Present.

Dr. Daniels: Ruth Etzel is our new member from the EPA, and I don't believe we have a representative from the EPA here on her behalf. Correct? She was not able to be here, but in the future will be. So EPA is one of the agencies that is going to be joining us.

Tiffany Farchione, I believe, is also not going to be able to be here from the FDA.

Michelle Harris?

[No response.]

Dr. Daniels: Maybe will come later. Elisabeth Kato?

Dr. Elisabeth Kato: Here.

Dr. Daniels: Thank you. Laura Kavanagh?

Ms. Laura Kavanagh: Here.

Dr. Daniels: Walter Koroshetz?

Dr. Walter Koroshetz: Here.

Dr. Daniels: Cindy Moore?

Dr. Cynthia Moore: [Off-mike response.]

Dr. Daniels: Linda Smith or Shantel Meek for ACF I believe are not going to be here today.

Dr. Daniels: Catherine Spong? Oh, Alice Kau?

Dr. Alice Kau: Is here.

Dr. Daniels: Larry Wexler?

Dr. Larry Wexler: [Off-mike response.]

Dr. Daniels: And Nicole Williams?

Dr. Nicole Williams: [Off-mike response.]

Dr. Daniels: Among our Federal members. So now public members. Dr. David Amaral was not able to be here today but will be here in January.

Jim Ball?

Dr. James Ball: Here.

Dr. Daniels: Samantha Crane?

Ms. Samantha Crane: [Off-mike response.]

Dr. Daniels: Geri Dawson?

Dr. Geraldine Dawson: Here.

Dr. Daniels: Amy Goodman?

Ms. Amy Goodman: Here.

Dr. Daniels: Shannon Haworth?

Ms. Shannon Haworth: Here.

Dr. Daniels: David Mandell is not going to be here today but will join us by phone around 3:00 p.m.

Brian Parnell?

Mr. Brian Parnell: Here.

Dr. Daniels: Kevin Pelphrey?

Dr. Kevin Pelphrey: Here.

Dr. Daniels: Edlyn Pena?

Dr. Edlyn Pena: [Off-mike response.]

Dr. Daniels: Louis Reichardt?

Dr. Louis Reichardt: Here.

Dr. Daniels: Robert Ring?

Dr. Robert Ring: Here.

Dr. Daniels: John Robison?

Mr. John Robison: Here.

Dr. Daniels: Alison Singer?

Ms. Alison Singer: Here.

Dr. Daniels: And Julie Taylor?

Dr. Julie Taylor: [Off-mike response.]

Dr. Daniels: Well, welcome to you all. And I'd like to turn this over now to Dr. Bruce Cuthbert, our chair.

Dr. Cuthbert: Good morning, everyone. And welcome to this first meeting of the newly reconstituted IACC.

It's a pleasure for me to be here to take over as the new chair of this group, and I want to thank Dr. Francis Collins for appointing me to this position. I'm looking forward to what we can all accomplish together in the coming months.

As you know, Dr. Tom Insel left NIMH in -- at the end of October. He did not retire, but rather is continuing his efforts in the mental health sphere, having moved to Google Life Sciences to

work on opportunities for big data and things that can be accomplished with the resources that Google has in the computational space.

I know that Dr. Insel played a very important role in leading NIMH's -- the NIH's autism efforts and this Committee over the past 13 years, and I want to acknowledge all his service and efforts in this regard. His leadership will be missed very much, but we will plan to go forward at full speed with our important business. And I'm certainly looking forward to getting to know all of you.

As you know, the IACC was reauthorized by the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014. And after a year's hiatus, during which the nomination and appointment process was conducted, we're now all together and appointed and ready to get to work.

It takes time to get these things done because this is actually one of the few committees which has an open nomination process, which, of course, involves the opportunity to have nominations and time to vet everyone through. But we are glad that we are finally together.

I do want to welcome all of the new members of this group and also to thank and welcome back all

the returning members who've signed up for another term with us to work on all of our different issues. The group at this table, indeed, represents a broad array of perspectives and expertise that will be extremely helpful to us as our Committee carries out its responsibilities to inform and advise the HHS Secretary on issues related to all matters pertaining to autism.

I should mention that among our Federal agencies, there are some continuing agencies and some new representatives who will be serving. I would like to note in particular two changes that we have. First, the Environmental Protection Agency, EPA, has joined as a member of the IACC. As you just heard, Dr. Ruth Etzel will be our representative, but she was not able to join us today. But we'll trust that she can join us in January.

And also the Agency for Healthcare Research and Quality, or AHRQ, is rejoining the IACC, represented by Dr. Elisabeth Kato, whom I heard somewhere is here at the table? Thank you. Good morning.

So I just wanted to tell you a little bit about my own background in taking over as chair of

the Committee. I had been at NIMH since 1998 with a 4-year hiatus while I was at the University of Minnesota on the psychology faculty. My major area of research has been of the psychophysiology of emotion and anxiety disorders and looking at individual differences in mood and anxiety disorders.

However, I have a long background with autism research. In fact, the first study I carried out in my scientific career was my undergraduate psychology thesis looking at an operant conditioning therapy for a young child who had minimal speech, and they were working on operant conditioning techniques to improve his speech functioning in the tradition of Ivar Lovaas, one of the first great behavior therapists who worked on treatments for early autism.

I've also had a lot of experience with autism through my own family's work. My wife is a doctoral-level educator who has been the supervisor of Section 504 disability programs and has led lots of IEPs and other work, both in schools and at district levels, for autism services. And we've had many conversations about this.

And my daughter was, for several years in the early 2000s, the autism services coordinator for the State of Wisconsin, tasked with actually implementing the specific services in that State that were directed broadly by the Federal law that came into effect at that time, and we had many conversations about the issues in providing appropriate services and defining what those would be.

More recently, at NIH and NIMH, I have been leading something called the Research Domain Criteria project, which is an effort to unpack the great heterogeneity and variability involved with all mental disorders and notably including autism, and I will bring that strong perspective to the leadership of this group. And you will hear more about that later today and, I am sure, as we go on.

So I really look forward to getting acquainted with all of you and working with this group in the coming year to help us carry out our responsibilities, keep the Secretary informed of emerging issues and opportunities in the autism field.

We also need to update the IACC Strategic

Plan, which is impressive in its scope and breadth and, I think, over the last few years all that has been accomplished. And we want to stay abreast of all the initiatives, programs, research projects, and other autism-related activities across the Federal Government and our many private organizations as well.

So I hope that in my role as chair, I can help foster all of these collaborations across the agencies and with our private foundations that are working on these issues. We've made a lot of progress in recent years, but there is still so much more to be done. So I look forward to contributing to advancing autism research and services work through my role as the chair of this Committee and as the Acting Director at NIMH.

I also just want to point out to everyone that the IACC does perform a very important function for input from the public, and I hope that the public will continue to provide their perspectives, concerns, and ideas with the Committee to help us as we work on various projects throughout the year. This is, indeed, a unique group across the Federal Government. I know of no other certainly like it at NIMH to work on

any of our other issues that we deal with. So this is a really important function that we look forward to hearing about more.

So that's all I want to say in a brief introduction. I'll have some more comments later, but I am very pleased now to introduce Dr. Francis Collins, the Director of the National Institutes of Health, who is a member of this group and has graciously found time from his very busy schedule to be with us this morning, to listen in on our startup and to say a few words.

Dr. Collins, thank you for being here.

Dr. Collins: Bruce, thank you very much.

Good morning to all of you. It's a privilege to be here in this first meeting of the newly constituted IACC, and I certainly bring you greetings also from my boss, Secretary Burwell, who hopes to attend a future meeting of this gathering, perhaps early in 2016. At the moment, she's in the midst of sort of an national tour, trying to increase attention to the opportunity for open enrollment for the Affordable Care Act, which is in one of those phases where there is a great deal of attention being made to being sure that everybody is aware of the opportunity. And

that is very much a big responsibility for her.

I'm glad I am able to be here. There was some question even a couple of days ago about whether I would. I should tell you I did have semi-emergency back surgery last week, and I'm still in the recovery phase. And I have to tell you that sitting is the worst possible position to be in.

So I hope you'll forgive me if I'm not able to stay for the rest of today's meeting. I just need to go get horizontal in a little bit. But very happy to be able to see all of you -- some of whom I know, most of whom I don't -- and just express my thanks to you for the role you're going to play in this very important group to advise NIH, to advise the Secretary, to advise the Government about what we should be doing in terms of coordinating our efforts to find answers for autism.

I also want to reflect briefly about the legacy that Tom Insel, who led this group so ably for 13 years as its chair, has given just in terms of the clarity of his thinking and the wise and thoughtful approach that he took to this problem, which, of course, has not been without controversy or with differences of opinion.

Tom, as you have heard, retired from NIH. A very interesting next step in his career to go and work at Google, and his determination there to try to see how the new developments that are happening, particularly with such things as wearable sensors, could be applied in the area of mental health, which mostly hasn't happen yet and which Tom is a brilliant guy to be able to imagine what that interface might look like.

So I'm sure we'll be hearing a lot from him in that exciting space that he's now landed.

I very much want to express my strong support for Bruce as your new chair. I think, as you have heard from him, he brings to this leadership role experience, both professional and personal, including his family's involvement in issues that are highly relevant to the IACC. And in getting to know Bruce and in making the decision to appoint him as the Acting Director of NIMH, I have great confidence in his ability to be a good listener, as well as a good formulator of visions that need to be put forward and a person who understands the critical need of group process in something as complex as autism research.

And so, Bruce, thank you for being willing to

take on this role in addition to stepping in to oversee a very complex part of NIH, the National Institute of Mental Health, while we are engaged in a search process for a permanent Director, which is already underway, but which probably, things being what they are, will not land on a candidate for several months.

So Bruce is very much the guy in charge and I think has already stepped into that with great energy and capabilities that we are grateful for.

I think you can also see by the membership in this Committee how much NIH is devoted to participating in a meaningful way with the deliberations of the IACC, with myself as a member. Although when I'm not able to attend, Josie Briggs, who is the Director of the National Center for Complementary and Integrative Health, steps in in my place.

But you also have four other institute Directors, two of whom are here in person -- Dr. Koroshetz, Dr. Battey -- who are assigned as members of this effort. I don't know of any other coordinating committee that has that kind of high-level representation from NIH, not even close, having this many of the leaders of our 27

institutes and centers personally involved.

And I hope you see that as a reflection of just how seriously we take the charge to this Committee to try to figure out exactly how we can at NIH do the best job in investing the resources that the taxpayers and the Congress have given us to find answers and answers that we are still searching for in many ways, although I think progress is being made. Compared to where we were 10 or 20 years ago, we've come a long way, but we have a long way to go.

NIH invested \$189 million in autism research in FY 2015, the year that has just come to a close on October 1st. And that is spread across a wide range of science, from basic to clinical and everything in between.

Specific programs I might mention that I think are relevant to this group would certainly include the BRAIN Initiative, which is one of the boldest enterprises that NIH has undertaken in quite a long time.

This initiative, initially announced by President Obama about 2 1/2 years ago, BRAIN is an acronym that stands for Brain Research through Advancing Innovative Neurotechnologies. And it is

a 12-year effort to try to develop and apply technologies that will allow us to understand how the circuits in the brain do what they do to accomplish amazingly complex tasks.

We all are excited, I think, about the potential of beginning to unravel the mysteries of the brain, that most complicated structure in the known universe. And yet it's clear that if we really want to get an understanding, we have to go beyond the ability to look at whole brain images, which are certainly revealing, or single neuron measures, to look at what's in between, all those orders of magnitude that would begin to reveal how millions or tens or hundreds of millions of neurons functioning together achieve complex tasks.

Initiating some kind of voluntary motor movement, interpreting incoming sensory information, laying down a memory and retrieving it. You would think by now we'd know how that works, but we really don't. If you ask the question in a tough way, we're still feeling our way in the dark.

And maybe it's time to take this serious effort, bringing together all the bright minds

that we can from expertise in engineering, from nanotechnology, from biology, from medicine, from computer science, to try to see whether we could, in fact, sort out some of those mysteries and figure out how those 86 billion neurons in the brain are achieving these amazing things that they do.

It is a very daunting task. We pulled together a really remarkable group of visionary neuroscience thinkers and charged them to spend a year designing what this plan would look like, and they did so. And I would say it has been unveiled and received with great excitement and enthusiasm because of the way in which they've put forward a series of specific goals and timetable.

The first 5 years of this are focused on developing these new technologies that we don't currently have that will allow you to actually see what's happening in these circuits and then gradually beginning to apply those. And the BRAIN Initiative is not designed as focused on any specific disease. It's really trying to understand how the brain works in the normal situation.

But obviously, everything we learn is foundational to our understanding of disorders

like autism, like schizophrenia, like mood disorders, like traumatic brain injury, like epilepsy. All of those fields will be greatly benefited as we build this foundation of understanding.

And I should say this is an effort which has, I think, inspired a lot of the community and no doubt will have intersections with what you talk about in the IACC. And I should say Dr. Koroshetz has been a significant leader in putting together what is now an \$85 million program, which we have funded already for 2 years and are hoping to fund the third year, assuming that Congress gets around to deciding on a budget for FY '16, which, of course, is still a little bit up in the air and we hope will get resolved before December 12th, which is the current deadline for making such decisions.

But I think there's a lot of enthusiasm for this program. A lot of enthusiasm for NIH from the Congress right now from both houses and both parties because of the promise of medical research, which has never been at a higher state than it is right now.

And I just wanted to mention that BRAIN Initiative because I think it has long-term

significant implications for anybody who's interested in understanding how the brain works and its implications for disorders.

I could mention several other programs that NIH is pursuing, but I won't spend time on them, only to just quickly mention the Autism Centers of Excellence program as an area where we have put a lot of hopes and dreams and investment into trying to be sure we're bringing together critical masses of investigators to study all aspects of these disorders.

We have a Biomarkers Consortium project that aims to try to improve the tools for measuring and treating social impairment in children with autism, biomarkers being a very exciting area across all of NIH in many different disorders. How do we come up with objective measures that would allow us to determine whether a particular intervention is working without having to wait years to be confident that we're on the right track? And that's certainly true in this condition as in many others.

There's an initiative to support research to enhance early diagnosis, intervention, and supportive services for people with autism

spectrum disorders across the lifespan. This is called ServASD. And I think many of you are familiar, the National Database for Autism Research, NDAR, which is an effort to try to be sure that what is going on in research in autism spectrum disorders is, in fact, accessible to anybody who needs to see that information in an organized and timely way.

And there are many other things that could be added to that list. I just mention these few.

Mostly, though, I just wanted to say to you all how important this Committee is in terms of providing HHS and other member Federal agencies -- and you've heard EPA now being added to this group -- with advice and input from the public. And we really hope that you will take that role with great seriousness. We depend on that to plan and implement the programs that are going to most beneficial.

We depend on that also to identify partnerships. We're very avidly interested in those -- whether they are with industry, with private foundations, with advocacy organizations - - to enhance services and to advance research that would benefit the autism community, and this IACC

is a really important place to identify those possibilities for partnership and make sure that we're not missing out on ways to do that.

And finally, I'd just like to thank Dr. Susan Daniels, who has been such an effective staff person at a senior level for the IACC during the past several years, and we're fortunate that once again she is willing to step in and take on that role and does a prodigious amount of work, maybe much of it behind the scenes that you're not aware of, to be sure that the deliberations of this group are captured and that the recommendations that are being put forward and the strategic plan that's being developed is done in an articulate and effective way.

And Susan spends vast amounts of time that other people don't even know about making sure that this Committee is as good as it possibly could be, and that's very much appreciated.

Finally, just thank all of you for the time that you will take, because this is not one of those groups that kind of is sleepy and gets together once in a while just because you don't have anything else to do. This is actually an energetic environment where there are no doubt

lots of strong feelings about what we should be doing. We want to listen carefully to all of those.

We do want to figure out how this group can be more than just a sum of the parts and how the various different perspectives that are represented here can be knitted together for a national agenda that's as effective as it possibly can be. And as NIH Director and speaking for my colleagues, we are listening carefully. We want to be your partners. We want to be responsible and be held responsible for the way in which we invest taxpayers' dollars in trying to make the discoveries and the advances that everyone around this table is waiting for.

So thank you very much once again. I appreciate the chance to be here, and I hope you'll forgive me for not being able to stay for the rest of the day.

Thank you.

[Applause.]

Dr. Cuthbert: Thank you very much, Dr. Collins, for those remarks.

So next we want to turn to getting to know everyone. So we've set aside a good bit of time

simply to let all of our members introduce themselves and let everybody know what they've been up to.

So we've set aside about 2 minutes for each of you to describe your own professional and personal involvement with the various aspects of autism. And so, Susan, if there is any other business before that, we could start that now. So let's start.

And take care, Dr. Collins, and good luck with your rehab. And thanks again for joining us.

So let's start at my left and with Dr. Geri Dawson. Thank you for being here for another tour on this Committee, and go ahead.

Dr. Dawson: Well, it's my absolute pleasure. And this is my third appointment to this Committee, and so it is an honor and a pleasure to serve again. And I'm really excited to see what we, as a new group, can accomplish together.

Just briefly, I've been in the field of autism for many, many years. I spent most of my career at the University of Washington, where I was founding director of the University of Washington Autism Center, which continues to be a thriving treatment center and research center there.

Then, in 2008, I joined Autism Speaks to be the first chief science officer there and was there for about 5 1/2 years and then, in 2013, returned to academia. And now I'm very proud to be directing the Duke Center for Autism and Brain Development.

And I also have the role of president of the International Society for Autism Research, which is the organization that brings together scientists not only in the United States, but really from around the world that are conducting autism research.

And later, when we talk about some new activities, I'll even talk about the most recent meeting that we had in Shanghai. So really reaching across the ocean to bring together scientists from around the world.

So, again, it's my pleasure to serve.

Dr. Cuthbert: Thank you very much for joining us again to bring your expertise, and we'll look forward to hearing more about that conference.

Next, Dr. James Battey, who is one of the two NIH institute Directors to whom Dr. Collins referred. Dr. Battey, thank you for being here.

Dr. Battey: Well, welcome, everybody. I'm

delighted you could all make it today.

I've had the privilege of serving on this Committee now since its inception and have enjoyed my service, learned a great deal. Very much look forward to participating in your deliberations.

And thank you all for all that you have done in the past and that you will do for us in the future.

Dr. Pelphrey: Hi. I'm Kevin Pelphrey. I'm the Harris Professor in the Yale Child Study Center in the Department of Psychology at Yale University.

Let's see, I'm principal investigator of an Autism Center of Excellence network that's focused on understanding the neurogenetics of girls with autism. So it's a major effort across sites to really pay attention to how autism is different in girls and pay careful attention to how that relates to broader autism phenotype expression in the siblings of those kids with autism.

I'm a neuroscientist, cognitive neuroscientist. I employ a variety of genetics and imaging and electrophysiology techniques to understand autism. And then probably the most relevant thing is that I'm a father of a little girl with autism, actually a big girl with autism

at this point. She's now a teenager, which is hard for me to accept, but --

Dr. Wexler: Good morning. Larry Wexler. I direct the Research to Practice at the U.S. Department of Education Office of Special Education Programs. Not my first visit to this group either.

I do want to acknowledge that today is the 40th anniversary of the signing of the Individuals with Disabilities Education Act. So that's a pretty big deal. I was supposed to be downtown for something today, but frankly, I thought this was more important.

My responsibilities include all of the discretionary grants in IDEA. So we have grants in technology, in personnel preparation with some significant autism investment, State personnel developing grants. We have a very robust technical assistance and dissemination program.

We fund 110 parent centers whose job is solely to support parents as they go through the process of addressing the needs of the kids with disabilities and how that interfaces with local school districts. I'm responsible for all of the IDEA data, which is about 6.5 million children,

including in 2013, 478,983 children with autism as reported by States, although that's an underreporting because a lot of kids are -- at a younger age are coded under a different category.

Appreciate the opportunity to again represent the Department of Education and look forward to our work here.

Ms. Haworth: Hello. My name is Shannon Haworth. I'm a new public member. My first job is a parent of an absolutely wonderful child with autism and comorbid mental health issues. He's changed my life for the better and put me on the road to advocacy. And I also have a spouse with autism.

Professionally, I am the public health program manager at the Association for University Centers on Disability, and I work on capacity-building projects to help the public health workforce include people with disabilities in their planning efforts.

AUCD is a membership organization for developmental disability-related training programs, University Centers of Excellence in Developmental Disabilities, and research centers.

Ms. Kavanagh: Good morning. I'm Laura

Kavanagh. I'm the Deputy Associate Administrator for the Maternal and Child Health Bureau, which is in the Health Resources and Services Administration.

You may not be that familiar with HRSA as you are with some of the other agencies around the table. So I want to talk a little bit about the agency. I have both a personal and professional interest in the area of autism, as both a family member, former teacher, friend, and colleague of those on the spectrum.

In the Health Resources and Services Administration, we have programs that provide healthcare to people who are geographically isolated, economically or medically vulnerable. So those people include those living with HIV/AIDS; pregnant women, children, and families; and those in need of high-quality primary healthcare.

We also support the training of health professions, and as the autism team lead within the Maternal and Child Health Bureau, I oversee our interdisciplinary clinical training programs, as well as our autism intervention research programs, and State programs as well. And I'll talk a little bit more about what we've been doing

in those areas a little later in the program.

Such a pleasure to be serving again on the IACC, and I look forward to meeting many new members.

Ms. Goodman: Hello. I'm Amy Goodman. I'm a new member, and I'm the Director of Autism Now at the ARC of the U.S.

I work in employment for individuals with I/DD, and I'm also part of the national self-advocate council. I, myself, am on the spectrum, and I actually was diagnosed as an adult and then went to the Autism Training Center in -- at Marshall University, where I actually got a master's in special ed in autism.

So I'm just glad to be here, and I proved them wrong, that I proved that you can do whatever you want because I actually am a square dancer as well.

[Laughter.]

Dr. Lawler: Hi. I'm Cindy Lawler. I'm here today representing the National Institute of Environmental Health Sciences, or NIEHS, on behalf of our Director, Linda Birnbaum, who will be joining you for many of the future meetings.

NIEHS is one of the NIH institutes. We're a

little bit different in a couple ways. One, we're in North Carolina rather than in the broader D.C. area, and we have more of a public health mission, compared to many of the other NIH institutes.

I, myself, manage a portfolio of NIEHS research grants that are looking at how the environment may affect autism. I've been at NIEHS for 15 years. Many parts of my job have changed, but the autism portfolio has stayed with me.

During that time, I've had many conversations with coworkers and colleagues at NIEHS whose families are affected by autism. In my broader work, in part through my attendance at these meetings, I've met many other parents, parent advocates, and self-advocates, and the passion, the stories, the challenges are always compelling. And I think that I bring those personal stories with me because they really do help make my professional work more meaningful.

And I'm hopeful that in my work I can contribute to some small way to helping answer the question of why.

So thank you.

Dr. Ball: Good morning. My name is Jim Ball, and my day job that I get paid for is the

president and CEO of JB Autism Consulting. I consult all over the country. I work with children and adults on the spectrum on a daily basis.

I started as a teacher aide in the field in the early '80s. Anybody here remember the '80s? And then have moved up and am now a board-certified behavior analyst, and I work with students and, again, adults that are pretty significantly challenged on the spectrum.

My unpaid job is as volunteer executive chair of the Autism Society. This past Saturday was our 50th year, and we are the oldest grassroots organization in the country. We have 106 affiliates and a national board of directors that I chair at this point, and I've been a part of the Autism Society for about 25 years now in a variety of different capacities and am very proud to say that our 50th year, we've come a long way.

And I will be sharing some of that information because we're doing some exciting work in adult services and our strategic plan that's coming up.

Thank you.

Mr. Parnell: Good morning. I'm Brian Parnell. I'm really excited to be part of a group with so many passionate and smart people that are devoted

to developing the field of autism.

Professionally, I work for the Utah Division of Services for People with Disabilities and manage our Medicaid autism waiver, as well as our community supports waiver that provides supports and services to people with intellectual disabilities and related conditions.

Personally, I'm the father of three children on the spectrum. I have a 24-year-old with ASD, a 16-year-old with Asperger's, and a 5-year-old little girl -- 6 on Friday -- who also has autism.

Dr. Ring: Good morning, everyone. My name is Rob Ring. I'm the chief science officer at Autism Speaks, and this is technically my second appointment, although I only participated in one, the last meeting of the past cycle.

But it's a real -- real honor, a real privilege to be here and serve with each of you. I'm really looking forward to the opportunities we have in front of us to make meaningful progress in the area of autism.

I'm a molecular neurobiologist by training, a neuroscientist, and I've been with -- with Autism Speaks for the past 4 1/2 years, and I oversee the entire science operation for our foundation, which

has a very diverse portfolio, as many of you know. And as we move forward, for those who don't know, I'm happy to educate everyone on some of the new areas we're working in.

Before joining Autism Speaks, I actually headed the autism unit at Pfizer, and that was the first dedicated unit in the pharmaceutical industry working on medicines development for autism and related neurodevelopmental disorders. And before Pfizer, over a decade before that, mostly in mood disorders and psychiatry medicines development.

Looking forward to the day and working with everyone.

Dr. Reichardt: I am Louis Reichardt. I'm here as representative of the Simons Foundation. I direct the Autism Research Initiative. In terms of background, I've got a Ph.D. in bacteriophage genetics, some distance from autism perhaps, but Cas and CRISPR made it closer.

I then after postdoc spent most of my career in San Francisco at UCSF, where my laboratory has worked on the roles of neurotrophic factors and a variety of cell adhesion systems, including integrins, cadherins, and some of the Ig family as

on development and function of the brain.

So this is sort of a second career for me. I've been here a little over 2 years. So, formally, I guess in the college terminology, I'm a junior, and I look forward to learning from all of you.

Thank you.

Dr. Kato: Hi. I'm Elisabeth Kato, and I represent the Agency for healthcare Research and Quality.

[Pause.]

Dr. Kato: My name is Elisabeth Kato, and I'm representing the Agency for Healthcare Research and Quality. I'm a medical officer in the Center for Evidence and Practice Improvement, and we've been involved in producing a number of systematic reviews on different aspects of treatment and diagnosis of autism in response to public requests.

And it's my first time here, and I'm really looking forward to learning from all of you.

Ms. Crane: Hi. My name is Samantha Crane. I'm the Director of Public Policy at the Autistic Self-Advocacy Network, and I'm also a self-advocate.

My undergraduate degree actually was in psychology. I focused on developmental psycholinguistics, and I actually included some research on how development and use of language correlated with autistic traits.

I ended up turning toward advocacy, going to law school, and during law school, I worked with the Massachusetts Disability Law Center, the American Bar Association Commission on Mental and Physical Disabilities, and the Department of Justice's Disability Rights Section.

After law school, I had a clerkship and worked at the Bazelon Center for Mental Health Law for about a year and a half, took a little bit of time to work at a law firm doing litigation, and then came to ASAN to work in our public policy division.

Since joining the Division of Public Policy at ASAN, we've published multiple toolkits focused on access to healthcare, access to behavioral health interventions, and access to community integration, which included Medicaid waivers and ensuring that people can get quality supports in the community.

I'm looking very much forward to working with

all of you and excited for today.

Dr. Williams: Hi. My name is Nicole Williams. I am the recently appointed program manager for our Autism Research Program over at the Congressionally Directed Medical Research Programs, which is under the Department of the Army. We are located in Fort Detrick, Maryland, which is about 50 miles north of here in Frederick.

My background is in biochemistry. Actually, I did work with bipolar disorder on the basic level. The ARP is a funding agency. We are directed by Congress every year. We fund everything pretty much from basic research to clinical trials.

This is my first year, excuse me, just taking over for Dr. Donna Kimbark. Very excited to be here and learn about the community, as well as backgrounds of everybody, and thank you.

Dr. Pena: Hello. My name is Edlyn Pena, and I am an assistant professor at California Lutheran University. It's a small liberal arts college in southern California.

I'm really excited to be on this Committee. I have a 7-year-old son with autism. He's very handsome and smart, and he's minimally verbal. He

uses an iPad to communicate, both icons and typing. So I'm personally interested in how people with autism can use AAC to communicate and participate in inclusive environments.

My research in higher education, I study research on supporting college students with autism. How to prepare them for college and university environments, what makes good teaching practices at the university level to support students with autism, and campus climate issues at various universities.

I look forward to getting to know all of you. Thank you.

Dr. Johnson: Good morning. I'm Jennifer Johnson. I'm with the Administration for Community Living in the U.S. Department of Health and Human Services. We are a fairly new Federal agency in HHS. So I thought I'd give you a little bit of background on our agency.

We were formed in April of 2012, and we brought together the Administration on Aging, the Office on Disability, and the office that I've been with, the Administration on Intellectual and Developmental Disabilities.

Since 2012, our agency has grown quite a bit,

with the addition of aging programs and disability programs that have been transferred from various parts of the Federal Government. So we have several lines of business in terms of aging and disability. None of our programs focus specifically on autism, but in the work that we all do, we address the issues that people with autism often face.

The mission of ACL is to maximize the independence, well-being, and health of older adults, people with disabilities across a lifespan, and their families and caregivers. So we are very focused on looking at community living and the services and supports, most specifically long-term services and supports that people need in order to live in the community.

As I mentioned, we have both an aging line of business and a disability line of business. In terms of our aging -- I'm sorry, our disability programs, we have several centers within ACL that focus on disability. We have the Administration on Disabilities that was newly formed in the summer of this year, and the Administration on Disabilities includes the Independent Living Administration and also the Administration on

Intellectual and Developmental Disabilities, which is the agency that I'm with.

We also have the National Institute on Disability, Independent Living, and Rehabilitation Research, or NIDILRR. Both NIDILRR and the independent living programs were in the Department of Education and transferred over to us under the Workforce Innovation and Opportunity Act.

We also have what's called the Center for Integrated Programs, where we have a number of programs that focus on both aging and disability issues. And then we also have the Center for Policy and Evaluation, which, again, is focusing on aging and disabilities in terms of policy and evaluation work.

We are delighted to continue to serve on this Committee. AIDD has been involved with the IACC since its inception. I, myself, have served both as an alternate and a member of IACC. So we're delighted to be back here and continue to participate in these discussions.

I am sitting in this morning for our Commissioner of the Administration on Disabilities, Aaron Bishop. He will be here this afternoon and will join in discussion then.

Thank you.

Mr. Robison: I'm John Elder Robison. I am an autistic adult. I'm also the parent of a young adult on the spectrum, and I have three grown step-kids with neurological differences. And I guess I'm part of one of those families where autism is clustered within us.

I'm honored to be reappointed here to this Committee. I was brought into Government service by Alan Guttmacher at Children's Health and Tom Insel at Mental Health. And of course, they've both retired. So now I'm kind of here on my own in that regard.

I'm the Neurodiversity Scholar in Residence at the College of William and Mary. I'm one of the founders of TCS Careers to College, which is a high school program for public school students with developmental differences, and I also write and speak about autism.

Dr. Kau: Good morning. I'm Alice Kau. I'm the program director for Eunice Kennedy Shriver National Institute of Child Health and Human Development. I'm sitting in today for our Acting Director, Dr. Cathy Spong.

My background is in developmental and clinical

psychology, and I have been at NIH for 11 years. Hard to believe, but yes, 11 years. And before that, I was an assistant professor in the child psychiatry department of Johns Hopkins School of Medicine.

And I look forward to participating in this meeting.

Dr. Taylor: Good morning, everybody. My name is Julie Taylor. I'm a new member on the Committee, and I'm really delighted to be here.

I'm an assistant professor of pediatrics at Vanderbilt University and an investigator at the Vanderbilt Kennedy Center for Intellectual and Developmental Disabilities. I've been studying the transition to adulthood for people with autism and their families for about the past 10 years.

Started -- when I started my postdoc at the University of Wisconsin-Madison, I was looking at how families interact with and are impacted by having somebody with autism in their family, and a lot of the families that we saw were talking about transitioning out of high school and what's going to happen. And so I got into the literature to see what we knew to tell these families -- this was 10 or 12 years ago -- and the answer was almost

nothing.

And so that really set my career on this pathway to understand not only what happens during the transition years and beyond, but what can we do, what's going to make those years a little bit smoother for people with autism and their families. So I'm really excited to be here and to work with you all and to learn about what all of you are doing in more detail.

Dr. Moore: Good morning, everyone. I'm Cynthia Moore, usually go by Cindy, and I'm honored to contribute to the work of the IACC on behalf of the Centers for Disease Control and Prevention.

I think you probably know CDC, but it is our agency's -- our Nation's agency focused on protecting the public's health. CDC is not a new member of the Committee, but I am new, and I'm very happy to be here.

By training, I'm a pediatrician and a clinical geneticist. My career at CDC spans over 24 years. For the last 5 years, I've been the Director of the Division of Birth Defects and Developmental Disabilities, where our autism program is located.

I'm also a clinician, and I continue to help children and families with their concerns related

to birth defects, developmental disabilities, and genetic disorders.

Thank you.

Ms. Singer: Good morning. I'm Alison Singer. I'm the co-founder and president of the Autism Science Foundation, and this is my third full term as a public member on the IACC. I'm very excited to be back and to get back to work because we have a lot of work to do.

I'm also the mother of an 18-year-old daughter with autism, and I also have an older brother diagnosed with autism back in the 1960s before there was an IDEA law. And it's great to celebrate the 40th anniversary of that law because it has changed the lives of so many people with autism.

I also like to add that I also have a daughter who is not diagnosed with autism. Sometimes she is called an "unaffected sibling." She is hardly unaffected by autism because autism affects the entire extended family. So sometimes I say I have one daughter diagnosed with autism and one diagnosed with empathy.

And I also want to be sure to thank all of the parents and self-advocates who worked so hard to pass the Autism CARES law so that we could all be

here today.

Dr. Koroshetz: Thanks. I'm Walter Koroshetz. I'm the Director of the National Institute of Neurological Disorders and Stroke, and I think this is my third term on the Committee. I'm happy to be back.

I think that the Committee kind of looks at the big picture of the challenge that autism brings not just to scientists, but to family members and to affected individuals. So I think it's an important motivating factor for the people at NIH. I think that's a big part of what I've gotten out of the meetings in the past.

Our institute, the neurologic institute, is one of the medium-sized institutes, such as National Institute of Mental Health. And we fund research that is split, about 25 percent of which goes to basic research on how the brain functions, how the brain develops. And that we do with other institutes as well.

About 45 percent of our funds go to the neurobiology of different diseases and disorders, and at our institute, we care for about 200 to 400 different disorders, depending on how you split them. And then we also run clinical research

programs to do clinical trials. We have a network called NeuroNEXT, which can run first in human trials of new medications, including children.

And we also run a translational research program, which is populated by very experienced scientists from the pharmaceutical industry that have been recruited to NIH to bring discoveries that come from the laboratory to the point where they can go to the FDA for the transition into clinical trials in humans.

This program is within NINDS, but it also serves what's called the "blueprint for neuroscience," which is the conglomeration of all the different neuroscience institutes at NIH, including the National Institute of Mental Health. So at our institute, I think, you know, we're very, very interested to try and understand what is the physical neural basis of autism and how you could manipulate that abnormality to help patients.

And so it's a great pleasure to be here with the group and to work with Bruce and the other institutes across NIH on this problem.

Thanks.

Dr. Daniels: And I guess I'll go last. So my

name is Susan Daniels. I'm Director of the Office of Autism Research Coordination within the National Institute of Mental Health. And I've been with the OARC now for 7 years and since 2008, when the OARC formed.

And I will be telling you a little bit about what our office does to help manage this Committee. My own background is I'm a neurobiologist by training. I worked on sensory behavior, and I've worked in the National Institute of Neurological Disorders and Stroke on Parkinson's, in the National Institute of Allergy and Infectious Diseases, and then at NIMH for the past 7.

And so I'm really looking forward to working with the new Committee and excited about all things we're going to do over the next 4 years.

So thank you.

Dr. Cuthbert: Okay. Thank you, everyone.

I especially do want to thank Walter Koroshetz. When I took over in this acting position, the heads at the NIH central office said that I should find myself a mentor whom they described as a "buddy," and Walter kindly agreed to be my buddy. So thank you for that, Walter, and

he has been very helpful to me in getting started up with this job. And so thank you.

It's also the case that NIMH and NINDS share the responsibility of leading the BRAIN effort that Dr. Collins mentioned, even though there are many institutes involved. And so I'm also looking forward to working more directly with Dr. Koroshetz on that as the year progresses.

So, overall, we can see that this is an extremely impressive group. We have eminent people here from so many different domains of functioning and activity.

We have an excellent representation from the self-advocacy community. We have many people who are family members, who are people on the spectrum and representing their various facets of that. We have an excellent representation from the Federal Government, from foundations, and from scientists both at foundations and at universities.

And many of you are clearly engaged in multiple roles in these aspects in your daily lives. So I think that we have a really strong group to work together in all of our important tasks for the months ahead.

As one of my major roles in this Committee as

chair, it's my job to keep everything on time, and I will certainly do that. So as we go ahead, you'll understand if sometimes I have to cut people short in their remarks. But of course, these proceedings are being videocast. So it's important that we stay on our schedule so that people who are tuning in for a given segment get to see what they expect.

At this point, however, we have the unexpected pleasure that we are actually way ahead of time. So we don't need to worry about that for the moment.

So what I suggest is that we simply take our morning break a little early right now, and break for the full 15 minutes that are scheduled. Dr. Daniels has advised me that, in fact, in going over Committee business, she has quite a large number of slides to go over our duties, backgrounds, and so forth. So let's just take the break now and return at 10:45 a.m., and then we'll have plenty of time for Dr. Daniels' presentation and any questions and discussion before we have lunch.

So see you in 15 minutes. Thanks.

[Whereupon, the Committee members took a brief

break starting at 10:33 a.m. and reconvening at 10:51 a.m.]

Dr. Cuthbert: Okay. I think that we are ready to reconvene. So I expect that this next session will take us all the way to lunch, and whether we go until 12:00 p.m. or stop a little short and have a little extra time to get acquainted, either way this will be our only activity until lunch.

So I'm pleased to introduce again Dr. Susan Daniels, who heads our autism office at NIMH, and her title of remarks is "Committee Business," but I think she will have a much broader presentation than that, having gotten an opportunity to see it.

I would like to thank Dr. Daniels for all her hard work and efforts throughout this period between the meetings of this group, and you can be assured that we have not slacked off in that interim while this Committee was being revetted. We have been continuing other activities, and Dr. Daniels is our lead here at NIMH and, I dare say, across NIH.

And so I want to thank you for your leadership and also personally to thank you for all the time you have spent getting me up to speed in the workings of the Committee and the issues that it

faces. So thank you again. And Dr. Daniels?

Dr. Daniels: Thank you. Oops, started advancing my slides.

So I am going to talk about Committee business, but it is pretty broad in this first meeting. I want to bring you up to speed with the Committee because some people have served before and others are new to the Committee.

So, as you all know, the Interagency Autism Coordinating Committee is a Federal advisory committee, meaning that it gives advice to the Federal Government. It was established originally under the Children's Health Act of 2000, and at that point, it wasn't deemed an official Federal advisory committee that had to follow the Federal Advisory Committee Act.

But then when it was reauthorized by the Combating Autism Act of 2006, it became an official Federal advisory committee, and it's had a few reauthorizations since then. It had the Combating Autism Reauthorization Act of 2011 and then now the new Autism CARES Act of 2014.

So within the IACC charter, there is a description of the Committee's role, and it includes the responsibility to coordinate efforts

within the Department of Health and Human Services and among Federal agencies, as well as member organizations concerning autism spectrum disorder.

To provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder.

To facilitate exchange of information on autism activities among the member agencies and organizations to enhance coordination, and that's where you all bring information into these meetings to help inform each other of what's going on.

To increase public understanding of the member agencies' activities, programs, policies, and research.

And to serve as a public forum for discussion of issues related to autism spectrum disorder.

So there are a number of things that we do for coordination and monitoring. So within our meetings, we share information about agency and organization activities, including any new and ongoing programs, initiatives, and reports. So we'll be looking to you all to help keep this Committee informed as we meet, and we will regularly have update periods where you can share

any new activities that are going on.

You can also be -- we'll be trying to coordinate more with some of the other Federal advisory committees that work on areas that are related to autism or disabilities, including the Interagency Committee on Disability Research, and I'm the new representative from NIMH on that committee. And there are some other NIH representatives and other agency representatives on that committee. So we will be trying to get them here to the IACC to talk to us about their activities so that we can coordinate, not duplicate effort, but be aware of what each other are working on.

The National Council on Disability and the President's Committee for People with Intellectual Disabilities are some other Federal advisory committees that do work that's relevant to the IACC.

And if any of you know of other committees that we should be keeping tabs on, please let me know, and we'll add those to the list and try to make sure that we are touching base with them periodically.

We also will be gathering and sharing data

from Federal agencies and private organizations to help inform the deliberations of this group.

So what can members do? You can plan when you come to these meetings to share important updates and reports from your agency or organization at each meeting. And if you have a longer presentation you'd like to do, please request time on the agenda for those presentations.

And depending on the urgency, whether -- if you have a presentation, we like to do things in a timely manner, and so if you have a new initiative, we'd like to give you time on the agenda to announce it close to when it happened and not 6 months later where possible. But we'd like to make sure that you're getting an opportunity to present your information.

Also if you are conducting research and you have important findings that you'd like to share with the Committee, we would welcome those kinds of presentations.

I will also continue to ask you -- I know that in one of my emails to you, I asked you to suggest issues and speakers for future meetings. And so when you leave this meeting today, please think about that and feel free on a rolling basis to

send me your suggestions about issues that you want to cover and speakers that you would like to see here at our meetings. We usually try to set aside part of the time from our meetings to hear updates from outside experts.

We also will be looking to identify opportunities for coordination and collaboration among the different groups represented here and outside groups that aren't on the Committee. But please be aware of that and thinking about that and bring it up if you see opportunities.

Please also feel free to actively contribute input to the Committee discussions because that's why you're here, and that's why the Secretary wanted to appoint you to be on this group, that the Secretary felt that you had really important perspectives and expertise to share. And so please be active in the discussions.

And as I'll talk about later, we're going to have some different subcommittees and planning groups, and so please volunteer to participate in those and also to lead them when it's appropriate.

So the responsibilities of the IACC under the law are to develop and annually update a strategic plan for ASD. And I know most of you are aware of

this. Many of you have been involved in previous iterations of the strategic plan, and this will be one of our important responsibilities going forward.

We also are required to have an annual summary of advances in ASD research, originally to inform Congress, but now also to inform the President of important updates in research on autism spectrum disorder.

We are to monitor Federal activities with respect to ASD, and I'll be talking about a number of ways that we do that. Make recommendations to the HHS Secretary regarding research or public participation in decisions regarding ASD.

So the Autism CARES Act of 2014 reauthorized the IACC to continue through September 30, 2019. So you all are signed on for a term for the next 4 years. Although if certain members have to move on to other roles, we will be replacing members as we go along to try to keep our Committee size the same.

That we -- the new law increased membership requirements for certain categories of members. Each category increased from one member required to two members required in the following

categories -- the individuals who are on the autism spectrum, parents and legal guardians of individuals on the spectrum, and representatives of leading research advocacy and service organizations for individuals on the autism spectrum.

And as you heard during the introductions this morning, though the law requires at least two in each of these categories, we have more than that on the Committee, as many of you have multiple roles in your personal and professional lives. And we really appreciate that you're willing to bring both your personal and professional perspectives to this Committee.

The new law also incorporated a greater emphasis on services and supports to various activities of the IACC, including the strategic planning and monitoring activities. And so we will be thinking together about how we will incorporate those -- the services and supports activities in a greater way in the work of the IACC.

The Autism CARES Act continues to require the IACC to prepare those annual updates of the strategic plan that I mentioned and a new edition of the summary of advances. It also requires that

the IACC Strategic Plan continues to address research but also includes, as practicable, services and supports for individuals with ASD and their families, as well as recommendations to ensure that Federal ASD research and services activities are not unnecessarily duplicative.

And so we'll be talking about how we can do those things to make those improvements that Congress called for in the law.

We also -- the law also requires that the IACC Strategic Plan and summary of advances be submitted to both Congress and the President. So we will, when you finish those documents, be submitting them to both places.

So a little bit about, first, what the IACC does not do. So the IACC is an advisory body, and therefore, it does not fund research. The Committee does not have a research budget, and it doesn't allocate research dollars. So it doesn't make decisions about how research dollars are spent or other services' activities dollars are spent. And it doesn't have control of Federal funding programs. It also does not set policy.

But what the IACC does is it provides advice to the HHS Secretary, and it does this in a number

of ways, including the strategic plan, which is probably its most visible form of advice, containing objectives and goals that the entire Federal Government looks for -- looks to when planning their programs; letters to the Secretary to inform her of emerging issues that she needs to be aware of; and sometimes the Committee also issues statements to comment on current affairs going on in the autism world.

The IACC also provides coordination for Federal and private member organization activities, including the strategic plan, which helps do some of that coordination; the monitoring activities, where we collect data from all of these organizations and provide it to you so that you have some idea of what is going on in the outside world, and that can inform your deliberations; and fostering collaborations between organizations.

The Committee also has a really important role to identify priorities to help focus and accelerate progress on both research and services, and it does this through the strategic plan, also through workshops and other kinds of activities the Committee hosts.

And another very important role of the IACC is to serve as a forum for public input. And so, as a part of every full Committee meeting of the IACC, we always have a period for public comment. We receive oral public comments at the Committee. We also receive written public comments, and I know that all of you in your packets have the written public comments. And all of this information is also available on our Web site with the meeting materials.

And so this is -- they are -- the IACC is a channel for the public to really have input into the Federal process, to share their concerns, ideas, and thoughts about what's going on in the autism world and what are the needs so that we can be informed as we move forward with our activities.

IACC core values that are shared in the strategic plan include a sense of urgency, scientific excellence, spirit of cooperation, consumer focus, partnerships in action, and accountability. And the original Committee put together this set of values for the goal of finding common ground.

And we all come from very diverse

perspectives, people with different needs, different places on the spectrum. But our goal is to find the common ground in the areas where we can work together to really move the field forward and provide for improvement in research and services for autism.

So some of the traditions we have during our meetings are we always have public comments, both written and oral. We provide research and policy updates. We provide Committee member updates. So that's the round robin, and we'll be having that this afternoon today, as many of you in the last several months, I'm sure, have many important updates to share with us.

And then I always will set aside some time for Committee business so that we can work on fulfilling our responsibilities required in the Autism CARES Act.

So I'd like to welcome you. The vision statement for the Committee, which I took the liberty of editing just a little bit, "The strategic plan will accelerate and inspire research and services efforts that will profoundly improve the health and well-being of every person on the autism spectrum across the lifespan. The

plan will set the standard for public-private coordination and community engagement."

And so those are words from the IACC Strategic Plan in 2011, which contains the latest iteration of the objectives.

So to talk a little bit more about these responsibilities that I mentioned earlier. The "to do" list -- well, maybe I should go back a little bit and give you a moment to -- I know I've just rattled off a lot of information, just sharing with you background. Many of you already know some of this, but I know there are many new members of the Committee, too, and we wanted to get on the same page and make sure that we have a common understanding of what the Committee is supposed to be doing.

Does anyone have any questions at this point?

[No response.]

Dr. Daniels: If not, I will keep going. So our "to do" list -- oops, I skipped ahead -- is to develop an update of the IACC Strategic Plan that will cover 2014 and 2015. And so one of the issues that we're going to need to think about in the next couple of months as we get started on the update is, is this a time to do a significant

revision?

Something that the last Committee did is in their strategic plan update, we did an analysis of the progress on the objectives, and we found that many of the objectives now have been fulfilled or are well on their way, and the timelines for most of those objectives have now passed. And so this may be an opportunity to really rethink the objectives.

The structure you have now, which you can review and think about, seems to be quite a strong structure that really covers most of the areas. But you may want to think about whether you want to write some new objectives or revise the objectives that are there.

The other thing is that the new strategic plan now is required to include guidance on priorities for services and supports activities, and we'll have to think about how exactly we're going to do that in terms of the structure of the strategic plan, whether we would want to put those priorities across all of the seven chapters of the strategic plan or if we would want to focus them in a couple of the chapters and how we would do that to keep it organized and clear and easy to

understand.

So those are some of the things that we will be discussing in a lot more detail in January. But I wanted to put them on your radar as important things to think about. And as you look through the strategic plan, your ideas of how we might be able to do that.

We also -- I would propose that we would need to develop two volumes of the new -- of the IACC Summary of Advances for 2014 and 2015. In your packets, I gave you a copy of the 2013 Summary of Advances, and for the past several years, we've been using this format where we -- OARC provides a list of research -- peer-reviewed research publications to the Committee, and the Committee then nominates additional publications that they think were important in that year.

And then we allow the Committee to vote on what were the most significant publications covering the seven areas of the strategic plan. And based on the vote, the summary is developed around the top 20. And we felt that, just to give you some of the background of what the Committee's thinking was, that 20 was a reasonable number, not overwhelming. It's something that people can

actually read.

And if we had 100 advances, probably no one would ever get through reading the document. And that we try to have a lay-friendly summary so that any person in the community can read this and understand what this research has accomplished and why it's important as a step forward in the field.

And so if you feel that that is still a format that works and that you would like to do that, I would propose that we do two separate volumes because if we try to combine 2 years, it will also be too long and hard to read. We are required by law to do it for each year. So we would want to cover both years.

And I mean, the other option would be to combine 2 years in one, but you might miss some important publications if you do that. And that's fine with me, but you know, you will want to think about how you want to do that.

At this moment, this would be helpful actually if the Committee wants to share any thoughts about the summary of advances and how you'd like to do the next updates. Would you like to have two separate volumes for 2014 and 2015 in the same format, or do you have thoughts about any changes

you would like?

Mr. Robison: I would just vote for, you know, doing as much a combined thing as we could and just bring them out together.

Dr. Reichardt: I would second that. Obviously, the publications will have to be different, but they can be segregated, and there will be some updates from 2015, which were not -- could not have been appropriately included in 2014. But it seems to me it's very simple to sort that out.

Dr. Daniels: Right. And we have the publications, we've been collecting in the office, separated by year. So that makes it pretty easy.

So what -- if we follow that same pattern, then we will do a lot of that work by email, and in terms of getting you to help nominate publications and then select the publications. And when you've finally made your selections, I'll let you know that those have been selected, and our office would work to get everything written up and produced in a volume for you.

So that's -- if that's the plan, then our office will move forward with trying to get all of that information together and start sending you emails about it in late December or early January

to get started. And hopefully -- it's two volumes this time. Usually, it takes us about 4 months to get it together, but we have two of them so it might take a little bit of extra time. But we will try to get those out as soon as possible.

And I know that there have been people writing in to the office asking for our latest version. So it'll be good to get caught up on that.

And I'm not sure if this was where I wanted -- if I put this in the right place in the presentation, but something I wanted to update you on is that coming soon is the new IACC Web site. This is something that we've been working on in the interim period, trying to get ready for the new Committee.

We will have a new Web site design, and it's going to, hopefully, be easier to navigate and have more information that will be useful to you. We will have tablet and mobile-friendly versions and new content, including a new section on disability reports because there is so much disability work that really overlaps with autism work, and we didn't have a great place to highlight that work before.

And actually, on our current designed Web

site, we've added a tab for that now. So we will try to keep up with both autism-related reports that are being issued across the Federal Government and disability reports. And if any of you are working on these and have something new that's been released, please send me an email if you can think of it, and we'll try to get that up on our Web site so that it's available for anyone who wants to know.

Oh, Larry?

Dr. Wexler: Thank you.

Susan, I was wondering, could we return for a moment to the summary of advances? I had a question. Are the questions that the summary of advances addresses in stone?

Dr. Daniels: So the questions that it addresses are the questions in the strategic plan, and so that's our current format. My suggestion would be to stick with that format for 2014 and '15, and then if, when we're doing the strategic plan update, if you decide that you're somehow changing the seven questions for the next years, that we would then incorporate whatever that new structure is.

Because it might slow us down if we have to

think about a new structure now, and we haven't actually written the strategic plan update, if that makes sense? Do you have a --

Dr. Koroshetz: We could always -- I mean, if there was something that didn't fit, we could potentially have an "other" category.

Dr. Daniels: Sure.

Dr. Koroshetz: Was there something you're worried about, Larry?

Dr. Wexler: Well, I don't know if it goes to worry, but you know, with the reauthorization of the law, there is an increased emphasis on intervention. And one of the areas that is not addressed here is the professional development around building competence in the staff to actually use an intervention with fidelity that has an evidence base to it.

And so my thought was a question related to strong professional development models that are being used to essentially staff develop. So, I mean, whether it could be fit under maybe a subcategory, I understand. But also if this comes out, you know, by the time it comes out with this format, it'll be another probably couple years before the next one comes out.

And it's an area that's of particular interest to my agency.

Dr. Daniels: So Chapter 7 in the strategic plan does cover workforce development, and in the strategic plan currently, it talks more about research workforce. However, that could be developed in the next iteration of the strategic plan to be more inclusive of other services-related workforce needs.

Also Chapters 5 and 6 you could add more information about workforce needs there. It's always a challenge trying to figure out how to make things so they don't overlap and you don't have two similar categories in different places because then it drives you a little bit crazy when you're trying to add up the numbers.

But we could -- there are definitely opportunities. And in the current summary of advances, if there is a workforce development publication that's really important, it could fit in either Chapter 7 or Chapter 4 if it's related, very closely related to intervention. So -- or 5, if it's kind of educational services.

So I think there are places that it can fit now. But certainly, the next -- if the structure

is changed in the strategic plan going forward, it would be the 2016 update, which will be next -- a year from January or so that we would be working on.

Dr. Cuthbert: Could I just -- sorry.

Dr. Wexler: Go ahead.

Dr. Cuthbert: Could I just add something relevant to that that's relevant both to services research and the provision of services? Recently, the Institute of Medicine completed about an 18-month survey of behavioral and psychotherapies -- the evidence base for them, how we establish what are evidence-based psychotherapies and behavioral therapies, and how we ensure that these therapies are being actually delivered with fidelity on an ongoing basis in clinical settings.

The research shows that even when clinicians are trained to an appropriate standard of providing evidence-based psychotherapies, often they tend to slack off over time for whatever reasons and do not actually continue to develop -- to deliver the therapies with fidelity. And so the question is how do we ensure, A, that providers are actually using evidence-based treatments, and B, how do we know that they continue to do so over

time in institute-appropriate evaluations that are feasible in a variety of clinical and other settings?

So that is obviously very relevant to this group, given the importance of behavioral therapies for various aspects of autism spectrum. So I just wanted to mention that, that that might be something we want to consider for the strategic plan and think about how we would work on that in this context.

One of the main ideas, for instance, is simply to identify the specific elements of evidence-based therapies -- what is it that makes them work, what mechanisms do they target, and how do we identify those things -- and then ensure through some kind of measurement of the therapeutic process that those elements are actually being delivered?

So that's just a thought of something we might want to think about as we look towards the new plan.

Dr. Wexler: Yeah, I'm fine with integrating it under other questions but would suggest that when the call for practices goes out that that be -- that be mentioned, that if you have professional

development, if you have things around fidelity of implementation, that they can be integrated under these areas.

Dr. Daniels: Thank you. Rob?

Dr. Ring: Not related to the last discussion, but to bring it back to the Web site and the "to do" list conversation, where are we at with bringing the portfolio analysis up to date in terms of searchable data on the Web site? And I know particularly among the funders, incredibly important to have 360-degree view of what's being funded in this space to avoid duplication of investment.

I know we're only, I think, online up to 2010 in terms of searchable portfolio data, even though we've provided that data as funders passed that date.

Dr. Daniels: Sure. So the 2011 and 2012 data are just being updated as a part of our Web site update. And so when we go forward with that, we will also include a refresh up through 2012. We've begun work with 2013, but it's not ready at this point to put up on the Web.

Any other questions?

Dr. Pelphrey: Going back to the point you made

about integrating some of what Larry said into the existing chapters. If in doing so, we could also highlight the synergies between service delivery and the state-of-the-art neuroscience work in humans where we're using the -- this provision of service in hopefully a high-fidelity way to then try to understand neural circuits involved and actually manipulate them and push them around so we can understand how that changes brain development. I think there's an opportunity there to argue for training of physician scientists and clinician scientists to speak both languages and bring that together.

And then I wanted to clarify. So for our summary of advances, are we talking about, you know, sort of one book that says 2014 and 2015? Because that seems to make more sense to me than not. It may be just purely aesthetics point of view, but it seems odd if we go back and have two volumes.

But if by law, we truly have to have two volumes, or are we just -- you know, it'd be an interesting opportunity to see if anything from 2014 replicated in 2015. Just as a scientist, I'm interested in that and having a 2-year long view

versus one-off studies.

Dr. Daniels: So I was suggesting having two volumes so that you could include 20 studies from 2014 and 20 from 2015. However, if you want to combine and just have 20 for both years, I'm okay with that if the Committee feels they want to do that. I didn't know how any -- that's really up to you.

We just want to make sure we cover both years, I guess, is the main mandate. But you can do it in whatever form you like. So how do you all feel about that?

Alison?

Ms. Singer: In the past, it's been very difficult to narrow it down to 20 for any one year. We usually get hundreds of submissions. So I would -- I would suggest that we would want to do one for 2014 and a second for 2015.

Dr. Daniels: Geri?

Dr. Dawson: Yeah, I was just going to make the same point that, you know, we've been really consistent about every year doing 20, and I think we wouldn't want to, just because of the administrative things that have happened at the last couple of years, then slight a year because

it is -- it is hard to choose 20, actually, because there is so much research that's going on, particularly because you want to represent all the different areas.

And so I think we would end up making our job actually harder to try to do 20 over 2 years.

Dr. Daniels: Brian?

Mr. Parnell: I want to support the idea, excuse me, also if it's a combined volume still of including 20 publications from each year. I think it would be a disservice for the sake of getting the job done if we just chose 10 from each year.

So I would either support two separate volumes, or if we choose to do a single volume still including 20 research studies from each year.

Dr. Daniels: Does anyone have a strong preference about one volume versus two? I was leaning towards two so that, you know, somebody could pick up one or the other and that they would have separate groupings. But it's really up to you. If you would like us to combine them in one volume, we can.

What do you think is simpler for people to read? Jim?

Dr. Ball: Yeah, I would just think the two separate would be better just because of the years. People can then differentiate between the years. If you stick it in one, they may all think it's from that one year, even though we differentiate it. So I would do two.

Dr. Daniels: Okay. So I think it sounds like we would be able to then go forward with just doing two, two volumes. So I'll be sending out the information so that you can start working on the nomination and selection process for that.

Ms. Crane: At the risk of saying something sort of a little bit different, I was wondering if we could include in the upcoming reports a little bit of a discussion, perhaps in the introduction or as an appendix, on research design? Because there is a lot of really good work going on in patient-centered research design, community-centered research design, encouraging researchers to include participation of self-advocates, parents, family members, and professionals during the process of developing the research goal and interpreting findings, even developing metrics to use during the research.

And I think that it's very important that that

aspect of research also be communicated to the public and to other researchers because it's really -- it's really useful to promote those kinds of advances.

Dr. Daniels: I would suggest that it would be great if you could nominate some examples of research that's been published using those kinds of designs for the summary of advances. But in terms of a discussion of the field and trying to encourage more research of that nature, I think that that would fit better in the strategic plan update. So I think that both places could accommodate some information on that.

Shannon?

Ms. Haworth: I also wanted to suggest it probably would be the strategic plan update, but there's research that addresses the needs of parents and caregivers and the supports and resources that they need. And also maybe think about mental health interventions with autism because of the high comorbidity rate.

Dr. Daniels: Yes, and I think that, similarly, if there are recent publications that address those, we would want them to get on the list for the summary of advances. But in terms of

discussing that area more broadly, I think that that would go in the strategic plan update.

Geri?

Dr. Dawson: One other quick comment, and this kind of relates to the Web site. So one thing that would be helpful, if possible, is on the Web site, in addition to having the summary of advances organized by year would be a way where someone could say I'd like to look in this category of information over the last several years of what the major advances were.

So if it could be set up to be searchable like that, I think that would be hugely helpful to people that just want to get a quick glance of the research over the last several years.

Dr. Daniels: Sure. That sounds like an interesting idea. It sounds like a project, which we love projects in OARC, but might take a little bit of time to get that. But I know our Web team is here, and they're listening.

Dr. Battey: You want to make it easily searchable, keywords help a lot. So that's certainly one way you could -- you could make it very easily searchable.

Dr. Daniels: Yes. And I don't know -- I will

have to find out from our Web team here. They already might be searchable. I know some of our items can be identified by a keyword.

Jeff, do you have any thoughts about the summary of advances is already in HTML. So is it keyword searchable on our Web site?

[Off-mike response.]

Dr. Daniels: Okay. So it's not currently keyword searchable, but it can be searched through the browser. But we'll take that idea into consideration for future updates. That might be something that we can work on as a project.

Thanks.

Dr. Cuthbert: Is everyone aware of the NIH RePORTER Web site? I don't see everybody looking - - I saw a lot of heads nodding, but just to make sure you know. There is a Web site called the NIH RePORTER, just like the name sounds, RePORTER. And this is a searchable database of all the funded grants across all institutes and centers of NIH.

So it's obviously limited in that way that it does not include many other Federal agencies or private foundations data, but at least for NIH, you can search by a variety of terms. For instance, I just did a quick search for "autism"

in the title of any grants and found 267 different grants listed, and I'm sure there would be more if you did a more exhaustive search, too.

But just so you know, that's available for the NIH grants.

Dr. Daniels: Right. And then there's a categorical listing in the NIH RePORTER that you can pull up the autism category and click on that, and you can get a listing of the grants for that year from NIH. And NIH RePORTER also does have some information from some other agencies, although it's a little bit limited in scope.

So there are many data sources. Our Web tool includes data from many different agencies but is in the process of being updated. So we'll keep you informed of that.

So additional business. So the IACC, part of the way it operates is through subcommittees and planning groups, and so subcommittees are large subdivisions of the group that can focus on particular areas for projects. And then planning groups are even smaller subdivisions under the subcommittees that also help us accomplish work so we can do focused work.

For example, when we're doing the strategic

plan update, we can divide up, and people can volunteer to work on particular chapters, or if there is an issue that we want to develop a project on, we can have a little planning group that works on that.

So the subcommittees of the previous IACC were the Basic and Translational Research Subcommittee and the Services Research and Policy Subcommittee. That was decided on by the Committee.

My suggestion is that if we have subcommittees, that we stick to two subcommittees as the team here is quite small, and running the full Committee plus two subcommittees I think is already quite a bit of structure. And then we can have multiple planning groups that can be stood up very quickly and used when they're needed, and then we can move on to other kinds of planning groups. And we can organize those around practically any topic that you want to work on.

So I think that that structure will work. In the past, we've usually had some type of a subcommittee that was focused more on research issues and one that was focused more on services issues. But I don't know, I think that that subdivision sounds pretty natural, but I'd like to

hear from you. And in terms of picking a specific name for these, we can worry about that after we kind of decide what kinds of subcommittees we might want.

Alison?

Ms. Singer: So the way these subcommittees have operated in the past, when the responsibility of the IACC was predominantly to write a research strategic plan, was that the Basic and Translational Research Committee wrote five chapters of the plan that focused on basic and translational research, and the Services Committee wrote the two chapters that were focused on services and services delivery.

The new law outlines that we should write a research plan, but the new law is really the minimum that the Committee should not, not the ceiling. And I think that services and supports has -- needs to be recognized as on par with research and that the Committee should consider writing a research strategic plan and a services and supports strategic plan.

The first IACC that was initiated under the Children's Healthcare Act of 2000, that IACC actually tried to write a services and supports

strategic plan. Unfortunately, that document was not successful.

But even going back that far, we recognized that there was a need in the community for a roadmap to help families navigate the extremely confusing system of services and supports. Even those of us who spend all of our professional time in this field have difficulty navigating the crazy system of services and supports through the Federal and the State level.

So my suggestion to the Committee is that we should think about creating one subcommittee to focus on research strategic plan, which would also include services and service delivery research, but then a second committee to focus on writing a services and supports roadmap strategic plan.

Dr. Daniels: John?

Mr. Robison: I think it's important to recognize that the Committee was originally chartered with the idea that it would produce a strategic plan that would be mostly used by the Government for its own purposes by trained people, if you will. And we have since emerged as the visible autism group for the Government, and we are the point that the public looks to.

And when the public looks to us, they look to, you know, really our failure as a government to deliver meaningful improvements in therapies and services. And I think that since the public is our largest constituency, we owe it to them to either focus a large part of our plan on the public's concerns in that regard, or we owe it to them to develop a standalone public document and perhaps a more technical appendix or another document that would be the plan with guidance for scientists in the field in all areas.

Dr. Cuthbert: John, can I just have you clarify that a little bit? I wasn't entirely clear whether you are supporting Alison's idea of a slightly different composition of these two subcommittees or whether it was something else?

Mr. Robison: Yes, I support Alison's idea of the subcommittee changes, but I also -- I also think that it's really important that we change our plan to speak to how are we going to serve the public, not just how are we going to serve the research community.

Because I think one thing that angers the public with the work of our Committee is we talk about the significant advances we've made in

research and the plans. We talk about the questions we're going to ask in next year's research, and those are valid things in research. It's true that we've made real accomplishments.

But from the perspective of a family living with autism, they ask what has that research done for me? And all too often, the answer is nothing. And I think that we need to be mindful of that and we need to be speaking in our documents and communications to the public to communicate to them how we're going to translate what we see as our accomplishments into things that will have tangible benefit for them.

Dr. Cuthbert: Thank you.

Dr. Daniels: Other comments? Jim?

Dr. Ball: I would just add to that if there is any possible way in the design of the new Web site to have that highlighted so you're looking at theory to practice, I think that would be awesome so that people could get that opportunity.

Dr. Daniels: What do you mean by that? I guess that doesn't --

Dr. Ball: If you go in and there's a research study out there, just a brief synopsis on "How can I implement this?" Or how is this implementable,

if there is those that are out there.

Because I agree with Alison that you need the two separate places in order to have theory and then also the services side because the services side, as John is saying, is more practical for families to look at to get something from the research to be able to actually implement with their children or even professionals.

Dr. Daniels: In terms of having interpretation of a study and how to implement it, somebody would actually have to do that, and I'm not sure that in our staff we would want to take that responsibility to attempt to try to translate that. I don't know if the Committee feels they would want to do that, but then you would have to decide which research you were going to do that with and -- you know?

Of course, it sounds like it's something that would be helpful to folks, but it would have to be done in a very thoughtful way --

Dr. Ball: Right.

Dr. Daniels: -- so as to be helpful.

Dr. Ball: But down the road, if that's kept in mind on there, that would be a great place for families to go to get that information.

Dr. Daniels: Oh, I see. In terms of just putting the information up?

Dr. Ball: Yes.

Dr. Daniels: I mean, we would put up anything that we produce in the Committee. So thanks.

Kevin?

Dr. Pelphrey: I wanted to, I guess, third Alison's idea, and then a plea for trying to articulate the ways in which those two subcommittees, and put it in writing, can inform each other. So I think that the next generation of translational research absolutely demands that the researcher -- the neuroscientist, geneticist -- understands how service provision works so that we can begin to roll out the treatments we develop, make specific predictions about how they should influence our outcome variables.

And then if we don't have that understanding, we're in no better shape than, you know, the parent trying to seek services if you want to roll out those services in any population-meaningful way.

And so I think that I love the idea, and then there's the opportunity to show the public, relating to John's idea and comments, how those

two things can synergize so that we can get the type of research that we all really want to do done.

Dr. Daniels: Geri?

Dr. Dawson: So in the strategic plan, we have historically had a preface section to various subsections that provides a context and interpretation for the various objectives that have been outlined in the strategic plan. And one idea would be that in the research -- if we end up having two components, in the research one, that at the beginning that we talk about a section of impact on policy and practice of this research, right? So that we actually articulate, you know, what is the importance of these objectives in terms of its potential impact on policy and practice?

On the flip side, on a service strategic plan, we could also have a preface section that talks about the empirical research that provided the foundation for these practices that are presumably empirically based that are now having impact on practice. So, you know, really articulating, you know, which is what I think you're alluding to, Kevin, the synergies between the services and the

research.

And the only other quick point I wanted to make is -- and I am very supportive of Alison's idea, and I think that the new emphasis on the services and supports is really important, and I support it wholeheartedly. That said, I do want us to keep in mind the research piece of it is really important because, you know, it actually has had an impact on the way in which research is funded at NIH.

So every -- every project that is submitted has to orient back and show how it fits into the IACC Strategic Plan. And also when we had the opportunity for stimulus funding, it was because we had a strategic plan that autism was able to get extra money. And NIH, you know, is the largest funder.

So, you know, it really has actually had an impact, and so I don't want us to kind of forget that in the work that we do.

Dr. Daniels: Walter?

Dr. Koroshetz: I was just thinking of precedents. So two things come to mind. One is there's another group that I run, the Interagency Pain Coordinating Committee, and they were faced

with similar issues. And so they did what's called a "National Pain Strategy," which I'll just read it to you.

So it was a document that includes objectives and plans related to key areas in pain and pain care, including professional education, training, public education and communication, service delivery and reimbursement, prevention and care, disparities, and population research.

And that's going to be followed by a research plan. So, again, an example of two modes of operating. And also in epilepsy, there is something similar where the HHS did an epilepsy plan that was not research, and then the research plan was next.

So I think there's precedence for doing that. The only thing I'd say is it's a full-time job doing each. So is it possible to do them and alternate, as opposed to trying to bite off both of them in the same year?

Because I think you don't want to do a -- you really want to do a careful job. And so I think it really does take a full year of people just getting into the weeds to put together the plan you're talking about as well as the research plan.

So in terms of the law now, what is the requirement for the annual report? Could we actually split it into two and alternate?

Dr. Daniels: So, as laws go, they usually aren't overly specific. They do give us room for interpretation. The law says that we need to do a strategic plan update, and the strategic plan should include more emphasis on services and supports.

However, if the Committee decided they wanted to do an entirely different document on services and supports, I'm sure that they would get credit for that document fulfilling that requirement.

So you know, there are some advantages and disadvantages to doing things in two different reports. One of the advantages is that you would be able to have somewhat different structures. You wouldn't be boxed into the structure of the current research strategic plan that was written around research if you have a completely different document that addresses services.

One of the risks of having two different documents is that you do have to be very careful to make sure they harmonize and that you don't have conflicting documents or duplicative and

overlapping documents that say sort of the same thing, but in a slightly different way, and that gets confusing. And I know that we have some issues with that even in our current strategic plan just because of the way it was developed in separate little working groups that sometimes had the same idea for two different chapters, and you'll find that two chapters talk about the same thing in slightly different terms.

And so if we have two whole documents that are different, we want to make sure that they don't have unnecessary overlap that would be confusing for readers. And then in terms of recognition with Congress and other people, being able to just make it clear that there are two documents and why we have two documents.

Right now, we have the strategic plan. That's our centerpiece document, and everybody goes to it and knows what it is. And so if we have another document, to make it really clear what that is and why it's important and who is the audience for that document. But I think it's doable.

So in terms of the work required, Walter, I do agree that significant work always goes into our strategic plan update. And if we decide to do yet

another document, I would suggest that we might not want to be trying to do both documents in tandem because I would be concerned that some things would fall through the cracks and our quality would not be all that great if we do both of them at the very same time.

And you also will be very involved in lots of planning group meetings, et cetera. And if we have two whole sets of planning groups, and you're on three or four of them, you will probably also not have the time or the bandwidth to handle all of that at once. So we might have to stage them so that one is happening and then the next one is taken on when the first one is finished.

So, John?

Mr. Robison: When I spoke earlier, I think I suggested even having two -- two plans or reports, and I -- actually, I've been thinking about that, and I think am wrong about that. I actually think that one of our great problems is explaining science to the public and explaining how we are going to use science to solve the very real problems of our community.

And I think that actually what I would vote for is a single strategic plan like we've had up

to now, and we might think about the way we do research grant applications, where there's a technical abstract and a lay abstract. So perhaps when we explain an advance or a piece of research for a question we ask, we explain it in one set of paragraphs with what that's going to mean to the scientists who are going to do the research, and we explain why that's important to the community who lives with autism.

I actually think to explain it that way acts to tie the scientists to the community, and I think that's an important part of our job, and it could be best done putting it together. I would volunteer to help write the connecting pieces, too.

Dr. Daniels: And when you discussed that, one of the advantages to that kind of document would be making these connections between services and research. You wouldn't have to kind of repeat the same thing in reverse order in two different documents if it's all in one. But I mean, you could do it, but you would just have to make sure that you didn't say something different in one than the other.

Mr. Robison: I think that's exactly right,

yeah.

Dr. Daniels: So I mean it could be done either way. Sam?

Ms. Crane: [Off-mike] -- sorry. Having a combined document for both services and research, and one consideration is that when you're considering the public's perspective, right, a member of the public is going to say, "I'm an autistic adult, or I have an autistic adult child, and there's nothing out there. There's no services. I don't know how to help them. We can't get a doctor to serve this person."

And that -- from the perspective of that member of the public, they might not know whether the problem is we don't know how to serve this person in the community, we don't know how to provide medical care to an adult with minimal speech, or we know how, but we're not doing it or the infrastructure isn't there.

And so I think if we segregate, separate our goals by problems, like here is a problem, you know, services to adults and healthcare for adults, and then say here is the state of the research and here is the state of the services and address them in a harmonized way, that way people

can see how these two issues are interacting with each other and what is the problem here, what is stopping us from going forward?

Dr. Daniels: Elisabeth?

Dr. Kato: To follow up on that idea, I mean, you could do some kind of a mapping exercise where you lay out the different areas of a problem and then, exactly what Samantha was saying, where is the problem occurring? And then that naturally kind of transforms itself into a roadmap for what needs to be done next.

Dr. Daniels: Alison?

Ms. Singer: I think a lot of these issues that you're raising are good ones and important ones, and they are issues that have come up in the past as we've sort of tackled this idea of how to incorporate services. The way the law is written, it requires us to write a strategic plan for research.

And so the Services Committee was really stymied last year. I was on the Services Subcommittee, and we were -- our hands were tied. It was a source of tremendous frustration for the members of the Services Committee because we were limited to really only discussing services

research and services delivery research, and we were unable to really get into the important issues that you're raising.

So my impetus for doing the second document was really a result of that sense of frustration that we all experienced for not being able to get to these issues. So I would -- I would reiterate I think it would make sense, and it would be -- we would better be able to address the issues that you are raising if we were focused on creating a document that was specifically designed to address these issues.

And it would be outside what's required in the law. It would not be subject to the restrictions imposed by the letter of the law. I think we might have a lot of difficulty getting those issues that you're describing into what is described in the law in a research plan.

So that was why I felt that we should have two separate documents.

Dr. Cuthbert: Could I just follow up to ask about that? In your earlier comments, you said that the new law sort of specified a minimum, not a maximum. And I had inferred from that that you thought the section on actual services and

supports would be compatible with our brief, with our roadmap.

And now it sounds like you're saying actually that's not true, and you need a second document. I just want to make sure I'm understanding what you're saying.

Ms. Singer: No, I think if we were to include services research and services delivery research in the strategic research plan, we would be complying with the law. I think we were in compliance last year when we included those two sections.

But I think there is a lot more that we need to report that I think the public wants to hear about with regard to services and supports and how the government at the Federal level and at the State level and at the level of individual organizations, how those services are being delivered and how they can improve the lives of people.

There is no place for that. There wasn't a place for that in the research plan because it wasn't research. And as I was saying, that was a tremendous source of frustration for many of us on the Services Committee.

So the idea came up last year that we should think about doing a second document that focused specifically on services delivery and opportunities for people to access services in the community. That was not included in the new law, but I see the new law as describing the minimum required by this Committee.

So the minimum would be to produce the strategic research plan. It doesn't say anywhere in the law that you can't also produce a document that outlines supports and services and provides a roadmap for families, and I'm arguing that we should do that.

Dr. Daniels: My interpretation of reading the new law is that it requires the strategic plan now include service delivery and supports issues within that strategic plan. So I don't see that same restriction from before as being as relevant now because the law actually says that we're supposed to include those things.

However, if the Committee chooses to make a separate document for that, I think, like I said, that would count. And so I don't think the Committee would get dinged for having made a separate document and not including it in the

current document.

But I think that now we don't have that restriction anymore. So, but it's really a matter of, you know, what the preference is of the Committee.

And like I said, I think there advantages and disadvantages to having two documents versus one document in several different ways. And maybe in January, we could go into some of the details of that a little bit more so that we could have a longer discussion about that.

But in the meantime, if you look at our current strategic plan update and also could take note of where there -- I mean, there's a lot in terms of service delivery and supports that is missing from the current document and where we want to enhance things and whether it seems like it makes sense to put that in a separate document or to just incorporate it in the current document.

I mean, we can, of course -- like I said, I think that it is an appropriate time for the Committee to be able to make significant updates to the strategic plan, and that can include any number of changes from updating the objectives to even changing the structure somewhat to

accommodate more of these issues that have been coming to the fore.

So please give that some thought. I think that we probably won't be able to resolve all of that today, but that's something that I want to focus us on in January.

Laura?

Ms. Kavanagh: If I could just make a recommendation for one of the things we consider in January? I think the need is great, and we've heard it from multiple audiences. What can we learn when we tried this before? Why didn't it work? How can this effort be more successful, too, as a committee?

I was not on the Committee when that effort was underway in the very first version, but I did see drafts of that, and it just didn't -- I saw drafts of a roadmap, as you referred to, Alison. So what happened? I mean, the Committee makeup is very different now. That might have been part of the issue, but I'd like to learn from that previous process, too.

Dr. Daniels: Right. I don't think we have much representation, and that roadmap even preceded me. It happened before I was -- before the OARC was

formed. So I don't have historical knowledge of it. I've seen the document. I've read the document. But I don't know that much about it.

I know Alison will have some memories of it. She may be the only person here that really remembers it.

So, but it's certainly something that we all really should review before going on to something new. However, that was many, many years ago now, and so I have the feeling the services world has changed dramatically, especially, you know, we have an entire new agency in HHS that is working on some of these services issues and just much research has happened.

So I think that likely there would be maybe a few of those ideas that might translate, but largely, I would think that you would probably come up with something kind of new that will reflect the current thinking.

Other thoughts?

Dr. Cuthbert: Could I just make one other comment about the idea of changing the composition of our two subcommittees? And Susan has made a very good case that two is as many as we can really handle practicably.

At NIMH, as with other NIH institutes, we often just envision what in the idealized case would be a seamless set of activities from understanding the mechanism of these conditions to starting to get ideas for different kinds of interventions which would respond to the needs, to trying those out in a services sector for the research to understand how best to provide the services related to those new ideas, and finally, to have them just completely disseminated and they're a part of our overall care system.

So, ideally, it's a continuum. So I think when we have to split that continuum in two for practical reasons, the question becomes what's the optimal point to split that to make our advances? Because, clearly, there is a consensus that we need these components about providing services and services supports and giving information to families.

So I think the question is if you put the services research part up with the basic and translational research, or you just have a research component and then a services component, is that optimal or not? And that's clearly this Committee's decision to make.

But I think you just might want to wonder and I'm wondering whether if you left the services research and policy with the section for providing services, whether that might be an optimal break, just because I can envision, as the group would work on the need for services -- and how do we provide the services, and how do we help families traverse this, you know, chaotic landscape of care -- the questions might well arise, gosh, actually, we need research on this question.

And so a lot of that services research agenda might emerge from deliberations about providing information about the care system -- who does what, how we organize these things. So that's just a thought to consider as we put this together. But I do want to reiterate, I think it's the Committee's decision as to how they approach this.

Dr. Koroshetz: Yeah, so I think that's a great idea to try to concentrate on the services aspect and incorporate research, as well as recommendations to the other Federal agencies on how, given what we know so far, can best benefit the folks. And so it's really splitting the strategic plan into two pieces.

But then opening it up so that the services

one is not just focused on research. The other one is going to be purely on the research side.

I am a little worried that the reason why the first one didn't work is because the manpower was split, and it was just too much to undertake. Because, I mean, I think this is going to be -- this is going to be very tough to pull off, and I think we need everybody's attention on it.

So to split into two groups and having two groups doing different things, I'm wondering whether that's a recipe for maybe not being successful.

Dr. Daniels: You know, we could potentially do it in a new way and rather than splitting into these subcommittees. I know that one of the issues we had in the past with subcommittees is everybody really wanted to be involved in a lot of things, and so a lot of times we'd have people sitting on multiple subcommittees and working groups. And sometimes, you know, I think that if we had fewer of them, maybe we could have saved people a little bit of time so that they're not trying to spread themselves so thin.

So we could, for example, with the strategic plan, if we're going to roughly keep a similar

structure in terms of seven questions, rather form seven planning groups that include both services and research. And so anybody who is interested in those, in that topic in general, whether it's the services or research aspect, could be on it and just have seven different ones and work that way together, rather than splitting it by services and research. That's another option that we could try.

Gerri?

Dr. Dawson: Yeah, as I listen to this discussion, my own thoughts are moving towards preferring the idea of keeping an integrated document. And I'll just say briefly why that's the case.

Partly, if you can imagine domains of topics or topics that you're thinking about both from the point of view of research, as well as translation, as well as service delivery, and you have people on the workgroup that are representing, you know, the different parts of the continuum I think that Bruce just articulated, you know, it really requires us to think about the relationship between those two things and how they mutually inform each other.

And it requires the people on the research

side to be thinking very carefully about, well, what are the implications of this for service delivery and what are the things that are needed to really have an impact of what's being done in science? I worry a little bit if we have two separate documents, first of all, that we won't force ourselves to think about that relationship. But also I think in general in the community, there's a lot of tension around this idea of funding services versus funding research.

And by articulating how important these are and how they're connected, we actually may bring a little bit more unity to that controversy in the field.

Dr. Daniels: Julie?

Dr. Taylor: You know, I'm also thinking, too, if we kept one document, maybe we could split out each of the questions along this continuum that we've been talking about. Or we would maybe start out within a topic area with some of the questions related to basic science all the way up to some of the questions related to implementing services out in the field.

And combine it in that way where we could make it very clear where the questions fall in this

continuum of basic science all the way to translation in the field, but also make sure that we're addressing each of those different points along the way within the same document.

Dr. Daniels: Other comments? Oh, Sam?

Ms. Crane: I just wanted to add that even within basic science, there are services connections. For example, you know, if we're talking about early detection and intervention, what are the first signs of autism? Screening is a service, and diagnosis is a service.

It's not just home and community-based supports, but also how families and individuals interact with medical providers. Those are all, I think, could count as service delivery.

Dr. Daniels: Anyone else? Edlyn?

Dr. Pena: I'm really hearing what Alison is saying, and I think if we were to move toward one document, which it seems like a lot of people are interested in doing, the piece that we don't want to lose is what's being driven by the people. So what needs are -- what needs are at stake, rather than having things driven only by what research has said, right?

So we know that a lot of the report has

research that's been published. We all have agendas as researchers. I'm a researcher. But not forgetting that if we do a combined publication or a report, that we really also think about what are the needs of the public?

Where do we need to navigate those systems or help families navigate those systems? Those things may or may not be in the research, right? So we need to come from that perspective as well to have a truly combined perspective.

Dr. Daniels: We do have a "What do we need?" section in each of the chapters of the strategic plan that was supposed to try to capture that, and that can always be elaborated, just to point that out.

I think hearing -- Amy, do you have a comment? Go ahead.

Ms. Goodman: I take a lot of I&R calls from parents, and one of the most common things they ask me or want to know about is how to find housing. I'm in D.C. I don't live in their State, but I always refer them to one of my chapters. But I don't know what to tell them if they're looking for housing or if they're looking -- another one is adult diagnosis.

Somebody said, "Don't you have a list of every State, like have a place where you can tell somebody to go?" That might be something to look into. Have somebody actually research out all the different places that you could get in adult diagnosis since they don't -- since a lot more adults are being diagnosed now with ASD.

Dr. Daniels: Right. Those kinds of calls come into the OARC, too. Unfortunately, it's a little bit beyond our scope to be able to track. It's always changing, and there are all sorts of service providers across the 50 States. But we usually look to our partners in the advocacy and service organizations to try to help out individuals who have questions.

So we've heard a lot of really good discussion, meaty discussion around the strategic plan today, and I think that I have enough to be able to summarize and probably put together some various options that we could start with as straw men at the next meeting, and then you could help refine some of that toward what you would like to do.

And I think by the next meeting, we'll be able to actually form our groups and get started and

through February and March, hopefully, have meetings to get going on our strategic plan update. So we've already kind of covered that.

And just I know that we're a little bit over time. I'm just going to be very quick. I had just a little bit of information about OARC, just to let you know that we're here to provide you with assistance for all of your needs concerning the Committee.

Things like we've done today, trying to help facilitate your discussions. We will help you to organize your documents and put them together so that they can be received by Congress, the President, the public. Help you format things, get them lay friendly, put things up on our Web site to help disseminate them.

We also work behind the scenes to help coordinate cross-agency efforts on a number of things and keep in touch with all our Federal agencies.

We do the planning of meetings, conferences, workshops, other kinds of activities that you might want to have, and when you want to invite experts in to talk with you.

We also facilitate the monitoring of ASD-

related activities. We do a portfolio analysis and we also help you keep track of publications and other kinds of reports and documents and activities across the Federal Government and private organizations.

We conduct analyses in our office and prepare reports for the IACC, Congress, and others. We help you with gathering input from the public and disseminating information. And so I just wanted you to know about some of the things that we do in OARC and to let you know who is on our team.

So we have a great team that works very hard to get all of this information to you, and I wanted to make sure you know that it's not just me, but we have a whole team together. We have two folks on our Web team. So Jeff Wiegand is our Web development manager, and he is out toward the side here, sitting on the side.

We have Nam-Andrew Kim, who is the Web designer working on our redesign and will be working on redesigning our Web tool to be even more friendly to the public so that you can get the information you need.

We have Chumba Kitur and Miguelina Perez, who I know many of you know. They work on all of our

operations and management issues and assist the Committee with all of your administrative and operations needs.

And Julianna Rava, who is a services health science policy analyst who joined our office this summer and is going to be working with us, especially on the services issues.

And so we are in the process of trying to recruit some new folks that will be joining us, hopefully, in the spring -- or winter, I hope. But this is our team. Can you all stand, please, so that people can see you and know who you are?

So this is our team. I hope that you'll all get to know them, and we thank them for all their work in helping prepare for this meeting and the future work that you're going to do.

So that's the end of the presentation. We are ready for lunch. There is a cafeteria upstairs, and we would ask that you return by 1:00 p.m. for the session on oral public comments.

Thank you.

[Whereupon, the Committee recessed for lunch at 12:09 p.m. and resumed at 1:04 p.m.]

Dr. Cuthbert: Okay. Good afternoon. Hello again. We are now ready for the next item on our

agenda, which is the all-important public oral comments session.

We have a number of people signed up to give comments. If you will each please go to the podium up there by the slide screen, and we will be eager to hear your comments.

So the first commenter we have today is Nicholas Gammicchia. Mr. Gammicchia?

Dr. Daniels: And I will just quickly mention before we start, everyone has the written public comments in their packets and the statements that go along with the oral public comments. And members of the public, this is all up on our Web site if you need a copy.

Thanks.

Mr. Nicholas Gammicchia: Okay. Hello, everyone. My name is Nicholas Gammicchia, and I'm 24 years old. And I have traveled with my family from Michigan --

Dr. Cuthbert: Can we get the microphone on? We can't hear.

Mr. Gammicchia: Hello, everyone. My name is Nicholas Gammicchia, and I am 24 years old and have traveled with my family from Michigan to be here today.

Thank you for today's opportunity to speak to you all. I am doing so because I --

[Pause.]

Mr. Gammicchia: Hello, everyone. My name is Nicholas Gammicchia. I am 24 years old and have traveled with my family from Michigan to be here today.

Thank you for this opportunity to speak to you all. I am doing so because I think it is very important.

For many years, my family and I have been told the goals, hopes, and dreams we had were not possible. However, what we have been done -- been told by others and what we do, thankfully, have not been the same.

My parents and I were told I would never earn a high school diploma. I did and left high school on the honor roll. My parents and I were told I would never be able to attend college by my Michigan Rehabilitation Services adviser. I am and have earned my associate's degree and have been on the dean's list.

I share these stories because I want you and others to look beyond the limitations some people think autism can bring. But it is also important

to know people struggle, and we need appropriate services.

What I think is important, please listen to us as you work to represent us. Look at what behavior is communicating. In many cases, it's medically based. I am where I am today due to medical treatment and a variety of supports and services. That is why I need to ask why doesn't the IACC have a treating M.D. as an appointed public member to help in this area?

If we don't identify as autistic, that is our choice. If we do, that, too, is a choice.

This front page story was featured in the Detroit Free Press on April 25, 2012. That is why I have to ask why have things not improved since then for many adults with autism?

I personally think we need funding to apply to research to develop many more programs and services for adults living with autism. We also must presume competence, individualize services, personalize supports, realize possibilities, look at overall wellness and medical needs. Think about people, not profit.

In closing, I'd like to ask that you consider the many different needs of individuals with

autism and work toward a plan of action to ensure our quality of life is the most it can be. To do so, I'd like to ask that the Services Subcommittee and the Safety Subcommittee be used again to assist you all in doing so.

Thank you very much, and smooth sailing with your tasks on the IACC.

[Applause.]

Dr. Cuthbert: Mr. Gammicchia, thank you very much from coming all the way from Michigan today to us and to share those comments. You very well illustrate the needs for services and other supports for people developing their lives who face challenges in the autism spectrum, but you also show us the inspiration and hope of how far you've gotten.

So thank you very much.

Our next speaker -- you're welcome. Our next speaker is Carolyn Gammicchia.

Ms. Carolyn Gammicchia: Hello. Dear Chair Cuthbert and members of the IACC, I stand before you today as the parent of a young man with autism. I'm very proud, and I'm sorry. Every time he gets up and speaks, it makes me cry almost because they told us he could never be able to

actually verbalize his wants and needs.

So it gets very emotional. So we're very proud of him. So, and thankful for the opportunity.

I also want to precursor my comments because when you read a letter, it may sound as though somebody may be critical or may be condescending. And I want to say that, first off, that I'm not in any way being critical. I'm just trying to voice some concerns that for many years we have as a family and a member in the autism community.

And I think it's very important, I've heard within your discussions today, in your future planning that you will be listening to the things that we say. It's very important because you all are representative of us, and this is not an easy task that you have been appointed to do.

So some of my comments are directed specifically toward the makeup of the current and new IACC, and I just want to voice, too, that as of Friday, we now know that autism is 1 in 45 children from the ages of 3 to 17. That should be a national crisis.

When our son was first diagnosed, it was 1 in 10,000. We are now in a place where better diagnosis is now increasing this number, and it is

a national epidemic.

I also have concerns because the last full meeting of the IACC was July 8, 2014, and the last charter was signed by Chair Insel in September of 2014. Why has it taken over a year to have this meeting and the new committee announced?

I've asked this because the charter stipulates there should be minimally two meetings per fiscal year, and due to the urgency of the needs of the autism community in the United States, being 1 in 45 children, I believe that that is an urgency that has not been addressed. We have not had a meeting in almost 18 months, a full meeting of this membership.

Additionally, the IACC members have been announced, and I'd like to know which members serve within which positions as public members. Additionally, there are three members who represent the Autism Science Foundation -- Ms. Singer, Mr. Mandell, and Mr. Parnell -- and also one additional member from the Simons Foundation, Mr. Reichardt, who represents an organization who has given the ASF a significant amount of grant funding for marketing of the Autism BrainNet.

Another new appointee, Dr. Amaral, is actually

the director of that program as well. And I think from the additional comments I made on this, that it shows or provides us a basis for concerns when we're addressing what has been discussed within the summary advances and those reports on an annual basis.

If you have a committee that a lot of the members are connected in some way, especially through funding, that may cause them some duress with them deciding what their position is on the committee. It also may limit some transparency as far as what the committee's actions may be.

Additionally, I'd like to know, too, where there is representation of organizations that meet with and speak with families on a daily basis to meet their needs. As in the past, we've been told that representation is from Autism Speaks. And unfortunately, the 2014 financial statement of Autism Speaks in the 990 indicated that less than 5 percent of their annual income goes to support families.

Additionally, I would like to commend the Committee on appointing Amy Goodman to this Committee, as well as Ms. Crane because of their background and as self-advocates. We've waiting

quite a long time for a female to be represented in the autism spectrum, and I think it's about time, and I congratulate you on those appointments.

Additionally, my letter stipulates some of the information from the IACC Web site. Dr. Daniels has already addressed this in today's meeting. So I don't want to waste your time with that, but we do have concerns regarding representation of the Committee within the appointed membership.

We currently have members reappointed to the Committee whose role it should have been to do what the task was at hand, which was listen to the public and concerns of the public. However, we had several discussions with parents about the current IACC appointments, and the following was of concern.

A parent of a 16-year-old son with autism didn't know that the IACC even existed. Nor within that same conversation that I had at a meeting with parents to discuss and support them did a mother of a 4-year-old child know that IACC existed. Many individuals I spoke with upon discussing letters to the IACC regarding concerns felt that it would be a fruitless effort.

No Government-appointed agency or committee should have that thought process from the public. We should be responsive to the public in the current needs. Everyone should feel that if they write a letter to this Committee they will be listened to.

Additionally, many individuals have expressed concern that the appointments will not provide for full inclusions of areas of concern felt by the autism community, especially with access to appropriate medical care or services and supports as indicated within our son's presentation.

Additionally, when the summary of advances research is nominated, we also aren't looking at other medical areas of need for individuals with autism. I will mention one of those areas.

Recently, the State of Michigan and the State of Illinois have addressed the use of medical marijuana for individuals with autism. The medical marijuana review panels in each one of those States approved autism as a qualifying condition for pediatric use.

Those are the types of research that we really need to look at. We need to go beyond what we feel it is and has been embraced in the past as -- I'm

sorry -- evidence-based practice, but actually look at what the needs of the community are.

In closing, I'd also like to say that I support Lisa Ackerman's TACA public written comments for this record as well and the past comments by representative members of the National Autism Association. These are organizations that I feel should be represented on the Committee, as well as parents of individuals who have navigated the system and do not have conflict of interest due to their work within privately funded research or as a service provider.

Additionally, I would like to say because my husband provided a written comment and there will be a comment regarding safety, I do think that it's very important to have the Safety Subcommittee reopened, as my son had indicated, and also the Services Committee reopened. And as Ms. Singer and Mr. Robison addressed, I do believe as well that there should be a separate report from this Committee due to the new legislation that oversees it regarding supports and services rather than just be research based.

And I'd like to thank you very much for this opportunity to speak, and good luck in your new

work effort.

[Applause.]

Dr. Cuthbert: Thank you very much for those thoughtful comments, Ms. Gammicchia.

I am not sure if we mentioned that as is our practice all along for the work of this Committee, we hear all of the public comments first, take notes, and then these are discussed in a separate period right afterwards among the Committee members.

So our next public commenter is Casandra Oldham. Ms. Oldham?

Ms. Casandra Oldham: Hi. I'm Casandra Oldham. I'd like to thank you for taking the time to listen to me today.

I have a lot of concerns that I'd like to bring to the attention of the Committee. However, I feel the need to focus on what is really happening with my family. As I tell you about my reality, please keep in mind that I am representative of many families. And for some reason, I'm really nervous.

You have not all met in over a year. Over the last year, I'm sure you can look back and remember your days off and your holidays. You've been able

to relax and enjoy life. Most people can do that with or without autism.

However, there is a subset of people who struggle every day, who have no days off and who have virtually no resources. They have no voice on this Committee. There is certainly no organization promoting a life like this, a life where an individual is trapped in their body, unable to communicate their basic needs, smearing feces, projectile vomiting, can't keep clothes on, can't communicate wants, needs, pains, OCD, psychotic episodes, and meltdowns. Or as I like to say, taking my family hostage.

Over the last year, a significant thing happened to place my life in a new dimension of hell. My 9- and 11-year-olds grew bigger than me. Behavior that I could at one time manage or control became too much. Without getting into too many descriptions of exactly what transpired, my purpose in bringing this up is to give a voice to these children. I believe no one here will.

If I did to my child what he has done to me, CPS would be called, I'd have charges, and my kids would be taken away. There are whole organizations devoted to helping women who are treated like this

by their spouse. Restraining orders are issued, and people are saved from the abuse. But when it comes to an autistic child, families have almost nothing.

In situations where officers have been called, the person with autism is often harmed, drugged, and placed in a place so inappropriate that if that person were a pet, organizations would be outraged, and charges would be filed. Michael Vick treated his dogs in the same care that often happens to these children.

Families trying to get help see how inappropriate it is, or that there is nothing out there, or there are waiting lists that last for years. My 9-year-old has been on the wait list for 7 years.

I'm afraid to be alone with him. I've spent hundreds of thousands of dollars on medical treatment and behavioral therapy. I have had to go to committee after committee to beg them to take my son. I could not face life living like I was.

I had to let go of how they would treat him or perhaps mistreat him. I had to look my child in the face, and I had to tell him, "I cannot be the mom that you need me to be." And he can't even

understand that.

The number of moms who live in situations of despair is growing. Some of them are even killing their children and sometimes themselves. They say ordinary people can do extraordinary things, but ordinary people who live day after day after day in despair can be driven to doing horrific things, ordinary moms like me.

I am left knowing I failed my kid, and I am told I am the lucky one. I got to send him off. Although I know I will seek help in order to get through this, this Committee and this nation should be scared because there is nothing more dangerous than a mom who has nothing to lose, who is in despair, and who is angry. These families, these children, these siblings, and our communities need to stop the leisurely pace at which we address autism and particularly this issue and confront it with the urgency it needs.

And we need to stop whitewashing autism. It's not all about the guy that can play basketball and the kid that can't socialize. There's a lot more out there.

Thank you.

[Applause.]

Dr. Cuthbert: Thank you, Ms. Oldham, for those comments. Your very expressive comments about your experience really help us get the sense of urgency that you describe and really outline the need we have to urgently provide more services, as well as more research.

Our next commenter is Officer Laurie Reyes from the Montgomery County, Maryland, Police Department.

Ms. Laurie Reyes: So for you, Mom, that just presented, I, too, get emotional. I know I have a uniform on, but I, too, get emotional, and you're the reason that I push past my nervous speaking in public and do what I do.

So thank you for giving me the inspiration and thank you for sharing that before I share what I'm to share. Thank you very much for that.

I'm Officer Laurie Reyes from Montgomery Country Department of Police. Thank you so much for allowing me this opportunity to speak to you.

I speak to you on behalf of the Montgomery County Police Department, and I wanted to let you know what we're doing in law enforcement to make the lives of individuals with autism living in our community better. Again, I can only speak about

what our department is doing, but I thought that you all needed to hear that, and hopefully, the message will carry on to other departments.

In 2011 -- can you guys hear me okay? Okay. In 2011, I stressed what I felt was the importance of providing insurance coverage through the ICD-9 House bill for the coverage of wandering safety tools. I felt that those tools needed to be just one layer in a total approach to autism safety. This is still a very important issue for me. I always say I'm not going anywhere.

I inform all I can about this potential coverage, as well as other potential legislation related to autism safety. So now let's focus a little bit on Montgomery County.

In Montgomery County, we average between two to three searches a week, two to three searches a week for individuals with autism or Alzheimer's. These are what we call or what we now call "missing at-risk searches." We knew in Montgomery County that we needed to do more than just respond to the growing number of searches. We needed to address the calls for service for individuals with autism that had not eloped but were the focus of other calls.

The goal was to provide a total approach to autism safety through education, outreach, empowerment, and response. Since 2010, all of our incoming recruits have received a block of instruction on the dynamics of interacting with and searching for individuals with autism.

We teach our officers to think autism and never underestimate a person with autism. All of the officers view a video produced by the Montgomery County Police Autism Outreach Program. The video showcases a family and their son John. John is a young man who has autism. He has been the focus of three significant searches.

John's parents share their experiences open and honestly. The video is moving and educational, leaving our officers with a sense of some -- some challenges in caring for an individual with autism. The video captures why it's so important that our officers are educated and aware of autism and what they can do to assist families.

We provide our current officers the instruction as part of our Montgomery County Police critical incident training. We have provided autism safety instruction to our public school bus drivers, ride-on drivers, medical

personnel, students, caregivers, social workers, and beyond.

We worked with Autism Speaks on the creation of a national safety video that tells the story of John and his amazing parents. We have also partnered with Pathfinders for Autism, another dynamic organization.

Outreach. In 2013, the Montgomery County Police held our first Autism Night Out. I invite you all to attend that event. It will be an annual event.

We provide many other dynamic services in the autism community. This event was created to bring law enforcement, first responders, and the autism community together in a fun, educational environment. And what it's turned into is an evening of reunions, friendship, togetherness, and awareness.

Officers, caregivers, and individuals with autism learn from each other. I believe that exposure leads to understanding. This event is a testament to that idea.

The outreach continues through our Montgomery County Police Facebook page, Twitter, local media, national media, print, awards, and beyond. The

program takes every opportunity to let caregivers and individuals with autism and the community know that we, the police, are here to assist them. We are here to serve them and ensure that any experiences that we have with them are positive.

The program provides follow-ups to the caregivers of individuals with autism. The follow-up consists of immediate contact following an incident of elopement, as well as our Montgomery County Police elopement/wandering safety kit.

The kit contains our Montgomery County Police autism safety T-shirts. The T-shirt is bright yellow -- and I understand the controversy of this. The T-shirt is bright yellow with a Montgomery County Police badge that says, "I have autism. Please call 911 if I am alone."

It should be noted this shirt is completely voluntary and is only provided for those individuals that cannot speak for themselves and are in immediate danger should they elope. They are not designed to label any individual who has autism, only to keep those safe that are in immediate danger should they elope.

I understand the controversy our shirts bring.

However, our goal is to save lives. In my experience of hundreds of searches, I can tell you these shirts will continue to save lives.

The kit also contains our Montgomery County Police wandering tip sheet, neighbor letter, and 911 script, with a suggestion to print out a Google map of their home to document bodies of water and other potential hazards, as well as home and vehicle window clings and other safety handouts.

We truly encourage caregivers -- this is what I really want to stress today. This is what we're really pushing -- to have some type of ID bracelet for their loved one with autism that may not be able to speak for themselves under stress. I understand yet again the idea that we don't want to label individuals with autism. I can only again express what we feel is the best way to help keep our young men and women safe with autism, especially for those -- especially for those navigating their way to independence.

I have been the autism outreach coordinator in Montgomery County since 2005. I'm not leaving, again. Did I mention that?

[Laughter.]

Ms. Reyes: I've looked into many different ways to inform our officers of those living with autism in our community that may be in need of our assistance from time to time, and I think that the answer can be found in the ID bracelet. Caregivers and the wearer can determine what the bracelet should be engraved with and what information is important.

Understanding the sensory concerns, I still feel it is an important piece of the safety puzzle. I've worked with children as part of our Project Lifesaver program who had a very difficult time initially wearing our Project Lifesaver bracelet. Over time, the wearers got used to the idea of the bracelet and began to associate the bracelet positively with the police to the point that it became a nonissue, and in many cases, many cases, a positive association between the bracelet and the police officer was developed.

I encourage caregivers, teachers, medical personnel, and social workers to work with our youngest individuals with autism to wear the ID bracelet of some type. Not only to wear the bracelet, but to have the young people show the bracelet to the officers in the community. The act

of showing the bracelet creates that familiarization between the bracelet and the officers.

It also provides the officers with an interaction with a young person with autism. This will break down barriers. It will also help us in law enforcement in three ways.

Many times we find the loved one with autism long before caregivers realize they're missing. The more information immediately available to officers, the better off we are to have a positive outcome.

As our young men and women navigate to independence, there may be bumps on the road. Even those that may have speech may not be able to speak under stress. This ID bracelet will allow individuals to show the bracelet, if necessary.

We teach our officers, again, to think autism. We teach them to look for the ID bracelets and ask about the bracelets. Showing the officers the bracelets allows them to share a little bit about the individual, and it makes the encounter more than just about autism and goes to build understanding.

We do not have all the answers to safety. I

just know what I have found to be an effective tool in keeping those with autism safe. If I could share anything, it would be that our goal is, of course, to educate, provide outreach, and empowerment.

So now I'll hit on empowerment, and then I'll close. Empowerment. This piece is as important for us as all the others. We recognize that we, the police, are in a position to provide empowerment to those with autism in our community.

In recent years, we have provided the Montgomery County Police Chief's Award to two deserving families and a young man with autism. We named our autism ambassador, Jake Edwards, who provided the keynote speech to our Autism Night Out event. Jake continues his role as a Montgomery County Police ambassador as a self-advocate, teaching our recruits about his autism superpowers.

I am proud to say that the White House recognize the importance of the partnership between Jake and I and all it represents. We were awarded as White House Champions of Change, and I am proud to say there are many partnerships with our officers and individuals with autism that may

not yet and may not ever be awarded by the White House, but they are no less special.

Finally, our response. The response to calls for missing at-risk individuals with autism is immediate and thorough due to the expertise of our Montgomery County Police-managed search and rescue team, coordinated by our Officer Jason Huggins. This unit completes our total approach to autism safety.

Officer Huggins and his team coordinate and effectively deploy our educated officers. The urgency of these calls is understood by our responding officers. Officers truly go above and beyond in an effort to ensure the safety of the missing individual.

We have shared our total approach with other police agencies, and they are listening. I'm here today to share this with all of you.

Thank you very much.

[Applause.]

Dr. Cuthbert: Thank you, Officer Reyes, for sharing that marvelous program with us. It seems like a model program that could be shared among many departments across the country, and that's good.

So thank you so much.

Our next commenter is Dr. Deanna Mulvihill.

Dr. Deanna Mulvihill: Members of the Committee, ladies and gentlemen, thank you for giving me an opportunity to speak today.

From society's earliest beginnings, there have been those people with particular diseases and handicaps that have been separated from others and left alone with only a few caring others. I believe that our nonverbal or minimally verbal people with autism are the 21st century example of this. I see all over the place that parents who have been unable to negotiate a safe school for their children have opted, out of exhaustion, for home schooling and not being able to provide really good resources as their child grows older.

Even in the autism organization and groups, their mission and their purposes are targeted towards the higher-functioning autistic child or at least the verbally competent. Campaigns that focus on awareness or acceptance are evidence of this.

People still look at this as a mental or psychiatric condition. Even our first speaker today talked about his medical conditions, his

physical conditions. Would anybody encourage a parent of a child that had congenital heart disease or cancer to just accept, or would we be satisfied if they were just aware of the fact that they had it?

Many of the children with autism are physically living in pain every day, and sometimes even when they go to physicians, they get a kind of a sneer or a doubtful look. So we still have to educate them.

My grandson was pulling out his hair, banging his head, and bouncing so hard that he had permanent bruising. All of this self-injurious behavior stopped after he had an IVIG treatment, after he was no longer in pain.

Most insurances -- this treatment costs \$8,000 a piece, and they usually need a series, one a month for 6 months. And most insurance companies do not cover it for a person who has a diagnosis of autism, though if he had the diagnosis of AIDS, they would cover it. And the blood work is very similar.

As far as the schools are concerned, we leave them -- we send them to school because there is a law that says they have to. However, because of

the nature of that law, it ends up being a very adversarial relationship not only because of the nature of the law -- and the fact is a law is adversarial. One person wants it. The other person doesn't want to get it, and it ends up with lawyers and costs like that.

But the other thing is, with the increasing numbers -- when I wrote this, it was 1 in 68. I know now it's 1 in 45 -- our school systems are bankrupt, right? So the thing is they -- you have to fight to get 30 minutes a day for a child that doesn't talk to get 30 minutes a day of speech therapy.

Imagine if you had a child like that, and you could not -- you fought for an hour, and you couldn't even get 30 minutes a day of speech therapy.

And the school system is all based on ABA, applied behavioral analysis, as if behavior was the problem. Who else sends their children to school to correct their behavior? We send them to school to get educated. But believe me, in an autistic classroom, there is very little educational component.

We do not ask blind or deaf children to learn

in the same way that we do. These children with autism have a sensory deficit. Their sensory system has developed differently than ours. The sensory channels are the way that we take in information. That's the way we assimilate them and modify it. That's what our education system is about.

But we don't even know this -- because of something happening to the areas in their brain, their sensory system has a maladaptive. We don't know whether their visual, auditory, tactile, kinetic system in their brains are connected with the right or left or both. And there are new science in brain plasticity, and there are some new teaching techniques that are using this to integrate.

But the important thing is that, you know, we cannot really know how a child with autism who hasn't integrated any of their system actually perceives an object or a scene. We can guess or intuit, but we really don't know.

That's why even, you know, I'm shocked when sometimes my grandson is having a meltdown when we're doing the same thing that we were doing yesterday, you know? Something has set him off. I

don't know what it is.

And as they get older, it's not cute anymore. He's not welcome places anymore, and I'm not welcome to take him there. So we are left alone in our houses.

Whatever causes autism or the list of deficits that cause an individual to be given this label, it is widely recognized that this is a brain disorder in some way, but many people don't look at the whole issue. And we need to use these systems, new systems to integrate this teaching so that these children can learn. Many people now are using what's called rapid prompting method, RPM, and their children are learning.

I attended a session where two autistic children -- one spoke through the computer, one spoke through a letter board -- and a therapist told them, "They told us that this is not a social disease. We want to make friends. Our body just -- we just can't get our body to do it."

Or "I can't sit here long enough. I have to get up and going." So we need to be listening to that.

Dr. Cuthbert: Dr. Mulvihill, I hope you can wrap up. I'm so sorry. The flashing light is over

time, and we do want to allow time for everyone to share their comments.

Dr. Mulvihill: Okay. Yes, I will. Thank you.
Yes.

The problems of communication are in great danger in the emergency room. The numbers of AIDS patients were much less than this when we, as health professionals, were mandated to learn how to treat and care for these patients. Where are the programs now in emergency rooms?

You know, my grandson had his finger amputated because I was trying to teach him to skate, and they wouldn't graft it, even though somebody had all the things there, because he had autism. I urge this Committee to listen to the people today, the people that are living with this, and to make recommendations for our hospitals, our schools, our government agencies, and to our physicians and healthcare professionals.

And to take some of the research money -- I'm not saying stop research. I'm a researcher myself. I'm not saying stop it, but make sure that it's pointed and it's not looking at one cause. There's more than one cause that's causing this epidemic. But develop programs for the people that are

struggling every day.

Thank you.

[Applause.]

Dr. Cuthbert: Thank you for those comments.

Our next presenter is Ms. Lisa Wiederlight.

And may I remind our presenters we do have a light up on the podium, and when the light flashes, that is the end of one's time. So if the light starts flashing, can you please wrap up?

We do want to make sure that we can hear from everyone. And if you don't get a chance to finish your oral comments, all the Committee members do have the written version of your comments available to them, and those are also posted on our Web site. So the full entity of your comments will be heard.

Ms. Lisa Wiederlight: Thank you.

I'm from New York. I can talk really fast, I promise.

So my name is Lisa Wiederlight. I'm mother to a 15-year-old boy with autism who is an amazing, intelligent person, who also endures gastrointestinal issues and had a grand mal seizure on May 28th of this year.

I've earned a master of public policy degree

from the University of Maryland, worked for a United States Senator and for the Executive Office of the President of the United States, and have administered millions of dollars in Federal grants. I can promise you that addressing my son's autism has been the most challenging endeavor of my life.

Life turns us in many different directions, and in the spring of 2015, I was honored to become executive director of SafeMinds. SafeMinds' mission is to end the autism epidemic by promoting environmental research and effective treatments for people with autism today.

Today, at this first meeting of this IACC, you have a blank slate. Much of the autism community feels disenfranchised, unsupported, and disappointed in the lack of a Federal response to the surging autism crisis. Taxpayers have spent \$1.6 billion in the past 10 years on autism, and yet there have been few significant and positive changes in the safety, health, education, employment, housing, and well-being of people with autism and their families.

Time for change and for increased collaboration is now. Today, SafeMinds asks that

the IACC convene four workgroups. Number one, 49 percent of people with autism wander or elope from otherwise safe environments. What would you think if your child was reported missing from school, especially if he was nonverbal?

Today, I ask that you engage the legislative affairs offices of both the Department of Health and Human Services and the Department of Justice to pursue passage of S. 163, Avonte's Law Act of 2015. This bill provides funding for law enforcement training on preventing and addressing wandering in people with autism and for community outreach.

Today, I also ask that you convene an ongoing workgroup on autism and wandering. Since May of this year, we have lost over 30 people with autism to wandering and elopement. These deaths are unacceptable, unacceptable.

Number two, autism prevalence has increased from 1 in 2,000 before the 1980s to 1 in 68 for children born in 2002, and now we have the new number of 1 in 45. Ask anyone seeking behavioral support services for their teens with autism if there is an epidemic. The waiting list at Kennedy Krieger Institute's neurobehavioral unit is 2

months for outpatient services and longer for inpatient services. There is a manifestation of the autism epidemic for you.

That autism requires a genetic susceptibility and environmental trigger is widely recognized, but Federal causation research funding has been predominantly focused on genetics, and prevention efforts are directed at early intervention to change the autism trajectory. Since there is no such thing as a genetic epidemic, and most children continue to have severe autism despite high-quality behavioral programs, today I ask you to convene a permanent workgroup on environmental factors in autism.

Number three, up to 70 percent of children with autism have gastrointestinal disorders, which can manifest as intestinal lesions and maladaptive behaviors. Many of us are told by our pediatricians that diarrhea and constipation are just symptoms of autism, and our children are not treated for these physical illnesses because of their diagnosis.

We know that up to 40 percent of people with autism have seizures, which affects mortality rates. Nothing can equal the fear a parent feels

when she is holding her son's head in her hands on the floor of his bathroom as he seizes in her arms. I know this personally.

And then no one can tell you why this happened and how to prevent it from happening again. Once more, we often as parents hear from medical professionals, "Kids with autism have seizures. We don't know why."

Research published in 2013 by Penn State University found that children with autism are 28 times more likely to commit suicide than their neurotypical peers. What has the Government done about this? To date, nothing.

Today, I ask that you convene a permanent workgroup on co-occurring conditions with autism. I hope that the medical professionals on this IACC will join the doctors currently on the Committee in the workgroup.

Fourth and finally, as you've seen today, you cannot take care of people with autism if you do not also take care of their parents and other caregivers. While autism is a spectrum disorder, many caregivers acknowledge that raising a child with autism is exhausting, overwhelming, isolating, depressing at times, joyful at times,

and extraordinarily expensive. And many parents of children with autism, like myself, are single parents.

While there are very high parenting highs and very low parenting lows, there are few supports for the caregivers who worry, absorb the aggressions and tantrums of their children, and cry at night wondering how they can help their children to get better and to thrive. We love our children, but many of us also need help.

Today, I ask that you convene a workgroup on caregiver support to ensure that all families thrive.

Thank you for listening to me. I wish to volunteer for each of these workgroups, and I'm sure you will have many other willing volunteers from the community.

Thank you.

[Applause.]

Dr. Cuthbert: Thank you for those comments and your very specific, targeted recommendations. Appreciate your commentary.

Next commenter is Albert Enayati.

Mr. Albert Enayati: Good afternoon. Dr. Cuthbert, I would like to congratulate you on your

new position, and I hope under your leadership, there will be a new chapter of hope for the children and adults for autism.

And also I would like to welcome the new members of the IACC.

I'm going to take the liberty to show a video of my son. I will have a commentary, and my speech is two pages. And I hope I can finish in 5 minutes.

[Video presentation begins.]

Mr. Enayati: This is my son, Payam. He is 25 years old. The patches of hair is missing from his head is because of the amount of hitting he gets in his head every day.

My son was perfectly normal. He regressed to autism through his childhood immunizations. What you see here, Dr. Cuthbert, is against human rights. It's against any moral value, and no one, no one is blamed except Centers for Disease Control and the scientific advisory board for causing this devastation of my son and paralyzing his brain.

My son is not alone. There are thousands and thousands of parents across this country. They believe vaccine causes their children's autism.

The rate of autism in the State of New Jersey is 1 out of 29, and no one to blame for this epidemic except Food and Drug Administration, the CBER division, Dr. Karen Midthun, for approving vaccine that clearly has a devastating side effect for our children.

This is production of vaccination, and I live with this and my family have to live with this devastation every single day. I have to have three people taking care of him during the day. And when I come from work, I have to take care of him all the night. Is this fair?

And I cannot be more agree with the previous presenter who have three -- where is my glasses -- with the three individuals Autism Science Foundation -- Ms. Singer, Mandell, and Parnell.

[Video presentation ends.]

Mr. Enayati: You're telling me that Ms. Singer is so valuable that she already been here twice already, 8 years, and she has to be another one, serve another time in here? And there's another two other person from her organization to be here. You're telling me throughout the whole United States there is no other people except these three person? There is something wrong here, and these

three individuals, they have to be moved from this organization.

Okay. You could stop it. Thank you.

[Pause.]

Mr. Enayati: My name is Albert Enayati. I'm a board member of SafeMinds and APRC, both volunteer organizations focusing on identifying and removing the harmful environmental agents contributing to the severe disability that frequently accompanies autism.

Sadly, despite of my 20 years of autism advocacy, we are still ignoring environmental risk factors, with no safe and effective medication or prevention strategy in sight. No conclusive biomarkers have been identified and no new treatment validated. Over the past 7 years of IACC coordination, Federal agencies have spent \$1.6 billion in many fields of autism, but the environmental research has been underfunded, and autism prevalence continues unabated, including severe disability cases.

It is time to dedicate resources to the more fruitful path, environmental causation of autism. Within this field, a topic in need of funding is the role of vaccines in autism etiology.

Please take a note that the recent study among parents by the Simons Foundation, this Simons Foundation, if you go to their office, you tell them that autism causes -- vaccine causes autism, they kick you out of their offices. This is how dedicated they are in the genetic study of autism.

And this foundation found that 42 percent of parents felt vaccines contributed to their child's autism. The IACC should not ignore this large segment of community, an observation by so many parents regarding their children's developmental history.

In 2009, the National Vaccine Advisory Committee recommended to this Committee a number of feasible research proposals on vaccines and autism. Not a single one has been implemented. Not even one single one, thanks to Dr. Thomas Insel.

My son Payam regressed after his vaccination. He is suffering from his autism and breaks my heart piece by piece. He has serious self-injurious behavior. He has run away from house, ended up in the emergency room, and been tased by law enforcement.

His finger was nearly amputated because of he cannot communicate his pain from infection. His

medication doesn't help. Meanwhile, the main decision-makers on autism research here at IACC, the NIH, Centers for Disease Control, Autism Speaks, and Simons Foundation have been discriminating against children like my son and many children across the country who parents reported regressed after their childhood immunization.

Even if it is unpopular, it is ethically imperative that we investigate these reports and study these children. Public health is not simply freedom from infectious diseases. Autism is not always a gift or alternate way of being. It often comes with a great cost. My son deserves to have attention paid to him and research done to help him have a better quality of life.

On many occasions right here at this IACC, Dr. Insel informed me that science does not support my point of view. In fact, very little meaningful science has been done on vaccines and autism. Only a small fraction of possibilities have even been looked at, and the studies that have been published are riddled with a conflict of interest, data manipulation, and in the case of Dr. Thorsen, indictment for financial research fraud.

In addition, Dr. William Thompson, a senior researcher at the Centers for Disease Control, who has a whistleblower status, has reported dumping inconvenient data in garbage can along with a colleague to avoid reporting an increased risk of autism in African-American boys who receive MMR vaccine. The rate of autism among the children, African-American children was 300 percent higher than the white people. I guess black people don't matter in this organization.

In 2011, a study of the Institute of Medicine's Immunization Safety Review Committee evaluated the evidence on possible causal associations between immunization and certain adverse outcomes. Just listen to this. In 135 of 158 pairs evaluated, they found that evidence is inadequate to accept or reject causal relationship. That means, if you do just the math, this U.S. immunization program has only 15 percent safety.

Dr. Cuthbert: Mr. Enayati, I'm sorry to interrupt. The red light has been flashing for some time. If you can please wrap up --

Mr. Enayati: That's fine. I can complete. Only I'm going to finish it. Even -- please don't

interrupt me.

They found no relation between MMR and autism, but given that their evaluation included studies like the one where data was dumped, the safety of our children demands that we allow for further research to inform the question.

Even the package insert for DTaP vaccine suggests that we need further study. Here is some quotes from 2005. This is the DTaP from Food and Drug Administration in 2005, 10 years ago. I'm not going to go through all the side effects. I'm going to go, tell you the one that is important.

It causes SIDS. It causes autism. And it causes Guillain-Barre syndrome. Do you think in 10 years they said this product cause autism? Do you think Centers for Disease Control goes to any of these vaccine manufacturers, says, "Look, this is causing autism. We have to do something." Nothing has been done.

In a recent study of 100 published papers analyzed by Science magazine, only 39 percent of published articles could be replicated unambiguously. We need to keep an open mind and start actually funding unbiased research into vaccines and autism.

A recent paper indicates that aluminum in vaccines may have a direct association with the increased rate of autism. Another paper found increased risk of autism from the birth dose of hepatitis B. The Vaccine Injury Compensation Program has compensated at least 83 cases with autism or autism-like conditions. Vaccines have been found to increase risk of seizure, tics, and mitochondrial collapses, and all of which commonly co-occurs in autism.

Dr. Cuthbert, I'm not going to go through the rest of them. I'm going to respect your timing, and I'm just going to stop. But what I'm saying here, I need a comprehensive, robust roadmap to look into the vaccines and autism.

This organization cannot ignore 43 percent of parents. I am Iranian Jew. I left my country to not be discriminated. That's why I moved to this country. Now my son is being discriminated because vaccine causes his autism.

How do you like that? How do you explain this to me? You have to respect me. This agency has to respect my point of view. I was there. I was in the theater. I saw how my son lost his language and how he has regressed through autism, and your

ignoring me is not going to work out.

I am coming here 2 years. I just came from California again. I have to move from New Jersey to California because of the incidence rate of autism.

I'm going to stop, but we need to talk. I'm going to talk to you. We have to add this the issue of the vaccine and autism, and I spoke to you about this aspect [inaudible].

Okay. Thank you.

[Applause.]

Dr. Cuthbert: Thank you for your comments and the video, which shows -- reminds us that the needs for autism are not only in children, but in adults as well. And so that really brought home the message for us.

Mr. Enayati: Thank you.

Dr. Cuthbert: Our next commenter is JaLynn Prince.

Ms. JaLynn Prince: Good afternoon. I'm a mother of a son who is 26 on the autism spectrum. And Officer Reyes, my son proudly wears one of his bracelets whenever he's out in the community. You are making a difference.

But I'm here on behalf of Madison House Autism

Foundation. We would like to welcome you here as the new IACC board. If you are as stellar as your biographies purport, this board will accomplish many great things.

Madison House Autism Foundation is one of the few national organizations working solely on the issues of adults on the autism spectrum. We are taking a comprehensive look at the issues facing adults from graduation throughout lifespan. We have supporters and partnerships, over 150 organizations across the country, several universities, colleagues across the country. And our activities and conversations focus on housing, employment, healthcare, education for those on the spectrum, and education of providers and concerns facing individuals and families as they navigate through the community.

We hope that you will take an active role in making certain that this population receives the attention that it deserves. Historically, a very small portion of any Federal funding has been allocated to increase knowledge about this population.

Only about 4 percent of primary research publications on autism have addressed lifespan

issues in recent years, whereas today's autistic children are rapidly becoming today's autistic adults, as Dr. Wexler pointed out, with 478,983 school children that are well on their way, along with those adults that are living with autism today.

There are many concerns for parents and individuals, and it includes all of the lack of services and what is happening to individuals after high school. And we are looking at things with employment and structure and the continuity of physical and mental well-being.

Many families have a difficult time navigating these services in housing, employment, and medical care when and if these services are available. Many parents are aging, and currently, public policy is leaning heavily toward individuals aging in place in the parental home.

We hear about parents every day in their seventies, eighties -- and yes, in their nineties -- contending with the physical and mental stress of being the sole support for community engagement and all other activities for their adult child.

We hear numerous stories about autistic adults being employed, yet who -- or are unemployed, yet

have skills that could be highly valuable for employers. According to A.J. Drexel Autism Institute, young adults with autism have higher unemployment rates and higher rates of complete social isolation than other people with disabilities.

Families also face restrictions, not being able to move across State lines and maintain needed support for their adult children. Parents may travel to locations to secure employment, but they may be unable to return to their home State because services and funding will be lost.

They may not be able to secure funding near family, or they may be placed on waiting lists decades long. Natural supports of families with aunts, uncles, grandparents are sacrificed for services, unintentionally forcing many autistic adults into living in isolation away from family.

As all people, when autistic adults age, they have typical medical issues. Few physicians and healthcare professionals have the knowledge or feel comfortable in treating autistic patients for typical medical issues.

We need to make sure that our physicians and other healthcare professionals are capable and

willing to treat our population and that physicians are not penalized financially when they need to give our adults adequate office time.

We need to make certain that universities can make appropriate accommodations when our population becomes part of their student bodies. We also know success looks different for all individuals, and that definition of success has been poorly clarified for our population.

As you see, there is a lengthy list of issues facing our adults, and I could elaborate on a whole lot more. The name of this organization is the Interagency Autism Coordinating Committee, and I hope that you take that name seriously as you call into play the agencies across our Government that can help make a difference in the lives of thousands of families across the country.

This is a large and complicated situation, and in cooperation in many arenas, we can ensure that the talents and abilities of this population can be realized, and those needing greater support services can access those without stressing families who are already stressed.

In fact, some of these families may have one, two, or three individuals on the spectrum. And as

we solve these problems, as was alluded to earlier, we may also be helping other populations as well.

We call for greater action on behalf of the adult population on the autism spectrum. Autistic children become autistic adults. Individuals and families need and deserve great minds and talents making the process of living with autism more positive.

And as a personal note, in arriving here today, I looked at the large black building over here on the corner. And I recall a meeting that I was in. It was a former FDA building. And my husband's scientific work had resulted in the approval of a new drug, Synagis. It prevents a pediatric disease called RSV.

The meeting came 3 years after it could have been approved, but it had been held up for unclear reasons. But 16 years ago, it was approved, and its generations have still remained the gold standard. As a parent, I have often wondered about how many children and families could have been helped during that 3-year period, that 3-year interim, avoiding a lot of sickness, a lot of heartache, and a lot of family stress.

Treatment delayed is treatment denied, and can we also say that services delayed are services denied. Please don't delay in looking deeply into the lifespan of adults on the autism spectrum. We cannot afford to wait years to take action.

Point one on your list is a sense of urgency. Madison House is here to be of any assistance that our 10 years in the field can offer. Together, we can formulate a new and better future for adults on the autism spectrum.

Thank you, and best wishes.

[Applause.]

Dr. Cuthbert: Thank you for your comments and for reminding us of the importance of services for adults. And I am sure that that will be an important part of this Committee's attention.

Our final commentator is Janet McCarty.

Ms. Janet McCarty: Good afternoon. I'm Janet McCarty. I'm director of private health plans at the American Speech-Language-Hearing Association, or ASHA.

I wanted to thank the IACC for allowing ASHA this opportunity to address the members of the Committee today. As you may know, ASHA is a national professional scientific and credentialing

association for more than 182,000 audiologists, speech-language pathologists, speech and hearing scientists, audiology and speech-language pathology support personnel, and students.

Speech-language and social communication impairments are core features of individuals with autism spectrum disorder for which speech-language pathologists play a central role in the screening, assessment, diagnosis, and treatment. On behalf of ASHA, I wanted to congratulate you, the new public members of the IACC, on their successful nominations.

ASHA and its members look forward to working with you, other Committee members, and the staff of the IACC in advancing research and care for individuals with autism.

ASHA's certified speech-language pathologists provide speech, language, feeding, swallowing therapy to individuals with ASD to help them acquire the skills they need to function in their home, their school, their social environment, and their work setting. Speech-language pathologists also treat related disorders prevalent in the ASD population, including social communication impairments, and are the designated professionals

for assessing augmentative and alternative communication needs that supplement or replace natural speech with aids, such as speech-generating devices.

Evidence suggests that diagnostic features of ASD are evident in very young children. Parents report abnormalities in their children's language development and social relatedness at about 14 months of age, making the speech-language pathologist often the first professional families meet.

The professional roles and activities of the speech-language pathologist include clinical and educational services, prevention and advocacy, education, administration, and research. Consulting and collaborating with other professionals, family members, caregivers, makes the speech-language pathologist a key member of the multidisciplinary team treating the individual with ASD.

While the Autism CARES Act extended the work of the IACC another 5 years, it adds a requirement for a report to Congress concerning young adults with ASD and the challenges related to the transition from existing school-based services to

those available during adulthood.

For transitioning adolescents and adults with ASD, social communication is a particularly important skill area to consider, and the role of the speech-language pathologist remains vital in this new focus. Communication rules in adolescent social interactions are often subtle and unspoken, and successful navigation within social settings requires awareness of these rules.

Speech-language pathologists provide interventions that assist individuals with ASD in postsecondary educational programs, employment, maintaining relationships, and acquiring the skills necessary for independent living.

So, again, I thank you for this opportunity to address the IACC. I congratulate you on your nominations, and we look forward to working with you.

Thank you.

[Applause.]

Dr. Cuthbert: Thank you very much for reminding us of the role of the ASHA and autism spectrum. Thank you.

So that's the end of our oral public comments. We are running very late on time, but John Robison

wanted to give a brief summary of the written comments. So, John, I hope you can make it as concise as possible, and we'll try to catch up a little bit.

Mr. Robison: As long as this may seem, I trimmed 1,000 words out of it while sitting there through the other.

So I'd like to just take a moment to recognize the 71 comments that we received in 100-some pages in writing. We are the only representatives in Government that many people living with autism know to speak to, and I feel that we owe them this duty.

Jenny Allan is upset about the blog of former IACC member Matt Carey and what she sees as its pro-vaccine stance and dismissal of vaccine allegations, although I think that's outside of our purview because Mr. Carey is not a Committee member today.

Clifford Zimmerman offers us a gift for children with autism, an audio therapy device. And in the written comments, you can find a link to his patent, and he awaits your phone call.

Regular IACC commenter Eileen Nicole Simon draws our attention to the possibility that head

injury and oxygen deprivation at birth may be implicated in autism. She particularly identifies the auditory pathways and basal ganglia as vulnerable areas, and she suggests autism may be an early form of schizophrenia. Ms. Simon submitted a total of seven comments to this IACC meeting.

She also says the requirement for self-advocates on the IACC is disturbing, and frankly, I have to ask why? Who better to help steer the ship of research, treatment, and services for autistic people, but autistic people ourselves. Frankly, Ms. Simon, that suggestion is nuts.

I'd like to take particular note of the younger autistic self-advocates who have emerged in recent years, and I'm proud to see them joining me on the Committee because I'm old. But we still need autistic self-advocates.

Ms. Simon thinks that acceptance, early intervention, and neurodiversity hinder the scientific investigation of autism. Well, you get a sense probably of what I think of that, too.

These concepts, I would like to point out, have emerged and risen to the fore in the past decade as a result of scientific investigation of

autism, not in opposition to it. And I think that acceptance of autistic people is, frankly, a basic human right, and it should not be up for discussion. The idea that we want acceptance does not mean that we do not want relief of suffering and relief of disability.

John Best takes us to task for harming babies and denying that mercury in vaccine causes autism. Mr. Best is the one commenter who has the distinction of having a significant portion of his comment redacted for profanity. Mike Hoover and Haven Delay take similar, but more polite positions to Mr. Best.

Former IACC member Matt Carey draws our attention to the plight of minimally verbal autistics. That's an area of concern that I happen to share and I will return to.

Carol Fruscella asks if we will be brave enough to take action, and she particularly mentions vaccines.

Teresa Holman and Susan Henderson bring really heartfelt pleas for respite care and services for their impacted adult sons.

Michelle Guppy has another heartfelt plea for us to help families like hers where autistic

children are self-injurious, prone to injury from seizures, and unable to care for themselves. She reminds us how few resources and supports there are for severely impacted adults and their families.

Deborah O'Leary, Courtney Reid, Kathy Blanco, Chanda Jackson, Donna Jo Kazee, Gabriela Ahlheim, Dave and Lesa Walsh, Christina West, Katherine Jakus, Sheryl Melling, and Patti Carroll draw our attention to William Thompson, the CDC whistleblower business and vaccine cover-up allegations, which I will point out really aren't on the table here because that is a matter being investigated by the CDC research ethics folks.

Michelle Mood asks for greater supports for her two autistic sons, age 10 and 16. She fears for their future.

Joseph Jason raises an important issue, the criminalization of people with Asperger's and other psychiatric differences. Andrew Gammicchia, which I believe is the father and husband of the two folks we heard presenting earlier, brings up some similar tips, and he actually offers some constructive links for advice about protecting autistic people from criminal trouble in the

comments.

And I think that that's a really significant point. I'll say that I was glad to see the Department of Justice starting to attend our previous incarnation of the IACC, and I hope that continues and we can build a constructive dialogue.

Nydia Olvera quotes a short passage on genetic testing from Children's Hospital in Philadelphia.

Michael Kazee is appalled at the lack of service for his teen son, and he is disturbed by the number of autistic kids he sees. He believes that we have an epidemic, and he asks if vaccines are involved. And he draws our attention to Mr. Thompson at CDC.

Katie Harris reminds us again of the need for adult services. Ruth Snyder describes her own journey growing up, seeking services and struggling to find acceptance.

In a particularly poignant comment, Jackie Igafo-Te'o -- pardon me if I said that wrong -- asks for respect and accommodation for her autistic son. And you know, it's really kind of -- it's heartbreaking the story she tells about how she and her son have been treated in their

community. And I share her concerns, and I surely hope that we can see greater respect and acceptance.

Heather Price raises a number of issues. She believes there are more severely impacted people. She wants Medicaid waivers to be portable State to State, something we've discussed in this IACC. She draws our attention to vaccine. She asks for additional therapies. She asks for IACC to include parents of severely impacted kids, which I actually believe we have had right along.

She reminds us autism is dangerous. She suggests that much research is duplicative, and she suggests that we ask the autistic community what we should be studying. And I would thank her if she directed that comment to Ms. Simon because here we are, several of us, and I actually would want to thank all of you who have welcomed us autistic people to this Committee and others to provide exactly that insight.

She points out also the need for respite and places for autistic kids.

Dwight Zahringer tells us how the stress of autism bankrupted his family and brought them to their knees. Better coverage is needed, and the

tragedy is really how common stories like this are, particularly in families with severely impacted kids.

William and Karen Fuller just want to take us to task for not solving the riddle of the autism epidemic.

Jessica Dowler asks for intensive early services for severely impacted kids.

Marcy Mullins tells us that the IACC has received millions of dollars to help families, and we have not met for 4 years. And Marcy, I do hear your plea for help, and I think it's well grounded, but we actually did meet just over a year ago. So it's not quite as bad as you say.

Laura Cellini asks why her child recovers from autism when he has a fever and suggests we study that. And again, I know that that has been both a point of discussion in IACC, and it's an interesting puzzle that is being studied.

Kathi Machle offers a statement on behalf of the Autism Society of Central Ohio. She expresses concern about lack of diagnosis, treatment, and services, and her society asks for more and better adult services.

Kerry Scott Lane offers us several peer-

reviewed articles citing links between acetaminophen and autism.

Lisa Ackerman offers a statement on behalf of Talk About Curing Autism, asking for better identification of autistic people, development of tests of subtypes of autism, development of better treatments for same, and better collaboration and what I would call out-of-the-box thinking.

She also raises the adult service issue and asks us to investigate environmental causes. She asks for recognition of autism as an epidemic and a public health crisis, and she suggests alternative members for this Committee.

Monica Kay draws out our attention to the bowel and GI issues that are so common among us autistic people.

Gwen Wise asks for employment opportunities for autistic adults, and she asks for more adult research.

Melissa Schneider draws our attention to the many autistic people who wander and die, particularly by drowning.

Christy Zartler, AmyLou Fawell, and Thalia Michelle draw our attention to the possibility that marijuana may help moderate self-injurious

behavior and help autistic people in other ways, and yet it is banned in much of the country.

Linda Varsou reminds us of the harm that can be caused when parents are in denial about a child's autism or the severity of that autism.

Janet Shouse reminds us how much work remains to be done and encourages us to get moving now, and she did put the exclamation point there.

Sheri Sponsler last night expressed the hope that we can meet more than once a year and asks us to think about transition services. She also thinks it would be good to have some autistic people on the Committee, and Sheri, I share your sentiment.

Finally, Rose Walker of Atlanta reminds us to be mindful of the gifts autism can bring alongside the disability, and she asks us to keep that in mind while teaching. It's nice, actually, to end this summary with kind of an upbeat comment.

The overriding theme of the comments that we've received is dissatisfaction at how little tangible benefit we have delivered to the public. Every year, we publish a summary of advances, but very little of what we describe trickles down to actually benefit families. Parents see their

children grow to adulthood in the life of this Committee while they feel they've delivered nothing to help them.

If you take away one thing from those comments, it would be this. We would be very wise to significantly shorten our research-to-consumer translation timelines and focus on therapies and treatments that will be impactful soon and not to the next generation. We have spent millions of dollars and years of time looking for the foundation causes of profound disability.

We've kept that primary course even with the emergence of knowledge that autism is not a progressive disease. And for many of us, the cure model is not applicable. Yet autistic people are stressed and suffering, and I ask what's wrong with that picture? I feel that we need research into benefits that we can use now.

Research into relief of suffering from various causes and research into teaching accommodation skills is fundamentally different from most of the current basic research seeking cure or prevention. To draw an analogy, in the years after World War II, one group of doctors studied the cause of polio while another group developed better

wheelchairs and braces. Today, everyone remembers Salk, the great inventor of polio vaccine, but we have to concede that both groups made truly great contributions to American medicine.

Thanks to Salk's team, polio is no longer a public health problem in America. But I would suggest to you that the accommodation work done by those other unknown doctors has actually found even wider use in American society for all other disabilities, and I suggest that something similar is true for work we do in autism accommodation.

The next point I'd like to speak to is the large group of commenters who expressed the view that vaccines cause autism. In the previous IACC when I read public comment and I saw the very high percentage of vaccine commenters, I asked the Committee if we have research into the concerns of autistic people, and indeed, we do.

Vaccine injury does not top that list. The major concern of families and autistics is solving the problems we live with today. And indeed, many commenters who raised the vaccine issue today also raised quality of life concerns. And I really wish in the most heartfelt way I can express to you that we could all pull together, whatever our

beliefs over divisive issues like that, and work together to deliver tangible quality of life improvements to autistic people rather than chasing in circles around a "whodunit."

In that line, we had a workshop in the last IACC on co-occurring conditions. We recognize the reality that anxiety, depression, intestinal distress, and seizures affect the majority of autistic people, including me. And I feel that it is time to address that as a part of the community's mission. I believe that we owe it to our community to extend the co-occurring conditions subgroup.

I also think that we need to be open-minded how we address the myriad issues of autism, and again, we get into language problems with the community. Some things are best addressed by researching cures. For example, epilepsy, there's no good side to that. Nobody wants it.

While other challenges, like speech, may be addressed by technology, not medicine. And others, like making friends, are going to be addressed through therapy, and then we have other issues like GI distress that are addressed by perhaps diet and medication. So we have very, very

different kinds of research for very different needs.

Many commenters have posited different causes of autism, and at the same time, we confront research that suggests that a fair number of autistic people come by our differences naturally through a stable set of genetic differences. And it makes for such a difficult situation because we have some autistics who are articulate and independent like me, and we have other people who are totally disabled, and parents rightly say how can he be like me? And yet we are.

And I guess I would have to say that, as an autistic adult, I hope that all of you share my feeling that whether we're autistic or not, we are the people who were chosen by Secretary Burwell to represent autism for the U.S. Government for the purpose of formulating a strategic plan.

And I hope that all of you will recognize that even as you look at somebody like me and you think, "Boy, he's really articulate. He speaks really well," I am speaking for a community that includes some very much more impaired people than me, people who cannot speak for themselves, people who do suffer tremendously.

And at the same time, I have to stand here and speak for autistic people who are articulate, who just want accommodation. We have to recognize the breadth of that spectrum, and we have to recognize our duty to fairly represent and serve every person on it.

And I hope that you can kind of get behind the idea that our job here is not an abstract thing. We are here to deliver tangible quality of life improvements to the autistic population.

I believe in science, and I believe we're going to do this through the power of science. One of our greatest challenges here is how to communicate that to the public, how to do that science, how to get the results, and how to deliver them.

And please take to heart the idea that the basic genetics and the basic biology are great. That's a path that has led the CDC and NIH to victory over other diseases, but it's not applicable to every challenge we face in autism. We need the equivalent of those splints, braces, and wheelchairs along with the quest for something greater for the most crippling components of autism.

And at the same time, we need society to recognize that we need both things. This isn't one or the other, and it needn't be a fight. And I just hope we can pull together.

So I've taken a lot of your time, and I hope you can join me in that and we can all do our best to really deliver some benefit to all of these families that have written in. And I want to thank all of you who commented to us, both written and oral, and I want you to know that when you write these comments in, I and many other people on this Committee, we read what you say and we take it to heart. And even if you don't see the action, I want it more than anything, and that's why I'm here to try and achieve it.

So thank you.

[Applause.]

Dr. Cuthbert: So, John, thank you very much for giving voice to all the people who wrote in their written comments and for providing that elegant summary of the comments and of your thoughts about this.

We could certainly consider this as the part of the opening section of the discussion comments. We are very far behind our time, and as Susan

mentioned earlier this morning, a critical part of our work is to exchange information from all the members of this Committee and give updates about what they are doing because, indeed, that's critical to our role of coordination.

So I'd leave it to the Committee whether there are any very brief comments about -- discussion about the comments we've heard. I might propose that if we were able to get started with the Committee member updates by 2:45 p.m. and everybody held rigorously to their 5 minutes of time, we could get back on time. That would leave us about 5 minutes for some brief comments about what we've heard, and maybe a 5-minute bio break, and then we could reconvene.

So, Kevin?

Dr. Pelphrey: I was moved by many of the comments, the oral comments, and I appreciate the opportunity to listen to those. I was left out of one comment. I also serve proudly on the board of the Autism Science Foundation and am a friend of Alison's and appreciate her work very, very greatly. So I wanted to say that for the record.

Dr. Cuthbert: Okay. Thank you. Any other comments? Yes?

Dr. Ring: Well, I just wanted to echo what everybody is thinking in their head and how grateful, how thankful we all are for the comments that it beyond being inspiring are really the compass for us as we head into this next body of work.

I actually have more of a question for Susan. It's process oriented because I felt there were several comments made that suggested the formation of workgroups that could take on particular areas where there is a consolidation of concern or interest, some of which may overlap greatly with our own interests here around the table.

What is that process for the formation of workgroups, and within our charter, are these permitted? And can you walk us through how that might happen, if it can?

Dr. Daniels: So you are permitted to form different kinds of workgroups, and so I talked about that a little bit in my discussion this morning. We didn't reach a firm conclusion, but I think in January, we're going to be talking about the strategic plan update.

So the two major jobs that we have to do within the next year, within the next calendar

year, are to do a strategic plan update that covers 2014 and 2015 and to do a summary of advances for 2014 and 2015. Those are things that are required in the law, and so one of my priorities is to make sure that you meet those requirements and finish those projects.

And so I think that in the beginning, we should focus most of our working groups on those projects and get them done. And when they are out of the way, we could then plan some additional working groups. But just in terms of capacity, I have a very small staff, and so if we're trying to run 25 different working groups at the same time, I don't think it's going to work well.

So we need to prioritize and move down the list. But in the past, we've been successful in doing that, and we did form some extra planning groups last time that did accomplish things like writing a letter to the Secretary about services provision. And we've had other types of working groups, the DSM-5 working group that also did produce a document.

So we have had successes like that in the past, and I think we can do that again. So, you know, the floor is open for forming working

groups, but I would suggest that we don't form them all on day one and attempt to hold all these meetings at the same time.

Dr. Ring: So just procedurally, is that done by vote, or what is the process that that's done through?

Dr. Daniels: So with working groups, it's a little bit less formal, and so we can talk about it. Like I said, in January, I'm going to talk with you about forming groups to address parts of the strategic plan that need to be updated, and I would suggest that we start having meetings on that soon after the January meeting concludes so that we can get to work and start accomplishing all of those things.

But that will be a very busy -- be a very busy time of many meetings, especially if we have, say, seven different working groups meeting, and they're each going to have three meetings or four meetings. I would prefer not to add additional working groups onto that kind of a schedule until those meetings have occurred and taken place, and we've finished the project.

But we can then in each successive meeting, we can talk about issues that you want to work on,

and if there is an issue that the Committee feels like there is some action you want to take, we can form a planning group to start working on the issue.

Dr. Cuthbert: Okay. Thank you.

Two more comments. Louis -- and then Alison -- I think, had his hand up first, and then we'll need a quick break.

Dr. Reichardt: I just wanted to say, I mean, I think we took away from these public comments the fact that whether we're representing private foundations or public entities that we're responsible for -- we're stewards and have the obligation to make the best possible use of any funds that are available.

The second thing that I got from this was it would be especially useful to have the most updated version of the total spending in all the areas by public and private entities in the various major question areas that the NIH has identified. And I'd say that this is really quite out of date.

And finally, I'd just say I thought the very impressive summary means that all of us, while we are very interested in CRISPR and optogenetics and

transformative approaches that I think we should be devoting a significant part of our resources to what I guess I would call low-hanging fruit. I mean things that have some promise for more quickly improving lives of people.

Thank you.

Dr. Cuthbert: Thank you.

And before turning to Alison for the last comment, I would just remind us all that this Committee, as Susan mentioned this morning, is an advisory committee. So we do not actually control the disbursement or direction of any funding. We simply provide recommendations to the Secretary.

Dr. Reichardt: No, I'd just say that, I mean, for those of us who do perhaps have more flexibility, that it's very useful to know what the spectrum of funding is not just from the NIH, but from other agencies. And in fact, it's especially helpful the more extent -- the more international information we have, the better.

Dr. Cuthbert: Right. So thank you. Point taken.

Alison?

Ms. Singer: So as John pointed out in his comments, for many years, the autism community

really did ignore higher-functioning individuals who are now self-advocates, and it's great that now we're able to do a better job of identifying individuals who can serve as self-advocates and finding ways to provide support and services. And I am glad that there are self-advocates who are on this Committee.

But I think that as we heard from many of the oral comments, specifically from Mr. Enayati, from Dr. Mulvihill, from Ms. Oldham, from Ms. Gammicchia, and several of the commenters who submitted written comments, including Ms. Simon and Ms. Guppy, there is tremendous frustration about a new group of individuals with autism who are now the ones who are left behind. And those are the more severely challenged individuals with autism.

I think parents in their comments were expressing an extreme sense of frustration as a result of children who have intellectual disability, who are self-injurious, who are aggressive towards parents and grandparents and other siblings. These are children who are struggling with daily living skills.

These are children for whom we're not really

concerned with self-actualization, or will they be successful in college? But rather, we're concerned with daily issues of safety and helping them to use the restroom and to sleep through the night and to manage their pain.

So I hope that as a result of these comments that we've heard not only today, but for the past 8 years, that this IACC will make it a priority to focus on this group of children who really now are left behind. These -- these are the children who are not able to be successful in mainstream public schools, who needed to go to specialized schools.

And how do we now expect them to be successful in mainstream employment or in inclusive -- in housing that's not supported? These are individuals who as children, as teenagers, and now as adults will require 24-7 supervision to make sure that they stay safe.

And I think that it's really incumbent upon this Committee that we give special priority to this group of highly challenged individuals who are not able to come and be self-advocates because many of them are not verbal or are impeded by their behavioral challenges and cannot sit at this table. And who rely on their parents and their

grandparents and their siblings to come to this Committee and stand up and very courageously give public testimony.

So I hope that the Committee will make this group a priority.

Mr. Robison: I just want to second what Alison said. You know, I'm really keenly aware that when I speak up as an articulate autistic person, despite my best intentions, people like me speaking can render less verbal people invisible, and we have to be very, very mindful that we don't paint a false picture at both ends of the spectrum. And because frankly, for people like me, suicide is just as big a death risk. And we can't forget either, but we have to be very, very mindful of our most impacted population.

Dr. Cuthbert: Thank you.

Samantha, can you make a very brief comment? You're the last comment, and then we're going to break.

Ms. Crane: Yeah. I'll try to make this as brief as possible, that there's a false dichotomy between self-advocacy and what we would call "functioning talk." I represent the Autistic Self-Advocacy Network in my daily job, and our

membership includes a very wide variety of people, including people who need significant amounts of supports in order to live their daily lives and people who do not speak and instead use assistive technology to communicate or letter boards to communicate.

This -- you know, I don't think that it is necessarily appropriate to equate self-advocacy with a focus on people who are higher functioning in the terms that people are using. And -- or with people who don't have seizures, people who don't have significant medical concern.

So I just wanted to point that out.

Dr. Cuthbert: Thank you. I think that's a very good note on which to end this section of the discussion to indicate that these are not such extremes of one end or the other as we think, but they are very interrelated and overlap.

So thank you. Let's take a break for 5 minutes. We'll reconvene at 10 of and go into the session of exchanging information among us.

Thanks.

[Whereupon, the Committee members took a brief break starting at 2:47 p.m. and reconvening at 2:57 p.m.]

Dr. Cuthbert: Okay. If we can get going, please, and everybody can gather back at the table?

So we want to really keep on time for this block because we have just about enough time that everybody can have about 5 minutes. So when 5 minutes are up, I have my trusty stopwatch and my iPad, I will raise a hand. And if it goes much beyond 5 minutes and 30 seconds, I'll be waving both hands.

So, and I will try to mind my own time as I start with the NIMH update. So, go.

So this is the update from us, and lots of things have been going on. Just to remind everybody who is new, we are 1 of 27 institutes and centers at NIH. As you've heard, we have several other people from other centers here today, and we support research on mental health, both basic and clinical research, but notably also services research.

The overall NIMH budget is about \$1.4 billion, of which we fund around \$1 million in research. The others going to our intramural program and staff salaries. And we have the largest portfolio of autism research at NIH, totaling about \$114

million, which is over 10 percent of our entire grants base, which, of course, also includes many other disorders like schizophrenia, bipolar disorder, anxiety disorders, depression, and so forth. And as you can see, we have a wide variety of research in our portfolio, all of which is applied to autism spectrum.

One thing we do want to highlight, in fact, is that we've had to push ourselves on services research. Last year, we awarded 12 new grants totaling \$15 million, as you can see, to develop effective real-world ready approaches to various aspects of services, both for children, transition-age youth, and adults with ASD.

And just a quick summary of these, we have 5 projects for the birth-to-2 years timeframe to figure out how we can best implement and work out strategies for coupling children who test positive in universal screens with referral to and engagement in services.

We also have four projects for transition-age youth and families, as you see there, to develop strategies for school-based service coordination of transition planning to help with these issues of disconnecting from the supports they need and

move towards more independent living.

And finally, three projects for adults to develop and test strategies to maintain engagement in community support, vocational and employment programs.

So these things are often hard for grant applicants to put together, and it's important to give them another chance. Sometimes you have kind of a good idea, but the review committee says, you know, it's not really quite all worked out yet. So we've had another RFA, so called request for applications, where funding is set aside that just came out, as you can see, on October 28th, a couple weeks ago, to essentially solicit another round of these kinds of services applications. And we hope that we'll get even more well-thought-out applications, both new and revised.

Another thing that we have just recently developed is an integrated biobank. The NIH BioBank and the privately funded Autism BrainNet are collaborating to form a joint biobanking effort, which will result in a national network resource for tissue specimens.

And the partners include the three NIH institutes, as you see there -- NIMH, NINDS, and

NICHD -- and then the three private foundations -- Autism Science Foundation, Autism Speaks, and Simons Foundation. And we have just found out that the press release announcing the official signing and blessing of this agreement has been released, just as of about 10 minutes ago. So I'm pleased to be the first to announce this major new development.

Yes, breaking news, indeed.

So we also have an important Autism Biomarkers Consortium project that is just getting underway. This has been in the works for a long time, and it's a very large effort, as you can see. Again, a collaborative effort with multiple NIH institutes to invest \$28 million to look at EEG and eye tracking as potential biomarkers to help us define subtypes and to be used as markers of response in clinical trials.

We've heard a lot today about all the heterogeneity across the spectrum and how can we think that two people are really the same, or what do they share in common when we see all the differences? So this is an effort to help us understand more specific subtypes of the disorder.

On that basis, going for that, I mentioned

this morning our Research Domain Criteria project, which is designed to help us move toward precision medicine for mental disorders. And essentially, this is an effort to unpack our diagnostic categories.

As you can see there, rather than looking at an overall disease category or what we might think of as a disease category of autism that we know is so heterogeneous, and we know the same thing is true for schizophrenia, depression, bipolar disorder, really any of our disorders, these are broad syndromes. And any two people who share the actual diagnosis may be extremely different on many factors.

So what we're doing instead is to say we need to develop more homogeneous groups of patients for whom we can apply the same treatment and really understand these specific groups. So the framework calls for attending to neurodevelopment because, of course, autism is a neurodevelopmental disorder that starts essentially at conception, and there are many risk factors in utero and throughout development.

And then we look at effects of the environment, and then we study a lot of different

measures, which you can't see clearly there, but involve neural circuits and their constituents of genes and so forth and the outputs, behaviors, physiological measures and so forth.

And we call for using that framework to study very specific domains of threats -- difficulty with earning rewards; cognitive systems, so important, obviously, for autism; social processes, another very important area; and arousal/modulatory systems like sleep. And as you can see, we've already funded some 20 grants involving RDoC that are related to autism, and again, this is from the NIH RePORTER, and you can see these readily if you do a search for autism and RDoC.

And so this is a promising development that we hope will contribute to figuring out and unpacking the heterogeneity in the spectrum disorders, and I'll talk a lot more about that in the meetings to come.

Okay. So that's that update, and I will pass it along, and I think we'll just pass the pointer down the line because our slides are actually in order going around the table this way. So thanks, Susan. We're all set up.

Oh, that's fine. No, no. That's fine. But we'll welcome your update.

Dr. Dawson: I'll try to make this brief. So I'm going to begin by talking about the activities of the International Society for Autism Research, which I am now the president of for the next couple of years. And this organization is really the place where autism researchers from around the world can gather, and the goals of the organization are to promote high-quality science, but also to promote collaborations among scientists.

We also have a very strong emphasis on facilitating the development of young people getting into the field, and that's all the way from students to young faculty. And then we have a very strong focus on promoting scientists who are from low- and middle-income countries. So, really, we represent countries from all over the world.

Wanted to mention that the next meeting, the International Meeting for Autism Research 2016 is in Baltimore in May, and I also want to mention that we are involved right now in developing and updating our strategic plan at INSAR, and you'll be hearing more about that in the next several

months. But there will be a new focus on translating science into policy and practice, including a new focus on developing policy and practice briefs.

Another change in terms of INSAR is a year-round focus, it's mostly been focused around our journal, which is Autism Research, as well as the annual meeting. But now we will start to see INSAR as a year-round organization.

An example of that was the summer institute that was held for the last summer, and we did this in collaboration with SFARI, and it was a wonderful mechanism. I'm laughing because my little prompt to stretch is coming up on my computer here. But anyway, yeah, this was a wonderful mechanism for people around the world to be able to access information about autism science.

And then, finally, we did have our first regional Asian-Pacific meeting. So we typically alternate between the United States and Europe, but this particular meeting, we held outside of those two locations in China. This was in Shanghai just last week.

We had 700 attendees, 95 speakers. Thirty

countries were represented, and one of the most interesting talks was by Dr. Poo, who is one of the leaders of the China Brain Initiative, which now has almost become like a competition to get to the moon as the way that China is thinking about it, which is good, I think. But one of the interesting things about the China Brain Initiative is, unlike the U.S., they are focusing on specific disorders, including autism.

Briefly, in my other hat as a professor at Duke University and as director of the Duke Center for Autism and Brain Development, we are -- we have a very robust treatment program that infants through adults. We serve about 2,600 unique individuals with autism annually. We do have a very strong focus on addressing medical comorbidities with very robust medical subspecialties there at Duke and a very strong focus on training, all the way from undergraduates to medical residents and fellows and junior faculty.

And our research program, which is funded by NIH, also by industry, and by foundations, we have a very strong focus on treatment and clinical trials, focus on behavioral interventions and

medical interventions with an understanding of their impact on the brain, using EEG and MRI as outcome measures. And this is all part of Duke's Neuroscience Medicine Initiative.

We also have studies, however, that are looking at the basic biology of autism, as well as very applied studies, such as looking at how one can use technology to improve screening and do primary care. And then all the way to, at the far end of the continuum, we just launched a program with Duke's MBA program, where MBA students are going to be consulting with SAP, which is a very large software company who made a recent commitment to hire 1 percent of their workforce on the autism spectrum.

So Duke MBA students are now working with SAP to enhance the Autism at Work program. And I love this because not only will it enhance the program, but it's also future business leaders in the United States, you know, getting familiar with autism.

Finally, I wanted to point out that we are part of the new NIH Autism Biomarkers Consortium, and I think this is a really important project. It includes Duke, Harvard, Yale, UCLA, and University

of Washington. And the idea here is that a major barrier in developing new and effective treatments is our ability to measure outcome and deal with the heterogeneity and identify those people that will respond to specific treatments.

So this consortium and this investment by the NIH, which I really, you know, am heartened to see this level of investment in this to address this challenge, I think will really help the entire field to be able to conduct better clinical trials and then, hopefully, bring more effective treatments to people with autism throughout the lifespan.

Dr. Cuthbert: Thank you.

Dr. Judith Cooper: Good afternoon, everyone. I'm clearly not Jim Battey. Dr. Battey had to go onto the NIH campus for an event.

My name is Judith Cooper, and I'm the Deputy Director at NIDCD. That's deafness and communication disorders. So you can imagine -- that's one of the NIH institutes. You can imagine what our autism portfolio pretty much focuses on, and that is communication disorders. And I actually am the program person also responsible for the language and communication portfolio and

autism.

I would point out that within the last several years, I'd say maybe the last 5 years, we've had a real focus on minimally verbal individuals with autism, and we've had some workshops. We did a couple of initiatives.

And earlier today, someone mentioned the Autism Centers of Excellence, the ACEs, those are major activities with regard to autism across a number of issues, and we actually are funding one of the ACE centers focused on minimally verbal children. So we're anxious to see more, and I have seen more and more research applications in that area.

The other thing I'd want to point out is that NIDCD, along with others that you'll hear from, other NIH institutes, make up the Autism Coordinating Committee, not to be confused with the IACC, but the ACC, which -- and we meet actually every month to talk about activities that are going on within our individual institutes, to talk about collaborative efforts, and to work on issues that perhaps come from the IACC that we want to try and address.

So just rest assured that once you go home, we

continue to work on a daily basis, and we meet once a month to deal with critical issues. So thank you.

Dr. Cuthbert: Okay. Thank you.

Dr. Pelphrey: So I made a list of updates. So I direct the Center for Translational Developmental Neuroscience at Yale, and this is a cross-disciplinary center that joins forces between the Child Study Center, genetics -- department of genetics, neurobiology, psychology, and some other departments as well. Pediatrics is a major one.

And so we have a variety of efforts underway. One major focus for us is our Autism Center of Excellence network that focuses on girls with autism.

So, you know, just to give you some highlights, we have 2 years left in the initial project, and we're starting to submit papers now based on our initial findings. And we're very excited that we think we've found a signature, you know, basically a biomarker of the -- what people are describing as the genetic resilience against autism in girls in general, particularly girls who are the siblings of probands with autism, boys or

girls with autism.

And also we've really surprised ourselves by showing that some of the things that we held most true about the brain and autism functionally speaking are really very different in girls. For example, we found no evidence for social brain disruption in girls with autism.

Despite severe presentation in terms of the phenotype, they're not showing these characteristic signatures. And so autism seems to be quite different, and so we're happy to unpack that and show people slides on that.

We also have an RDoC-funded grant. Thank you very much. This is focused on aggressive behavior. Most of our participants we're finding are coming from groups of oppositional defiant disorder, you know, in terms of classic diagnoses, and then a lot from our autism studies. And so we're getting cross-referrals because so many parents are presenting with the primary concern for their child of, you know, my child is aggressive and beyond control.

And so we're actually implementing cognitive behavioral therapy with those individuals and using neuroimaging, as well as electrophysiology

with my colleague Mike Crowley, to understand stratification biomarkers, biomarkers in terms of treatment progress, and outcome biomarkers with those individuals so we can understand how cognitive behavioral therapy works. And when it doesn't work, we can understand whether or not we could have predicted for whom it would work.

And this is across disorders. And what we're finding is that our stratification biomarkers in particular are really applicable across disorders, and then unsurprisingly, the manner in which the aggression recedes, when it recedes, the underlying indicators of the mechanism, as measured within the gene and electrophysiology, are different depending on the overlaying disorder.

So very excited about that. We're in our third year of that project.

We have a large training component. I direct an NIMH T32. So thank you again for that. And so we are focused on training clinician scientists to do extraordinary, we hope, research.

We've been very proud -- I'm in the -- this is in the 32nd year of funding, and so, obviously, I have not been the PI. It's been around almost as

long as I have. And so I am taking over from Jim Leckman, and we're kind of refocusing this on a much more developmental translational neuroscience perspective.

We also have -- so that's a bit of advertising for leading figures in the room. If you have graduating medical students or Ph.D.s, send them our way.

We also have a training program funded by Debbie and Larry Hilibrand specifically focused on training the next generation of scientists and clinicians to address issues related to adults with autism. So definitely send us your students for postdocs.

And then the last thing I want to highlight is our work on childhood disintegrative disorder, and this is funded by the Simons Foundation. And we're excited about this, particularly given, you know, one of the videos we were watching earlier where a child experienced a profound regression.

So it's rare, but it's a very distinct phenotype to experience a regression. And so we were able to go back in our records and identify this rare disorder, 32 of these individuals across 10,000 people that have been seen at the Child

Study Center over the years, and go back and get genetic information from them.

And we actually scanned their brains, and this is no small feat because the average IQ amongst these individuals is 30 to 40. And so this is kind of a first picture of brain imaging data in very low-functioning individuals with autism.

And again, what we're finding is something quite surprising. The things we thought we knew about autism and the autistic brain from studies of high-functioning individuals, very different in these individuals and not necessarily worse, different.

And so, and then also the genetics. Whereas the genetics in idiopathic autism seemed to focus on a particular portion of prefrontal cortex in early to mid-fetal development, the genes that seem to be driving regressive autism are actually expressed later in fetal development, and there are underlying genetic causes. We were able to find candidate genes.

We were very excited about this. This will come out in a pretty good journal very soon. So stay tuned for that.

And that's all from Yale.

Dr. Cuthbert: Thank you. Very interesting.

Dr. Wexler: Good afternoon. The Office of Special Education Programs has been involved in funding the development of both professional development and graduate student or undergraduate student modules in the area of ASD. These are all evidence-based modules.

I would encourage you to look at IRIS -- which is our center -- dot-Peabody-dot-Vanderbilt-dot-edu. They have probably 100 different modules, but we kind of commissioned them as a result of the IACC, and a lot of the discussions around the DSM-5 and the changes in that.

So one of the modules, there's a focus on the differences, the changes in the diagnostic categories. The other is Afirm. And I would just Google, A-f-i-r-m -- not two, one F -- modules or autism modules, and they're an outgrowth of our Autism National Center on Professional Development. They've updated all of the research in autism, and we supplemented them a bunch of money to then translate that into training modules.

Thank you.

Ms. Haworth: Hi. I'm Shannon Haworth, and my

connection to autism is very personal. As you can see, that's my son. It's a shameless plug for him, I know.

He's 9 years old, and he's the reason I'm here. I'm one of those parents who stay up at night worrying about their son and their future. I've experienced the frustration of getting a diagnosis for my child and getting appropriate services for him. So I feel the pain of parents, and I can understand those comments.

My biggest -- our biggest problems are his co-occurring conditions and also school. So he has mental health conditions -- anxiety and mania. He's been hospitalized eight times since he was 5, and he's only 9 years old.

So I'm oftentimes scared I'm going to lose him. So that's also echoed in some of the comments as well. That's a big problem, co-occurring disorders.

And also school, you know, he was suspended multiple times and sent home with no plan for his return. So that is also a struggle of a lot of families. So I'm here to be their voice as well.

So organizational activities. I work for the Association of University Centers of Disabilities,

and get ready for the acronyms. We have Leadership, Education, and Neurodevelopmental Disabilities programs and Development Behavior Pediatrician programs. We have -- sorry, we have 43 LEND programs, and we also have 67 University Centers of Excellence in Developmental Disabilities programs and 15 Intellectual Disability and Developmental Disability Research Centers. I got that out of the way.

So, and the last year, over 2,000 LEND and DBP trainees completed coursework about the early signs of ASD and developmental disabilities, as well as screening and diagnosis and evidence-based interventions. Over 1,200 of these trainees also completed coursework covering the early signs of ASD.

Almost 90,000 infants and children received interdisciplinary diagnostic services to confirm or rule out ASD or DD by our trainees, and also almost 2,000 faculty and fellows worked in clinical settings located in underserved populations.

We also have -- we have a meeting of CARES grantees, Autism CARES grantees every year. And our 2015 meeting, I have some links. There are the

resources from that meeting.

We also have an Autism Special Interest Group, which I am on. I personally work on the including people with disabilities and public health workforce competencies, trying to get public health professionals to increase their capacity to include people with disabilities in their public health program planning efforts.

And we also did a recent commentary in Pediatrics magazine on system-wide solutions to improve early intervention.

So what I'm hoping the IACC can address is -- thank you -- is to increase the number of LEND programs originally intended under the Autism CARES Act to target the lack of trained professionals to diagnose, rule out, and provide evidence-based interventions. Just something that this was of concern to my organization, I approached my organization and asked them what they wanted me to talk about.

These last three are mine. The school-to-prison pipeline for minority children with autism. Suspension rates are very high, and sometimes police are called. And that is my biggest fear. Because once you touch the justice system, there

is nothing mommy can do. So I'm very fearful of that.

Also autism and mental health, which I just talked about. And lastly, I asked the self-advocate in my office what she wanted me to say, and she said, "I would like an effort to allocate a higher percentage of research for and about autistic adults with the focus to be on services and improvement of quality of life and independence. More community-based participatory research that partners with autistic adults would be wonderful."

Thank you.

Dr. Cuthbert: Thank you.

Ms. Kavanagh: The joys of following Shannon is that the AUCD represents the organizations that we fund. So you've already heard about LEND. And Shannon comes from a LEND program as well.

We're funded through the Autism CARES Act, like the IACC. And CDC receives money, as well as HRSA. Our roles are to increase public awareness, promote research into the development and validation of reliable screening tools and interventions, promote early screening, increase the number of health professionals who are able to

confirm or rule out the diagnosis of ASD, and increase the number of providers who are providing evidence-based interventions.

We collaborate very closely with CDC on these areas, from "Learn the Signs. Act Early." to the Act Early Ambassadors. You'll hear more from CDC later.

We fund three program areas. One is around autism intervention research. One is in the areas of training both developmental and behavioral pediatrics fellows; LEND, which I'll talk about in just a moment a little bit more, Leadership, Education, and Neurodevelopmental Disabilities; as well as State implementation grants.

Our intervention research portfolio is relatively small, certainly compared to NIH and others. We support 5 research networks and 12 autism intervention research projects. Our two largest networks focus on autism intervention research for behavioral health and one on physical health as well.

Our newest investment is in Healthcare Transitions Research Network. That's looking at a variety of areas to address health issues, as well as family and social needs of adolescents and

young adults on the spectrum. It was just funded in 2014. So I went to the early kickoff meeting for that, not that long ago.

LEND is one of our interdisciplinary training programs. We have 43 -- as Shannon mentions 43 programs in 39 States. We're trying to not only train wonderful clinicians, but also make sure that they are practicing in an interdisciplinary fashion. They're trained in an interdisciplinary fashion, and I'll show you the disciplines that we train.

They're focused on family-centered care, and we also want to make sure that they have policy and advocacy skills as well and not just trained as clinicians. And they're also dedicated to caring for children with neurodevelopmental disabilities, including autism, and we have a good track record in them remaining in the field over time and being leaders in the field.

These are the disciplines that are funded through LEND programs across the country from medicine, social work, speech-language pathology, OT, PT, psych, genetic counselors, health administration, and you can see the rest.

LEND fits within our larger autism efforts.

We're increasing the number of professionals, but we're also trying to influence curricula over time.

Families are an integral part of our LEND training programs as well. They're required to have family faculty as part of the training endeavor. They've trained an average of 1,300 long-term trainees, 3,200 medium-term trainees, and 11,000 short-term trainees each year.

Oops, that was the previous slide. I apologize.

We also fund developmental behavioral pediatrics. These are fellowship programs. There are 10 programs across the country, and we also fund State programs in 13 States, 4 planning grants, and 9 implementation grants.

These are focused on a variety of ways to improve State systems of care for those with ASD, including improving early screening, family engagement, family-centered services through a medical home, and also preparing families and youth for the transition.

And this is my contact information.

Dr. Cuthbert: Thank you.

Ms. Goodman: Okay. Like I said before, my name

is Amy, and I work for the ARC of the U.S., and I'm the director of Autism Now, which is one of our programs. And some of the new things that we have on there that a lot of people don't know about is that I have a consulting service where I like to go out and do speaking engagements.

And, but that's just one of my roles. One of my other roles is to work on the employment at the ARC, employment in ASD. And so as part of the grant for Autism Now, we created a manual or a handbook for employers on how to work with individuals with ASD, called "Talent Scout: Employing Individuals with ASD."

It's written from the perspective of individuals on the spectrum, and our goal is to sell it to employers to help them meet their 503 hiring goals in the Government, but also to any employers that want to learn anything about ASD and how to work with individuals on the spectrum.

So I'm just going to put a plug in for it since we have a new program at the ARC called the ARC at Work. So we have a separate Web site called, it's www.thearc.org/thearcatwork, where it tells you all the things that we do in employment and different initiatives and things that we're

working on for individuals with intellectual and developmental disabilities, as well as autism.

And other than that, my other role is the national self-advocate council of the ARC. We have a group of people where we meet at our conferences every year, but we also have like monthly meetings to discuss issues of self-advocates. So that's another thing I do.

Dr. Cuthbert: Okay. Thank you.

Dr. Lawler: Hi. I'm Cindy Lawler. The Autism Research Program at NIEHS is focused on supporting research studies that address the role of risk and protective factors, environmental risk and protective factors for autism. We're estimating that in fiscal year '15, our portfolio is going to be around \$12 million.

This has increased significantly over time. In 2002, it was about \$1 million. So I'm really delighted in that increase, which reflects in part the growing interest in the scientific community and the ability of investigators to write compelling applications in this area.

I want to call your attention to two recent initiatives that I think are very exciting. The first is a 3-year research initiative program

announcement with a special review on environmental contributors to autism spectrum disorder. I should point out that this initiative, the research being solicited was very well aligned with the objectives in the IACC Strategic Plan.

The overall goals were to identify environmental contributors to risk and expression of autism, to understand the underlying biology, and we were looking at approaches from -- all the way from model systems to studies that add new data collection to existing human epidemiology studies, and we were really interested in applications that looked at environmental risk in the context of genetic susceptibility.

I would also want to point out that this initiative was really a work product of what Judith had mentioned earlier, this very collaborative ACC, Autism Coordinating Committee. So this initiative was, you know, sort of co-written and vetted through this committee. NIEHS is leading it, but we're doing so with our partners at the Child Health Institute and Mental Health as well.

And I'm pleased to report that for the first year of this 3-year initiative, we've made 10

awards. So 10 applications were successful. The exposures that are under study in those 10 projects are very diverse. The approaches that are used are diverse as well, from in vitro model systems to human epidemiology studies.

So we have investigators looking at how environmental chemicals that act as hormonal mimics. You may have heard the term "endocrine disruptors." Compounds such as phthalates and plasticizers, flame retardants, PPGEs, how they may affect risk.

We have studies looking at different components of air pollution, aspects of diet and nutrition, immune activation. And several of the studies are trying to understand a joint contribution of genetics and the environment.

So that initiative will be active for 2 more years, and we'll be able to report back to you our new studies that are funded in the subsequent years.

The second activity I wanted to call your attention to is also just now underway, and it's called CHEAR. And CHEAR stands for Children's Health Exposure Analysis Resource. And this initiative was made possible because of

redirection of funds that were allocated to support the National Children's Study.

So the CHEAR initiative is very much in keeping with the spirit and intent of the National children's Study, which was to, you know, understand how the environment impacts children's health. NIEHS is leading this initiative on behalf of NIH.

And the way it works is this is a resource for investigators who have existing study in any aspect of child health. So it's not focused on autism, but it will certainly be open, and I'm very much encouraging our autism researchers to consider it.

So for those researchers who are looking at aspects of children's health and who have biologic specimens, whether it's blood, urine. It could be hair. It could be toe. It could be newborn bloodspots, a wide range of biospecimens. And can come in and ask for a laboratory network to do either very targeted analyses of those biospecimens to look for exposures or biologic response to exposures as marker of past exposure, or they could come in and ask for very kind of untargeted hypothesis-free approach, using

metabolomics as an example of that.

They would get those data back. They'd also -- there's a resource to provide statistical and consulting services. The data from those exposure analyses will be deposited in a database along with companion data that were collected under the parent grant.

And you know the idea is that we'll be able to provide this service to a significant number of existing studies and through integration of the data that are in that database really support the collaborative analyses. So the real goal here, the outcome that we're hoping for, is more studies that are including environmental exposure analysis as one part of their study.

There is also some, you know, technical research that's being supported as well to help improve the exposure biomarkers and some work to help develop and implement common vocabulary or terminology that could be used within environmental health sciences so that when you have multiple studies, the data can be more easily integrated because the terminology is similar.

Those -- the multi-component initiative was just funded several weeks ago. We have a kickoff

meeting over the next 3 days. So I'm sure our director will in future meetings keep you updated on the progress.

Thank you.

Dr. Cuthbert: Okay. Thanks, Cindy.

Dr. Ball: Thank you. Just wonderful things going on from the Autism Society in the last couple years. We've now embarked on our 5-year strategic plan. Our board will get the information in December, and hopefully, we'll be starting to implement it in January.

And the implementation is really going to look at advancing individuals on the spectrum, especially the adults, the information and services in order to maximize their quality of life from life stage to life stage, and we'll be advancing our efforts to be all measurable outcomes. So we're really going to look at how we define success as outcomes related to the advancements in the quality of life.

We just completed a detailed study on adult services needs and how a State and national public policy agenda can address these needs. The study was paid for by the Hussman Foundation in conjunction with the Autism Society and

Congressman Chris Smith's office. So we will be publishing a paper coming out also in January discussing those policy needs and how we will address them with that group.

And the last thing from the Autism Society is that we were very active and strong leaders in getting the passage of both the Autism CARES Act and also the ABLE Act.

Dr. Cuthbert: Okay. Thank you.

Mr. Parnell: Lots of good work going on. At the Utah Department of Human Services, one of the hats that I wear is as the Medicaid autism waiver manager. Most of you are probably aware already that recently, the Centers for Medicaid and Medicare Services provided guidance that State plan Medicaid does cover autism treatment for children. And so those States that have Medicaid autism waivers have been encouraged to provide transition to those children receiving treatment through a waiver program on the State plan.

Utah has just completed that transition. The good news for us is that rather than serving, we had at a high point about 330 children in treatment, estimates of the numbers of children who can get treatment now through State plan

Medicaid is about 4,000 throughout the State. So autism treatment is now available to a lot more children in the State of Utah because of that guidance.

Utah has an autism State plan. Essentially, it's a strategic plan, and our plan is now 5 years old. So we're in the process of just beginning to update that.

It's a pretty far-reaching State plan. It covers issues from education, transition into adulthood, certification of autism treatment providers, really most of the things you can think about that would improve the quality of services and the array of services for people with autism and for their families that care for them. So that work is just beginning, and I look forward to giving you updates as we continue to meet.

And then, finally, in their last session, our legislature passed our State's autism insurance mandate. So beginning January 1st, most insurance providers doing business in Utah are now required to cover at least some treatment for children who have autism.

Dr. Cuthbert: Very good. Thank you.

Rob?

Dr. Ring: So it's a pleasure to share some updates from Autism speaks. Just not enough time to really cover the full sort of comprehensive work that's being done across the organization in family services and advocacy, much of which has already been touched on, particularly our work with Autism CARES and in ABLE well, a jobs portal that was just launched, and these are things that I'm happy to go into detail in later meetings.

So I'll focus on a few high points in the area of our science mission, which is very intertwined with our other pillar areas.

Already mentioned, Bruce, was the Autism BrainNet. We're really, really very pleased that Autism BrainNet and our collaboration with the Simons Foundation in getting that up and running, and what Alison and her organization has done to help build awareness for the importance of donation is a really, really, I think, special accomplishment. And to think that we're going to be working closely with NeuroBioBank moving forward is just -- it's fantastic.

And this, for us, is really, you know, satisfying, given, as you know, we had operated our autism tissue program for over a decade. And

in order to make that happen, we spun that program out to help get things going.

In other areas of investment, longstanding work that we've done, our Autism Treatment Network, for those of you who are not familiar with this, this is a network of 15 clinical centers across North America that see over 35,000 or have over 35,000 unique clinical contacts annually with the autism community.

We're really pleased to have renewed funding from HRSA. This year, we'll be serving as the AIR-P for physical -- the Autism Interventions Research Network for Physical Health. We're really pleased about that. A lot of our focus moving forward is going to be on underserved populations and developing comprehensive medical models of care for adults in transitioning into adulthood.

Perhaps a thing that is capturing most of our work and we have a lot of visibility around is our MSSNG program, which many of you heard about. This is a large collaboration we have with Google to build a genomics database online in the Google Cloud.

The goal of this database is to have whole genome sequenced 10,000 individuals with autism

and their nearest family members and to have completed that by the first quarter of next year. I'm pleased to say that we've already completed the whole genome sequencing of 5,500 genomes. That's already one of the largest complete genomic databases in the medical research space, and we're really on track to hit that 10,000 mark by the end of first quarter next year.

The portal, which allows researchers in an open access manner to visualize the data there, analyze it, spin up the whatever compute horsepower they need from Google to make sense of that, has already gone live. We have over 70 researchers around the world working on that data as we speak, and we expect that community to continue growing in time.

On the collaborative front, just to bring up some studies that are going to read out in the near term, our SUCCESS study that is being run out of South Carolina and one of the CDC ADDM sites. This is a study that was aimed at looking at two different prevalence methodologies, the same methodology that is used by the CDC to determine prevalence and more of a population screening approach that featured in the South Korea study

that many of you have heard of.

That study actually showed a prevalence of 1 in 38, or 2.64 percent. That study is actually due to read out at the end of this year, and we might be hearing results at the beginning of next year.

Nice little twist on that study. In addition to looking at population-based approaches here in the United States, the group is also looking at the difference between DSM-4 and DSM-5 prevalence estimates based on different diagnostic criteria.

Just would wrap up by making note that we're really happy with a -- you'll see this more from Autism Speaks, more focused RFAs on specific problems, many of them inspired by discussion that has happened here in IACC over recent years. We had an RFA just last year that is starting to read out. This RFA focused on the gut-brain axis and understanding the implications of GI disorders for treatment development.

We had two really fantastic projects. One just focused on a very, very straightforward clinical trial trying to build an evidence base for constipation treatments to provide parents and clinicians with evidence that this actually works so there's no more resistance to even just simple

approaches, is the here and now type of read-out for us. And we have really nice metabolomics approach to studying the gut microbiome.

Last two things. We just celebrated our 2015 Weatherstone class. This is our pre-doctoral fellowships. So we're very, very happy with our training program. We give out both pre- and postdoctoral fellowships and really happy how the fellows are going out there and actually making contributions to the field.

Through our venture philanthropy arm, DELSIA, we've actually invested in a company called Akili Labs, and some folks here are actually involved in this clinical trial. Akili is actually developing a therapeutic game for autism. So really trying to push the boundaries on the modalities of treatment and recognizing that we need multiple modalities available.

The development path for technologies is less encumbered than what you would see in a pharmacological path, and so we're really excited to see what that company is doing and happy to support their work.

The last thing I would wrap up is we have really enjoyed, as many of you, the wind, if you

will, in the sails of the legislative activities here in D.C. with CARES and ABLE having so much momentum. I think there's a real opportunity for the autism space to take advantage of that and engage into some of these other legislative activities like 21st Century Cures and the Precision Medicine Initiative.

And that's one area that you'll see a lot of activity for us as a foundation moving forward. That said, really happy to keep you guys up to date as we move forward. And if you ever have questions on any of the work that we're doing, I'm happy to answer them, or you could always go to our Web site for information on us.

Thanks.

Dr. Cuthbert: Okay. Thank you.

So, Louis? Jumping across the table.

Dr. Reichardt: So for the last 2 years, I've directed the Simons Foundation's Autism Research Initiative, and I'd just remind you that our mission is really to support science that will overcome the barriers that limit our understanding, diagnosis, and treatment of autism. And so when you come onboard, you've got to create a strategic plan. So we have some experience, and

I'll just summarize very briefly that we have four major priorities.

One is to identify risk factors, and I stress whether these are genetic, environmental, or epidemiological, that we want to use human and nonhuman organisms to understand how these risk factors alter brain function and behavior. We also have a mission to promote preclinical and clinical investigations to improve diagnosis and therapy. And finally, we've had a major goal to increase the size and quality of the autism community, as well as the quality of knowledge on autism with which they work.

And so just going back to risk for a minute, I'd say obviously the low-hanging fruit has been genetics. Over the last year, I think the work that we and others supported when put together identified more than 70 genes and 20 copy number variations that are very strong risk factors. And I'd just say the gold standard in this has basically been de novo risk -- de novo genetic alterations that show up multiple times.

We have piloted a whole genome sequence project using the Simons Simplex Collection, which is very deeply phenotyped. And what we can say at

this point, what our hope is this will shed more light on particularly the genetics of high-functioning autism that it's clear that we're identifying promoters and enhancers that become strong risk factors.

So these are promoters and enhancers in genes that through these other mechanisms, loss of function studies have been implicated already as autism risk factors. We'll see where that goes, but we're committed to sequencing the whole collection.

Very importantly, we'll shortly, and any of you who are interested, I'd encourage you and your families to enroll, initiate a project to assemble a group of 50,000 families across the country where somebody in the family has autism. And we expect to do this mainly through clinical centers, but also directly through the Web.

We will exome sequence using saliva samples produced by members of this family, and if we have risk genes of the certainty that I just described among this list of 70, for example, we will return this data to individuals through their healthcare providers. So in some ways, it can help families. Just the knowledge I think can be helpful.

And so the pilot phase of this will start in about a month, and if people are interested, I'd encourage you. It's absolutely free, and we will obviously provide ongoing support, and if somebody feels like they've been let down, obviously you're free to withdraw from the study.

But the hopes for the study is this will further increase the number of risk genes that we can say with some certainty are autism risk. We will reevaluate this list annually. So I'd say even if somebody doesn't come up initially, it may come up in a couple of years or 3 years.

Our hopes are that this will be a cohort that's sufficiently large that it will be attractive to agencies such as the National Institute of Environmental Health Science, be used for these environmental risks and epidemiological risk studies.

We also hope that this will be a cohort that is additionally used and of interest and help for scientists, will encourage pharma to enter the space more vigorously. Because we think that with this number, we will be able to identify sub-cohorts of individuals that share specific risk and specific phenotypes and so that this is

attractive to pharma.

On the biology side, you know, that we've put a lot of effort into both human imaging and studies on nonhumans, animal models to understand circuits and functions that are disrupted in autism. I'd say at this point one major goal is to understand, since we have in some cases, for example, repetitive behaviors, linked defects from specific genetic alterations to alterations in specific circuits and specific synapses to understand how widely these are shared across the spectrum.

Because, obviously, the more wider they're shared for any specific behavior, the more attractive they are to pharma. And in some way, you could say the simpler in conceptually the interventions are. And so I don't know the answer to this, but this is something of high interest to us.

We've supported recently focused grants on the innate immune system, which goes under the microbiome immune interactions. We recently sponsored a study on fever, and we expect to support some work on this to understand what the basis is of many individuals that have

improvements in behavior when they have fever.

And we're very interested in sex differences, and I know Kevin was just there at the foundation yesterday for one workshop that we had, which was focused on brain imaging. We had a separate workshop on single cell analysis, and we expect to provide some support in this area also.

And as I said, I think everybody is very enthused that we can collaborate with the NIH, Autism Speaks, the Science Foundation, and so on. And promoting the Brain Bank, accumulation of the Brain Bank.

I have taken away from this, and I think you'll hear more from us shortly, about what I call the low-hanging fruit endeavors. I mean things that we think may be tractable to improving the quality of life of individuals, such as improving sleep or GI function, short of completely correcting the disorder.

Translation. As I say, this 50,000 cohort, which we're calling SFARI, to really the center of our activities. But in preparation for it, we supported work to get more accurate biomarkers, a recent study which is still ongoing with Cathy Lord and her colleagues.

There is two drugs that we've looked at, one outside the foundation, bumetanide -- which is a study which will be unblinded at the end of, I guess, January by Neurochlore, a company in France. So it's requiring foundation support -- and Baclofen. And let me just say that we'll step back and we're looking at this.

Finally, I should just say that we recently completed a competition for a transition to independence award where we're -- and we will support six very outstanding postdocs. They will get \$150,000 a year for the first 3 years once they have an independent position. And so we've made the decisions, but they haven't been announced yet. And so I can't tell you who they are, but we're very committed to supporting the next generation of scientists interested in autism.

Thank you.

Dr. Cuthbert: Thanks very much for that thorough report on all your activities.

Before we move down the table, Dr. David Mandell is a member of this group but was not able to be here in person today. We think that he is with us on the phone. Dr. Mandell, are you there?

[No response.]

Dr. Cuthbert: No. Dr. Mandell, you're not on mute?

[No response.]

Dr. Cuthbert: No. So maybe we will hear from him in January. We wanted to give him a chance, but it didn't work.

So, okay. Dr. Kato, please, go ahead.

Dr. Kato: Well, the primary involvement of AHRQ in the field of autism has been through the production of five systematic evidence reviews, which look at what evidence is available to answer different questions about the treatment of autism, questions that we've received from the public.

And we're currently in the process of updating one of those reviews, looking at medical treatments and interventions targeting sensory effects on autism. And we had convened a group of patients and researchers and policymakers to draft what they felt was the most important key questions in this area.

Those draft questions are now actually on our Web site and available for comment. So if you have time to go and look and give us your opinion of how those questions could be made the most useful

for your work, that'd be terrific.

The Web site is effectivehealthcare -- that's all one word -- dot-ahrq-dot-gov. And if you go there, on the front page, there will be a link with this particular review, and there will be a place for you to give comments on how you think the questions could be improved. They'll be up until December 7th.

Thanks very much.

Dr. Cuthbert: Thank you. Samantha?

Ms. Crane: I'm Samantha Crane. I'm sorry. I've got to move this a little bit.

I'm with the Autistic Self-Advocacy Network. I want to reiterate during this time that the Autistic Self-Advocacy Network is focused on a wide variety of policy goals for people across the spectrum, including people with very high service needs.

In fact, in the recent Autism CARES reauthorization cycle, we were one of the primary organizations, I think maybe the only organization, that was specifically requesting -- we spearheaded a request -- to make sure that at least one self-advocate on this council was someone who received home and community-based

services through Medicaid. And that to be eligible for home and community-based services, a person has to have a very high level of care need.

Self-advocates are currently still the least represented of the three mandatory groups on this council, and we still believe as a goal that we want to include a self-advocate who uses home and community-based services in this Committee.

We are informed by a disability rights perspective, and that perspective includes everyone at all levels of disability. John Elder Robison mentioned polio as an example of the importance of accommodating people in addition to addressing the medical concern.

And actually, polio is an extremely good example because polio survivors were some of the most vocal, most active proponents of the disability rights perspective. They were very clear that they did not just want to be seen as patients. They wanted to be seen as participating members of society, including people who had very significant mobility and respiratory problems as a result of their experience with polio. So that's actually a very good example of our perspective.

Acceptance of people on the autism spectrum

means making sure that we have access to appropriate supports. Medical care and access to medical care is one of our primary goals.

We worked with a research collaborative called AASPIRE, A-A-S-P-I-R-E, to develop a participatory research model identifying barriers to healthcare, especially barriers for adults seeking healthcare in the community who might have very significant difficulties managing their health and communicating with healthcare providers. That toolkit that came as a result of that research model is at autismandhealth.org.

We're very concerned about comorbid conditions, as seizures are an example. Connective tissue disorders are another example that I don't remember hearing mentioned today but are very significant.

We are also spearheading work on supported decision-making for adults in healthcare contexts, especially people who have significant communication impairments and might otherwise have difficulty communicating with doctors about their healthcare choices and their goals.

Access to communication supports, as the commenter ASHA mentioned, is very important to us,

and that goes across the lifespan from the educational context in schools straight through to adulthood. Without access to communication, many other goals, such as community integration, education, medical treatment and access to quality healthcare for health concerns are going to be very difficult to obtain.

We need to understand that many things that we see as behaviors are attempts to communicate. We've been working to really include communication supports in the complement of autism interventions. We recently published a toolkit on behavioral health in the Medicaid context.

That toolkit, one toolkit was aimed at individuals and families receiving Medicaid. Another one that we recently published last month is aimed at Medicaid administrators to understand the full range of supports that need to be included in State plans, as Mr. Parnell mentioned. And we're working on updating that toolkit for the private health insurance context in the coming year.

We also have published a toolkit on the home and community-based services settings, including the needs of adults, not just young adults, but

also the aging population for quality residential services, healthcare supports, and employment supports. We really need to address the needs of under identified populations, and that includes people of color, who are much less likely to be diagnosed with autism; adults, including older adults who might not have been identified; and girls.

And while we're talking about the needs of under identified populations, the school-to-prison pipeline is also a very big concern of ours. We see students who are not receiving the services that they need in schools. Their behaviors are being treated as criminal problems, not as autism, and that is often because they're not identified.

Finally, we are very concerned about the needs of families and caregivers, but we're also concerned about the extremely high rates of abuse against autistic individuals from childhood to adulthood often at the hands of caregivers, service providers, even people who might be serving the individual in school or in the community or in an institution. We really need to engage in significant research into abuse prevention. How to identify the signs of abuse,

especially in people with significant communication impairments.

Dr. Cuthbert: Okay. Thank you.

Dr. Williams: Hi. Nicole Williams with the Autism Research Program.

Since we always seem to get our funds late and we're always playing catch-up, I'll just talk about our FY '14 cycle, which just closed not too long ago. We offered two award mechanisms. One was the clinical trial award. The focus of that award mechanism was to make a major impact on the treatment or management of ASD.

The other award mechanism we offered back in FY '14 was the idea development -- excuse me, idea development award mechanism, which is more of a high-risk, high-reward type innovative project awards. We funded three clinical trials and then four projects under the idea development, and I'll just give a brief overview of the three clinical trials.

The first one was -- is going to test an outpatient behavioral treatment I guess over an 18-week period for kids 7 to 12 years old with high-functioning autism.

The second one is to determine the social

effects and safety of sulforaphane, which is derived from broccoli sprouts, again in children younger age, 3 to 12, with moderate to severe ASD.

And then the third one that was funded was to test 24 weeks of direct instruction language for learning in children 5 to a little bit less than 8 years old with ASD and moderate language delay.

So, again, we just funded those. So we're not going to see those results, unfortunately, for another year at least.

So FY '15 -- I should have mentioned before in FY '14, we were given \$6 million from congressional appropriations. Again in '15, we received \$6 million again. Our program panel decided to continue with the clinical trial award mechanism and the idea development award mechanism again.

For FY '15, they -- our panel decided to focus on areas of interest, as they've done in the past. Some of these include behavioral, cognitive, and other nonpharmacological therapies, pharmacological treatments, therapies to alleviate conditions for co-occurring with ASD, environmental risk factors, factors that promote success in transitioning to independence, and then

a big one for our group is dissemination of effective behavioral interventions.

Our applications were due last month. We are going to have our scientific review next month, and then the list of those awards that will be recommended for funding will be held in February. So we have a little bit more to go, but we're getting there.

Dr. Cuthbert: Okay, thank you. Edlyn?

Dr. Pena: Hi. I'm Edlyn Pena. And again, I guess I play a dual role. I'm a faculty member at Cal Lutheran University in California, and I'm also a parent to a 7-year-old son. So I'll talk a little bit about both of those things.

I don't have a lot of updates because I don't represent a large organization. I'm pretty much doing research on my own, and I'm very jealous of all of you who have lots of research money. I have about \$1,000 a year. So I'm inspired to apply for grants now.

So I just presented a paper last week on the campus climate experiences of college students with ASD in the University of California system. So it was a survey of over 150 students in the UC system. And what we found was, not surprisingly,

that there were more negative experiences in terms of campus climate for students with autism.

Specifically, students felt less respected by their peers in and out of class, and they also -- another finding was that they also experienced more unwanted sexual contact than their peers.

We also found a statistically significance difference in terms of students with ASD coming from families who were not first generation in terms of college. So that research was presented in Denver at the Higher Education Conference.

I also am in the middle of writing up findings for a larger study -- a larger study that was done with qualitative interviews, I should say. Forty-one families who prepared their students with autism or their children with autism for college. And I guess not surprisingly what we're reporting is that the majority of participants, over 90 percent of the participants, came from high-income, Caucasian families who had already been to college.

So more than 90 percent of them made -- the families made \$90,000 or more. There were a couple of people of color in the study. While those findings are not generalizable because it's 41

participants, it's still indicative and suggests that we need to do more work in terms of closing any gaps in achievement or access for marginalized communities to gain access to college.

And then on a more personal parent level, my son is pretty much nonverbal. He's minimally verbal. He uses an iPad to communicate, and so I am putting together a conference in southern California that will probably have between 300 and 400 people. And we are -- the focus of the conference, although I'm not an SLP or speech-language pathologist, I am very interested and compelled to educate communities about options for communication for students with autism or people with autism who need support in that area.

So we are bringing people who type to communicate. For example, the gentlemen from the Wretches & Jabberers documentary are coming as keynote speakers, and we're also having Ido Kedar, he's a book author, teenage book author, who types to communicate. He is going to be another keynote speaker.

And we'll be bringing in SLPs and educators who include children who are mostly nonverbal and type or use assistive technology to communicate.

That will be March 19th in southern California.

Thank you.

Dr. Cuthbert: Okay. Thank you.

Mr. Aaron Bishop: Good afternoon, everyone. I apologize that I couldn't be here with you this morning, but I know that you were in good hands with my colleague Jennifer Johnson from ACL.

My name is Aaron Bishop, and I'm the Commissioner for the Administration on Disabilities, which is within the Administration for Community Living at the U.S. Department of Health and Human Services. We are the smallest, but the newest operating division within HHS. And as our name indicates, we focus on community living and every aspect of it.

And we are not only focused on healthcare and research, but also transportation, housing, employment, and other areas. I'm going to go quickly because I have a lot to cover. But ACL was originally brought forth looking at two distinct, but very powerful groups of people within the community, that being the aging community and the disability community.

And we were brought together because of the similarities that the two populations tend to

experience when it comes to access to services such as home and community-based services at some point in time in an individual's life. Now I'm going to focus more on the disability side of our agency versus the aging side, given the work that we're here today to speak about.

So we have several centers that are funded across the Administration for Community Living, and one of them, as you heard earlier, was recently brought over from the Department of Education called the National Institute on Disability, Independent Living, Rehabilitation, and Research, otherwise known as -- used to be called NIDRR. Now it's known as NIDILRR.

NIDILRR is currently funding eight different research grants that in whole or in part are targeted to individuals with autism. They vary in subject. They are from training programs for Latino kids with autism to analysis of State home and community-based budgets and utilization of services by families and individuals living with autism.

So within that center, we have quite a bit of work that's being done specifically related to autism and ASD. We also have what we call the

"middle center," which is our Center for Integrated Programs, where we see work that's being done in the area of disability and aging. The largest program that we have there, and some of you may be familiar with it, is our No Wrong Door policy and our No Wrong Door program, which is an initiative that started back in 2003, and it's with ACL, CMS, and the Veterans Administration.

And what the No Wrong Door system is supposed to do is similar to the Workforce Investment and Opportunity Act and the One-Stop centers that we had created at one point in time. This is really making sure that we can provide and build a system, a service delivery system that anybody can go to at any point in time and find the appropriate services that they need for themselves and/or their families.

So we're currently working right now and have grants in 33 States, and there's two in particular that I wanted to bring up because they made sure that they reached out and are working specifically with the autism community.

The first one being in Nevada in which the Commission on Autism Spectrum Disorder is part of

the ADRC's -- Aging and Disability Resource Centers is what they're specifically called -- Advisory Council. And then in Wisconsin, where the Autism Society of Wisconsin refers people specifically to the ADRC in that particular State.

Now I'm going to focus on the center that I oversee, which is the Administration on Disabilities. And the Administration on Disabilities is comprised of two major units. The first one is the Administration for -- the Independent Living Administration, which is the newest component. That consists of all of the independent living programs and State councils for independent living, and then the Developmental Disability Act programs and the Administration for Intellectual and Developmental Disabilities.

So for those of you who are not familiar with independent living, the ILA, or the Independent Living Administration, which, again, is new, manages programs, advocates in policy development, and helps establish and strengthen State and community networks of service providers in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities.

Each State develops their own State plan, but we do have specific -- we have States and specific centers for independent living that are focused on autism. For instance, we have, and I'm just going to go through this list, we have the Progress Center for Independent Living in New Jersey, one in Long Island in New York, Lehigh in New York and Three Rivers as well. They're really focused on direct services to individuals with autism.

Technically, CILs have to provide services to anyone that walks through the door, but these three or four are focused specifically on autism. Also the technical assistance provider for the CILs maintains a directory of CILs and CILCs that provide independent living services directly or through information and referral to consumers living with autism. So I would go to their Web site, which I believe is ILRU.org, and look for that specific information.

Finally, and these programs are the ones that you may be familiar with, AID supports the Developmental Disabilities Act programs through the Administration for Intellectual and Developmental Disabilities. Those are your 56 State councils on developmental disabilities, your

57 protection and advocacy agencies, and your 67 University Centers for Excellence in Developmental Disabilities.

And each one of those programs has specific work that they're doing in the area of autism. And I could provide you many specific examples of each one, but I'm not going to.

However, within that, we also have funding through our Projects of National Significance, and hearing individuals speak today during the oral portion and during what was said by John, there were a few things that were highlighted that we're funding with the small pot of the money that we have.

One of them is a project that's focused on families, and how do we do a better job at supporting families? We know right now that 75 percent of families with intellectual and developmental disabilities are not connected to the formalized service delivery system. Are not.

So what are those families receiving? What type of support do they have to keep the families as whole or intact as possible? And we're working with a few of our university centers, a few of our DD councils and other groups to really figure out

what it is that we need to do and how do we need to support families better and not specifically focusing on family support programs.

We're doing work in support of employment, supported decision-making, data collection, and then the last two that I'll mention are self-advocacy, which we've heard time and time again and figuring out how can we do a better job at supporting self-advocacy, and then underrepresented groups. Knowing where we are today in the U.S. and what it's looking like, we have to make sure that we're being as inclusive as possible and addressing issues such as the prison pipeline issue.

So thank you very much, and I'm glad to be here today.

Dr. Cuthbert: Okay. Thank you very much for telling us about that very comprehensive set of programs.

John?

Mr. Robison: I already took up a lot of the Committee's time. So I'll be quick here. At William and Mary, you know that I'm the neurodiversity scholar and I'm the co-chair of the campus neurodiversity initiative. We are

continuing to develop it in our third year. We really have two goals, which make the program kind of unique.

First, we want to make the campus comfortable for students with autism and other neurological differences. But the other thing we want to do, and I think this is what sets us apart, is we want to teach every student who comes to William and Mary the value of neurodiverse people.

Earlier in this Committee in the course of public context, you know, we had a comment, you know, questioning the value of having us here. And frankly, I don't see that any different from saying I don't believe black people or Jewish people belong on this Committee. I see it as really something that we shouldn't even be arguing.

And yet the fact that people make those comments, and they do it in good faith -- and I'm sure that it was not done in a spirit of meanness or anything like that -- it means that we have a substantial education job ahead of us. And that is what we intend to do at William and Mary.

We want to teach the value of neurodiverse people, whether we are disabled, whether we are

gifted, whether we talk, whether we don't talk. We all have value, and we all deserve that respect. And so we're going to continue that message.

And in January, I'll tell you folks about our collaboration we're developing with Drexel in order to translate that into the workplace.

So there. I was quick, see?

Dr. Cuthbert: Thank you.

[Laughter.]

Dr. Kau: So I'm Alice Kau from NICHD. First of all, as you all notice, Dr. Alan Guttmacher has retired. And Dr. Cathy Spong has assumed the acting directorship of NICHD since Alan's retirement. The search for a permanent Director will be open through January 4, 2016. So if you or anyone you know is interested in the position, I'm sure the search committee will be happy to hear from you.

And NICHD has a very vibrant autism research program. We fund research in areas of screening, diagnosis, intervention for very young children and adolescents in the full spectrums of basic, translational, and clinical trials.

We are an active participant of NIH ACC. We enjoy working with our sister institutes in

formulating a lot of initiatives. For example, the NIH NeuroBioBank, the National Database for Autism Research, and the newly funded Neuro -- the Biomarker Consortium.

And most importantly, the Autism Centers of Excellence that Dr. Collins mentioned and Cindy and Judith mentioned. And the current Autism Centers of Excellence program will end in fiscal year 2017 and '18, and we are working towards continuing this program.

Additionally, the ACE program in NICHD resides in the Intellectual and Developmental Disabilities Branch. So we are very interested in issues unique to this population. So every time when I go out, I hear comments and I always think that that's really a very important component of needs in autism research, and we are very, very interested and highly committed to it.

In fact, our -- the NICHD, one of the NICHD's signature programs, the IDDRC Network program, the Intellectual and Developmental Disabilities Research Center program conducts research, as well as providing core services, core support to other researchers conducting research in this area.

So I also -- finally, I also had the pleasure

of attending the Asia-Pacific IMFAR regional meeting, and it's been a very eye-opening, valuable experience for me. And I know Rob is there and Geri is there, and I just want to share three of my observations.

First, that the local participants were very interested in the discussion of air pollution -- contribution of air pollution to autism, and I think it's because, you know, the well-known air quality in China. And so, and I noticed that they were very worried. The parents are very worried, and there's not much they can do in a sense. But there were some suggestions from the presenters that was very helpful.

Second observation is that due to the changing policies, a relaxing of the one child policy in China, the participants, especially the ones who came up to talk to me, were very interested in issues related to the aging, older fathers and the subsequent pregnancies, the second pregnancies. So that these are all the same issues that we -- you know, that we're very interested in in here, too.

And finally, one of the professors, and I can't remember her name, terrible. But China has launched a very comprehensive prevalence study.

So, you know, the results of the study will contribute to our understandings of autism, and I'm anxious to know the progress of that study.

And that's all.

Dr. Cuthbert: Thank you.

Dr. Taylor: And I have a few slides, for better or for worse, but okay.

So I'm going to talk briefly about three studies that are going on in my lab at Vanderbilt. I'm actually going to talk really briefly about the first two to make sure that I have time for the third because I think that'll be of most interest to the Committee here.

So the first is some secondary data analysis we have in our lab looking at a pretty large sample of families with adolescents and adults with autism. I began working on the study during my postdoctoral work with Marsha Mailick at the University of Wisconsin, and we continue to collaborate on this dataset.

I think one of the most exciting things about this dataset is we had data collected on these families for 12 years. So we can really look at what changes are happening in the lives of these adolescents and adults over this time.

A few key findings that I want to highlight just from the past few years. We found, as have a lot of other people, that getting a job or getting into a postsecondary program was really hard for a lot of people with autism. But what we found, too, is that as hard as it is to get a job or to get into a program, being successful in that job and program over time, maintaining that position is even more difficult. It seems to be just as big of a problem, I would say.

We found certain subgroups of people with ASD that might be at increased risk that we should be thinking about maybe in a little bit of a different way or in a targeted way. We found that those people with ASD who don't have an intellectual disability are falling through the cracks in our research, having a harder time finding services, more likely to be sitting at home and doing nothing as opposed to being out in the community.

We also found that women with autism are able to -- tend to get jobs or go to college at the same rates as men, but have a much, much harder time even than the men at maintaining those positions once they are there. And we're looking

into right now figuring out why that's the case.

We have some analyses where we're looking at what jobs the women are doing. Are they choosing jobs that have heavier social loads? There are lots of reasons for why women may be having a more difficult time than men maintaining a position once they get there.

We've also found that having some sort of thing to do during the day, job wise or education wise, actually does seem to matter for behavioral development. It actually serves as a catalyst for behavioral improvement over time in adulthood.

We have another study funded by NIMH where we're really focusing and zooming in and taking a real deep dive at the specific transition years where we collect data while youth with ASD are in their very last year of high school and then collect data again when they've been out of high school for about a year.

And we're looking at stress response profiles, behavioral profiles, environmental resources, looking to see how those change when youth with ASD leave high school and how do all of those factors influence post transition outcomes. Our existing publications on this dataset that have

all come out in the past year or so have focused on that first wave of data because that's what we had.

Looking at service receipt, unmet service needs, we have a paper describing the bullying experiences of these youth at this time and what they think their lives are going to look like after they leave high school. And now we're knee deep in analyses looking now at this pre- to post high school change, looking at changes in social participation, behaviors, and service profiles.

The other thing that's come out of the study that I think is one of the most important findings, although you won't see it in a publication, is that when we brought in these families at the first time point -- so all of their sons and daughters were going to leave high school within the next 12 months -- we would ask them what do you think is going to happen? What services and supports will be available to you?

And they didn't know. They weren't getting that information. They were having a very hard time finding out what services and supports they may be able to get after their son or daughter leaves high school.

So that led us to submit one of the service research initiatives that Dr. Cuthbert was talking about, one of the survey esteem mechanisms that was looking at developing and testing parent advocacy training to promote transition outcomes. We call it a parent advocacy training. What it really is, is a 12-week program that teaches parents how to navigate the adult service system.

So each week is a different type of service. We talk about eligibility requirements, help parents in the group figure out whether or not this might be a good fit for their family. And then we do have a couple of sessions that are actually on non-adversarial advocacy skills as well.

And our idea is that if parents get this training, then they'll be better able to advocate on behalf of their sons and daughters, which will lead to improved service access and improved transition outcomes. And we're going to test that out in a small sample.

So we finished Phase 1. That was when we adapted the curriculum. We pre-piloted the program with families of youth who'd recently left high school basically to see if what we're telling you

has any bearing -- or what we're teaching -- to what your experiences are out in real life, in the world.

And families seemed to like the program reasonably well. They felt like they had increased advocacy skills. They felt better connected with people in the community and also with the disability community, and also with people in their group. That was a real big finding from this.

A lot of these families didn't know any other families who were in their same boat. So even being connected in a 12-week program with other families who are going through similar experiences they found to be very helpful.

We are in the first year of Phase 2 now. So we recruited 45 transition-aged youth and their families. We randomly assigned them to either get the program now or in the spring of 2017, and we'll be looking at whether participating in this program actually leads to differences in services and community integration at 6 months and 12 months after the program.

That's all.

Dr. Cuthbert: Thank you very much. Cindy?

Dr. Moore: Hi. I'm going to give you some updates from CDC. What I'd like to do is talk about some of the activities and accomplishments since the last meeting in the IACC and then some things that are going to be happening in the future.

I'm going to try to go through this rapidly, but I was born and raised in the South. So I think I'll probably start slowing down after about two bullets. But here we go.

So in January this year, CDC launched a new phase of funding for the Autism and Developmental Disabilities or our ADDM Network. It's the only collaborative network to monitor the number and characteristics of children with ASD and other developmental disabilities. We do this in multiple communities throughout the United States.

CDC will invest more than \$20 million over 4 years to shed light on important issues, such as gaps in the early identification of children with ASD and the impact of DSM-5 diagnostic criteria on ASD prevalence. So another project there.

We published an analysis of almost 20 years of trend data on the number and characteristics of children with ASD and other developmental

disabilities who were living in the metropolitan Atlanta area. Our researchers found that estimates of the prevalence of children with cerebral palsy, hearing loss, intellectual disability, and vision impairment have remained pretty stable over the last 15 to 20 years.

However, not unexpectedly, they found a large increase over time in estimates of the prevalence of children with autism. These findings have implications for communities and, of course, the services they provide, such as healthcare, early intervention, special ed services, and others to support children with developmental disabilities and their families.

We, along with several of our colleagues in CDC's Division of Reproductive Health and some external collaborators, published three studies in 2015 looking at the relation between assisted reproductive technology, or ART, and ASD among a group of children born in California between 1997 and 2007, and some of the main findings are as follows.

Overall, children conceived using ART were twice as likely to be diagnosed with ASD compared to children who were conceived without ART.

However, the evidence suggests that the increased risk for ASD for children conceived through ART is largely due to the higher likelihood of adverse pregnancy or delivery outcomes, such as being born a twin or other multiple birth, being born too early or being born too small.

More research is, of course, needed, but the findings of these three papers suggest that using a single embryo transfer for ART when appropriate may reduce the risk of ASD among children conceived using ART.

And finally, from the National Center on Birth Defects and Developmental Disabilities, from our team, over the past year, working with many partners, our "Learn the Signs. Act Early." program has made great strides in incorporating developmental monitoring tools and resources into early childhood programs, including the Administration on Children and Families Quality Rating Improvement system and their early education centers, as well as Early Head Start programs and national technical assistance centers.

So I also want to present a study that it's been referred to a couple of times in this -- in

our sessions today. CDC's National Center for Health Statistics recently issued a report on ASD prevalence based on a survey of parents, and that was the National Health Interview Survey. And this is a survey that's sponsored by HRSA and analyzed by NCHS.

They estimated the prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. So the title indicates that this was particularly a method study, which focused on the change in prevalence estimates after -- or in the 2014 questionnaire. These were changes in the wording of the question, changes in how the question was asked, and where the question was placed in a list of questions that were asked to families.

So they arrived at an estimate of 1 in 45, and this was 2 times higher than the previous estimate, which was over a 3-year period, 2011 to '13. And that using this same survey.

It is -- even though it's two times higher, it is a number that's consistent with an estimate from the National Survey of Children's Health that was from 2011 to 2012. So the -- I invite you to

read the full report, look at the strengths and limitations of that study, and at present, CDC's estimate of the prevalence of autism remains at 1 in 68.

So where we're going and what we're doing. Very shortly, and I'm hoping it's in the next week and a half, we will release a new funding opportunity announcement for the continuation of CDC Study to Explore Early Development, or SEED. This will be the third phase of funding for the study and will enable us to continue to investigate factors that put children at greater risk for ASD and other developmental disabilities.

We are also going to explore how we might conduct longitudinal follow-up with children who've been enrolled in the study as they grow into adolescence. The SEED 1 participants are now adolescents. So we can begin to assess some of the long-term impacts of having ASD. We're excited about that opportunity.

Next month, the Journal of Developmental and Behavioral Pediatrics will publish the findings of a pilot project that we've called Early ADDM. Through this pilot project, we used our record review tracking method to examine the

characteristics of preschool age children with ASD in five communities across the United States -- these are 4-year-olds -- and compared them to school age children in those same five communities.

We hope that tracking ASD among preschool age children can help us understand more about the characteristics of children who are identified with ASD before kindergarten.

We expect to publish our next ADDM prevalence data in the spring of 2016. It will provide the latest estimate of the number of children who have been identified with ASD based on 8-year-old children living in 11 communities in the U.S. And again, our current estimate based on 2010 is 1 in 68.

And finally, in the coming year, our "Learn the Signs. Act Early." will release Milestones in Action. This is an illustration of developmental milestones that are on all the Learn the Signs checklists with photos or videos, making them easier for parents to understand and recognize, and we will also be releasing a Milestones app to make developmental monitoring more accessible to parents and providers.

Thank you.

Dr. Cuthbert: Alison?

Ms. Singer: Hi, everyone. I'm Alison Singer. I'm the co-founder and president of the Autism Science Foundation. The Autism Science Foundation was founded by scientists and families working together. Our mission is to support autism research and accelerate the pace of autism research to improve the real lives of real people.

We have three, I'd say three pillars of our mission. The first is our direct funding of autism research, and here we focus on providing early career support for autism scientists. Our goal here is really to build the workforce and train the next generation of autism researchers.

We want to be attracting the best and the brightest young researchers and encourage them to study autism. And we think the best way to do that is to provide them with early funding.

So we fund -- we started with pre-doctoral and postdoctoral fellowships. We added a medical school gap year research fellowship because we heard from our families that when they were talking to their doctors, their doctors had never spent any time learning about autism or studying

autism.

So we now offer a 1-year research fellowship. There's also included in that a lot of time in the clinic. So we hope people will take advantage of that. We do a 3-year early career award to bridge the transition between postdoc and assistant professor. And we also offer treatment grants.

And then 2 years ago, we added a new mechanism that has been incredibly successful for us. It's undergraduate summer research grants. We've been offering undergraduates the opportunity to pair with an established research mentor and work for 8 to 10 weeks in a lab. Of the, I think 18 undergraduates that we have funded, all 18 of them say that they want to continue either in autism research, or they want to go to medical school and work with children with autism.

So we think that program has been incredibly successful. But the goal here with all of our research funding is to focus on finding the causes of autism and developing better treatments for autism for people of all ages, for babies, for school age children, for teenagers, adults, and senior citizens.

And you can't see it, but that's actually Matt

Maenner was one of our first grantees on the right. And he was one of the authors of the study that Cindy just described from the CDC.

Our second -- our second pillar is what we call our research acceleration portfolio, and here we offer a mechanism called research accelerator grants. This is a funding mechanism where if you have an unexpected finding, something that was -- you think is novel or needs just additional funding quickly and you don't want to wait for the next grant cycle, we can provide funds to really exploit an unexpected finding or try to we call it move the boulders out of the way.

So we do this twice a year. The next opportunity, I think, will close in April.

We also work with Autism Speaks and the Simons Foundation and the UC Davis Mind Institute on the Autism BrainNet, and the goal here is to collect brain tissue. Our role at the Autism Science Foundation is to do outreach into the community and help stakeholders with autism understand how critically important it is for them to register to donate brain tissue.

Louis spoke about this a little bit, as did Rob, but really, the way you understand how to

improve lives is by studying the affected organ. That's the way we learn about diseases and disorders, and in autism, that is the brain.

And we have really -- research has -- the pace of research has suffered because of lack of access to brain tissue. So the goal of this project is to encourage people to donate postmortem brain tissue.

And then the Autism Sisters project is a project that we actually just announced last month. This is not what I would call low-hanging fruit. I think this is very high-hanging fruit, but it's a really important project. It's a difficult project.

What we're doing here is we're trying to really leverage our understanding of the fact that four times as many boys as girls are diagnosed with autism. And so for years we thought that that meant that there was something about being male that conferred risk for autism.

And what we've learned from the genetics is that that may not be the case because there's a cohort of females who have the genes that in boys would cause autism, but these girls show no clinical symptoms. So we're trying to turn the

hypothesis on its head and say instead of being male -- instead of maleness conferring risk, what if femaleness confers protection?

So we're -- the Autism Sisters project is our attempt to try to understand what this female protective effect is. Because if we can find it, we can really use it to help both boys and girls and try to prevent the most debilitating aspects of autism from emerging in the first place.

So we are trying to collect DNA from unaffected female sisters of autism because that -- because we think that is an enriched population. Those girls may likely carry the genes that in boys would manifest as clinical autism. So our goal is to collect DNA from those girls, and we are partnering with the Seaver Center at Mount Sinai on this project.

And then our third pillar, the third pillar of our mission is stakeholder education. As part of that, we are the producers of the annual autism TED-style conference. It will be the third time we have produced the autism TED talks. This year, they will be on April 14th in New York City.

We'll be announcing the speakers in December, but I will tell you today we sourced two of the

topics this year from our social media sites. So we asked our families what are the topics that you would like to hear? And the two that we're going to be including are treating anxiety in autism, and the second is implementing wearable technologies in autism classrooms.

So we have a terrific lineup, and I hope all of you will choose to attend on April 14th. It'll be from 10:00 a.m. to 3:00 p.m. in New York City.

Also as part of our stakeholder education efforts, we offer travel awards to the International Meeting for Autism Research that Geri described. So we offer travel stipends to individuals with autism, to parents, to siblings, grandparents, special education teachers, regular education teachers, therapists, anyone who's studying autism. Graduate students, undergraduates, high school students if they come with a parent. So really it's an opportunity for those stakeholder groups to share their experiences with scientists.

And then we also are now producing a weekly podcast. Our new chief science officer, Dr. Alycia Halladay, who is amazing, every week she combs through all of the publications in the scientific

journals. She translates them into English, and she shares them in a weekly podcast that you can download on iTunes.

And it's really picked up in popularity. I really encourage everyone to take a listen to it.

And then I also want to add that both my daughter with autism and my brother with autism are among those who are extremely challenged by their autism. My brother is nonverbal. We've tried augmentative communication devices. We've tried the iPad. We've tried PECS. We've literally tried everything. We continue to try.

But non- or minimally verbal doesn't always mean that that person can communicate using an augmentative communication device, and we have to make sure that we are focused on those individuals as well.

And then I will just add about my daughter. She is 18. She was in and out of the mainstream. She was never able to access the mainstream because of her cognitive disability, and so now this notion that somehow when she becomes an adult she's going to just magically be successful in a house with three other girls, three other women in the community I think makes no sense to me.

She has been most successful where she is right now, which is in a residential school setting, where she has amazing supervision. She's doing work she loves. She has made friends with other girls who are diagnosed with autism, where she has never been able to make any friends with people who are not diagnosed with autism. So for her, inclusion means being with people with whom she can make friends.

So I think sometimes we lose sight of this small segment of the population, and I -- you know, again, I urge everyone on the Committee to really keep in mind that not everyone was a candidate for mainstreaming. Not everyone is a candidate for community-based living.

There are some people who really need, who in order to thrive need to be in a more restrictive setting, and that is the setting in which they will be the most successful.

Dr. Cuthbert: Okay. Thank you.

Walter, you get the climactic update.

Dr. Koroshetz: Okay. I'll be quick. So as Alison said, the problem with autism is a brain problem, and we just don't understand how the brain works well enough to give solutions for

patients, which is a heart-rendering problem.

But, so our institute is invested heavily in trying to understand how the brain works in different regions, different aspects. In terms of autism research, we fund about 55 grants for about \$60 million that are related to autism.

A lot of those, a lot of the grants that we fund are related to types of autism which are genetically determined. So tubular sclerosis is a very big one right now because of some of the inroads that have occurred in understanding the biology of tubular sclerosis. But some of the other mutations as well.

We fund one of the ACE centers, which, again, is focused on tubular sclerosis. One of the big questions that they're looking at is how to predict which kids with TS will develop epilepsy and try and find out beforehand. And it looked like they're pretty successful using EEG to do that. Brings up the next question of whether or not treatment early can prevent epilepsy in TSC.

A lot of the other research we are doing is with regard to epilepsy. So we fund about \$160 million of epilepsy research. Some of that research is actually epilepsy in autism.

So we also work with Bruce and NIMH on a couple of other projects worth knowing about, the BRAIN Initiative we talked about today. Certainly, the purpose of the BRAIN Initiative is to understand how brain circuits work and how we can detect and interrogate them or manipulate them. And clearly, in autism, it's a circuit dysfunction problem, and so the technologies that potentially could come out of the BRAIN Initiative could really change things for how we approach autism.

The other project that we do together is the Connectome Project, which is an MRI project to develop the best means of looking at the connections between the different brain regions. And so there is a lifespan Connectome Project, which has children in it and people of different ages all the way up until the elderly.

So it will give an opportunity to look at what the normal variation is in terms of how people's connections differ and give the opportunity for studies to occur in children with autism to see how that interacts with what's known in normal individuals.

So this is just an example of the kind of things we do to try and get at some of the basic,

really kind of give some of the basic foundations that will allow better autism research to occur and, hopefully, better treatments to occur.

As I mentioned before, we have a network to do first in human trials, and that group is actually looking at a potential autism trial now. So we'll see what happens.

Thanks.

Dr. Cuthbert: Okay. Susan, a few comments from you.

Dr. Daniels: Okay. Well, thank you so much for sharing. This was a great set of updates. A lot has happened in the last several months, and I hope that you all found some common ground, some areas that you may mutually work on with other members, and that outside of this group you will have a chance to do some coordination and collaboration.

I also wanted to point out that among the meeting materials, I gave you a list of reports from various Federal agencies, organizations, and advisory groups around the Government, and that is an update just on some of the latest reports that have come out. We may in the future have people come and speak about those but wanted you to be

aware of some of those items. And if you have items like that in the future, please send them our way prior to meetings.

I wanted to just go over a couple of action items that we heard from earlier today. One is that we will be beginning our work on the summary of advances for 2014 and '15 after this meeting, and so you'll be hearing from our office about the first steps towards preparing those documents.

And in the next meeting, that we're going to consider models for updating the strategic plan, decide on the model we're using, and how we're going to structure our activities to get that done.

And I'd like to just again remind you to send suggestions for upcoming meetings. We'll keep a running list and use those suggestions as we plan future meetings.

Thanks.

Dr. Cuthbert: Okay. Thank you.

So we heard about an incredible diversity of efforts in this last session this afternoon looking at the complete range of functioning across the autism spectrum, looking at also the age range from early childhood through to adult

and, indeed, even old age. We've looked at a variety of kinds of research from genetic and biological research through to looking at functioning in the world and various kinds of treatment efforts, and finally a variety of settings, families, schools, ranging from elementary school to universities and other settings.

So this is a wonderful start. I think in terms of thinking about our advances and also revising the strategic plan, I think and hope that this will be very useful to everybody in thinking about all of the things that we've heard and all the components that comes into our planning.

But certainly we are starting from a really good level, and we can see that there is activity everywhere across all of these ranges that will help contribute to how we can build on these efforts and decide specifically what we need to do to move forward. So I think we have our action items in hand, and so are there things you need before the next meeting Susan that you would like to hear other than what you just said?

Dr. Daniels: So I think that I've gone over the main items that I think that we need to keep

in mind for the next meeting, and we'll be in touch with you about all of that.

Dr. Cuthbert: Okay. Our next meeting is scheduled for Tuesday, January 12th next year. And as of now, it's scheduled to be in Building 31 on the NIMH main campus. I know. That's hard to get to, yes.

So, and of course, we will be sending out more information about room numbers and so forth.

Are there any final parting comments, questions, other input for us before we adjourn?

[No response.]

Dr. Cuthbert: Okay. Thank you very much to all of the Committee. Thank you to all of you in the back of the room who have patiently stayed with us all day.

Safe travels home, and thank you for your commitment to this cause. And we'll see you in January.

[Whereupon, at 4:54 p.m., the Committee adjourned.]