INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, April 17, 2019

The full Interagency Autism Coordinating
Committee (IACC) convened in Rockville,
Maryland, at the Neuroscience Center, 6001
Executive Boulevard, Conference Rooms C and D
at 9:00 a.m., Joshua Gordon, M.D., Ph.D.,
Chair, presiding.

PRESENT:

JOSHUA GORDON, M.D., Ph.D., *Chair,* IACC,
Director, National Institute of Mental
Health, (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary,*
IACC, Office of Autism Research Coordination
(OARC), NIMH

MELINDA BALDWIN, Ph.D., LCSW, Administration
for Children and Families (ACF)

JAMES BALL, Ed.D., B.C.B.A.-D, JB Autism
Consulting (attended by phone)

LESLIE CAPLAN, Ph.D., (representing Jennifer
Johnson, Ed.D.) Administration for Community
Living (ACL)

JUDITH COOPER, Ph.D., National Institute on
Deafness and other Communication Disorders
(NIDCD)

PRESENT: (continued)

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

GERALDINE DAWSON, Ph.D., Duke University
(attended by phone)

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

ELAINE COHEN HUBAL, Ph.D., (on behalf of
Environmental Protection Agency (EPA)), EPA
(attended by phone)

ALICE KAU, Ph.D., (representing Diana
Bianchi, M.D.) *Eunice Kennedy Shriver*
National Institute of Child Health and
Development (NICHD)

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

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

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

DAVID MANDELL, Sc.D., University of
Pennsylvania

EDLYN PEÑA, Ph.D., California Lutheran
University (attended by phone)

LAURA PINCOCK, Pharm.D., M.P.H., Agency for
Healthcare Research and Quality (AHRQ)
(attended by phone)

PRESENT: (continued)

LOUIS REICHARDT, Ph.D., Simons Foundation
Autism Research Initiative (SFARI)

JOHN ELDER ROBISON, College of William and
Mary

MARCELLA RONYAK, Ph.D., L.C.S.W., C.D.P.,
Indian Health Services (IHS)

NINA SCHOR, M.D., Ph.D., (representing Walter
Koroshetz, M.D.) National Institute of
Neurological Disorders and Stroke (NINDS)

STUART SHAPIRA, M.D., Ph.D., Centers for
Disease Control and Prevention (CDC)

ALISON TEPPER SINGER, M.B.A., Autism Science
Foundation (ASF)

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt
University

LARRY WEXLER, Ed.D., U.S. Department of
Education (ED)

CHERYL WILLIAMS, Social Security
Administration (SSA)

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

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<u>PROCEEDINGS</u>

DR. JOSHUA GORDON: Thank you very much everyone here in the room, members of the coordinating committee and members of the public and others joining us through the web. Welcome to the Meeting of the Interagency Autism Coordinating Committee that takes place every April during Autism Awareness Month. We are really pleased to have you here today and we have what we hope is an exciting agenda for you. We are going to hear from the CDC. We are going to hear from our friends to the North, who might be hopefully not telling us that winter is coming. We are going to hear from the FCC, a new contribution of the IACC. And we are going to have a panel presentation in the afternoon on disability employment and we are also going to hear from our National Autism Coordinator later and have a bunch of committee business to take

and of course public comments. It is a full day. We are glad to have you.

With that, I will turn it over to – actually, before I turn it over, we will remind people that the live feedback link is open for public comment. If you give us your public comments this morning, then we will add them to the comment report out during the public comment session in the early afternoon.

With that, I will turn it over to Susan Daniels for roll call, minutes, et cetera.

DR. SUSAN DANIELS: Great. Yes. And the live feedback will be open until before the public comment period. So it won't be open in the afternoon. So anyone who would like to get your comments in, feel free to do that.

We also wanted to just let you know because there were questions in previous meetings, we are offering CART today. There

is a quiet room to the side of this room.

There is closed captioning on the videos.

There always has been and other

accommodations available. Please let us know

if there are any other needs that need to be

fulfilled.

Right now, we are going to go ahead and

take a roll call. Starting with Josh Gordon.

DR. GORDON: Here.

DR. DANIELS: Judith Cooper.

DR. JUDITH COOPER: Here.

DR. DANIELS: Alice Kau for Diana

Bianchi.

DR. ALICE KAU: Here.

DR. DANIELS: Cindy Lawler for Linda

Birnbaum.

DR. CINDY LAWLER: Here.

DR. DANIELS: Carrie Wolinetz for Francis

Collins. Elaine Hubal. Tiffany Farchione is

here but had to step out. Melissa Harris or

Marguerite Schervish. I believe Melissa

Harris is joining us later by phone. Jennifer

Johnson or Leslie Caplan.

DR. LESLIE CAPLAN: Here.

DR. DANIELS: Laura Kavanagh.

MS. LAURA KAVANAUGH: Here.

DR. DANIELS: Walter Koroshetz.

DR. NINA SCHOR: Dr. Koroshetz will be

joining this afternoon.

DR. DANIELS: Nina Schor. Great. Laura

Pincock.

DR. LAURA PINCOCK: Here.

DR. DANIELS: Thank you. Marcy Ronyak.

DR. RONYAK: Here.

DR. DANIELS: Stuart Shapira.

DR. STUART SHAPIRA: Here.

DR. DANIELS: Melissa Spencer is now

gone. Representative from the Social Security

Administration. If you are representing the

Social Security Administration, you can be up

at the table so our folks can help you get seated. Larry Wexler.

DR. LARRY WEXLER: Here.

DR. DANIELS: Nicole Williams.

DR. NICOLE WILLIAMS: I am here on the phone.

DR. DANIELS: Melinda Baldwin. David Amaral is not here today. Jim Ball on the phone.

DR. JAMES BALL: Yes, I am here on the phone.

DR. DANIELS: Thank you. Samantha Crane, I think, is going to be here today later maybe. Geri Dawson, are you by phone.

DR. GERI DAWSON: I am here by phone. Sorry I can't join you in person. My flight was messed up this morning.

DR. DANIELS: Thanks for joining us by phone. David Mandell.

DR. DAVID MANDELL: Here.

DR. DANIELS: Kevin Pelphrey, I think, is not going to be here today. Edlyn Peña is going to be with us by phone.

DR. EDLYN PEÑA: I am here. Good morning.

DR. DANIELS: Louis Reichardt.

DR. LOUIS REICHARDT: Here.

DR. DANIELS: Rob Ring. Are you on the phone? John Elder Robison.

MR. JOHN ELDER ROBISON: Yes. I am here.

DR. DANIELS: Alison Singer.

MS. ALLISON SINGER: I am here.

DR. DANIELS: Julie Taylor.

DR. JULIE TAYLOR: Here.

DR. DANIELS: Okay. So we're done with the roll call.

Now, we can take a moment to look over the minutes from the last meeting. Does anyone have any questions or concerns or comments about the minutes? Would anyone like to make a motion to accept the minutes?

MR. ROBISON: I will move to accept them.

DR. DANIELS: Is there a second?

DR. REICHARDT: Second.

DR. DANIELS: All in favor of accepting the minutes as written say I? Anyone opposed? Does anyone wish to abstain? It sounds like unanimous move to go ahead and accept these minutes. We will post them to the website after the meeting. Thank you.

DR. GORDON: The first item on our agenda we have a special guest this morning we are very pleased to have from Canada, a member of the Canadian Member of Parliament, the Honorable Mike Lake. Mike is the father of an adult son on the autism spectrum and one of Canada's leading autism and disability advocates. We are very happy to have him down here to visit with us today to spend some time along with his son, Jayden, and to give

us a special message and recognition of

Autism Awareness Month.

MR. MIKE LAKE: Good day everyone. We did

not bring the cold weather with us. It tried

to follow us, but we drove just fast enough,

I think, that we escaped it coming down.

Talking to some friends, it seems to be the

winter that never ends back home. I think we

get a lot of snow, but in Ottawa, they had

snow at least one inch of snow for a longer

period of straight time than ever before. We

managed to escape that.

Now this is Jaden. Jaden is going to say

hi to you and when he says hi to you, you

have to applaud for him.

MR. JADEN LAKE: Hi.

MR. LAKE: It is great to have him. Of

course, I was here two years ago and my

presentation is going to be a little bit

shorter this time. You are going to see a

couple of things that you have seen before.

And what I kind of hope to get out of it is

just to have a conversation. We will have a

little bit of time for questions afterwards,

but just to kind of give you a little bit of

the –

What I am going to do is just walk you

through a few videos. I think the first one

you may have seen last time I was here, but I

always like to show it. A few years ago, we

discovered that Jaden likes to sing in his

way. My daughter took a 35-second iPhone clip

in the basement and we posted it on YouTube

on Facebook. It got 1.4 million views. I

figured a good way to start any morning is

Jaden singing.

(Video)

MR. LAKE: I think I mentioned when I

showed this last that one of the comments I

got first overall was from someone on the

autism spectrum who said wow, you have a lot of remotes. That was the observation. I think I know what two of them actually do. I don't know what the rest of them. I think I used to have something that they ran.

Anyways, the next video I'm going to show you is actually my statement that I made in the House in Commons just last week. I get a chance to do a one-minute statement every year and usually with Jaden or always with Jaden sitting in the gallery. It's one of those unique moments. You watch your politics down here. It is pretty rough and tumble. It's like that up there in the Westminster System that we have.

But when I make my annual World Autism Awareness Day speech, it's funny. Within seconds, you can kind of hear shh and everybody gets quiet from all parties and

afterwards they all applaud for Jaden at the end.

I think sort of my motivation for this year's message was really some of my conversations over the last couple of years was self-advocates and the whole conversation about self-determination. Of course, in Jaden's case, Jaden would have a difficult time fully self-determining because he doesn't understand danger and if he just was left to make all of his own decisions, the very first day would probably be trouble for him the second he went out into traffic to go somewhere that he wanted to go or ate way too much of something. He has certain things that he loves to eat. I don't know if drinking Italian salad dressing could be dangerous for you, but he would drink no end of it if he had his choice.

But really the statement kind of speaks for itself and it seems to have kind of resonated with a few folks.

(Video)

MR. LAKE: That one minute that I get to do that statement in the House of Commons sort of knowing what's coming and seeing Jaden in the front row of the gallery looking down is probably my favorite moment in the house. Sometimes I'll mention something like puppies or dogs or whatever and all of a sudden you're not supposed to talk when you're in the gallery, but then you'll hear this ba, ba, ba from up in the gallery because Jaden's heard me say something that he just wants to know a little bit more of. The next video I'm going to show you is from actually just after I spoke here last time. It's the House of Commons again, a little bit more

political, but I think it will be interesting
for you to see the political dynamic. We had
a campaign for something called a Canadian
Autism Partnership, which would've done some
work similar to what happens in your meetings
here. It was something that went through a
two-year period and then came to a vote in
2017 with three of the four national parties
aligned in favor. Unfortunately, the
governing party was opposed to it.

But this two-minute moment that I'm
about to show you is a little bit longer in
the actual timeframe is something that I
hadn't seen. Three leaders standing up one
after the other after the other from three
different parties using limited question
period time that we have to ask the
government about the Canadian Autism
Partnerships. This is three of the national
leaders at the time asking the fourth

national leader about the Canadian Autism
Partnership.

(Video)

MR. LAKE: To give you a little bit of an
idea of the conversations that we were
having. That debate is ongoing right now.
There's some challenges – been some
challenges with the roll out of an autism
program in Ontario, our largest providence
right now and some of you may be aware of
that conversation that's going on. It's
something that when I have the opportunity to
do media or talk a little bit about it, I
have yet to see a government that gets autism
right the first time around. I think that's
what's so important to what you all are doing
here and what we're calling for there in the
Canadian Autism Partnership is the idea of
having authoritative, knowledgeable, credible
voices, sitting in a room like this,

involving the strong voice of self-advocates,

involving the voices of parents, involving

the voices of experts from across the range

of professions to see if there can be some

common ground finding in a sense and advise

governments.

I was sitting in a conference a few

weeks ago and someone was speaking at that

conference saying that you have to assume.

They were talking about lobbying for things

that you care about. You have to assume that

the people on the other side of the table are

really smart, but know nothing about that

thing that you're talking about. I really

think that that's sort of the approach from a

political standpoint. The more we can come

together, find that common ground on

evidence-based interventions in whatever it

is that we are talking about across the

lifespan, diagnosis, early intervention,

education, housing, employment, all of the things that we talk about. It's critically important to be able to find the common voice and to translate our knowledge into something that's going to make sense to someone that hasn't lived autism like we have and sort of challenge you with that and maybe we can have further conversation about that.

The last video I'm going to show you many of you in the room will have seen this video. It's what I close with all the time. It's Jaden and I a couple of years ago at an event called WE Day with 15,000 students in an arena. Jaden doesn't get nervous. He gets excited when we go out to these things. Right now, he's a little bit tired because we were up late driving and watching election results from my home province. The election was yesterday so we were watching those results late into the evening. He's a little bit

tired today, but he gets very excited to come out and speak. You'll see in this clip. I'm doing my thing talking to these students and Jaden is just hanging on my shoulder. He's making eye contact with seemingly every person in the entire arena, all of the 15,000 kids.

But what I love most about this clip is at the end, there's a 45-second clip that includes Jaden's sister from now six years ago. She's 19 in a university, but the clip in this video is from when she was 13 years old, asked a question that is probably one of the toughest questions that has been asked in any interview I've been a part of and she just as a 13 year old I think blew it away. And then we'll have a little bit of conversation about that and take any questions you have.

(Video)

MR. LAKE: I get a chance to do this presentation a lot. In fact, actually, we just did it at Duke with Geri, who is on the phone. Hi Geri. Jaden, say hi to Geri.

MR. LAKE: Hi.

DR. GERI DAWSON: Hi Jaden. Hi Mike. Sorry I can't be there in person.

MR. LAKE: We had a great time down there. We were just at Duke a couple of nights ago. We were at the MIND Institute with David Amaral back in January, the Oklahoma State-wide conference in the fall, I believe. But the biggest audience for this presentation – well, it's a modified presentation of this. It's a longer 45-minute presentation is intro-psyche students across the country.

I love that clip because it kind of leads into some thinking about normal and how we define normal. One of the things I'm

always quick to point out is that Jenae
didn't have a choice. She was born into
family with Jaden in it. She is three and a
half years younger. And so Jaden was part of
her normal by default.

But the school they went to did have a
choice and the school they went to was a K to
12 school that decided early on with some
prodding from Jaden's mom and myself to
include Jaden in a regular classroom with a
full-time aide. And so he had a full-time
aide with him all the way along.

And while we thought that when we put
him that classroom that it was for Jaden's
benefit. Every one of the kids that graduated
with him would say that their life is better
off because Jaden was in it.

One of the things that I sort of close
with in the presentations with the university
students is as we kind of think about normal,

think about almost like a video game. This works with students well. Think about a video game where you are a character and there's a circle around you that follows you everywhere you are, but that circle extends as far as you can see. That's pretty much for all of us our normal. I am 49 years old and my normal is that circle following me around for 49 years wherever I am. Every once in a while a computer monitor or a TV finds its way into that circle too, share something from outside my circle, but for the most part, my normal is what I'm surrounded by.

For too often and for too long, our normal have included people who are just like us and they haven't included people who are different from us who have different skill sets, who come from different places. When we do that, we limited ourselves. We limit ourselves because if everybody around us is

just like us then they have the same strengths as us and our strengths aren't even strengths anymore. If you think about it, the same weaknesses as us, which means that there's nobody to compliment us. There's nobody to fill in for our weaknesses.

I come from a country with a very diverse population in many ways and we're infinitely better for it. Our skill sets are broader. We've got people who have life experiences, dealing with things. It's unbelievable how often we have a conversation where we are trying to solve some problem and someone who wasn't born in Canada talks about what the solution for that problem was in the place that they were from and it's something that we hadn't thought about.

Interesting global conversation about diversity happening right now, I think a really important one. And all the more

important that as we're having these

conversations, we look to be as inclusive as

we can, not for the people that we're trying

to include, but because as a society, we're

better off having done that. We're going to

benefit greatly from the skills and abilities

that everybody brings to the table.

I think with that, I'll close this part

of my presentation. And I think if you have

questions at all, we have a few minutes

still.

DR. DANIELS: Yes, we have time for

questions. Thank you so much for being here.

(Applause)

DR. DANIELS: Alison.

MS. SINGER: Thank you for that

presentation. We really appreciate both of

you being here today. I'm curious as to what

was the sticky issue that prevented the

Canadian Autism Partnership from moving
forward.

MR. LAKE: I think like always, politics
probably more than anything. It was put in
place a working group was established prior
to the 2015 election. Then there was a change
in government. And I think as happens
oftentimes, governments don't move ahead with
the thing that was presented by the other
party. I think probably mostly just that. I
don't know what it's going to take to re-
ignite the conversation because the amount of
money wasn't a big amount of money in Canada.
It was $20 million over 5 years.

Most of the delivery of services happens
at the provincial level. This was really the
idea of putting together a partnership of
autism stakeholder's experts from across the
country to gather the best evidence in the
world and advise governments in their

jurisdictions in autism policy. It should've
been a no brainer. And I think a lot of
people saw it that way, but for whatever
reason, I think sometimes politics just get
in the way of things like this.

DR. DANIELS: David.

DR. MANDELL: Thanks for that
presentation and for your advocacy. I
followed from afar some of the challenges in
Canada around funding and granting access to
services starting with early intervention
services and as people age. I know that
Canada is in the midst of some transitions
around its service system for people with
autism.

I wonder if you could share where you
see that going and if we have any lessons to
learn as you try and develop a more
comprehensive autism service system.

MR. LAKE: I would say a few different things to that. First off, I'm not an expert. I have a business background. I worked for the Edmonton Oilers, who are unfortunately again out of the playoffs. That's what I did before this.

My sweet spot is I do understand autism having worked in it for a long time with a lot of great people and most importantly being Jaden's dad. I do have a unique position as a legislator, as someone elected.

My advice when I get the chance is to say first off take lifelong view of autism, a comprehensive view of autism because everything is going to fit together at some point anyway and we're better off if we can structure things with that in mind. That can be challenging for governments because governments work on two and four-year cycles and so that can sometimes be a challenge.

When I've had a chance to sit down with the government in Ontario right now, that's — the one piece of advice is get beyond the silos. Bring your Minister of Education, your Minister of Health, your Minister of Children Services together and have the experts in the department sit around the table like this along with the experts in the autism community. Put in place a panel to tackle autism, again, comprehensively. Yes, you need a strong early intervention program, but that can't be done in isolation from a strong education program because sometimes they're going to cross over and sometimes there's going to be transitions from one to the other.

Early intervention is going to be made obviously way more impactful if you've got a really good system of diagnosis and you're diagnosing earlier. But you also have to take

into account that there a lot of adults walking around right now that have autism and don't yet it. They haven't been officially diagnosed and so we have to take that into account as we're talking about diagnosis.

Everybody hopefully is going to move into a time period where they're going to consider post-secondary education. Employment is going to be an issue. Housing is going to be an issue. Those have to be part of the conversation as well.

You all know this, but I think that the challenge is communicating that to policymakers who don't live in that world so hitting that point that I hit a little bit earlier and sort of bringing it together in an easy to understand package and I understand. When you're coming in this room, it's not like you've got a – I don't know how many people are involved in the process, but

I'm hundreds by extension. It's not like those hundreds of people are all completely on the same page on every issue. Is that fair to say? You guys battle about a few things in this group probably from time to time? But try and find that common ground whenever you can so that it makes it a little bit easier to understand especially what's really easy for governments to do. Does that make sense?

That comprehensiveness is the big thing because every government I see is they're trying to put out that fire that is right in front of them on one particular issue and just not taking that time to look at the whole picture.

MS. SAMANTHA CRANE: Thanks for coming and thanks, Jaden, for coming too. I have a question. This is sort of a follow up on what you were just saying. In terms of like home and community-based services for adults in

Canada, what are the biggest challenges that you're facing in Canada? I know a lot of us in the US there are home and community-based services to help people stay in the community when they're adults, but there are huge waiting lists and they can be hard to access. How does it work where you are?

MR. LAKE: I would say it is not different. The challenges oftentimes that we face in Canada are very similar. We have a provincial structure where most of the delivery of services is at the provincial level similar to what it is here.

We also have a situation that I think many people in this room would be able to relate to in a sense that there was sort of a wave of people with autism. Again, I'm not a scientist on the numbers, but it seems like actually right around the time Jaden was diagnosed in the mid to late '90s. There

seemed to be a little bit more of a wave coming through a diagnosis of people that age and that wave now is moving into adulthood and suddenly we're focused. This is that idea of suddenly we're focused on transition issues to adulthood. When we probably had just following aging patterns for millennia would've known that our two year olds were eventually going to become 18 and 22 year olds probably could've started preparing for that a little earlier.

We're also – as we're having that conversation, we're also having a conversation about what housing should look like for people with autism. And of course, for each individual with autism, it's going to be about meeting their needs and what it is that they want. And I don't know what that is for Jaden at this point in time. He seems to want to live with his mom or I at this

point in time. But eventually, we're going to
have to be looking at something else for him
and it's going to be really important for us
to have conversations with Jaden and try and
identify what it is that's going to work for
him. I don't have an easy answer on what
works. I know that there are a lot of models
that seem to be working, but you probably
have better experts in this room to talk
about some of those. It's a conversation that
we need to have more of.

On the employment side, we're still –
what are we looking at? 80 to 85 percent
unemployment for people with autism. We've
just got to find ways to do better than that.
I know there are a lot of people focused on
it.

I have a young woman in her mid-20s
working six hours a week now in my office.
It's interesting. Her role is a self-

advocate. Her role in the office that she's

seizing is reaching out to autism advocacy

organizations, particularly self-advocates.

So it's kind of cool to have a self-advocate

having conversations and getting feedback

from other self-advocacy organizations and

have just been invaluable to me.

MS. CRANE: ASAN has a Canadian affiliate

if you want to reach out to them too.

MR. LAKE: For sure. Yes. And there's an

organization in A4A in Ontario that has been

quite vocal over the course of the

conversation right now and I've had the

chance to meet with them as well.

But anybody in the room that wants to

point me in the direction of others that we

should talk to, I'd be glad to have those

conversations.

DR. DANIELS: Alison.

MS. SINGER: I just want to – I'm sure you're probably aware of this, but the International Society for Autism Research annual meeting this year will be in Montreal. We're hoping to have a lot of participation from Canadian organizations and advocacy groups, self-advocates, families. It's a wonderful opportunity to bring scientists and advocates from all over the world to Canada. We look forward to being there.

MR. LAKE: I'm going to try and get there. It's really actually close to Ottawa. The one thing I would say is in those formal meetings for those of you that have been part of the formal organization, it's tough for someone that's not a researcher myself to get a speaking slot or anything like that. It's one place that doesn't seem to fit for that very well. But I'm if there's a side event that anyone thinks it would be worthwhile for

me to come and say a few words. I'm glad to do that. I've done that a few times. I did it in Salt Lake City and Toronto when the event was in Toronto. It's easy for me to make my way over there and thanks for that.

And the one thing – I mentioned this last time around kind of related to the stuff we're doing. We are really trying to move in a direction and get some traction around a concept of a global autism partnership. With my other hat or previous hat in parliament, my role by the way in parliament, I'm in opposition. I'm in a conservative member of parliament. I'm in opposition right now and I'm the shadow minister for youth, sport, and accessibility. So I'm a lead on youth, sport, and accessibility. I get a chance to talk to universities and to students and other accessibility organizations.

My passion over the years has been international development so working on international efforts to save the lives of moms in and around childbirth and kids under five and a lot of work on the rights of women and girls and those kinds of things. But through that work, I've had the opportunity to meet some pretty fantastic organizations like the Global Partnership for Education. Alice Albright runs that from down here and sort of the plans and world visions and save the children and USF.

I have this vision for a global autism partnership that would bring autism organizations from around the world together and working together, hopefully draw some funding from governments and then have these organizations partner with organizations on the ground in the developing world to introduce evidence-based interventions.

One of the things that we've really been focused on is putting autism sort of vertical in place in these other organizations that are not autism-specific organizations. Imagine a world where Plan and UNICEF and Save the Children and World Vision and the Global Partnership for Education and others have someone who is an autism expert involved in their organization and perhaps we could have a situation where World Vision, who has Wi-Fi-enabled offices in rural Ghana, for example, can train their community health workers who go and assess the health of kids in Ghana out in the hardest to reach areas. What if you taught them via web video or something like that what autism looks like, train them to go out and find these families who are often hidden in countries like that because there's such a stigma attached and offer them the opportunity, the families the

opportunities to come back to those same Wi-Fi-enabled offices for some training, parents' skills training or caregiver skills training that we could offer? If you start to think about that, multiply that by thousands and thousands and thousands of opportunities because of the plans in UNICEF and Save the Children are doing the same thing in addition to hundreds and hundreds of smaller organizations around the world. Just plant the seed there for a conversation that I know Autism Speaks has been a big part of over the years, but there are other organizations that are doing some big work.

Do you know that there is an International Disability Alliance that is an alliance of disability organizations that just co-hosted the Global Disability Summit in London in the summer? And did you know that the International Disability Alliance

doesn't have an autism partner because there

is no global autism organization? That's one

of the criteria for their organization. Just

something, a seed to plant for you. We're

still trying to flesh out what a governance

model might look like and who the willing the

partners would be. But it seems like there is

a lot of interest in that conversation.

DR. DANIELS: Any other questions from

the committee for Mike and Jaden? Again, we

really want to thank both you and Jaden for

being here. It's really a pleasure to have

you and thank you for helping us recognize

Autism Awareness Month and we look forward to

seeing you next time.

(Applause)

DR. GORDON: Thank you both.

Next up we have a presentation from

Stuart Shapira, member of the IACC and chief

medical officer and associate director for

Science at the National Center on Birth

Defects and Developmental Disabilities at the

CDC, the Centers for Disease Control and

Prevention.

Stuart is going to be presenting to us

about a new tool, the Center for Disease

Control and Prevention Autism Data

Visualization Platform. Stuart, thanks.

DR. SHAPIRA: Thank you, Dr. Gordon. Good

morning everyone. It's a real pleasure to be

here this morning to present on the launch of

the Autism Data Visualization Tool. Now, this

data visualization project was not just a CDC

effort, but also included valuable input from

individuals and several other federal

agencies in some of those individuals include

Michael Kogan, Reem Ghandour, and Laura

Kavanagh at the Health Resources and Services

Administration or HRSA, Melissa Harris at the

Centers for Medicare and Medicaid Services or

CMS, and Larry Wexler at the Department of Education.

What is the Autism Data Visualization Tool? It is an interactive website that provides up-to-date autism spectrum disorder or ASD prevalence data among children in the United States. There are four different data sources that are included in the tool and year and state data are presented when they are available. And the four data sources are the Autism and Developmental Disabilities Monitoring Network at CDC, the special education data from the Department of Education, Medicaid data from CMS, and National Survey of Children's Health Data from HRSA.

The tool also includes a description of how the different data sources were used to estimate ASD prevalence. The tool makes it very easy to find available ASD prevalence

data in each state and in the US overall. It highlights changes over time for specific states or communities. It improves access to data for public health researchers, for state health officials and for the public. It improves the understanding of ASD and its impact across communities in the United States and it can be used to plan for services to guide research and to inform policies to help children with ASD.

The first data source that I mentioned is the Autism and Developmental Disabilities Monitoring or the ADDM Network from the CDC. The tool features published ADDM prevalence estimates between 2000 and 2014 in the participating communities in the ADDM sites. ADDM data prevalence estimates include record review of 8-year-old children and combines information across communities.

The numerator for the prevalence estimates are children needing the ADDM ASD case definition and the denominator comes from the National Center for Health Statistics Bridge Population Estimates. The large sample sizes in the ADDM Network allow for more detailed data at state and community level.

The second data source from the Department of Education is special education information. These data include special education primary exceptionality classification of autism. The numerator is individuals with disabilities, education act, autism classification for 6 to 17-year-old children and adolescents and there are individual state counts as well as US counts overall. And the denominator is the National Center for Education Statistics School Enrollment Counts for grades 1 through 12.

These are publicly available data from almost every state and available for almost every year. Currently, there are data available through 2015, but the tool will soon be updated with another year of data from 2016.

The third data source, Medicaid data coming from CMS. The data source is known as Medicaid MAX where MAX is Medicaid Analytic eXtract. And the numerator is children with an ASD medical billing code or an ICD code for one or more inpatient or two or more outpatient claims in a given year. This is the same algorithm that CMS endorses in order to identify children with autism in the Medicaid data. The denominator is children enrolled in Medicaid during each year and data are available for 2000 to 2012 for most states.

And the last data source of the four is the National Survey of Children's Health from HRSA. And the estimates in the tool match the published National Survey of Children's Health data. This survey uses complex survey design and weights in order to provide national averages.

The numerator is children with ASD or more recently children with current ASD. So the survey questions have changed on ASD over time. The denominator is children participating in the National Survey of Children's Health each year and as I mentioned, it's a nationally representative complex survey sample. The years of available data are shown on the slide and the survey was redesigned beginning in 2016.

Some of the features of the tool are that the data are downloadable and they are downloadable into spreadsheets to allow for

custom analyses. The tool contains links to the primary sources of the data as well as deeper technical notes and other information for each data source. And updates as new data are available are being made to the tool. As I mentioned that the special education updates will occur soon for a new year of data.

The individuals at CDC who were involved in the development of the tool are shown on this slide and the real shakers and movers involved in the development are shown in bold font and they include Patty Dietz, Bruce Heath, Chrissy Hillard, Matthew Maenner, and Sarabeth Mathis.

I thought it might be best to actually go to the tool and to show folks how easy it is and how the data are laid out. The link is shown on this slide. And by clicking on it, it takes us directly to the tool. It's hosted

on a CDC website. And as I scroll a little
bit down the tool, there are five buttons at
the top that take the user to various
sections of the tool and they are labeled
data, explore, methodology, about, and
resources. Now rather than clicking on these
buttons and jumping around, I will just
scroll down the tool and talk about what's in
various sections.

In the first section, data, this section
describes the sources, the four data sources
for the tool and provides additional
information about them for the user. These
four tabs at the top were on special
education child count and one can click on
National Survey of Children's Health and
obtain more information, Medicaid and finally
the ADDM Network.

Scrolling it further down, one can start
visualize the data. I will orient everyone to

the charts because these graphs are very similar. On the side, this is the prevalence of ASD per 1000 children. And across the bottom are years, for example, 2000 up to 2014. And each of these data points if one hovers a cursor over the point, it shows the year as well as the prevalence number. For example, this one for 2000 is showing a prevalence of 6.7 per 1000 children. So one can do that for all of the data points.

And what we're looking at here at the top above the chart – there are two drop down lists. One can look at ADDM data and then shifting to Medicaid data. This is for the US or total overall and, again, during those years and can then similarly go to National Survey of Children's Health and there are four data points during this period of time and special education or child counts. This is for the US overall. But one can look at

individual states or communities of interest. This drop down menu to the right lists all the states and communities. For example, if I click on Maryland, this shows Maryland data from 2010 to 2014, the prevalence coming from special education counts as well as Medicaid data in Maryland, ADDM Network in Maryland and so on.

Scrolling down, there's also a heat map approach to the prevalence data. This map of the United States and I'll orient you to the key. The lightest blue color is a prevalence of less than 10 per 1000 children. Slightly darker blue is 10 to 20, 20 to 30, and finally 30 or more children per 1000. We're now also on the ADDM Network for the year 2014. We could go back to 2008 for the ADDM Network and show the prevalence in the various states. Medicaid, which covers most states and this is again 2008. One can look

at other years like 2012 for Medicaid and so on and so forth. And then the others are shown here as well. The National Survey of Children's Health as well as special education counts.

There's a lot of interest in the difference in prevalence between boys and girls and one can also view those data. They are only available for the ADDM Network because of the size and the way that the data are collected. One can calculate prevalence of boys versus girls.

This is for the US total overall in 2014. The prevalence numbers are shown here to the right so overall was 16.8 per 1000, boys 26.6 per 1000, girls 6.6 per 1000. And one can look at various dates in the ADDM Network data collection of the ratio between boys and girls and overall or one can view individual states, for example, North

Carolina. If there are no data, it will say

data are not available for either a

particular year or a particular jurisdiction.

But here's Alabama, for example.

Another demographic for which their data

is presented is race ethnicity and this is

shown in a graphical format from 2000 up to

2014 and this is also ADDM Network data where

on these graphs non-Hispanic white are shown

in green, non-Hispanic black in blue,

Hispanic in purple and Asian Pacific Islander

in this orange color. This is the US overall

during this period. One can look at

individual sites in the ADDM Network such as

New Jersey, showing the prevalence and the

changes over time between the various racial

ethnic groups and the identification of

children with autism spectrum disorder,

Alabama, another example, and so on.

Now this last section I will show
examples of is called Explore and I think
this is really cool because one can compare
two data sets together or components within a
single data set. First, across the top here,
these are the four data sources, the special
education child count. And the blue dots
represent the years in which those data are
available from 2000 up to 2016. The National
Survey of Children Health always combines two
years of data so here are 2003 to 2004, 2007
to 2008. Under this, the orange dots in
Medicaid and then the ADDM Network data in
these purple dots at the bottom.

This is the US overall, but if you are
interested in a single state, let's say we
were interested in data available on Hawaii,
there are only special education data and
Medicaid data available on that state. But
there are data available for every state in

every jurisdiction in at least one of the

four data sets.

Now, what's very cool about this is

let's say I look at the US overall. I can now

compare the prevalence of the US overall in

the ADDM Network and that's what's shown here

on the graph in purple. I can compare that

with another location. I can look at let's

Arkansas and so I can compare the US overall

in purple with the Arkansas prevalence shown

in blue or I can prepare the US overall with

Georgia and that they are very similar

between the Georgia prevalence and the US

overall prevalence.

I can also compare between data systems

so this is now comparing the ADDM Network

data shown in yellow with Medicaid data shown

in – I'm sorry. The ADDM Network data shown

in purple with the Medicaid data shown in

yellow. I always have to look at the legend

here to see what does the yellow stand for,
what's the purple stand for. You can compare
individual states with overall US data or you
can compare estimates between two different
data sources.

Further down, there's information for
how the data are gathered and specifics on
that for each of the data sources, ADDM
Network, Medicaid, so on, National Survey of
Children's Health. Significant additional
information. And then at the bottom, I'll
show that there are resources provided for
each of the data sources as well as extensive
technical notes for each of the data sources
that the user can view.

In summary, I hope you'll appreciate.
This is very user friendly, very easy to
navigate, and a lot of information at the
fingertips for users who are interested in
learning more about the prevalence of autism

spectrum disorder. Thank you very much for your time.

(Applause)

DR. GORDON: Thank you, Stuart. That's really wonderful to have this resource. I just want to point out one feature which you did not focus on, but beneath the visualization tools are descriptions of the data sources and more importantly descriptions of what the quality and manner by which these data are acquired and how that informs the estimates. I think that's really important when we talk about prevalence. It's not just numbers because as you were showing us implicit in the data you were showing us, prevalence estimates differ depending upon the method used and that explanation at the bottom to explain those differences are really crucial.

DR. SHAPIRA: Absolutely.

DR. GORDON: I want to thank you for that. I have a couple of questions. Let's start with John and then we'll go with Louis.

MR. ROBISON: Your ADDM reports have always stated that you were estimating prevalence among 8 year olds. And today you're here showing us a prevalence tool with three other data sources. Those data sources should have data for kids all ages up to 17, but you don't mention anything about age in that. I wonder why is that.

DR. SHAPIRA: In the tool, it's described at the beginning the age ranges for individuals and I mentioned that on the slide. For example, for special education, it was 6 to 17-year-old children and adolescents and Medicaid is also children in that broad age range as well as the National Survey of Children's Health. I believe that it's mentioned in the description of the data

sources where the data come from, the age

range. You're correct that the ADDM data is

focused on 8 year olds. The other data

sources include a broader range of

individuals.

MR. ROBISON: If I could make a

suggestion then to clarify that, I was

looking at your text before I asked the

question and I saw, for example, a text said

that the data represents children 0 to 17

year old in one example. And it wasn't clear

if you had data sorted by the age of the

child and you had only chosen to display 8 to

make it directly comparable to ADDM or if you

were showing that total range. I do see what

you mean.

DR. SHAPIRA: Great. Thanks for pointing

that out. We'll make sure that it's clear

that the age or age range for each data

source are clearly stated so the user

understands we didn't limit the other data
sources just to 8 year olds. They include the
broader age range in the other data sources.
Thanks.

MR. ROBISON: Thank you for making that
clear.

DR. GORDON: Louis.

DR. REICHARDT: I am just curious what
you think this data really means when we are
dealing with a disorder that has a very high
genetic contribution. Are you really looking
at differences in autism between states or
differences over time or are you simply
looking at differences in access to health
care, interpretation of data? I'm just
worried that people will misinterpret this.

DR. SHAPIRA: I think that it's actually
all of the above so differences in services,
differences in recognition of autism,
differences in how children are assigned to

autism exceptionality classification or

differences in how practitioners identify

autism spectrum disorder, differences in how

physicians code for autism spectrum disorder

in claims data. There are a lot of variables

in this, but I think that it's important to

provide this information for researchers, for

public health officials, for the public to

understand that there is no one single number

for autism spectrum disorder that it's a

prevalent condition and that it indicates

that as children grow and mature into

adolescents and adults, there are needs that

these individuals will have.

DR. REICHARDT: I would just say my

concern would be that it can spawn some what

I think are likely to be false impressions to

the autism as a spreading epidemic like

measles that you are either safer in

Mississippi versus California from autism. I

think many of these differences do give rise

to misinterpretation at what's really going

on.

DR. SHAPIRA: That is very good point.

Thank you.

DR. GORDON: I just want to add to that

point. I think, Stuart, one of the things

that you said is something that the public

has a challenge understanding. We've

encountered this in our discussions with

advocacy and public communities and even

legislatures in other disease categories. The

point that prevalence is not a single number.

And I think this website really nicely

illustrates that.

Prevalence variant across geography

though I'm not sure and I haven't read

through the details down at the bottom of

that page, but it would be important to note

that there might be many reasons for

prevalence based on geography having to do

not with the biology of the illness.

But, again, just to commend you one more

time and commend the CDC for putting this out

there. What gets out into the press quite

often is the ADDM number because you have a

release to it and it says this is the number

that we've gotten it and despite all the

actually important and scientifically

accurate disclaimers that you put out there

when you put the number out, press often just

repeats the number. Having this out there for

press to refer to is important.

I think it's also important that when

CDC does release that ADDM number from year

to year that they remind them that it's not

just one number. Maybe you do it already. I

know that you do a good job of explaining why

the ADDM number may not be representative,

but referring them to this page each time

that thing is released maybe also important
moving forward.

DR. SHAPIRA: Yes, thank you. That's a
great point. And we do focus on trying to
make it clear to the media, to policymakers,
to the public, to researchers that the ADDM
number is representative of just the
communities that are involved in collecting
data on autism prevalence. So it's not
nationally representative. It only reflects
those 11 communities, for example, in the
previous report. It's not necessarily the
entire state. In most cases, it's only a
segment of the state.

But the ADDM data is so rich in that the
researchers and the group are able to drill
down to things such as the age of initial
diagnosis of autism, the age at which the
child is beginning to receive services, the

differences in demographics and the

prevalence and the differences in sex.

We are keenly aware that it's often

misunderstood by the media that the number

means the US number, but we strive to try and

make that clear in the information that we

put out.

But I agree. Pointing the media and

others to this site will be very helpful in

the future.

DR. GORDON: David then Alison then John

then Larry.

DR. MANDELL: It is a really beautifully

put together tool and easy to explore. I just

want to echo Louis' point though. It is that

the data are put together and presented

almost without comment and yet contradicts

each other. For example, if you take the

survey data, the National Children's Survey,

the numbers are between two and three times

higher than any other of the prevalence
estimates. I don't know if you're using the –
has a health care provider ever told you or
does your child currently have to make – you
know there are huge – as I'm sure you know,
there are huge differences in those numbers.
And yet Medicaid, which has a much higher
treated prevalence of autism than private
insurance numbers, is a third of that. I
don't know who the health care providers are
that are – clearly, there's some
misconception of the question and the survey,
but the numbers don't add up. Even the
distributions of the data over time aren't
the same.

Prevalence is one number. What's not –
what leads to more than one number is how we
define the condition and the methods that we
use to ascertain in a given sample. But there

is a true prevalence out there based on a certain definition.

I think it would be really important for the CDC not to refer to these as prevalence data, but as either as surveillance data or data that are ascertain in certain ways and to be a little more explicit in a larger font about what the limitations are of the methods that are used to collect the data.

I appreciate very much researchers like Maureen Durkin who has a recent paper trying to figure out whether there may be some ascertainment bias, for example, in why the number for Hispanic children are lower and finding – there's a little bit, but it can't account for the differences and pointing to differences in access to service and other things as maybe driving that. If that's what's driving it then it's not a prevalence estimate.

I think it's really important to look –
you know that that this is my soapbox and
I've been on it once, but I think it's very
important that the CDC approach these numbers
more critically and share concerns about
differences in ascertainment on the website
when they are making these data available to
the public for exactly the reasons that Louis
described.

DR. SHAPIRA: Really good points. Thank
you very much and I agree that it's not black
and white. There is a lot of fine tuning to
understanding how these data are collected
and you're correct. Whatever the magical
prevalence number is if one were able to do a
very detailed test on every single child that
one point in time instantaneously and make a
diagnosis of autism spectrum disorder, which
has challenges in and of itself since it's a
behavioral phenotype and not something you

can just get a yes or no answer to from a

blood test. But if one were miraculously able

to do that for a large segment of the

population, one could then identify that

precise number. These are all estimates

around that number whatever it is, using

various methodologies as you pointed out. And

the methodologies all differ for the four

data sources. The numbers even though they're

called prevalence estimates, these are

estimates based on the data sources

themselves. You're right. Maybe it's

surveillance rather than prevalence, true

prevalence.

But I think it's important to point out

these differences so that those who are

interested in autism prevalence understand

the complexity of coming up with a number.

But I think the bottom line is that

there are a lot of children who have ASD and

they are growing into adolescents and adults.

And as children, they require extensive

services and will continue to do so as they

grow into adults and those prevalent estimate

numbers seem to be going up in all data

sources and whether it's better recognition

or better receipt of services or better

identification, those are all feeding into

it, but still our challenge is to make sure

that these children and as they age continue

to have services that they need to thrive.

DR. GORDON: Well said. Alison.

MS. SINGER: I agree with that and I

think in the advocacy community, the value of

a tool like this would be in using it to plan

for services and using it to try to effect

policy changes at the state and federal

levels.

We've talked a lot over the past years

about the CDC needing to get more granular

with regard to the data, not just the number

of people who have autism, but how many have

intellectual disability as well as autism

because, for example, the services needs of

someone with intellectual disability vary

greatly from someone who has average or above

average IQ. Similarly, planning for people

who have co-occurring psychiatric conditions.

I know that back in 2014, the ADDM

Network started to collect this granular

level data and that has been incredibly

helpful for us. I would encourage you in the

2.0 version of this tool to incorporate some

of those data because they are really key to

our ability to affect meaningful policy

change.

DR. SHAPIRA: Thank you, Alison.

DR. Gordon: John.

MR. ROBISON: I believe that it is of

vital importance that Americans be able to

trust our public health agencies and what they tell us. And I think we are in a very unfortunate position where there is a fundamental breakdown of trust between the autism community and CDC.

And what concerns me here is that I see in this tool the potential for furthering mistrust because CDC doesn't take clear positions to explain the questions that people should be asking. For example, Louis raised a very good point. There is absolutely no evidence that there is a material difference in autism rates in Montana or New Jersey and yet they are strikingly different in your reports and you provide autism by state as if autism by state is a meaningful number.

The question the public asks is they say what's going on in New Jersey. Is there an autism that's caused by toxic waste? What

causes it? When, in fact, you and CDC could make a clear statement. You could say we don't have evidence of a reason that an autism rate would be different and we believe that it is a difference in ascertainment. CDC could guide the conversation in both a constructive and scientifically correct direction. I think that's a really important thing to do.

Then when looking at the data, as you pointed out, there is a huge difference between the National Survey of Children's Health, the special ed data, and the ADDM data. And as David rightly points out, they can't all be right. So CDC must have a position on that.

When the Children's Health Survey says that there are three times as many autistic people as Medicaid or twice as many as special ed, what do we believe? Do we believe

that as Alison suggested that a significant

number of autistic children identified in the

survey of children's health have sufficient

cognitive skills that they do not need

special ed support. That would be a very

significant finding and it would be important

for us to say it.

Do we believe that these ADDM data is

higher because the ADDM centers have a

superior ability to recognize autism? And if

that's so, these other groups are failing in

a duty to American children.

I think that that's the kind of thing

that CDC should be explaining in order to

build public trust in the agency. I would

suggest to you that you've collected a lot of

valuable information here and it is really,

really important to me as a representative of

the autism community that we deliver it with

the explanations that allow people to make

scientifically sound judgments and go forward
trusting our government.

DR. SHAPIRA: Those are great points.
Thank you so much, John. And just to go back
to the first one, I agree about the
differences in states that it can be
confusing to those who aren't familiar with
the issues related to identifying children
with autism so there are always going to be
those concerns as to why is it higher in
state X versus in state Y.

CDC does make an effort in its autism
data release surveillance reports every two
years to codify the differences that are seen
between various sites, why New Jersey is so
much higher compared to other sites. It's a
challenge to know for sure what the reasons
are. There are certain factors that we
believe are playing a role, but we do try to
make that clear in the surveillance reports

as well as in the information that's provided

to the media and press releases so that when

the media communicates with the public, the

public has an appreciation for why it's

higher in one site compared to another site.

But there are challenges with communicating

that and we recognize that and we'll strive

to make that as clear as possible in this

tool as well as in the reports.

And then the differences between the

various data sources and the prevalence

estimates of autism is also something that

we've been very attuned to because the

question comes to CDC frequently that what is

the correct prevalence because – why is the

National Survey of Children's Health coming

out with a different prevalence than the ADDM

report?

The tool focuses specifically on the

differences and how the data are collected,

as we mentioned, the age ranges of the
children who are included, and how the data
are collected. Is it by parent report? Is it
assessment of school and health records? Is
it billing codes and so on? There is perhaps
no ideal manner in order to develop a true
prevalence estimate that these give us
indications as to what possible or likely
prevalence is. And then as Alison mentioned,
we have the opportunity to drill down to look
at some of those other factors such as
intellectual disability and age at diagnosis
and so on.

Your points are great and we'll take
them into consideration to see if we can be
clearer in this tool in moving forward in CDC
data releases of autism prevalence estimates.

DR. GORDON: John and Stuart, I really
appreciate this exchange and I think it's
really wonderful because it gets down to the

heart of the issues that data are limited in terms of what they can explain and yet the community needs and often demands, appropriately, answers that the data can't always give. I referred again. We wrestle with this issue not only in autism, but for many other disorders throughout medicine.

Prevalence estimates are really bad at revealing mechanism and by mechanism I mean everything from genetics to biology to infection to social causes to differences in ascertainment, et cetera. Prevalence estimates are good at telling you how many we think using this assessment method might have the disorder. But they are really, really bad at answering the questions that are really important questions from a policy perspective that you raise, but the prevalence can't really answer.

One has to think when one is designing –
study is not quite the right word, but
evaluations and analyses of the data. What is
the question you want to answer? And then
look at whether the data exists to answer it.

ADDM does a really good job at answering
lots of questions about – that require a
deeper look, but not a very good job at being
able to compare rates and things across
cities.

Stuart, I applaud your efforts both on
this page and moving forward to try to
clarify why there are a range of prevalence
estimates. We fight the same battle in trying
to figure out what the prevalence is of other
disorders. And I think we just have to
remember that prevalence statistics are
helpful and completely unhelpful at the same
time, depending upon which questions you want
to answer.

Sorry. I took my chair's privilege and interrupted the flow here. Larry and Sam and anyone else just so I can get you on the list. Go ahead, Larry.

DR. WEXLER: Thanks, Dr. Gordon. Let me start out as I will applaud CDC for what they've put together here. Now, there is a bias here because one of the data sets is mine. I put that on the table.

I think it's important to recognize that you're never going to have methodological purity in any of these data sets. I think it's more important to recognize that there's a difference between scientific data and the use for scientific purposes and the use for policy.

Now, when I came up and I've been doing this a few years, what I was taught is when you're dealing with policymakers, the most complex statistic you should use is percent

and that three out of five is better than 60

percent. I say that and I'm being really

pretty serious about it because the people

who make national policy aren't scientists.

Any way the data are represented in a way

that's comprehensible is to be applauded from

my perspective.

The other thing is that I think the

differences are the strength of this tool and

the variance is the strength of the tool

because what it drives is questions. And any

time we're driven to ask questions especially

in a policy context that's a great

contribution. And, again, I think – I really

think this is terrific.

But I think Stuart said something when

he first started talking is that put those

four data sets together and this tool allows

you to do it. And there's simply no denying

that no matter how methodologically impure

those data sets are, the line is going up.
And if I go back to when IDEA, the
Individuals with Disabilities Education Act,
was the last reauthorization was in 2004. And
in 2004, autism was listed specifically as a
low incidence disability and it still is
listed that way. In those 14 years on all of
those data sets, there's no doubt there is an
incredible trend upwards. I certainly can't
answer why, but the question of why is it
this percent in New Jersey versus this
percent in North Dakota is a wonderful
question that we are forced to address. And
if this data system, this data set supports
asking those questions then again I think
it's terrific. And as another agency, I say
bravo.

DR. GORDON: Thank you, Larry. Sam. This
will be the last before the break.

MS. CRANE: I'm actually going to raise an issue that I don't think is going to be totally resolved here, but I just needed to bring it up in response to some other comments.

I think that knowing prevalence in order to determine how much we need to devote to services is absolutely essential. I think that is going to be one of the primary things that we use this data for.

But I don't want to get into a trap where we assume that people with intellectual disability are going to need certain types of services, people without intellectual disability are going to need other types of services because this is something we're already seeing in states. We've got people who are completely unable to access home and community-based services waivers because they

haven't been diagnosed with an intellectual disability.

I have friends, close friends who can't make a sandwich independently, can't remember to eat, can't independently navigate outside their house, but aren't getting any services whatsoever except for what their friends and family can provide because they don't have an intellectual disability and the same thing is true of special education services.

I know many parents who are at their wit's end. Their kid is having behavioral meltdowns on a daily basis because their needs aren't being met in the classroom, but they're being denied special education services because their test scores are fine. So they're not in class, but since they're turning in homework and the homework has correct answers, they're not getting any kind

of special education services. I just wanted

to raise that as an issue.

I think we do have to find some way of

measuring the level of intensity of services

that people need, but I don't think that a

lot of the times what people use as a proxy

for that isn't necessarily the one that we

should be using.

DR. SHAPIRA: That is a great point.

Thank you so much for that, Sam. That's very

critical to understand.

But I do want to correct something that

Dr. Gordon said. He said that this was my

tool or my work and I just want to point out

again on the last slide. These were the real

movers and shakers that help put this

together. My colleague, Patty Dietz, who is

the branch chief for the Developmental

Disabilities Branch at CDC where all of the

autism work goes on. She's here in the room

and she's really been the driver behind

achieving this and has done a great job. I

thank her and I hope you'll thank her too.

DR. GORDON: Thank you, Patty, and the

rest of the crew. Thank you very much.

We're going now take about a 14-minute

break. We'll be back here at 10:40 for a

presentation from the FCC.

(Whereupon, the Committee took a brief

break at 10:27 a.m. and reconvened at 10:40

a.m.)

DR. GORDON:

We are really pleased to have a

presentation from a federal office that is

not represented on the IACC, but they come

today to talk to us about an issue that is

directly relevant for many of those

individuals on the spectrum who have

challenges in communicating. It's my pleasure

to welcome Theodore Marcus, the deputy chief

of the Disability Right Office in the

Consumer and Governmental Affairs Bureau at

the Federal Communications Commission. He's

going to be discussing recent FCC activities

on facilitating communication for individuals

with disabilities. Thank you, Mr. Marcus.

MR. THEODORE MARCUS: Thank you. Thank

you very much, doctor. Before I begin, I

thought I would take advantage of owning the

floor for the moment because I did have some

comments on what I heard in the most recent

presentation, but also Minister Lake's.

Let me share with you an anecdote. I got

a call several weeks ago from a father in

Ohio who had two autistic children. He lived

in a trailer development. He found out when

he moved there that the landlord had entered

into what's called an exclusivity arrangement

for multiple dwelling unit, exclusivity

arrangement for the broadband provision

there. It was one ISP, internet service provider.

And it turned out that the service that was being offered – there is some hijinks in this so I can't get into that, but the service that was being offered was insufficiently powered to enable the resources that the two autistic children needed as a part of their broadband connection. He was terribly frustrated with this. He made every effort to contact the folks at the Ohio Public Service Commission. They're great people. And they were struggling with it.

It turns out that there is a federal law from this entity called the Federal Communications Commission that speaks directly to the question of exclusivity arrangements for broadband in multiple dwelling unit places.

Although I can't go deeper into the facts, I did want to say when you think about where's broadband available, at what speeds, what could it power, who needs to use it, where the unserved and underserved populations. Where are people who are vulnerable? You may not know this, but every drop of that is a part of the FCC's purview. Every drop of that is something that we're studying, that we care about, that we need.

When Minister Lake talked to us about – basically presented a SWOT analysis. He said there are strengths and there are weaknesses and if all of our strengths are the same, if all our weaknesses are the same then we're not really going to be able to address a complex set of problems. I think that's absolutely accurate.

We're multiple nations, right? You're a body of researchers and scientists and

policymakers in that space. We are in the
communications space. And we regulate the
availability and accessibility of
communications products and services. We
should be engaged especially now. Legacy
technology was a twisted copper pair that
enabled point-to-point communication. Okay.
That was yesterday's communications.

Today's communications are as complex
and rich and challenging and wonderful as
we've ever been able to imagine. And so, for
example, Dr. Shapira. You have data. That
data may tend to show where folks with autism
or where folks who have ASD are. It may be
statistically challenged. I understand that.
But we might be able to use that data to
understand where we should be driving
resources, how we should understand where
universal service is best deployed, where is
the availability of the persons with ASD for

broadband. Where is that? The data may not be perfect for every purpose, but it might be useful for other purposes.

To borrow from Minister Lake, we should be talking. We want to be engaged with you. We want you to be engaged with us because it may very well be that we have something to bring to bear, to assist.

I want to say good morning and I want thank you for this opportunity to engage with you and to participate in this critical conversation in a very big month and a very big time on ASD.

I want to thank the persons who are here who are associated with accessibility for this meeting. I want to thank the event planners for assisting with logistics and pretty much everything else.

I've got a couple of colleagues who are here with me with the Disabilities Rights

Office, but also from our larger bureau,

which is called the Consumer and Governmental

Affairs Bureau and that's David Savolaine and

Rosaline Crawford.

But I also want to thank some folks who

helped get this presentation ready who aren't

here today. That's Will Schell and Erica

Rosenberg and Suzy Singleton, and Darryl

Cooper, all of whom are our subject matter

experts, our boots on the ground, if you

will, in this space.

Look, the conversation about empowering

persons who have ASD and enabling them in

their lives, orother cognitive disabilities

quite frankly, involve information and

communications technologies that come within

the FCC's regulatory purview, as I've

described. And what we do at the FCC is work

within our mandates and within our scope of

authorities to ensure those technologies are

accessible and usable for persons with disabilities.

We are well-known, I think, I suppose, for the work that we've done for a long time to ensure access to telephony and video programming for persons who are deaf or hard of hearing or blind or visually impaired. But we actually - our work applies to all persons with disabilities and that includes persons with ASD or other cognitive disabilities. We want to make sure that we are engaged. My presence here is some proof of that desire.

The presentation that I'm going to try to do is going to basically fall into sort of two spaces. One is going to be sort of the talk through the foundational elements, why are we relevant. What makes us relevant to this conversation? That's kind of foundational or to update that language. What's that platform?

And the second part of this conversation or this presentation is going to be our build out. What have we been doing and what's next? What are the opportunities that are on the table?

With that in mind, let's move on to the slides. Let's do a little bit of discussion about background. Our foundation initially is the Communications Act of 1934 as updated or amended, if you will, in 1996.

Let me step back. Communications or telecommunications. We have some general definitions there. It basically refers to the making and receiving of calls over the telephone network. That's the legacy understanding of what telecommunications is. For our purposes, it's sufficient.

In 1996, Congress said that telecommunications services and equipment must be accessible and usable for persons

with disabilities. The caveat in the Act for
that is that accessibility has to be readily
achievable. What that essentially means is
that it's easily accomplishable, able to be
carried out without much difficulty or
expense.

If accessibility is not readily
achievable then services and products and
equipment must be compatible with assistive
technology, commonly used by individuals with
disabilities to achieve access if
compatibility was readily achievable.

For example, if you are a person that
uses a hearing aid and you pick up your
telephone, there should be compatibility
there. That is something that you bring to
the table already and the phone should be
compatible with it if you're not enhancing
the sound or otherwise making it accessible
to the user.

With respect to usability, for a product or a service to be usable, people with disabilities must have access to the full functionality and documentation associated with that product or service and that includes instructions, product documentation, user manuals, bills and technical support like help desks, as that is provided to persons without disabilities.

In 2007, we want to say that we extended those requirements beyond legacy telephony to VoIP, Voice over Internet Protocol telephony. This would be telephony that's connected to the public switch telephone networks in that particular instance, but there's also VoIP that's not connected to the public switch telephone networks, which we'll address in a moment.

The next sort of pillar of our foundational -- the next big piece of our

foundation is what's the 21st Century

Communications and Video Accessibility Act,

which we call the CVAA. This was in 2010 when

Congress amended the Communications Act to

update it and to update is accessibility

requirements for persons with disabilities

consistent with advances in the

communications' marketplace.

ACS or Advanced Communications Services

includes, so is statutorily defined, text

messaging, instant messaging, interoperable

video conferencing, and the newer VoIP

services or Voice over Internet Protocol

services that didn't exist at the time and

would've been covered prior to 2010 under

Section 255 of the Communications Act.

The rule under the CVAA is that ACS, or

Advanced Communications Services and ACS

equipment, must be accessible unless not

achievable. So now you're hearing that word

achievable again. In the prior iteration
under the Communications Act, we said readily
achievable. Congress now says achievable so
it has a slightly different definition and
I'll give that. It's got to be achievable and
achievable means accessible through an
accessibility solution that's available at a
nominal cost and there are some implications.

Computers, tablets, devices,
smartphones, and software used for advanced
communications services must be operable with
limited cognitive skills.

Electronic messaging service such as
text messaging, instant messaging or email,
internet voice chat service such as using
your computer to talk to a friend and
interoperable video conferencing services are
part of what has to be accessible and usable.

One thing I want to note on that is that
equipment manufacturers and service providers

has to build accessibility into their
products and services or rely on third-party
accessibility solutions that are achievable
that are available to consumers at a nominal
cost and that's a cost that's small enough
that it's not a factor in the consumer's
choice.

An accessibility solution that the
consumer may get from a third party, from
another company, that is, might be an
application of software that simplifies the
display of a smartphone to enable an
individual with a disability to send and
receive email and text messages.

These requirements, however, don't apply
to advanced communications services or
equipment that's customized for the unique
needs of a particular business and are not
offered directly to the public by the service
provider. In such cases, the business may

have accessibility obligations under other disability law such as the Americans with Disabilities Act.

Just like telecommunications for advanced communications, products or services to be usable, people with disabilities must have access to the full functionality and documentation for the product.

Now for both telecommunications and advanced communications services, the thesis at the FCC is functionality. We focus on functional abilities and we define the term accessible in that context to mean that input control and mechanical functions must be locatable, identifiable, and operable. For example, it should be all of those things without vision. It should be all of those things with low vision and limited and no hearing, with little or no color perception, without hearing, with limited manual

dexterity, with limited reach and strength.
If you have a prosthetic device, without
time-dependent controls, may need time to be
able to use the service. It shouldn't be
rapidly going past you before you have the
time to engage. Without speech, with limited
cognitive skills. By providing a mode that
minimizes the cognitive, memory, language,
and learning skills required of the user.

Before I move on from sort of the
platform of why the FCC is in this space with
you, I want to tell you about our bi-annual
report. Every two years since 2010 – so this
is the CVAA. Every two years the FCC submits
a report to Congress about the accessibility
and usability of telecommunications and
advanced communications services and
equipment.

Now what this report does is it assesses
industry compliance with our requirements. It

addresses accessibility barriers to new
communications technologies. It addresses the
effective accessibility related record
keeping and enforcement requirements on the
development and deployment of new
communications technologies. And finally,
provides information about the number and
nature of and the actions taken to resolve
complaints alleging violations of these
requirements.

Now to assist the FCC in the preparation
of our bi-annual report, we ask for public
comment on these issues. Industry usually
provides input on the ways in which they were
designing and developing their products and
services to meet the needs of people with
disabilities. They attribute some of the
increases in accessibility to the
availability of accessibility features that
are built into operating systems and

platforms such as iOS, Android and Windows.
Which communications at developers can tie
into a mute. Over the years, the consumers
have noted increased accessibility in
communications technologies, but also
identify areas that still have room for
improvement.

We do issue this report every two years
and we do issue it on the basis of material
that is presented to us. This group can
present information to us or knows people who
can. Let's make sure that we are getting in
our bi-annual report making the grist for
that particular mill and we invite you to
reach out as needed and as you are able to
get folks to contribute to that process.

You can go online to request assistance
through the FCC's Consumer Complaint Center
by selecting access for people with

disabilities and the discussion of the bi-annual report will be found at that site.

I am going to move past the platform. We have the CVAA. We have the Communications Act of 1934. We have a bi-annual review requirement that we do, which allows us to take input on accessibility and how technologies are actually doing for persons with disabilities.

Now, I want to talk a little bit about – I don't want to spend too much time, but I'll talk a little bit about how we've applied those mandates historically and where we're going next.

One of the first areas of our build out is very well known is with respect to relay services. This is for people who are deaf or hard of hearing. They may be deaf, blind, or have a speech disability. Relay service is a phone service that allows persons with

hearing or speech disabilities to place and receive telephone calls.

TRS providers are compensated for the cost of providing TRS from either a state or federal fund and there's no cost to the TRS user. There are several forms of TRS and those depend on the particular needs of the user and the equipment available.

What's key to remember about TRS services is that they help people who have auditory or speech processing disabilities. Especially two services, speech-to-speech relay services and captioned telephone service.

And now we'll move on to closed captioning requirements. Closed captioning displays, the audio portion of a television program as text on the TV screen. We've all used it. Frankly, even though I am hearing person, I no longer watch any program if at

all possible without the captions. I have no idea what the actors are saying and I'm constantly asking my wife what did he say, she did she say, what did they say. And she's constantly saying, "I don't know. We get into interesting arguments there. We decided that we would start using captioning and it has enabled the entire experience and so captioning requirements are there.

It provides a critical link to news, entertainment, and information for individuals who are deaf or hard of hearing. Congress does require video programming distributors, which we call VPDs, cable operators, broadcasters, satellite distributors to close caption their TV programs. In general, most captioned programs as shown on TV must be captioned when reshown on the Internet.

Another area where we are building out
this space is with respect to audio
description requirements. What audio
description does is it assists those with
visual processing disabilities, among others,
by inserting in natural gaps in video
programming what's going on. It's a
discussion of what's going on. It may
describe a facial expression. It may describe
context. It will allow the person who is
using it to really understand what's
happening when they are otherwise locked out
of that understanding.

One of the CVAA provisions that's having
a big impact on people's lives frankly is
audio description. These short verbal
descriptions of action or key visual scenes
in a program such as the setting, costumes,
facial expressions are provided to add
context. The descriptions are inserted into

pauses within a program's dialogue. Our rules require local TV station affiliates of ABC, CBS, FOX and NBC, which are located in the top 60 TV markets according to Nielsen that they provide about four hours per week of audio described. You'll sometimes hear it as video described. It's the same thing. Audio described programming, prime time and/or children's programming.

About three hours per week also of further video descriptions during the hours of 6 a.m. to midnight. Also the top five non-broadcast networks – right now, it would be HDTV, History, TBS, Discovery, and USA must provide the same amount of coverage.

Now, it's our understanding that video description or audio description, if you will, can be a useful tool for persons with autism. For example, video description often identifies the emotions characters are

displaying, names the person who is speaking and can help explain the context for actions on the screen.

But on the other hand, video description may add to audio overload. Inserting your audio into the pauses between dialogues may contribute to that.

To our knowledge, we haven't received complaints or comments from the autism community regarding video description. We'd be interested in knowing, does it work, does it help, does it not. Can it be improved? What can we do to assist?

Another big area that we built out in under our mandates is with respect to emergency information on television. Information about crises. Everyone has to have access to that. Some persons who are vulnerable, it should be argued, need better access, faster access because they may need

to arrange for care that's above and beyond
what others might have to have so it's a
critical area for us.

Our rules require that emergency
information or televised emergency
information has to be visual. What that means
is emergency audio information must be
provided in closed captioning or through
other visual means of presentation and that
can get very raw. When tech goes down and
people are in crisis, it could be Gulf Coast
disasters. There could be all kinds of
things. Sometimes it is literally writing out
on a poster board exactly what the emergency
information is. Where can you get water?
Where is shelter? What are the evacuation
routes? We stay engaged. When tech goes down,
we're still there making sure that the visual
presentation of emergency information for
persons with disabilities is there and we try

to stay very deep into that and into those weeds.

Emergency scrolls and closed captioning can't block each other. It also must be audible. Emergency text calls must be made audible on the secondary audio stream and audible tone must accompany emergency scrolls. People have to know there's something in an emergency space that's about to come and they can go to their secondary audio channel to get that information.

We require broadcasters and cable operators to make local emergency information accessible to persons who are deaf or hard of hearing and to persons who are blind or have visual disabilities. Those are the specifics that we have addressed in our rules. What this rule means is that emergency information has to be provided in both audio and visual formats. We would like to know if the autism

community has unmet needs regarding emergency
information on TV.

What have we been up to on cognitive
disabilities with respect to which ASD is for
want of a better term a subset? In 2015, we
had a summit on the telecommunications needs
of persons with cognitive disabilities. We
held that in October of 2015. The FCC also
has a Disability Advisory Committee. This is
a FACA. Many of us know what that is. But
it's a Federal Advisory Committee Act
advisory committee. We are now on our third
edition. It has a two-year mandate. DAC 1
would have been around – I guess that would
be – so this is 2019 so that would be 2014.
But in any event, we had a Disability
Advisory Committee Cognitive Disabilities
Working Group that produced best practices
recommendations around accessibility and

usability for persons with cognitive
disabilities including ASD.

Indeed that group produced or it led to
the production of a white paper, which we
have copies of, I think. We have copies here
that are being made available to you. You can
get them and we certainly can make more and
we also have online access to that white
paper, but this was a white paper on
individuals with cognitive disabilities,
barriers to and solutions for accessible
information and communications technologies.

And we also have within my shop, and
although I'm new to the shop, it's sort of
immersion. We have dispute assistance and
consumer complaints and outreach efforts. If
a person is experiencing inaccessibility or
un-usability of communications, products or
services that we've mandated the exact
opposite, they come to us depending on the

statute to get their disputes resolved so
that they have access or if it is a certain
type of dispute or problem, it's a complaint.
And we will assure the rules and vindicate
them by managing those complaints.

I also wanted to note that back in 2015,
the FCC held a summit and expo on the
telecommunications needs of people with
cognitive disabilities, which was followed up
with guidance on accessible emergency
announcements for people with cognitive
disabilities and of course the white paper,
which I've just described.

I want to leave on the screen how to get
in touch with us, how to talk to us, and I
want to turn to the DAC and to some final
comments on what we can do together.

With respect to the Disability Advisory
Committee, we do have representation of the
community of persons with cognitive

disabilities. There's ways to get on the DAC, very straightforward. You apply. And it's all vetted and ultimately what the DAC needs it's going to get.

If we don't have the right voices or if there is a way to enhance the voices around ASD and cognitive disabilities on our Disability Advisory Committee, which of course makes recommendations to the commission, which then can be implemented as rules, then offer to join us or find out who should be on so that we are sure to have the kinds of working groups and recommendations and expertise and subject matter expertise that we have to have in order to develop useful recommendations around ASD, accessibility, and usability.

And then finally, I just want to say I think there are basically three places where this community and persons with whom it is in

one or two degrees of separation can really

help us. I've divided it in sort of three

spaces from my old oil and gas background.

First is upstream, second is midstream and

third is downstream.

Upstream is policy. If we get, for

example, the prevalence data on persons with

ASD and we get to see that on a state-by-

state level, yes, there may be some problems

with the data and those caveats might need to

be expressed. But at the same time, it can

help us with broadband mapping. It can help

us understand where resources ought to be

devoted. It can help us have a lens on what

not serving this particular community would

mean in this state or that state or the other

state. It's not un-useful.

I say that to say we're making policy

contribute to that. Let us know what we

should be thinking about. We have open

dockets in all these space that I just

described. Sometimes we don't have an open

docket, but maybe we should.

We receive comments, comments on a bi-

annual report that we just talked about.

There are other places where comments can be

made. We have meetings. Some of them are ex

parte and some of them are not with respect

to ongoing proceedings and we should be

having them. So those are sort of on the

policy development pieces of what I call

upstream.

Midstream is product and service side

engagement with manufacturers and providers.

They have to take into account individuals

with disabilities, accessible and usability

needs. They have to try to bake it in. And,

of course, at the end, they still need to

have input. Advise them. Offer to advise

them. And if they say no, let us know.

Finally, downstream. Folks have complaints. Folks are struggling. They have reason to dispute the accessibility or usability of a service or product that they are getting. They can call us. They can make online efforts with us. They can even write us. We'll take all inputs. And we will assist them in getting the accessibility and usability that they're entitled to.

If you are dealing with persons on the advocacy side, let them know where we are. Let them know that we're here. Share with them how to get in touch with us and let us see how we can assist.

Again, I want to thank you for allowing us to participate in this conversation. It's very important to us. I don't know if I have any time left, but I'm happy to hear from you, what's happening, what should we know about. I will take notes on this and I will

take them back and we will get to work. Thank

you.

(Applause)

DR. GORDON: Thank you. Are there

questions? John.

MR. ROBISON: Thank you for coming to

present to us today. One question that I

didn't see addressed in your presentation is

people with cognitive disabilities often have

by definition communication disability. And

one thing that has emerged in the last 20

years is the Internet has provided a

mechanism of communication for a great many

such people who didn't have anything before.

But given that many people with

significant cognitive disabilities also have

limited financial means, has the FCC done

anything to ensure that broadband providers,

for example, are required to provide those

services to people with disabilities at a

cost they can afford, recognizing that what

they can afford is often rather than

different than what the general public may

afford in their market area?

MR. MARCUS: The short answer to the

concept of the question is yes, but let me

get granular with it. The FCC has a couple of

key mandates that affect the answer to that

question. One is universal service. We have

to make sure that the communication services

that people need are available to everybody,

including persons with disabilities,

including persons who are part of underserved

or underprivileged populations, if you will.

We have four programs under that sort of

mandate that address this to some degree. One

is called the E-Rate program. This is the

Schools and Libraries program designed to

ensure Internet access and connectivity for K

through 12 at various levels of need. It is

as high as – we need 90 cents on the dollar to pay for this. There's low as 20 cents on the dollar to be able to pay for Internet connections.

Another program is a Lifeline program. Lifeline initially was established to ensure telephone connections at affordable rates for persons who need it or who are at or near the poverty level and could establish eligibility. This has also been expanded to include broadband. Those are works in progress and not everybody agrees on how much money should be made available, but it is a constant debate and we do provide – we do ensure that the Universal Service Fund is purposed toward broadband accessibility and availability for all Americans especially persons who are in certain populations to define the statute, which would include persons with disabilities.

MR. ROBISON: Thank you.

DR. GORDON: David.

DR. MANDELL: I was wondering in addition to putting out – to enforcing the laws in this area, are there any best practice guidelines that the FCC comes out with that can support people attempting to make technology more accessible?

MR. MARCUS: Well, for example, I think the white paper was a follow-on on best practices recommendations by the Disability Advisory Committee's Working Group. There are some there.

We're constantly in the best practices development space, but, again – and that's not really enforcement stuff, right? Best practices by definition are these are the things that we have seen collectively are working for persons with specific disabilities. Let's all sort of agree that we

should be doing that. But what should those best practices be requires input from communities that actually know.

Again, in a sense, it's engaging at the manufacturing level and baking in accessibility and usability with service providers and product manufacturers and equipment manufacturers and the FCC saying you're entitled to do that and they have to take it into account and then sort of bringing together groups to ensure that best practices are identified. And we provide the forums for that. For example, the Disability Advisory Committee, which I just mentioned.

There are new ideas and concepts, but we will stay engaged and we have not since – I think prior to 2015, we haven't even been in that conversation as it relates to cognitive disabilities in ASD. We're in it now and we

should be developing those best practices and
they're going to need some help.

DR. GORDON: Larry.

DR. WEXLER: Thank you. Thank you for
your presentation. Just to mention that all
the special education programs invest
millions of dollars every year in captioning
and description and specifically in
programming that the FCC does not require
especially around instructional materials and
we do it in multiple languages.

And in addition, we support research
into making description fairly successfully
much more efficient and effective. It's an
incredibly labor-intensive task.

And just a plug since my old NIDRR
friend is in the room is that OSEP and NIDRR
way back were the ones that supported the
research to develop closed captioning. We
have a long history together and we are now

working with some of your staff on some

accessibility issues. We thank you for your

presentation and support.

MR. MARCUS: Great. That's great. May I

ask you for what might be trade secrets? How

much are you spending? What's the gap?

DR. WEXLER: I am sort of – I would say

about $8 million to 10 million a year, but

that's a guess without my budget sheets in

front of me. It is a pretty sizable

investment.

MR. MARCUS: These are the strategic

issues that when we have an open docket or

when we have a disability advisory committee

group sort of determining recommendations in

this space, I think we need to be able to

think about all of this. It may be that we

have to take incremental steps. Of course,

we're all familiar with that. But incremental

steps that are strategically intelligent I

think is where we want to be. If we're not
hearing enough about where is the fallout,
the $8 to $10 million that needs to be
covered by somebody, is there something that
we're doing in the universal service space to
address some piece of that? We have to hear.

DR. GORDON: Speaking of numbers –
speaking of numbers, does the FCC monitor the
use of some of these technologies? Do we know
how often people are using closed captioning?
Do we know how often people are using the
video description programming, et cetera?

MR. MARCUS: Rosslyn, do we know the
answer to that? We do not monitor it other
than anecdotally. Part of what we do with
complaints is we get data from people telling
us what they're using and a level of
sophistication that they have will appear in
the fact pattern of the complaint. Because
it's anecdotal, we're not able to launch from

that, but it does point to policy development and questions that we can ask in our open proceedings and new proceedings.

DR. GORDON: Gotcha. Larry.

DR. WEXLER: You wanted a trade secret. Something that we've done that we think has really stretched our money is that in the past, we have – when we've done description, we have to essentially buy the rights to the program first and then describe it and then turn it loose.

But what we've been able to do especially with some of the major networks is we've crafted agreements with them where they will supply the program for free in exchange for we give it back to them described and then they can use it any way they seem fit. We've taken -- our investment dollars have been stretched dramatically through that approach.

MR. MARCUS: But it sounds like you are targeting that at the midstream level. That's exactly what I was talking about. This is special education programing, right?

DR. WEXLER: Yes.

MR. MARCUS: So you are getting a lease of the content in order to add value in the description and then you give it back to them and then that's when they produce it and they put it out there.

DR. WEXLER: Correct. We've also done a lot of work on born accessible with producers and publishers in this.

MR. MARCUS: What did you call it?

DR. WEXLER: Born accessible.

MR. MARCUS: Thank you. I apologize. I had not heard of that. Anything else?

DR. GORDON: Thank you very much.

MR. MARCUS: Thank you very much. Thank you.

DR. GORDON: We are going to move onto the last segment of the morning, which we've reserved for committee business. I'll ask Dr. Susan Daniels to take over.

DR. DANIELS: Thank you. Thank you, Mr. Marcus, for being here. It was nice to have a first interaction with the Federal Communications Commission. We look forward to continuing to work with you.

I'll take us through our committee business. We have a number of interesting updates to share with you all. Just to make sure I acknowledge our staff at the OARC who help make this meeting possible and all the different events throughout Autism Awareness Month and throughout the year for the committee. Thank you to all of you for all that you do.

April is National Autism Awareness Month and actually World Autism Awareness Month, as

it has been declared. We have a number of
activities that have been going on across the
US government and around the world. I just
wanted to point out some things that we do
have on our website. We do have an Autism
Awareness Month page and there you can find
the 2019 Presidential Proclamation from
President Trump. You can also find the 2019
UN Secretary-General message from Antonio
Guterres, the message on World Autism
Awareness Day.

The Autism Awareness Interagency
Roundtable that took place at the Indian
Health Service. The information for that is
also available on our website. The United
Nations had a special event on assistive
technologies. You probably noticed in the
public comments that were shared for this
afternoon the written comments. There were a
number of people that commented on issues

related to that. Also, the National Institute
of Environmental Health Sciences here at the
NIH had a Reddit event that's there.

And I'd like to bring your attention to
an event that our office is hosting on behalf
of the National Institute of Mental Health.
Next week our special event that we hold
annually for Autism Awareness Month. And this
time we're going to be featuring a
presentation called A Woman's Voice:
Understanding Autistic Needs that will be
featuring authors and editors from two books
about the experiences of women on the autism
spectrum. The two books featured will be
Spectrum Women and Autism in Heels. And on
the slide we've listed the editor of Spectrum
Women, Barb Book, and two authors, Liane
Holliday-Willey and Dena Gassner, and the
author of Autism in Heels, Jennifer Cook
O'Toole. They will be here with us and we're

going to have them present their books and

have a conversation with us and there will be

an opportunity to meet them after the event.

It's open to the public. It will be here on

the NIH campus and we welcome anyone to join

us either by webcast or in person.

In terms of committee business, I'd like

to bring your attention to the 2018 IACC

Summary of Advances report that is now

available. We have hard copies here in the

room and it's available online. This annual

report that's required by the Autism CARES

Act of 2014 features lay-friendly summaries

of the top 20 most significant advances in

ASD biomedical and services research that

were selected by the IACC through processes

that we've had here in this meeting

throughout the year.

We also include articles addressing all

seven topic areas of the IACC Strategic Plan

so you will want to look at that. And in the
slide set – I'm not going to read all of
this, but I will – we've listed what the
articles are and that's for your reference if
anyone is going back to the slide set.

The next report I'd like to share with
you as some of you have been waiting for
this. The Autism CARES Act Report to Congress
is now available. This was just published and
made available to the public last week and it
has been received by Congress. This, as I've
said, is required by the Autism CARES Act of
2014 and it's a report that covers the
activities of all US federal agencies that
are doing autism-related work. Our office
coordinated this on behalf of the Department
of Health and Human Services. We did in
partnership with 21 different federal issues
and departments. And this report details
progress on activities related to ASD and

other developmental disorders across the

Federal Government. So there are descriptions

of various programs, initiatives, and

activities and so you'll want to review that

to learn more about what the Federal

Government has been doing and for the

committee in particular with regard to the

strategic plans, some of the different areas

that are covered.

This is just a list and I think the next

slide also of the different federal agencies

and departments that participated. And then

the next three slides, which I'm not going to

read, but just to point out. There's a table

that tells you what different parts of the

strategic plan are covered by which agency

and this was something new that we added to

the report this year that you might find

helpful and want to review later. We put it

in here for reference and it's also in the report.

Moving on to the next report, our office does do a lot of reports. We have a new report coming out soon that I wanted to bring to your attention. I know I've discussed it before in various stages, but we're close to being able to publish this one. We're going to have a first IACC International ASD Research Portfolio Analysis Report. OARC has been leading a collaborative effort to produce this first report that will involve more than just the US.

We're using the 2016 data set and it will describe and compare trends in ASD research funding across four countries: the US, the United Kingdom, Canada, and Australia. We are really looking forward to seeing this and you'll be able to see what areas of strength each country brings to the

table and some of the comparisons of these
research data and we will be putting the data
right into the OARC and IACC Autism Research
Database so people – anyone can access it. We
expect to have the hard copy for you in the
July meeting and we'll probably release it
before then. But we'll be happy to share a
little bit of the data at the next meeting.

Another update I wanted to give you just
based on a recent meeting that I attended on
behalf of the NIH. The International Society
for Autism Research held a meeting on autism
and suicide research priority setting at the
University of Nottingham in the UK and I
wanted to bring this to your attention
because I know the IACC has been interested
in this issue of suicide and autism and we
are going to be covering it in upcoming
activities.

The first bullet is just a little bit about the background on autism and suicide that autistic people are significantly more likely to die by suicide than the general population based on recent data. And that this problem has been discussed in the IACC as something of concern that we want to address through research and service related activities.

This meeting was held by partners including the University of Nottingham, Newcastle University, Coventry University, Autistica, INSAR, and the James Lind Alliance.

Following a three-year, multi-tiered series of meetings and requests for public input that were conducted by Autistica and these others partners in the UK, they were able to collect information from the public

and then prioritize into 48 priority areas
for research for autism and suicide.

At this meeting, the goal was to narrow
this down to the top ten research areas that
would form a research agenda and so the
meeting was successful and came up with a top
ten. This is going to be released at the
upcoming meeting of the International Society
for Autism Research in Montreal.

I think on the next slide there is a
little bit of information. By the way, the
meeting that I attended involved 30 workshop
participants including self-advocates, family
members, researchers and other community
members. And one of the strengths of this
process has been very significant involvement
of stakeholders from the community who had a
very strong voice in putting this together
and also at the meeting, it was really very
striking the number of stories shared about

the impact of this problem and also the

generational impact. Many of the families and

individuals who were there described this

being an issue over multiple generations of

their families and wanting to see a solution

that would help them to be able to overcome

this problem.

There were certainly significant

interests in both addressing service and

support needs that would help people to be

able to avoid these issues as well as

understanding any biological factors that are

playing into it.

At the INSAR meeting, we have some

information on May 3. There's going to be a

presentation on this. And Dr. Sarah Cassidy,

who was the co-chair of this workshop, will

be a speaker at an upcoming IACC workshop

that I'm going to tell you about in a minute

on addressing the mental health needs of
people on the autism spectrum.

To give you a brief update on the IACC
Health Outcomes Working Group, as you know,
we've convened a working group on health and
wellness issues for individuals with ASD. And
the co-chairs of this are Dr. David Amaral
and Dr. Julie Taylor. The scope involves
health and wellness, co-occurring conditions,
premature mortality, patient provider
interactions and parental and family member
health.

The working group has held a number of
different activities including some
conference calls. We had a workshop in
September that covered health epidemiology
and several co-occurring conditions, physical
health conditions and issues related to
patient-provider interactions in the physical
health space.

We now have an upcoming activity, which we discussed at the January meeting. We've planned a workshop that will be on addressing mental needs so people on the autism spectrum. And this will be taking place on May 21 just down the street at the – it says Neuroscience Center, but I believe it's happening at the Hilton Washington Hotel just down the street in Rockville.

And the workshop will focus on mental health-related topics, including anxiety, depression, suicide, self-injurious behaviors and aggression and the mental health services. We welcome anyone to come to this. It's going to be open to the public and webcast as our usual practice. And we will be putting out a special call for public comments that are related to these specific topics so you can be watching for that.

And the working group is going to continue working through some conference calls and producing a written document and we'll keep you up to date on that.

Julie, do you have any comments you'd like to add to that brief update?

DR. TAYLOR: I don't think so. I think you've summarized it pretty well, Susan. As we talked about in the last meeting, something that came up that we didn't get a chance to talk much about in the first meeting were mental health conditions. We're really excited to have a whole day to really dig into what we know, what we know about treatment and what we need to know and what we want to maybe think about putting in this written document.

DR. DANIELS: Excellent. We look forward to keeping you posted. We will be sending out emails and other types of information to help

you get ready for this. And IACC members of
course are welcome to come and we will help
take care of your logistical needs for that.

The next slide is an update on the IACC
Housing Working Group. We're happy to say
that this housing working group is in the
process of being convened and we're going to
be covering a scope including research and
best practices on housing, implementation of
current federal regulations, and housing
issues that are faced by autistic individuals
with more severe disabilities or just across
the entire spectrum and across age as well.

Our chair is Alison Singer from the
committee. As I said, the working group is in
the process of being convened so waiting to
confirm all of the membership, but we will be
sharing that information with you when it's
finalized.

The activities will include working group conference calls and a town hall meeting or an activity along those lines. And our target date is June 2019, but we'll update you on specifics as soon as those are available.

This working group like the other one will run through September 2019, which is the period of the authorization under the Autism CARES Act of 2014. We are awaiting a reauthorization. There are bills both in the Senate and the House, but they have not been enacted yet. We anticipate that there will be a new autism law available, but right now we are planning to run through 2019 September 30. That's when the activities of these working groups will conclude.

Maybe I should stop for just a moment before moving on. Are there any questions about working groups or anything? I know I've

been in touch with pretty much everyone here
about those. But if you do have any
questions, please let me know and we'll be
happy to keep you updated on those activities
and we'll share updates at the July meeting.

MR. ROBISON: Is IACC going to disband
and be reformed in September?

DR. DANIELS: We will have to wait for
the enactment of the new law and whatever the
requirements are under that new law, the
Secretary will convene a new committee based
on the new requirements. I know many of you
have been through that process before that
some people are reappointed and others are
new people that are appointed by the
Secretary. In July, we should have more of an
idea of what has happened and we'll keep you
updated, but for the moment, we do know that
bills have been introduced on both sides, the
House and the Senate.

Next, I wanted to share with you the
IACC Strategic Plan Update, which we've been
working on. As we told you in January, we
proposed to you the idea of having a
strategic plan update. It's really just an
update of the committee's activities that
relate to the strategic plan as we went
through a one and a half-year process putting
together the previous strategic plan with all
new objectives and completely new updates on
research and services and policies. We felt
that it wasn't really necessary to go re-do
all of that just within another year.

We have now put together this first
draft of this report that just basically
reads out what the committee has been doing
with regard to the strategic plan. You have
that draft in your packets. I sent them out.
And it's also up online.

Basically, the three components that are there now are the summary of the Health Outcomes Working Group and 2018 workshop, which I just described. We also have a summary of 2016 IACC Portfolio Analysis Report, which is the first portfolio analysis report to address the specific new objectives in the strategic plan, and then the summary of the Autism CARES Act Report to Congress that just came out. Those are the three components we have now.

And the plan is to also include a summary of the mental health workshop that we're going to be having in May and the Housing Working Group in any of its activities. And the plan would be to include all of that material and then by the end of the term of this committee to submit that to Congress as our report and it would cover both 2018 and 19 activities together.

With the draft – I'll send you another email that gives you a deadline, but I'll give you some ample time to be able to review it and let us know if you have any feedback if there's anything that you want to see us add to it or modify in any way. We'll have some time to work on it and by the time you see it in July, we'll have incorporated those changes plus the new material.

Our hope would be to get a provisional approval in July maybe with a few additional changes you want us to make before publishing it, but then we would be able to complete it before the end of the term.

Are there any questions about that? Great. We'll keep you posted on that as well.

We can go to the next slide. Maybe this is the best one. It's lunch. For lunch, we have some orders. I know the committee

members made orders with Panera. Those should be coming.

(inaudible comments)

DR. DANIELS: We are ahead of schedule. That's great. Great news. It is a time that if we did want to have any additional discussion on any topics, this would be a good time. We could do that. I know John Robison – maybe before we break for lunch, I didn't realize that we had been so incredibly efficient that we were early.

John, you had mentioned that you had an issue that you wanted to share with the committee. I don't know if this would be a good time for you if you would like to bring that up before we break for lunch.

MR. ROBISON: I published a commentary in the Autism Research Journal in the last issue. The topic is what we don't know about autism in adulthood and it kinds of ties in

with what we saw in the CDC presentation earlier today.

We have a lot of data coming to us about adult outcomes that are frightening or alarming. We hear that we are at risk for suicide. We have a life expectancy that is 17 years shorter or in some cases 20 some years shorter. We heart that we are more vulnerable to all manner of diseases and disorders.

But in looking at that data, I've begun to question who does it really apply to, how much of the autistic population. Because I realize that the vast majority of the adult autistic population is unidentified and probably unaware. And therefore the statements that we commonly hear and we heard them today. A couple folks said I understand 80 percent of autistic people are unemployed. That's a real common quote. But in fact, we have no idea what percentage are unemployed

because we don't even know who 5 percent of
them are.

The thing that I raised for discussion
in my commentary is this. We have two sources
of a prevalence data that are credible. We
have on the one hand – we have this array of
data from our CDC and other national public
health agencies and other countries and that
suggests a significant rate of autism whether
that number is one and a half percent, two
percent, two and a half, three percent. It's
significant.

Then we have the Brugha series of
studies that were conducted about ten years
ago and we discussed Brugha a few years ago
when that was published. But those of you
who've read that, you will recall that Brugha
found a similar rate of autism in adults no
matter what era they were born. But Brugha

found that the older adults were not
diagnosed with autism.

We identified some evidence for
consistent autism prevalence through the 20th
century, but diminishing awareness as people
get older. That's pretty consistent with
modern knowledge.

If you take that and you then compare
that to the public health studies that make
the most alarming predictions about autism,
you see a potential disconnect. For example,
we have praised the study from Kaiser Health
Systems. In that study, we looked at the
results, which showed strikingly worse
outcomes for autistic people and we saw that
the methodology seemed really good. She took
every autistic person who was in the Kaiser
Northern California system and she compared
their health issues and mortality with a
similar large population of non-autistic

people in the system. And we think what better information can we have. But we never really discussed how representative the Kaiser Health System's autistic population is of the true autistic population. She found 1500 people in that Croen's study. And we think that's great because 1500 is a bigger sample that we see in any other study.

But in fact, if you look at what we know of prevalence data, there should be 20,000 or 30,000 people in the sample, not 1500. What does that mean? Does that mean that most of these people do not have enough disability that they require autism services? Does it mean that they get autism services in some other way? Does it mean that no services are available?

When I look at all of the problems that the Croen's study identified, it's difficult for me to believe that we can answer that by

saying all those people are out there and they are very disabled, but there are no services for adults because Croen – she identified a lot of problems.

And that leads me to conclude that we have a real pressing issue here. If the Croen's study and these other studies that we have done are truly representative of the large autistic population that's unidentified, we have a major public health problem that is not being addressed and is of long standing.

If on the other hand the people are not identified because there isn't a need to identify them because they don't have sufficient medical problems related to autism in adulthood, that's a positive outcome finding that I would think every autistic person would want to know.

It seems to me that if we look at studies like Croen, like Autistica, these studies all draw for an autistic population. They draw autistic people in a public health database or they draw autistic people who are connected to Autistica in the UK or who are residing in group home settings in various places. And when we study those people, are we truly studying a representative sample of all autistic people because most autistic people according to the evidence are not in those settings and are they not in the settings just by chance or because they don't have sufficient problems to put them there?

I guess I'm concerned that there are several strikingly different interpretations of this. I think the only way we can answer it is by a large-scale adult prevalence survey. And I think that it is really vital to do that.

I would like to find that the outcomes for autistic adults are truly much better and that studies like Croen and the Autistica study on suicide only apply to a small portion of the autistic population. But I know that that might well not be true. They might well apply to all autistic people. If so, we are seriously underserving the population and such a survey would provide a powerful tool with which to empower our legislator to address the situation.

In my paper, I called on our public health agencies to consider addressing this problem by conducting a large-scale study of that sort in the United States. Now, Josh and I have already talked about this and he has described some alternatives and some ideas on that, which he might offer here.

He also pointed out that one could interpret the fact that most autistic adults

are unidentified as to say that we don't need

services for those people and that is one

very hopeful outcome, but I don't think at

this moment there is any evidence that says

we're providing too many autism services and

that means we can cut back on them.

I think rather what it means is that if

we are providing these billions of dollars of

autism services in schools, if we were to

expand the level of autism service we provide

in schools to also deliver those services to

adults, we would be talking about hundreds of

billions of dollars that is not given to

adults today. Can we make a case for

significantly more? Is the status quo enough?

That's a discussion, but I don't think the

discussion is could we diminish the services.

I want to make clear that my commentary

was never intended to suggest that we deliver

too much. All of you hear me I know always

argue the opposite. But I think that this is a thing that we really – we need to reflect upon. I think that we've had so many blanket statements, 80 percent unemployment, 70 percent divorced, all these portrayals of failure. And the fact is we have no idea if those things are true. That was what I wanted to bring up.

Perhaps what we could do is we could circulate a link or something like that to the paper to go with this.

DR. DANIELS: Sure. We could add a link to that paper to the website. We could even do that during the meeting here today as a meeting material.

DR. GORDON: Let's see if we can't get that up so that people can look at it and if you have time to look at it through the day, we can re-enter this discussion if there's

time towards the end of the day during the

round robin.

I want to commend you, John, for the

paper, which I'm not sure I read a final

version of, but I read the version that you

had sent me earlier this year.

MR. ROBISON: I just changed - I added a

paragraph at the end after you and I talked,

but you read the whole thing.

DR. GORDON: I am looking forward to

reading that paragraph as well.

From an NIMH perspective, as we were

discussing earlier, the issues of accounting

for the prevalence of autism in childhood are

complicated even though we have all these

different mechanisms to ascertain it be it

through Medicaid, be it through school

records, be it through the ADDM survey.

I think the issues of doing so in the

adult population are even more challenging

because care where delivered is going to be more fragmented. And because as you point out quite eloquently in your article, people aren't getting care and that makes assessing the need for care even more challenging. That doesn't mean that we shouldn't do it.

At the NIMH, our concerns are as we all know building off of earlier recommendations from this committee, trying to figure out what the best way to deliver services are to adults as opposed to trying to quantify the need, which is more typically done by other federal agencies.

I'll make just one more comment which is – coming back to that comment I made earlier again on the prevalence estimates that the CDC presented earlier today, which is you really do need to think about the question that you want to ask when you're trying to figure out what study you would like to have

happened or that this committee would like to recommend.

In my opinion and it is just my opinion and I don't even need to represent the NIMH and I'm saying this because I don't think we've thought through it yet to formulate an official opinion. In my opinion, it's less about knowing how many people have autism, and I know that's not what you're suggesting in your editorial, but rather what are the unmet needs of adults with autism. That's going to change what kind of a study you are going to want to perform. But those are just the comments that I have off the cuff.

Nina, you wanted to make a comment and then others as well. If you just raise your hand, I'll write down a list. We have some time to discuss this before lunch.

DR. SCHOR: Just a brief comment. I wonder about the wisdom of thinking as we

very often do, I think all of us do, of
adults and children as discrete populations
because I think often about whether in fact
and I'm totally unencumbered by data in this
arena. I think often about whether in fact
the appropriate and timely and complete
provision of services to children gives at
least some fraction of them the strategies
that they need to then not in fact need a
large number of services when they become
adults. I have no idea whether that's the
case or not. It is the hope of those who
provide services in childhood that we equip
those children for adulthood in a way that
they wouldn't otherwise be equipped. But I
have no idea if that's the case or not.

MR. ROBISON: In my paper and in other
writings, I have raised the issue of this
idea of emergence from disability. For
example, there are a number of autistic

adults, myself included, where we see that over periods of 10 and 20 years our ADOS scores may remain the same, but our practical ability to function in society is transformed dramatically for the better.

We hear presentations here and I know some of you – Alison, for example, Amy Lutz who came and presented to us have children whose trajectory does not appear to get better. We have had papers presenting that idea. There seems to be a point that's maybe not solidly defined where outcomes do not improve as the person gets older and then above that they do.

I think that that speaks to the heart of a concerning divide that's emerging in the autism community. This year, we have had the – or last year we've had the emergence of groups talking about what they are calling severe autism and we have a conflict

seemingly set up by what is described as a neurodiversity faction. I don't think we should see that as a conflict.

I suggest that when you think about this and what happens with these adult trajectories, we recognize that the autism spectrum is a very broad one. There is not only the pool of people who are sufficiently affected to rise to the level of diagnosis on an ADOS. There is this broad autism phenotype with some traits, but not rising to a diagnostic threshold beyond that. That's a very large pool of people. Some people are so impacted that they would have a very high ADOS score and they would not have improvement in aging and they would have a very limiting ability to care for themselves. All of that represents - as Louis would say, it represents inherited naturally occurring neurological diversity.

Now there is also – there are multiple other pathways in autism. I don't want to dismiss those. People could be injured by environmental exposures, by physical injuries, by disease, by disease in their mothers. Those are absolutely real. But it is also fair to say that people are naturally born with all degrees of exceptionality and disability.

I think we should consider that there is a point where what we might describe as diversity shades into pathology. It's no less diversity, but we get to a point where a rational person would not look at that particular example and say I'm just going to call this healthy diversity. A rational person would look at that and say I want help. I want medical science to help me make this better.

I guess I would like to see us be able to come together as one community and pursue a common goal. I think that we can recognize that there may be the same biological basis for a person who is seemingly much more impaired than, for example, myself.

But I think that we need data on adult outcomes to know where this goes. If, for example --

DR. GORDON: John, John, I'm going to interrupt you. We're pushing up against lunch and you're very eloquent, but I think you made your point. I know that Sam would like to make one comment or question.

MS. CRANE: I will try and make it really fast. I'm sorry that I missed much of this discussion. I think that a lot of the time -- I wanted to respond to the concern about whether or not services early eliminate the need for services later. I think that from

the perspective of people who use services
that can sometimes be the wrong question. I
have friends who – colleagues who use
services, but they are working in the
community. Now if they stopped working and
then spend every waking hour trying to take
care of their basic needs, they might not
need as many services. But the question is
what are their outcomes.

Many of us even though we might not need
services in order to fulfill the basic
functions of life, we might still need
services in order to actually live in the
community. That goes for hours of services
too. Some people might be able to scrape by
on two hours of services a day, but they're
not having fulfilling lives and they would be
able to do much more with more services. A
lot of us are going to be thinking about
those outcomes more.

And the same with – as John pointed out, many of us might develop competencies over the course of our lives, but I don't know that many autistic people really on any part of the spectrum who are like my goal is to get a better ADOS score. That might be a metric that approximates some competencies, but the things that we really need to be focusing on are like do we have friends. Do we have a rich life? What are the things that make a rich life? That is what I was just going to say.

DR. GORDON: Thank you, Sam. Thank you, John. Let me just point out that I really appreciate this discussion. We would've liked to have been able to have a fuller discussion of this issue prior to the closing of the window of this particular IACC group September 30, but unfortunately we just don't have time in the schedule with all the other

issues and the reports that we are going to
need put out from the work groups, et cetera.
We are really pleased to be able to have this
mini discussion. I'm glad we were able to fit
it in.

We hope to be able to and expect to be
able to continue the IACC passed September 30
with the renewal of the law. We will look to
putting a discussion on adult outcomes and
service use later on.

Thinking about this, we had several of
these discussions a few years ago as I said
that led to a lot of research being initiated
by investigators, funded by the NIMH and
we're hopeful that in the coming year or so,
we'll start to see the output from those
data, from those studies. We may be able to
have a discussion that's informed by a little
bit more data, probably not yet as much as

need as, John, as you've thoughtfully pointed out in your commentary.

MR. ROBISON: Thanks Josh and Susan for working that in. I didn't actually expect that at all.

DR. DANIELS: Glad that worked out. This afternoon when we hear from the National Autism Coordinator, she's going to be talking a little bit about outcomes for transition age youth, which relates. It's on that same continuum. That might be something to add and that will precede our round robin so maybe we might have time to come back to it as well. So glad we were able to fit that in.

And now I think we can have lunch. I see that the lunches are here. For those who ordered from Panera, your lunch is here. And in the area if there's anyone here who is not familiar, there is a little shopping center called Pike & Rose that has a lot of

different little eateries and you are welcome

to pick up some lunch there. There are a lot

of options.

DR. GORDON: We're going to start up at 1

o'clock sharp for the public comment session.

Thank you.

DR. DANIELS: Yes, we'll see you at 1

o'clock.

(Whereupon, the Committee recessed for

lunch at 12:02 p.m. and reconvened at 1:00

p.m.)

DR. GORDON: We're going to spend the

next hour hearing from members of the public

who are here, and also who have submitted

written comments in advance and also a live

feedback comment. And then we will have time

for us to discuss these comments accordingly.

I want to start out this session

actually – we had apparently one comment

through the live feedback feed this time, but

so I thought I would share it with you because I think it's a good way to start and it's positive.

It's a comment that comes to us from someone who is not associated with NIH. "Dang, sorry I missed that, but did hear that Jaden changed the people around him as much as being in the regular classroom changed him. I had the same experience in a severe profound classroom I worked in when the kindergarten teacher invited our kids in, she normalized specialized needs kids for her kindergarten. Beautiful." I thought that's a great way to go ahead and start the public comment session.

Susan, are we going directly to oral comments first? Okay. We are going to start out with oral comments. We have two individuals who are here to present oral comments. First, we have Lisa Wiederlight. I

hope I'm pronouncing that correctly. Please correct me if I'm not. She's from SafeMinds.

MS. LISA WIEDERLIGHT: Good afternoon. I am pleased to present these comments on behalf of SafeMinds for the IACC's April 2019 meeting. We are going to focus our comments on the reauthorization of the Autism CARES Act.

The bill as introduced does not provide an amount for autism research. SafeMinds supports the IACC's recommendation to increase autism research funding to $685 million, as stated in the IACC's 2016-2017 Strategic Research Plan. Data from page 102 of the Strategic Plan shows research spending to be flat since 2012, despite autism prevalence having increased 50 percent from 1 in 88 to 1 in 59. Unless the authorizing bill asks for an increase in research funding, a higher amount is unlikely to be appropriated.

Having flat spending on autism research is clearly inadequate given the rise in prevalence and its associated costs. As the Federal Government's Advisory Committee on Autism, the IACC should recommend that research funds be doubled in the Autism CARES Act.

The Autism CARES Act should direct the CDC to enhance its ADDM epidemiology research methods so that a more accurate count of adults and children with autism across the US can be estimated. Improved methods include active case finding to rule in or out autism cases, a nationally representative sample, data based on comprehensive medical and educational records at all sites, and consistent sites and case finding methods over time to allow for trend analysis.

Not knowing how many people are diagnosed with autism and their associated

features makes appropriate resource allocation and future planning for services and related programs across the lifespan difficult, if not impossible. Yet the CDC has drastically cut funding for ADDM research for the current data collection cycle, has changed the sites for data collection, and has changed the case identification methods. As the Federal Government's Advisory Committee on Autism, the IACC should recommend that the ADDM budget be restored and that the Autism CARES Act directs the CDC to improve the ADDM methodology.

Autism research should be responsive to clearly-defined policy priorities, and result in findings that are relevant to the needs of people with autism today and in the future.

By way of example, what policy changes will have occurred as a result of the research and workshop done on co-occurring

health conditions with autism? What outcomes
can we expect?

How can we increase the number of
appropriate autism diagnoses, and decrease
the age of diagnosis among all ethnicities
and socioeconomic groups?

How can we ensure the timely initiation
of treatments and interventions?

How do we improve linkages to well-
trained and appropriately compensated
medical, therapeutic, and educational
professionals?

How do we identify best practices for
educational, vocational, and medical
treatments for people with autism?

The increased research funding should
support a balanced approach to finding the
genetic, environmental, and epigenetic causes
of autism, and how some of the symptoms of

autism may represent physical issues that may be addressed and treated medically.

As a mechanism to leverage research into policy goals, SafeMinds supports the creation of an annual National Autism Strategy, which sets priorities for the federal autism response. It should contain measurable goals, objectives, and outcomes and hold the federal government accountable for finding the causes of the rise in autism prevalence with improved methodology at the CDC.

It should identify effective ways to address the needs of the autism community based on research and community outreach that result in significant improvements in the lives of people with autism and their caregivers.

The strategy's goals should reach across the jurisdiction of many federal agencies,

including HHS, Education, Labor, HUD,

Justice, and Homeland Security, among others.

Recognizing that the part-time federal

autism coordinator position currently housed

within HHS would not have the time or focus

to lead this strategic effort, SafeMinds

supports the appointment of a full-time

federal autism coordinator in the Executive

Office of the President, as recommended by

Candidate Barack Obama in 2008. Appointing a

full-time federal autism coordinator who is

experienced and successful in federal

interagency coordination would ensure that

autism gets the priority it deserves in the

federal government, while enhancing oversight

and accountability of the federal response to

the autism crisis.

This point person on autism would be

responsible for presenting the annual

National Autism Strategy to Congress and to

the President. He or she would work to identify and remove bureaucratic obstacles and coordinate the work of each of the executive office agencies as they relate to autism, including HHS, Education, Labor, HUD, Justice, Homeland Security, DoD, among others.

As the Federal Government's Advisory Committee on Autism, the IACC should recommend that the Autism CARES Act include a provision of the establishment of a full-time federal autism coordinator in the Executive Office of the President who would be charged with creating a national autism strategy.

It is difficult to imagine that taking a status quo approach to addressing autism as we have since 2006, and which is reflected in the 2019 Autism CARES bill, will result in different outcomes than we have already seen. We are hopeful that these proposed changes to

the Autism CARES Act will be given every

consideration by the IACC. Thank you.

DR. GORDON: Thank you very much. Is

there any desire for immediate comment or

questions? We will return to a larger, fuller

discussion, but John.

MR. ROBISON: I would just – she has

already stepped down, but it sounds to me

like you know that we have autism

coordinators and staffs doing these things.

You're asking for a – it sounds to me like

you're asking for a higher level version of

what we have now.

MS. WIEDERLIGHT: What we are asking for

is that there is one person within the

federal government who is responsible for

working with these coordinators to make sure

there's no duplication of effort and to

leverage resources to coordinate what

everyone is doing. There is a precedent for

that in the Office of National Drug Control

Policy as well as other organizations. It

wouldn't be only within one organization. It

would be someone who would call people

together and someone who would go to the

agencies to collaborate with them.

DR. GORDON: Thank you. We will move onto

the next commenter. We have Dr. John Martin

who is coming to give some oral comments.

Thank you, Dr. Martin.

DR. JOHN MARTIN: Good afternoon. I am a

pathologist with boards in anatomic and in

clinical pathology, subspecialty training in

immunopathology and in medical microbiology.

I have worked at the National Cancer

Institute and also the National Institute of

Allergy and Infectious Diseases. From 1977 to

1980, I was the head of the Viral Oncology

Laboratory of the FDA Division of Virology.

I have described viruses which differ from the viruses from which they are derived in that they no longer evoke inflammation. This is because of the deletion or mutation of the genes coding for the relatively few virus components that are normally targeted by the cellular immune system. I refer to this immune invasion mechanism as Stealth Adaptation. Steal-adapted viruses were described in a major pathology journal in 1994 and reported in children with autism in 1995.

This research met with resistance from public health officials. It really became clear that certain stealth adapted viruses came from or rose from cytomegalovirus of African green monkeys. Kidney cells from cytomegalovirus infected African green monkeys were routinely used to produce live polio vaccines. DNA from monkey

cytomegalovirus is detectable in several previously licensed polio vaccines. When humans are infected, the viruses can then pass human to human and can also be transmitted to the unborn child during pregnancy.

Stealth-adapted viruses induce severe behavioral illnesses when inoculated into cats. The animals clinically recover after several weeks of severe illness even though there is no inflammation; therefore, although the cellular immune systems fail to effectively recognize these viruses, they can still be suppressed. The mechanism of suppression is through the alternative cellular energy or ACE pathway. This source of cellular energy is different from the cellular energy obtained from the calories in food. It's expressed as an added dynamic or kinetic quality of the body's fluids.

The ACE pathway can be enhanced in humans using various methods. The publication that was distributed before my talk is an example of a protocol that achieves significant clinical benefits in children with autism.

Conversely, boosting the immune system with immunizations can trigger a fresh immunity against some of the residual viral components that are not normally responded to by the cellular immune system. This can lead to further brain damage. Symptomatic stealth virus infected children should not be included in the current rather intense vaccine schedule.

As members of the IACC through your respective institutions, you had the opportunity to culture stealth-adapted viruses and to implement and evaluate various ACE pathway based therapies in children with

autism. I would be pleased to assist you in these endeavors. Thank you.

DR. GORDON: Thank you, Dr. Martin. Are there any comments or questions of immediate import from the committee before we go into the written public comments? Louis.

DR. REICHARDT: I just wanted to ask you, how do these viruses invade the innate immune system, which has components designed to detect cytoplasmic DNA and cytoplasmic double stranded RNA. It seems implausible.

DR. MARTIN: The viruses, as I said, were inoculated into animals and cultured from patients. There is no inflammation to be seen in the tissues. So they asked why the innate immune system, which too probably has its own limitations, but the viruses go into animals and there is no inflammation.

DR. REICHARDT: How are these viruses –
what are the characteristics of these
viruses?

DR. MARTIN: Again, the best
characterized steal adapted virus is a
derivative of an African green monkey simian
cytomegalovirus. What is not generally
understood is that with even large viruses
like cytomegalovirus, relatively few
components are targeted by the cellular
immune system. Specifically, 90 percent of
the cytotoxic T cell response against
cytomegalovirus target only three components.
It's relatively easy for a virus to have
three components deleted or mutated and then
with other adaptations can continue to
replicate and induce cellular damage. The
cellular immune response will not respond if
those components are not there and I presume
by selection the innate immunity is also not

effective because the viruses are infectious between individuals and the viruses were inoculated into animals, as I mentioned, can induce disease.

DR. GORDON: Thank you, Dr. Martin. Are there other questions?

Let's proceed to the written comments. I believe we're going to have a presentation from Oni Celestin in the Office of Autism Research Coordination here at NIMH.

DR. ONI CELESTIN: Good afternoon. Since the January Full Committee Meeting, the IACC has received written public comments from 28 commenters. For the purposes of this presentation, we've organized these comments into four broad topics. The committee has been provided the comments in full, but they will be summarized briefly here.

The first topic is assistive technologies and communication supports.

There were 18 comments received on this topic. The committee received 14 individual comments from Dr. Sandra McClennen, Dr. Clarissa Kripke, Ms. Darlene Hanson, Ms. Chantal Sicile-Kira, Ms. Jennifer Binder-Le Pape, Ms. C.J. Shiloah, Ms. Allison Thurman, Ms. Cami Berkau, Mr. Damon Kirsebom, Ms. Tracy Lattanzi, Ms. Elizabeth Vosseller, Ms. Mary Ellen Wells, Ms. Christine McKee, and Dr. Casey Woodfield all were commending the United Nations for highlighting assistive technologies and active participation at their recent World Autism Awareness Day event.

They request that the IACC focus on these issues at a future meeting and invite non-verbal autistic people to present. They hope that calling attention to the needs of this population will result in greater

support for and understanding of alternative communication methods.

Mr. Hari Srinivasan wrote about his experiences as a non-verbal autistic individual particularly his family's difficulty in getting appropriate educational placements and supports for him in the public school system. He encourages special education programs to focus on teaching alternative communication skills. He also wrote about the need for policy changes that would increase access to communication and inclusion in society.

Ms. Rita Rubin wrote about the experiences of her daughter, a non-verbal autistic adult, who uses AAC to communicate.

Ms. Christine McKee wrote about her daughter's experience with supported typing and letter boards. She is concerned that users of these modes of communication are

unfairly treated with skepticism because of previous controversies and false allegations about their use.

She also highlighted the successes of students in a Washington DC Public School that has incorporated a facilitative communication program.

Mr. Matt Hayes wrote about his experiences as a minimally verbal autistic adult. He believes that communication is a right and that it is essential for community inclusion.

The Autistic Self Advocacy Network or ASAN cautions the IACC against making claims that any particular form of communication is not "evidence based". They encourage more research to identify which methods of communication work best for which subsets of autistic people.

The second topic is potential causes of autism. There were six comments received on this topic. Ms. Stephanie Dorr is concerned that autism is caused by vaccines. She submitted several articles, letters, and videos linking vaccines and autism that she would like the IACC to consider.

Ms. Sally Pacholok is concerned that children with Vitamin B12 deficiency are mistakenly diagnosed with autism. She recommends that women be screened for B12 deficiency during prenatal visits and that infants receive the same screening at 3 to 6 months of age.

Ms. Elissa Leonard believes that Vitamin B12 deficiency is more common than currently accepted and that many children with this deficiency are misdiagnosed as autistic. She believes that poor diet, medications that block B12 absorption, folic acid supplements,

and the lack of knowledge have all
contributed to a rise in B12 deficiency.

Mr. Suresh Kalkunte believes that
exposure to radiofrequency energy may be a
cause of autism.

Dr. Eileen Nicole Simon thanks the
committee for discussion of her proposed
research investigating the role of the
inferior colliculi. She submitted several
potential lines of research for comment by
the committee.

Dr. Kerry Lane would like the IACC to
address several papers linking Tylenol use to
autism.

The third topic is service needs,
resources, and policy implications. There
were five comments received on this topic.
Mr. James Strack wrote that he was prevented
from joining the military because of his

autism and he would like help advocating for a policy change.

Ms. Whitney Ellenby shared a link to an online video sharing her personal experience with her autistic son.

Ms. Pamela Vandergrift wrote about the experiences of her son in the criminal justice and mental health systems. She believes that her son's mental health issues have not been properly addressed and he has been mistreated because of it.

Ms. Jeanine Davis is concerned about the practices of her local social services agency.

The Autistic Self Advocacy Network or ASAN is concerned that there is too little research funding devoted to improving services and supports based on the IACC's 2016 Portfolio Analysis Report. Specifically, they believe that practitioner training

should not be considered as services research.

They are also concerned that 74 percent of the funding on lifespan-related issues is focused on the transition to adulthood while only 6 percent of this funding is focused on general quality of life issues.

Additionally, they are concerned about the proportionally large amount of funding devoted to understanding the biology and causation of autism. They would like the IACC to advise the federal government to invest more on research that supports and benefits autistic people.

ASAN would also like the IACC to focus on research that examines gender in autistic adults, gender identity and sexual orientation, and racial and socioeconomic disparities in autistic people.

Finally, ASAN would like the IACC to encourage federal funders of ASD research to include a diverse cohort of autistic adults in research and to consult specifically with autistic individuals rather than with family members or with caregivers.

The final topic is treatments and interventions. There was one comment received on this topic. Mr. PrabhakarGupta Garla would like the IACC to discuss the potential for intrathecal autologous adult stem cell therapy in the treatment of ASD.

This concludes the summary. Thank you again to everyone who submitted public comments.

DR. GORDON: Thank you, Oni, very much. We now have time, plenty of time necessary for discussion of the public comments. We can discuss any of the comments you heard about and it would be a good idea for us to try to

discuss them because we've heard from our constituents that they like to hear responses and discussion from members of the committee.

I see John's hand raised. Sam, do I see yours? And David.

DR. PEÑA: I would also like to speak as well. This is Edlyn Peña.

DR. GORDON: Thank you, Edlyn. I've got you. Let's start out with John.

MR. ROBISON: I would first like to thank the commenters for the tone of comment that we got this time around. Some of you know that I have taken issue with comments in the past and I would like to applaud the commenters for delivering us thoughtful, reasonable, constructive commentary, which is what we need to move forward. I think that is really good.

I saw with respect to the virus comment that there was a sort of an incipient

question or consideration between Louis here
and the commenter. It made me realize that in
some cases our commenters express opinions
about things we ought to do like we heard
that we ought to have a higher level or more
influential autism coordinator or we ought to
conduct more research that would benefit
adults. We can all understand those
statements. But most of us do not understand
the debate that began to emerge with Louis
and the virus commenter.

I have suggested before in meetings that
some of these commenters that raise complex
medical or scientific issues have obviously
put a lot of thought into what they come here
to say and folks like I and many people who
are psychologists – we can't comment or
understand that. We really have to turn to
you, Josh, and others for help and

understanding that. I guess I would just

appreciate if we can do that.

DR. GORDON: I can provide some context

for Dr. Martin's discussion of the issue of

stealth viruses. I will try to avoid coming

down with too firm conclusion one way or the

other except with the issue in regard to the

relationship to vaccines because I think

that's where we can say there is definitive

science.

I am not familiar intimately with the

science behind the issue of stealth viruses.

That's something that I would have to look

up. If there is a scientist in the room who

would like to – from NIMH who might be able

to provide more details on that, I welcome

that.

But I am familiar with what is a long

history of trying to investigate the role of

viral infections in the development of

autism. There have been a number of studies over the years. I would say that the rough conclusion from them is that viral infection particularly in the prenatal period probably plays a contributing role to the development of autism, but it is not definitive. That is, if the mother has a virus infection during the pregnancy – everyone has one or other viral infections during pregnancy. If anything, it's going to raise the risk and the question is how much. And in general, the risk raised by such infections where it has been documented is akin to the risk that we see raised by any given gene, which is generally pretty low. It's a pretty small effect.

As many of you may know, the thought is and there's data to support it, but I wouldn't say we've definitely proven it that it's not the viral infection per se, but the

maternal immune response to that viral

infection, which raises one's risk for

neurodevelopmental disorders of all sorts

including autism. That, I would say is the

scientific consensus right now, but I would

not say it is a definitive one. And there is

certainly room for a minority of individuals

with autism having a more definitive cause

that we have not yet discovered.

Dr. Martin referred to the finding that

stealth viruses were obtained from

individuals with autism. Again, I am not

intimately familiar with the field of steal

viruses, but I did a quick PubMed search

while he was talking because I was curious

myself. The only mention in stealth viruses

in autism that I could find in PubMed and it

may be that -- somebody could look harder –

was Dr. Martin's own report in 1995 of a

single stealth virus being isolated from an

autistic child. I don't know, but I would
imagine that if there were further research
into this, we would know about it one way or
the other, but I have not been able to locate
it in my quick search.

I, at this point, can't put much stock
in Dr. Martin's hypothesis that stealth
viruses per se play a role in the development
of autism, but the notion that viruses and
the relationship to immune responses play a
role in autism is a well-founded scientific
notion. It is one which we are investigating
very heavily across multiple institutes at
NIH and it's one which we hope someday might
yield further insight into both the
mechanisms of autism ways to prevent it
and/or ways to treat it.

Coming back to the issue of the
relationship with vaccines. If Dr. Martin's
hypothesis was correct and the vaccine

interaction with stealth viruses were playing a significant role in the causation of autism, we would know it by now definitively, including a paper which we are going to discuss later today in the summary of advances discussions. There have now been enumerable epidemiologic studies. And although the signal would be small potentially if only a small minority of children with autism was infected with stealth virus and then had it activated, if you will, by a vaccination, we would see that signal unless its contribution was so small as to be meaningless. I think we can definitely say that particular aspect of the hypothesis has been disproven in the 20 some odd years it has been since the stealth virus hypothesis was raised.

I have next on - let's go to Edlyn on the phone and then we'll continue with Sam and David.

DR. PEÑA: Hi. Can you hear me okay?

DR. GORDON: Yes.

DR. PEÑA: Perfect. Thank you. I wanted to follow on the comments regarding the UN panel on assistive technology. I was heartened to read the public comments in support of the topic. And to be completely transparent, I'm really passionate about supporting people who type and spell to communicate who would not otherwise have a voice to advocate for themselves, communicate, or participate in different opportunities in education or the community.

I do research in advocacy work on this topic. I think it took a lot of guts for the UN to put on this panel because there has been quite a bit of controversy surrounding

the extent to which the messages generated by people who type and spell to communicate are authentic.

There are a few, but very loud naysayers in the autism community who argue that methods like facilitative communication and rapid prompting message should be stopped all together. These forms of communication do require communication partner for those of you who aren't familiar with these methods. And to different extents, the communication partner offers physical or verbal prompts depending on how independent the communicator is or how the strong the relationship is between the communicator and the communication partner.

I certainly think it's healthy and appropriate for ask questions about validity of the method being used to teach typing and spelling to communicate. There has certainly

been research that shows that they can be

influenced by the communication partners so

I'm not ignoring that. But I've also seen and

met individuals who now communicate

independently. And what I mean by that is

that their communication partner is in the

room with them, perhaps sitting nearby, but

not offering any physical supports or

prompts.

And other individuals who type and spell

are attending colleges including places like

UC Berkeley, which we all know are very

competitive. These individuals exemplify

what's possible with these communication

methods and you can even look up the videos

on individuals who type and spell to

communicate. There's a great website by an

organization called United for Communication

Rights or Choice. I'm sorry. United for

Communication Choice.

I want to support the comments that were made today. I believe IACC should take the opportunity if the committee agrees to continue the conversation that the UN panel started.

I don't think it's a topic that has been addressed by the IACC in the past to my knowledge, but I do believe that leaving non-speaking individuals without a form of communication or without a voice is an injustice. I encourage us to consider inviting speakers who use these forms of communication to present to the committee in the future so we can have a meaningful conversation about how to support the development of these methods, the validity of these methods, the support, and the people who choose to use these methods. I'm happy to assist in organizing that if that's ever something that comes to fruition. Thank you.

DR. GORDON: Thank you, Edlyn. Let me pause. We have Sam and David next, but I wanted to ask if there was anyone else on the phone who would like to contribute to the conversation. I'll put you on the list.

DR. BALL: No thanks.

DR. GORDON: Sam.

MS. CRANE: Thanks. I'm glad that Edlyn sort of started what I was also going to say. Before I go on to communication, I do want to acknowledge the commenter who said that he was unable to join the military due to an autism diagnosis. This is an issue that sometimes come to our attention to where people will be told that they can't join the military, they can't get a pilot's license, not based on an individualized assessment of what the person can and can't do, but because the diagnosis alone will be considered a

contraindicating disqualification to getting
the license or entering the career.

I think we do really need to – we have
to realize that many of these fields are a
big part of American life. Many of us have
not been in the military. I've never really
considered joining the military. But it's one
of the nation's biggest employers. It's
something that if you feel called to serve,
it's really devastating to be barred from
serving this country because of a diagnosis.
I think we really do need to acknowledge that
and maybe have a conversation about areas of
life that autistic people are still barred
from.

On communication, I think that as Edlyn
pointed out, there is controversy and
wherever there is controversy, it's a really
great place for science to jump in. We
haven't had much new research on

communication methods for a while. There was a little bit of a spate of research on things like facilitated communication about 20 years ago. The number of people studied was actually pretty small. All of these studies had a very small sample size. The samples might not have been great samples. I think that, as Edlyn pointed out, there is some sketchy stuff going on in the world of assistive communication and there is some less sketchy stuff going on in the world of assistive communication.

I think we do need to continue researching and continue trying to find new ways to assess the validity of communication. I think it's something that IACC has the potential to take a leadership role in actually saying what would good research on this look like and I encourage us. I think we should talk about that at some point.

DR. GORDON: Thank you. Did you want to go ahead and respond to that?

DR. COOPER: I am with the National Institute of Deafness and Other Communication Disorders. I just want to say a couple of things with regard to assistive and augmentative communication. One, our institute has been involved in supporting that research for a number of years. We have a program person who coordinates that research. We have a funding opportunity announcement, which is a way we tell the research community this is a topic we would really like to see research in and we have one focused entirely on augmentative and alternative communications. We're soliciting research in that area on a number of different topics from – and not just focused on autism. Certainly there are people with severe communication disorders who cannot

communicate verbally. We've done workshops
and we have a research portfolio right now in
that area. Our institute is interested. We
support and we would welcome more
applications in that area.

DR. GORDON: It might be worthwhile if we
think about a session on this topic of
communication assistive devices if we started
out by hearing from your institute about the
portfolio that you do have both for autism
and other disorders. That's something to
think about. Again, we're pretty much full up
for topics in this incarnation of IACC and
NIDCD – will be right along with us in the
next one I'm sure. We can strongly consider
that as we move into the next iteration.

I'll put you on the list again, John,
but next I have to go to David.

DR. MANDELL: I wanted to respond to that
comment both from SafeMinds and also from

ASAN about the need for more comprehensive

services research in autism and the way the

budget is apportioned.

My understanding is at least from NIMH

and from other agencies, there have been a

number of calls specifically for autism

services research that have not been as

successful as the program directors would

like both in the quantity and the quality of

the submissions and that we also have a

substantial disconnect between findings from

services research and how it influences

policy decisions.

I wonder if one of the activities of the

IACC could be to support that work in very

specific ways. That is, I think we have a

growing number especially junior

investigators and other investigators who are

moving sideways who are very interested in

these issues, but don't necessarily have the

skills and experience they need to conduct
research that would be policy relevant and we
don't have very good mechanisms other than
presentation of research findings to groups
like this for moving those research findings
into practice in a meaningful way.

It seems like one of the things that
IACC could do would be to create training,
mentorship, and support opportunities to
build the infrastructure needed to conduct
that research in a meaningful way and use its
connections with the relevant federal
entities to think more meaningfully about how
those findings could be used in practice to
bridge that research to practice divide.

I wonder your thoughts on that and
whether there are concrete steps we could
take to move that forward because this is an
issue that comes up almost every IACC meeting
recently.

DR. GORDON: I'm wondering if Ann Wagner if you're in the audience if you might be able to join us here. I'm going to ask you in a moment to comment on the first part of what you said, which is the quality and quantity of services research applications. But let me address the second part first – training issue. I think we were reflecting. There were other comments also by SafeMinds, really interesting about the issue of training the next – not just the next generation, training professionals who can give care with autism. I think that plus the training researchers is really important.

Without even specifying the services component, which I agree is a particular challenge at times, child psychiatry research is an area where we often struggle. In fact, autism is a relative strength in child psychiatry research. It's a reason lots of

people are wanting to go into it. We do need

to think more creatively about ways we can

enhance the training of our workforce, be it

for research or for care. I think that's

another interesting topic for IACC to

consider.

David started out by making a comment,

which I don't think is terribly off base that

we've had challenges developing the services

portfolio on the autism side. Would you like

to comment about that at all, tell them about

what we've tried and what has been more or

less successful, not just for David, but of

course for everyone listening?

DR. ANN WAGNER: David probably knows

what we've tried, but for people who don't,

we have had a series of requests for

applications with set-aside funding. It aimed

at different age developmental periods I

guess we think about. And the mechanism was

designed to support either early stage exploratory research for areas that seemed like they were kind of new and growing or more developed areas.

Those three RFAs – the one aimed at early childhood got a good response. The ones aimed at older adolescents and adults had a smaller response. I think the quality was good, but I think it was reflective of how many people are actually in the field.

As a result of that, there were some RFAs to fund some career development awards to facilitate people either autism researchers, who are not services researchers, taking on service research or service researchers who haven't been in the autism field moving in. The number of applications for those awards was less than we would have hoped.

I don't think we've given up by any
means, but we are very happy to hear
suggestions.

DR. GORDON: Let me just say by way of
introduction, and I know most of the people
at the table know, but maybe not people
listening in. Ann Wagner has been in charge
of the – several wonderful colleagues here at
NIMH and across the Institute for Autism
Research efforts and NIH for some time and
last year was appointed by the Secretary of
Health and Human Services as the National
Autism Coordinator. I asked her to speak
about this primarily because of her knowledge
of the research side.

DR. WAGNER: Maybe I could just make two
other points. At NIH, I think that at least
in the institutes that have major autism
portfolios, I think NIMH is the only one that
has a formal services research program so

that's true. But there are other departments
and agencies in the government that do
services research. I'll mention a couple of
them when I get to my talk on outcomes and
measures, but there are other places where
it's happening too.

DR. GORDON: Great. Thanks. Did you have
a follow up, David, or should we move on to
the next?

DR. MANDELL: I don't want to leave also
the part about translating research – and I
wonder if there's a more specific role that
the IACC could play?

DR. GORDON: I'll just comment. I think
that's exactly true and maybe we can come
back to this one when Ann does give her
report because I think to some extent, that's
what the National Autism Coordinator – one
potential role for that National Autism
Coordinator.

Let me just say by way of editorializing for a moment, we struggle with this across the entire NIMH portfolio. In fact, given the fractured nature of health care delivery in the United States, we struggle with that across the entire portfolio. Where we are relatively successful with translating research into practice is where there are commercial entities that can take it over like with drugs, devices, et cetera. It tends to happen a little bit faster than service packages, particularly those that are primarily psychosocial intervention based, which frankly what we have in autism space right now are psychosocial interventions, behavioral interventions, et cetera for the most part. I agree that that's a big problem and I also agree IACC can play a role particularly through influencing the

activities and National Autism Coordinator
and we can talk more about that later.

I have you on the list, Sam, but John,
you were next. Sorry, before you go. Anyone
on the phone who wants to get in the queue?
Okay, John.

MR. ROBISON: A couple of things. With
respect to the commenter who wrote in to us
that he could not join the service because of
an autism diagnosis, I absolutely sympathize
with that and I would say in response to him
that I have been in communication with folks
at the various service war colleges about
studies that they are seeking to undertake
about changing the current ban on people with
autism diagnoses serving in the Armed Forces.
But, Sam, you didn't hear this, but at the
last meeting, which I don't think you were
at, we had a presentation from a medical
officer in Defense and I specifically asked

him about that ban and he repeated to me his

support of the maintenance of it. So it

clearly is a thing that there are two schools

of thought in the military right now.

But to the extent I can, I'm working

with the folks at the war colleges to change

it and would encourage others of you to think

about it.

The thing that I wanted to say about the

assisted communication and the related

comments in the written comment stream, is

that I have seen some really harsh

condemnations of assisted communication of

various types and I do understand that

there's tremendous potential for abuse when

someone purports to speak for another person

who cannot speak directly. I understand how

if that speaking happens to include

accusations of sexual assault and such, like

we've read about, maybe you could feel
strongly about it.

But I've had students come to my classes
at William and Mary with assistance, and I
have engaged those people and I've looked
straight at them, asked them questions, seen
them think about it, and then answer me with
the aid of their assistant. It's obvious to
me that there is purposeful interchange.

I guess I would just urge those of you
who read that exchange and listened to it.
Don't be so quick and harsh to judge that
something is absolutely true or false. I
think there are a lot of shades of gray
there.

DR. GORDON: Thank you, John. Sam.

MS. CRANE: I just wanted to chime in on
soliciting research on services and I think
it's very difficult for us to find out what's

going on there in terms of why we're not
seeing the kinds of response that we have.

So as a self-advocate, I'm going to fall
back on the principles of Nothing About Us
Without Us and suggest that we reach out to
people who are doing work on services and are
doing research on adults and see if - I
definitely heard anecdotal complaints from
people in this field saying they were having
a hard time with the IRB or they submitted a
proposal and the people reviewing the
proposal didn't really understand what was
going on and they felt frustrated by the
process. I think we need to hear from these
researchers because if people feel like the
process isn't working for them, they're not
going to stay in the field. They're not going
to keep doing that research and they might
not advise people to enter that field.

I think we need to hear from people themselves about what's going on; otherwise, I don't think we're going to be able to solve this mystery.

DR. GORDON: That is a good point, Sam. To a certain extent, we do that at the NIH. We can always do a better job. In fact, I have a work group within the NIMH to try to find out ways to get better regular feedback from our investor community and they've come up with a number of suggestions. We're going to try to implement some of those that are most workable.

Research is a challenging field to go into. And some of those challenges we want to maintain. One of those challenges being we want the research that we fund to be high quality, high impact research. Others of those challenges we have to struggle to try to overcome.

Other questions or comments about –
remember, we can talk about any of the public
comments that were made. Louis.

DR. REICHARDT: I would just like to say
briefly that we would welcome social
scientists using the SPARK cohort, which is
basically intended to make all sorts of
scientific and social research easier.

DR. GORDON: Thanks Louis. Would you just
– for the benefit of scientists who might be
listening in who might be interested,
describe the SPARK cohort briefly.

DR. REICHARDT: This was a cohort started
by the Simons Foundation a few years ago and
the goal has been to get 50,000 families. I
should say actually at this point we have
more than 60,000 individuals with autism
who've enrolled through about 25 clinical
centers and also online, but about two-thirds
of the cohorts available through clinical

centers. And everybody is consented for
research.

If people asked for – people simply have
to submit an application, which is only
screened really for scientific merit and then
we do our very best to put the scientists in
contact with the people that meet their
research specifications and obviously then
it's still up to the individuals whether or
not they choose to engage in a project or
not. But we've had, I believe, about 40
projects, which they have either gone through
or in process. It's pretty amendable to
social science as well as genetics and other
types of science.

I think what I can say is the people
welcome research. They want to be engaged.
They want to contribute to solutions. And the
more that people use this cohort, the better
sense of well-being or sense of progress that

the individuals within it will get, I think.
It's a mutually positive thing or at least
that's our intention.

If there are things that make it
difficult, obviously we'd like to know. We
tried to do our best to correct deficiencies.

DR. GORDON: Thanks Louis.

DR. MANDELL: My group has actually tried
to take advantage of SPARK to do this and we
would be thrilled to talk with you about ways
that a few questions could be added or the
instruments could change a little bit that
would make it more amenable to services
research. My understanding is only so far one
service out of those 40 projects has been a
services research project and I think that's
because of some of the difficulties in using
this cohort for that. But I think with a few
changes, it would be a great resource for
services researchers.

DR. GORDON: Louis, can you use the mic?

DR. REICHARDT: Let me suggest that – my assistant now and just suggest maybe we can set up a time to chat probably next week.

DR. GORDON: Thank you. Other comments or questions about any of the public? We have a couple of minutes left. Anyone on the phone like to make any? Okay.

We're going to right into the panel presentation. You can stand up, take a deep breath. We have a few minutes while they set up, but stick around. Next, we're going to have a panel presentation on disability employment.

Julie, are we ready for it or you need to set up? It looks like we're ready for it. We'll go right into it. It's my pleasure to introduce Dr. Julie Taylor, an IACC member and an associate professor of pediatrics at Vanderbilt at the Kennedy Center there.

Julie's going to introduce the rest of the panelists as we go along.

Let me just in advance thank you for helping us organizing this panel. We're very excited to hear what you have to say.

DR. TAYLOR: I'm actually going to start today by giving just a little bit of background really on some of our work that discusses the challenges of employment and then I'm going to move from that into introducing our panelists who are all doing really innovative programs of research and practices around improving employment for people on the autism spectrum. I'll kind of set the stage with challenges and then we'll move into what people are actually doing about it - really promising.

I'm going to talk a little about current research and future directions. And I'm going to actually bring up a lot of themes that

have already come up today in the presentation so everybody has done a really nice job of setting the stage for some of the things that I will talking about.

The first thing is when we're trying to understand employment. Even trying to wrap around what are the rates of employment is a little bit more complicated than we would think as is I think most things in science. I think John brought this up really nicely earlier in the presentation and I just pulled out a couple of examples of studies that show how the rates of employment really differ depending on who your sample is and how you ask the questions.

One of the earlier studies looking at this was a study by Pat Howlin in the UK, a follow up study of adult show had IQs greater than or equal to 50. She found that around 30

percent of adults were employed, adults with autism.

Meg Farley had a Utah cohort that she looked at. These were adults who had average or above IQs. She looked at current work and found that 60 percent of the adults in her cohort were currently employed.

Dr. Marsha Mailick and I looked at this in a relatively large sample of about 300 adults with autism, about 70 percent of whom had an intellectual disability. We found around 30 percent of adults who were either working in the community or were in college.

That same year Paul Shattuck from Drexel looked at rates of participating in work or post-secondary education for young adults who had recently exited the school system, who identified through special education with autism. They found over 60 percent were working or in college, but they looked at

things a little bit differently. This was the rate of adults who had ever worked for pay or ever been in college at any time over about four years after leaving high school. Important data, but a different question. Current rates of employment.

They followed this up looking at current employment specifically, in the next year. They found that 30 percent of the young adults were working. Now these were adults who on average were four years out of high school and they didn't look at post-secondary education in this analysis, so it probably underestimates the rate of young adults who are engaged and work is post-secondary education.

Meg Farley from Utah went back and looked at adults in the mid-30s in Utah. They had a broader sample this time. About 75 percent of adults who had an intellectual

disability, and they found 30 percent who
were currently working.

We've had the opportunity to work with
individuals from the Interactive Autism
Network, Project IAN. This is a sample of
self-reporting adults who fill out an
Internet survey, and in that sample over 60
percent of the adults were working or in
college.

And then finally, the National Core
Indicators Survey is a sample of adults with
disabilities receiving services, autism being
one group of adults in that survey. And they
find out under 20 percent of adults are
employed.

So I think the take home for this is
that depending on who your sample is and
depending on how you ask the question, the
employment rates are kind of all over the

place. I would say anywhere from 19 percent to over 60 percent.

I don't know that we have a really good handle on in terms of the population of individuals with autism, what is the rate of employment. But I think we can all agree that unemployment is a significant issue for many adults on the autism spectrum.

Unemployment is only one issue because something that we see a lot in the people that come into our studies, and I think all of the panelists would probably agree with this, is that we also see a lot of under employment. We don't have, at least not that I know of, a ton of good data on this, but we see a lot of adults who are working fewer hours than what they would like and are working at jobs that are less skilled than what they would be capable of. Unemployment

is really only one of the issues. We also see
a lot of under employment.

And we've heard in this committee about
a number of really promising programs that
have been developed by individuals and groups
to improve employment whether it is providing
employment opportunities for individuals on
the autism spectrum, whether it's providing
skills to get people into employment. I think
it was last year at this time we heard from
three different panelists and presentations
about I think some really promising and
innovative programs.

Our researchers really lagged behind. I
think as researchers we've not been
particularly helpful to these programs in
terms of generating evidence-based knowledge
that all of these entrepreneurs and people
out in the community can use when they are
designing programs that will be maximally

effective in improving employment for

individuals on the autism spectrum.

With that in mind and keeping that, I'm

going to talk just a little bit about some of

the work that we have been doing over the

last seven or eight years or so, and

highlighting what I think are some of the

important directions for future research to

understand how to better support individuals

on the autism spectrum. And the things that

I'm going to be highlighting here are things

that I think will begin to be addressed in

the rest of the presentation that will be

coming up in this panel.

So I'm going to talk a little bit about

the importance of promoting stability in

employment, not just helping people get jobs,

but helping them keep them once they get

them. And I'm going to talk about how

important it is to at least understand and focus on the needs of different subgroups.

Our first pass in our research of really trying to understand how employment changes over time, was looking at how vocational activities change over ten years. We did these analyses back in 2012. And at that time, there were at least to my knowledge, no studies that looked at how employment changed over time. There were quite a few studies even at that point that looked at employment kind of at point estimates at different rates, but in terms of understanding whether individuals on the autism spectrum were on upwardly mobile trajectories over time, were trajectories flat, was there instability, we really had almost no information.

I had been working with my postdoctoral mentor, Marsha Mailick from Wisconsin, on her study of 400 families of adolescents and

adults on the autism spectrum. At that point in time, we had data collected over ten years in the lives of each of these families, and there were over 150 adults who were out of high school at the start of the study.

We decided to follow them over time and look at the data and see how does independence in vocational activities change over time for these adults. We used multi-level models. And what we found was that on average vocational activities were becoming less independent over the ten-year period.

Now errant multi-level model analyses, we could look to see what are the characteristics that predict where somebody starts out in terms of how independently they're working and what are the characteristics that predict change over time in terms of how independently someone's working.

And in terms of the predictors of initial status, what we found were I think what I call the usual suspects. These are the characters that predict employment, or independence in almost every study that looks at employment or independence in autism. One was whether or not the adult had an intellectual disability. Some studies break this out and look at IQ and adaptive behavior separately, but these are characteristics that are highly related to employment and independence as well as other behavioral variables like how severely autism is and what other behavior problems might be present and that was what we found in our analyses too. These factors were highly related to how independently somebody was working at the start of the study.

But they were not related at all to how independence changed over time. And we only

found one factor that was related to

independence and it was actually the sex of

the person with autism. What we found in the

study was that males on the autism spectrum

were pretty stable in terms of how

independently they were working over time,

but the females were significantly declining

in the independence of their jobs over time.

This was a little bit of a surprise to us. We

kind of put this in as a control variable

because we should be accounting for sex and

gender and then that was the factor that

predicted change over time.

It's important to note here that there

were no differences between the groups at the

start of the study and the males and the

females in the sample were actually basically

identical on all of the behavioral variables

that we looked at and the family variable.

It's not as if they were coming to the table

with something different. Also, none of the females in the sample were married. This doesn't seem to be accounted for by people staying home to take care of children or family. This was sort of our first finding here that we thought was interesting and unexpected.

The other thing to note about this sample was that 80 percent of the adults had an intellectual disability. And the last time point of data in this analysis was 2010. And many of these adults were primarily spending their days in sheltered settings such as adult day programs or sheltered workshops.

We were interested in what kinds of patterns of stability we might see if we looked at adults who were more likely to be spending their time out in the community.

We did another set of analyses using the same larger data set, but point out the

adults on the autism spectrum who did not have an intellectual disability and looked at their patterns of employment over time at seven time points for up to 12 years. And we grouped the adults into three different categories. The first were adults who at every time point that we saw them in the study, they were either working in the community or they were in college and that was 25 percent of the sample that fell into that category.

The next group was adults who sometimes when we saw them they were working in the community or in college and sometimes they weren't. This was our sometimes employed group. That was about 42 percent of the sample. And the last group was adults who at none of the time points that we saw them they were working or in college and that was about a third of the sample.

If you put the green and the yellow bars together, what this study suggests to us is that working in the community or going to college is a fairly common occurrence. About two-thirds we're doing this at some point of the adults in the sample, but consistently participating in those activities were relatively rare.

The next thing that we wanted to look at then is what distinguishes between those adults who are consistently participating in activities and those who were sometimes participating in activities. And the only factor that distinguished between those groups was the sex of the adult on the autism spectrum.

And what we found was that 30 percent of the men were consistently working or in college and none of the women were in our consistent category. It was a pretty small

sample of women. There were only 73 total. It was just under 20 women, but not one of them though in this consistent group. We'll come back to that in a few minutes here.

Both of those analyses actually – in this data set, we were really looking at stability and type of activity, but not in activity specifically. We didn't really have the level of data needed to look at specific activities. For example, if somebody was working in a job in the community, they got fired from that job and then at the next time point they were working at a different job in the community, they would be in our stable group because they had jobs in the community at both time points. But there isn't a whole lot that's actually stable about that pattern. We followed this up.

This is data that was collected as part of my career development award that I had a

small sample of families of young adults on the autism spectrum and we collected data at three time points. We collected data when they were in their last year of high school and at two time points after high school exit. And because it was a small sample, we could actually collect really in-depth detail about a whole lot of things, one of them being what they were doing with their days after leaving high school.

We took that data and we coded each of the young adults into what we called either a disruption or a no disruption group. We really wanted to distinguish instability from disruptions because some instability actually reflects upward mobility. If someone goes from a two-year to a four-year college, for example, that's sort of a change in activities, but that's different than somebody who would get fired from a job, for

example. We had the data to be able to

distinguish that.

And what we found was that of this

relatively small sample, half of the young

adults experienced a disruption within that

two and a half years after high school exit.

And, again, these were things like getting

fired from a job, needing to leave a job that

one would have otherwise really liked because

of problems with co-workers, having to drop

out a college program, et cetera.

Then we looked at what are the

characteristics that we had measured in high

school. Before they left school and before

they had the disruption, that might help us

distinguish between those who experienced a

disruption and those who don't. And the usual

cast of characters didn't distinguish here.

When we looked at IQ of the young adult,

adaptive behavior, autism severity behavioral

problems, those did not distinguish the people who had a disruption versus didn't. And the effect sizes were actually quite small. In fact, the only factors that came out in this analysis were indicators of family functioning and family mental health. This was depressive symptoms, anxiety symptoms and quality of life.

In the adult research world, I feel like we get findings a lot that are surprising because so little is known. And this was another one of these surprising findings and we spent actually a lot of time talking with families after we got these findings.

I think what might be going on here is that families are oftentimes working very hard to support their sons and daughters after they leave high school. A lot of families are not getting the services and supports that they need. And in the absence

of that, oftentimes parents are stepping in
and kind of filling in the gaps and
scaffolding and supporting their sons and
daughters, not in every case, but in a lot of
cases. I could tell you lots of examples of
families that we've seen that are doing
exactly that. But if parents are struggling
and if the families are struggling, they may
be less able to effectively do that. That's
kind of what we think is going on. We're
hopeful to be actually test this out in a
larger sample and make sure it's not just
something funky that we see in the small
sample here.

But I think overall what this tells us
it's probably the most important for this
discussion is that getting a job or getting
into college that's only half the battle,
maybe even less than half the battle. But
actually being successful in that position

once you get there is a real significant
challenge. In the other presentations that
we're going to talk here from today I think
there's going to be a lot of discussion
around really helping people become
successful once they're in those positions.

And the other I think important take
home from this is that if in fact this data
is replicated and it's true and if the
factors that predict someone keeping a job
are different than the factors that predict
them getting a job, that's something that we
need to understand because we're not doing
people any favors by helping them get a job
and get into the work place, but not knowing
how to help them be successful once they get
there.

And the last thing that I'm going to
talk briefly is the importance of
understanding the needs and supports of

subgroups. This has already started to come up a little bit today and certainly over the course of this committee. This has come up many times.

But when we are talking about autism, we are talking about such extreme heterogeneity that we have to take into account in our research and in our services and in our programs. One pretty obvious factor or aspect of heterogeneity that comes up a lot is cognitive functioning. And in terms of understanding – really at the front end of understanding of how might the needs differ for people along the range of cognitive functioning. How should our outcomes differ? Should they differ in terms of what we are thinking about outcome? Should they be the same? Kind of going back to this discussion about how do we define outcomes and how do we

take into account heterogeneity when we do that.

Something that's coming up in our work quite a bit that we are pursuing that I'm happy to talk about later, but won't really have time here is how might the needs and supports need to be different for people of different sex and genders. Again, what we have found in these analyses is that women on the autism spectrum seem to obtain vocational and educational positions at the same rate as men, but have a more difficult time maintaining those positions over time and they have some analyses with other data sets that we are really trying to flesh out why that might be and develop some hypotheses around that.

And of course those are just two aspects of heterogeneity. There are all kinds of other behavioral variables and family

variables that impact the supports that people may need in employment. Just a handful. Adaptive behavior, social motivation, co-occurring, physical, and psychiatric mental health problems, what families bring to the table in terms of socioeconomic status and on and on. We are really again at the front end of really understanding this.

I think what we do know though is that to really best support employment, it's going to need to be a multi-faceted process. We'll probably need to be thinking about how to better support individuals and this can be things like – it doesn't have to be changing the autism per se, but it can be things like supporting people for daily living skills, mitigating the impact of mental health symptoms, for example, working on soft skills, job skills, things of that sort.

The work in our group would suggest that we can really help support employment by better supporting families, certainly better supporting employers and work places to better employ and to be more effective in employing people on the autism spectrum would be helpful and making our services and systems more effective in terms of supporting people.

And, again, these are all different pieces that I think are going to come up in the presentations that we'll be hearing from now. I will now introduce our speakers and we'll go from there.

First, we'll have Dr. Paul Wehman, who is professor of physical medicine at rehabilitation at Virginia Commonwealth University and director of the VCU Rehabilitation Research and Training Center. And he will be talking about competitive

employment for youth with significant autism and results of their multi-site randomized control trial.

Next after that we will be hearing from Erik Carter. Erik Carter is the Cornelius Vanderbilt Professor of Special Education at Vanderbilt University. Erik and I had to catch up here about some things that we would like to work on together even though his office is one floor below mine in the same building. That's how it works sometimes I think. And he'll be talking about the TennesseeWorks Collaborative, lessons learned on elevating employment outcomes for young people with disabilities including those with autism.

And finally, we'll be hearing from Hala Annabi, who is an associate professor at the Information School at the University of Washington. She'll be talking about autism

ready work places, creating and scaling

autism hiring initiatives.

DR. PAUL WEHMAN: Good afternoon. I'm

really glad to be here. I share our work. I

think Julie has really covered a lot of the

things that we would do quickly. I think I'm

going to be able to jump very rapidly

probably into some of the things that my wife

says people prefer to watch than words and

that is videos.

We've done that already. In fact, we've

done a tremendous job in the last ten years

of essentially documenting the problem and

almost admiring what the problem is and we're

now moving into an era where we're trying to

figure out how can we help people where they

are currently at to have a career, be

employed, be less under employed and be more

independent in a career.

We think that the keys to changing this is clearly to focus on people's strengths, go from a strength-based approach as opposed to a deficit-based approach to look at interests and preferences. Every time you work with different people with autism, you learn something new differently. Individuals have so many gifts. It's extraordinary. The more time you spend working with people with autism or autism-like characteristics, the more you realize what the strength and the power is that they have and they just are being grossly underutilized.

If you are looking at a goal of education, you are looking at a place to call home, places to go, people to see and how do you get that? How do you get to that life? You should have a real job and a real job is working with people without disabilities being integrated and immersed into the

workplace, not into sheltered workshops or daycare centers, the places that the US Department of Justice is now closing, courtesy of Title I and the Americans with Disabilities Act. Fortunately, most families of kids with autism do not want to be in segregated programs.

What is one evidence-based pathway to competitive employment, real work for real pay? That was a question that we asked. We said how can we figure out what we can do that would be different and would reverse the paradigm that Julie has just described. We knew we couldn't solve everything so we said let's try one thing that we think might work. With the courtesy and the support of the National Institute of Disability and at that time rehabilitation research – project officer is here today, Leslie Caplan. Some of you – many of you know her, I'm sure. We use

an internship-based model. It was based

originally on a program out of Cincinnati

Children's Hospital called Project Search. We

have since adapted it. But it is a model that

required 900 hours of work from essentially

Labor Day to Memorial Day, four students that

were entered into the program and received

training at a local hospital. The first study

was a pilot RCT.

However, before going into that study, I

want to show you a picture of the type of

people that we're working with and one

individual specifically. It's about four

minutes long.

(Video shown)

DR. WEHMAN: One reason that I wanted to

use this video is because when we started

this, we not only wanted to pick a pathway

like an internship that is common whether

you're a student teacher or you're a nurse or

you're an OT, people get internships. They understand that as a concept that would be a precursor to actual employment.

I think watching exactly what the employment specialists who are trained in applied behavioral analysis and in job restructuring and in support employment – by watching it, it's a much better story than me trying to put it up on a slide with a bunch of words.

Let's just go ahead and take a look and see what happened between 2009 to 2013 with the 54 people that were enrolled over a four-year time period into one hospital in Richmond, Virginia.

We started out with a large number of controls. We lose controls, of course, each year because what happens is that families become frustrated. As each year went by, more and more families wanted to participate and

were unable to get in because we were randomizing.

They all started at the same – at the beginning and then if you look at the 74, the 74 percent at graduation were offered jobs. Remember, this is one hospital and they all loved having these folks. The majority who were non-verbal, less than second grade reading education. They all enjoyed having them as interns and they were fighting over who was going to be hired there.

At three months, it was 90 percent employed and 12 months later, 87 percent employed. And the retention rates were all 12 to 36 months later on this group. We knew we were on to something here. It was a good deal. But we said to ourselves, is this just because it's a nice hospital and they feel sorry for people with autism.

We went back to NIDILRR and we said we would like to do another study that would be something more of an efficacy study, taking what we had learned with the one hospital and going to four hospitals in Central Virginia and Tidewater, three school divisions, multiple job coaching agencies and we ended up again this time with a larger end of 156. As you can see, the rates of graduation from hiring were much slower. At graduation, we only 30 percent employed. That's not bad. But six months, we had 63 percent and 73 percent at 12 months later. Again, long-term retention rates, excellent. Once folks get locked in, they're locked in. And they're doing jobs that are – I'll get to those in a second.

Let's talk about the effect of the employment on how independent people became because it's not just enough to get the job.

What does it mean to have the impact of a job? Jobs are life changing. They're transformative. So many individuals came to us and at least a third to half had an aide in school because they were so dependent.

We used the American Association of Intellectual Developmental Disabilities Support Intensity Scale. We tracked them over 12-month periods. We found that the control group stayed the same. They did not over the different domains, which I'll show you in a second have any differences. The treatment group almost immediately became more independent. These were in areas such as employment, community living, home living, health and safety, lifelong social activities. We also run this now on the group that we've just finished with and because it's not published yet, I'm not able to apparently tell you, but looking good.

Let's look at Stefanie real quick.

(Video shown)

DR. WEHMAN: In the remaining time I've got, I can't help but think as I look at both of these, the last slide that Julie mentioned, which I think was individuals, family services, work places. That's exactly what has been all brought together in this particular last eight years of our work.

I think I have about two minutes left and I can cover that. What kind of jobs do these folks acquire? Entertainment, education, facilities management, distributor, hospitality, food service. And what's interesting to me in this is in the second larger group, very few of the host hospitals hire people. In other words, the hospital effect that Dr. Caplan and I were concerned about did not show itself. The

model worked across a variety of different types of companies and industries.

It took about three to six months – graduate in June and then be off for a couple of months. But from the point of graduation and did about three to six-month period to get people employed.

I have to tell you. I don't have research on this, but I can just tell you that in three of four decades of doing this type of work, I have never seen coworkers and supervisors embrace individuals with significant disability like this. I am convinced because not only are they incredibly good workers, but they have incredible personalities. The folks that I've had the opportunity to work with have very unusual personalities and we're already beginning to – we're meeting tomorrow with Dominion Power and they are wanting to climb

on and do the same type of thing. We're
extremely excited about this.

I will close by saying that we're
looking at increasing morale among co-
workers. We're looking at increased sense of
mission among staff, increased productivity
in the units, and I know that because we are
studying that right now through additional
funding that we're receiving and we're
looking at why people have been wanting to
hire people with disabilities in autism.

I do not have time to explain to you all
the hard and fast details on how we did this,
but it is in the archived Power Point. We
were obviously using the combination of
support employment and customized employment.
I will stop right there. Thank you.

(Applause)

DR. ERIK CARTER: Good afternoon. It's an
honor to be before this committee among so

many individuals who care so deeply about the

thriving of young people on the autism

spectrum. I think that pathway to meaningful

employment is an important part of

flourishing for so many young people, not

just because of the paycheck, but also

because of the connections and the

relationships and the contributions and

valued roles that come from having the right

job.

I was asked to highlight some of the

movements that we're making in the State of

Tennessee to change the employment landscape

for young people with autism and intellectual

disabilities and other developmental

disabilities. Young people who live in urban

and suburban and rural communities all across

the 500 miles of our state from Memphis in

the west all the way to Bristol in the east

with some initial funding from the

Administration on Intellectual and
Developmental Disabilities through their
Projects of National Significant grant and a
few others along the way, we launched
something called the TennesseeWorks
partnership in 2012. This is a systems change
effort in our state that involved more than
50 state agencies and organizations and
community groups all working in concert to
really raise the aspirations and
opportunities and supports and preparation
that young people receive to enter the world
of work before they graduated, but certainly
after in those early years of adulthood.

And the Vanderbilt Kennedy Center for
Excellence in Developmental Disabilities was
really the hub organization for this work.
But it included a number of other entities as
well.

And I think is true in a lot of the other states across the country as Julie referenced and Paul implied, there were a number of barriers in our state that prevented young people who wanted to contribute in the work place from having those kinds of opportunities. Expectations were often uneven among parents and educators and professionals. State policies were inconsistently aimed towards integrated employment in our state. The availability of strong professional development in training was really hard to come by. Accessible resources and information were very difficult to find. And that commitment to be an employment first state didn't always penetrate practices. We had a lot more silos than we had collaboration.

These were some of the issues that you have to address that extend beyond just a

single program or intervention to really
change the landscape in a community or a
state.

Since the very beginning of that
project, we've – I guess I would say in terms
of thinking about the last six years of the
systems change work, there have been a number
of themes that kind have emerged from that
work that I think have relevance potentially
to other states or other regions that are
trying to make these kinds of changes. In my
17 minutes left, I wanted to highlight nine
key takeaways from the systems change work. I
left a tenth just in case I think of one
before the end here as well.

I'm going to walk through each of these.
But I think since the beginning of our work,
we've been convinced that all of our work has
to be aimed towards the aspirations of young
people with disabilities that there's really

no separate set of dreams for young people
who are on the autism spectrum. No
substantially separate pathway that we should
assume should take hold. I think our own
conversations with people across our state,
young people in our schools affirms a point
that is also true I think in research that
the presence of that label of autism is not
at all a reliable predictor of what young
people want for their lives.

I too brought a short video and I want
you just to listen to some of the young
people with a variety of disabilities who
came to our recent employment summit who
responded to a question all of you were asked
a million times when you were in high school.
What do you want to be when you grow up?

(Video shown)

DR. CARTER: So a common question with
pretty ordinary answers. The thing is young

people in our state aren't aspiring to
unemployment or under employment. They're not
talking about earning piece-rate wages in
segregated settings. They are really talking
about having gifts and talents they want to
bring to the workforce.

I think that may sound a bit anecdotal
to lots of you, but you should know the
plural of anecdote is data and that's what
the data bears out as well.

If you look at the most recent National
Longitudinal Transition Study 2012, they
found that a striking 95 percent of youth
with autism expect to have a job after
graduation and their early years after school
up to age 30. And yet in a prior iteration of
that national longitudinal study, the NLTS2,
they found that after leaving high school up
to four years later, only 47 percent of young
people with autism actually were working.

Hours per week were the lowest of any disability category. Only 38 percent said they liked their job very much. It's that gap between aspirations and outcomes that we're working to change across our state.

To this end, we really strive to make sure that young people with disabilities and their aspirations are at the forefront of the systems change work, making sure that they're part of all of our partnerships work groups, that they're having a strong presence at all of our employment summits, that they're present doing advocacy down on our Capitol or on the Hill and in many other places as well.

The second theme from that work is that we've come to see that our own expectations have to actually match or even exceed the aspirations of young people with disabilities. One of the most powerful forces that we know in changing employment outcomes

turns out to be the expectations that educators and parents and others hold.

In our own research, we found that young adults with autism and intellectual disability whose parents expected them to obtain work after graduation were nearly five times or more likely to have paid jobs in the community in the first couple of years after exiting school. It's a finding that Paul and his colleagues have also found as well.

And the expectations of educators are also powerful. We found that high school students with disabilities who had teachers who expected them to obtain paid summer jobs were 15 times more likely to have that paid job in the community when we track them over time.

Early in our own project, we launched a study aimed at understanding the views of more than 2400 parents across our state on

unemployment, about half of whom had sons and daughters with autism. Eighty-three percent of them said they expected paid part-time or full-time work for their sons and daughters, more than twice as many who mentioned sheltered or segregated options as well. But they also emphasized the quality of that work, not just whether or not their son or daughter had a job, but that it was a job that brought personal satisfaction, that matched their sons and daughters' interests, that provided opportunities for interaction, that allowed for friendship development. Pay an hour per work mattered, but other qualitative aspects of work mattered as much or more.

We've also been taking steps to track the expectations of educators in our state and begin to raise them as well. We've done three large-scale surveys of more than 2000

middle school and high school teachers to
help us figure out what resources they need
to strengthen their commitment and capacity
to prepare young people for the world of work
and then we incorporate what we learn from
those teachers into the professional
development and training of resources that
were developing.

Third, we've come to see something that
Paul mentioned just a bit ago, the importance
of telling a very different story about
disability and about autism. One that focuses
primarily on the gifts and the strengths and
the passions and the assets and contributions
that young people can make in the workplace.
Employers want to hire strengths and that's
perfect because the young people that we're
working with have incredible strengths to
bring to the workplace, but that requires
helping professionals think differently about

young people and choosing different

assessments that don't just focus on what

people can't do and struggle to do, but help

them identify talents and strengths and then

figure out where in the community does

someone need exactly those sorts of things.

Some of you may be familiar with our

state's October Disability Employment

Awareness Month campaign called Hire My

Strengths. This is exactly what we're trying

to do is showcase the strengths of young

people and then invite employers to consider

a broader segment of their community when

they think about who exactly to hire.

The fourth theme that comes out of our

systems change work is this issue of aligning

our policies. We've learned that it's

absolutely essential to make sure our

policies align with those aspirations and

also those high expectations. We've

established a state employment roundtable

policy workgroup that's tackling this work.

It's comprised of agencies from all corners

of our state leadership who are striving to

align those policies towards integrated

competitive employment. Just trying to bring

some consistency and focus and leadership to

make sure those state policies actually match

those aspirations.

There are lots of examples that come to

mind, but one of the early successes was

getting our governor to sign the Employment

First Executive Order in 2013, which

established this taskforce on employment and

then became the catalyst for strategic

statewide movements, policy changes, and a

series of annual reports that come out each

year that outline what progress we've made

and where we need to go next. It's built in

an accountability in the state in terms of this.

But a number of other policy changes around access and support to higher education, lowering the requirement for transition planning down to 14, trying to equip the American job centers to address the needs of people with disabilities. That's what this work group is trying to do and we know the policy work has to move in order to get the practices to change as well.

We've also recognized that we've got to do a better job of equipping professionals and I heard this mentioned earlier in the comment period. We've worked to make sure that those policies that we're implementing are actually permeating practices and that educators and service providers and employers actually have to be fluent in best practices

if we're going to actually get outcomes changed.

If they're going to have the very best chance of improving outcomes, they have to know the very best of what works. This is really hard for practitioners who are trying to figure out how do we find effective training and practical resources to guide our work. We've taken a lot of investments really to try to make sure that professional development is available and accessible and actually effective.

For example, we work with our Department of Education to develop a free, online professional development series for secondary and transition educators. Now more than 5000 middle and high school teachers in our state who never had any training on transition in their pre-service training now have access to really high-quality training and resources

wherever they are in the state. They don't
have to travel to Nashville for a conference
or enroll in a post-secondary program to get
this kind of information. It's available to
them on demand.

We've made this available to you all too
if you're interested in accessing this
resource. For the next 24 hours, it will be
free for you. And then after that, it's also
free. It's just always free. I just wanted to
create some urgency.

We are always trying to create a
companion module for pre-employment
transition services as well in partnership
with our Department of Human Services as
well.

But we're also then trying to track
whether that training and professional
development actually reaches all corners of
our state by systematically figuring out

which counties have teachers who are being trained and are using those resources which are not to a more data-driven approach to professional development and making sure that in our state we have adopted a more tiered approach to information dissemination. We're not just trusting that because we develop something and wrote about it, it makes its hands of educators and parents were actually systematically planning for that and tracking whether that actually takes place.

Six, we've learned the importance of making information accessible. This came up also as well a little bit earlier on. I think we are very prone to sharing our research within peer reviewed journals and academic circles and policy documents and those sorts of things, but when we talk to parents and educators, they prioritize alternative ways of getting information to them. Practice

guides, downloadable resources, websites,
videos and apps and employers and community
leaders who are not connected to disability
networks would never find out about the good
practices that we've learned about through
our research unless we find other ways of
communicating that to them.

We've developed a website through our
TennesseeWorks partnership that organizes
content by stakeholder group whether that's
self-advocates, family members, employers or
agencies, features upcoming events, a data
dashboard, success stories, a video library
and searchable resource databases. It has
joined thousands of unique visitors each
month and then we're also trying to push
information out through social media and
newsletters and just in time avenues. That's
the way of making sure that you don't have to
be deeply connected to the research

literature or access to journals to be able
to know what works and can impact things in a
state.

For families, this also means finding
other ways of sharing Tennessee disability
specific information, establishing family
coalitions across our state, launching a
parent-led blog that demystifies agencies and
programs and policies in language that
families can understand and then telling
success stories and sharing those with other
families who struggle to catch a vision for
employment. But when they see another parent
who has a son or daughter with similar
characteristics as theirs, they start to see
a path to employment because of that.

We've also learned the importance of
engaging communities. Strengthening formal
services and supports is absolutely essential
to this work, but it's at the local level

that policies and practices ultimately play
out. So many communities are uncertain about
how to move in this space that lead to
employment opportunities for young people
with autism. And rarely do we actually draw
upon local community ideas to inform our
policy change and system change as well.

A hallmark of our work over the last
five years has been efforts to hear from and
to engage and raise awareness at local
community levels and ways of bringing
together local civic leaders, employers,
businesses, community groups, faith
communities, families and others in
innovative ways that allows us to figure out
how do we make movements here in this local
town or county or community.

Local change of course is really hard.
It's not changed by a single program or
intervention. There are multiple components

at a local community that have to change.
Both Julie and Paul referenced this. It's not
just about what schools do or what families
expect or what employers are willing to do or
how agencies support. It also requires
thinking about the attitudes and
accessibility and engagement of local
communities as well.

We've been launching a series of things
we call Community Conversation Events. This
is our primary way of learning from and
listening to local community members. They
involve really bringing together a cross
section of citizens at the level of a town or
a county and we require that at least half of
those attendees be people who have no
connection to disability or the service
system. They just know their community well.
They care deeply about it and we invite them
along with families and disability service

providers and others to think about how that

community can make local changes that elevate

employment outcomes for people with

disabilities.

We've had 60 of these events around the

State of Tennessee on a variety of topics

that you can see up here. Some on employment.

Some on other issues as well.

And eighth – promise only two more here.

We've realized the importance of data in all

of this. Does any of this work actually make

a difference in our state? Elevating outcomes

requires that we also measure well. We have

to collect good data and then find ways of

sharing those data with all the stakeholders

in our state as well.

Data was perceived as a four-letter word

in our state about seven years ago. And I

think people are now excited about what's the

data telling us about whether any of this is making a difference.

It makes me think about that Yogi Berra quote. If you don't know where you're going, you might not get there. We didn't know where we were at any point in our state until we started to embed research and other data collection activities into our TennesseeWorks partnership.

And then we created a data dashboard so that information was available to others in our state as well as objective goals for our state and in this case, to reduce the gap in employment between people with and without disabilities by 5 percent by the year 2023.

We now have a clear measure that every state agency and community can get behind that gives us a reference point to figure out whether what we're doing is actually making a difference.

And then we've coupled that with the research community who are carrying out a series of studies to help us evaluate different aspects of this partnership and to be able to document what's happening at each of those different areas that were making investments.

These are just a sample of some of the studies that have come out of that project and we can certainly make those available to you as well.

And the last of these themes that we've learned are really important is this issue of relationships among state agencies and other partners. Systems change work like this does really take an investment in relationships and we've seen the power of building strong connections among all of our different state agencies whether that's economic and community development, labor, education,

Department of Intellectual and Developmental

Disabilities, our P&As and a whole host of

others, getting them in the same room,

conversing with one another and developing

relationships that then can endure the

constant changing of personnel in those

different agencies to create shared

investment over time. That has really been

critical for getting these movements

sustained over the last six years.

With my time just wrapping up now, I

just want to emphasize that the systems

change work is a slow process, rarely

proceeds in very predictable ways, but it's a

critical investment. We're not going to

change outcomes just by having a single

intervention, but really figuring out how we

move all of the different parts in our state

in tandem in the same direction and over time

we anticipate that will start to lead to not

only more employment outcomes, but better

high quality employment outcomes that lead to

a life of flourishing for young people with

autism. Thank you.

(Applause)

DR. HALA ANNABI: Good afternoon. It's

always good to go last in a panel because you

can skip a few slides that have been

repeated. One of the things I want to note

and maybe alert you to is that you will hear

some similar themes from my perspective and

it's really interesting to hear those

consistent themes from researchers from three

different disciplines, from three different

parts or four different parts of the country

doing this kind of work.

As Julie mentioned, I'm from the

University of Washington. My background is in

organization science and information systems.

I come at trying to understand employment

opportunities for the autism community from
the employer perspective and particularly
from for-profit organizations, from
businesses, who are engaging in creating
opportunities, equal opportunities for the
autism community.

I'm going to talk about an initiative
that we just completed. We just collected our
data this fall and winter and this is
literally hot off the press. This is a
different type of work because it's
qualitative work to understand some of the
practices of organizations. I will talk about
that.

I'm going to skip a few slides because
it has been discussed so I can spend more
time on the fun things.

As mentioned by Eric and others, in
order for us to provide equal opportunities
and to really address the challenge of

unemployment for the autism community, all members and all partners have to be involved. Around 2000, some in the technology industry in particular took a special interest in the unemployment for individuals with autism and wanted to create some programs that will have a social impact. More and more industry members are taking note of the talents and the diversity of the autism community and trying to understand how we can engage them in the employment and various industries that they can contribute special talents to.

More and more interest has been taken by industry members and researchers from business schools and organization science to understand the diversity of skills within the community and how we can engage it.

This is where many started talking about and identifying some unique talents like attention to detail, analytical thinking,

systemizing, visualization, that can be helpful to a variety of industries.

And the technology industry in particular, took a special interest in that. My research has focused predominantly in the early phases on the technology industry and on individuals with autism without intellectual disability. And that is where this research talks about quite a bit.

But also the industry started also looking at research that has been done on employment and identifying employee characteristics like trustworthiness and reliability and innovation that has been surfacing around autism employment programs and really try to communicate that and understand that better to provide equal opportunity, but also to use that to better industry as well. This is where the rise of autism employment programs came about.

Around 2004, in Denmark, an individual noticed some of the unique talents of his son who was on the spectrum, around attention to detail and around some testing of software, and designed a technology firm that provides services for a variety of industries to do software testing and quality assurance.

He built a model to identify strengths, unique strengths of different individuals and matched them with jobs in his consulting firm. He developed a model that then was copied by a variety of industry members.

The first one and the largest one that really gave a platform for autism hiring programs particularly in the technology industry, was SAP. I believe last year Jose, from SAP, talked to your committee as well.

SAP created an autism hiring program that intended to provide employment opportunities for individuals on the spectrum

by breaking down the barriers that
traditional recruitment methods present for
individuals with autism through career fairs,
and different interview processes, that
didn't work very well. Others like Microsoft,
Ernst & Young, Ford. that worked in the
technology industry, but were also seeing
other companies like SENTAS and Rising Tide
who are providing a variety of positions as
well. That's what gave rise to these autism-
specific hiring programs.

These programs have great potential.
They can provide a lot of resources. They can
provide opportunities. They take a strength
perspective. But challenges still persist.
There's less understanding about how to
create these programs and create really true
equity and inclusion of individuals who are
entering the workplace through these
programs. Many unanswered questions.

Particularly this is where I collaborated with the Employer Roundtable that represents a lot of companies that are engaging in these programs to try to understand how can organizations change, develop supportive programs, develop interventions that are more inclusive and provide more opportunities for individuals on the spectrum in industry.

We looked at what is it about these organizations. What are the organizational characteristics and what are the intervention characteristics that maximize opportunities and minimize the barriers? In other words, what is it that organizations have to do in industry to change so that we can provide an environment that is equitable and inclusive?

This is where our work started. We looked at this by looking at four organizations and really try to understand

what works and what doesn't work. What do
these hiring programs look like? What are the
key organizational characteristics and what
are the best practices?

And what we developed was actually what
we call a guide book, a play book for other
organizations that are interested in
developing autism hiring programs across a
variety of industries, companies of different
sizes that can utilize and really learn about
these best practices so that we can create
more opportunities across a broader range of
organizations and not just large technology
firms, for example.

And the way we looked at this and this
is consistent with Erik and Paul's work to
take a strengths perspective, but real look
at what is it that organizations can do. What
are the interventions that can address the
barriers that exist in our workplace but also

that can raise awareness and education in the
workplace around autism, the diversity of
autism, the talents, and also address the
diversity of needs and desires and
expectations of members that are entering the
workplace that are on the spectrum,
understanding that the diversity and the
heterogeneity of the community requires a
variety of interventions and requires a
variety of accommodations and also how we can
learn from those diversity of needs that will
help us change the organization so that any
individual whether they want to disclose
their autism or whether they know they're on
the spectrum can come and engage in the
workplace in effective ways? That's what we
took a look at.

And, again, what we focused on
specifically is why are companies engaging in
these types of employment programs. What are

their objectives of these employment

programs? What are the methods and the

practices they use to create those

opportunities and to support members of the

autism community coming into the workplace

and how do they measure the impact of these

programs both on the individuals, but also on

their organization as a whole so that we can

understand it better and we can understand

how it works?

I spent quite a bit of time with the

four firms: Ernst & Young, J.P. Morgan Chase,

Microsoft and SAP. And Microsoft actually

partially sponsored this work because they

wanted to share their best practices and they

wanted to identify best practices across what

we think of as the original four and the

first four companies within the US that did

these programs. We spent a lot of time

talking to them, looking through their

documentation.

I also conducted a research workshop

last year with industry members as well as

academics to identify some of the challenges

and the questions that are unanswered. I'm

going to talk about that as well. And we did

some data analysis. I'm going to share with

you some of the preliminary results here.

First, what we learned about why firms

of different sizes and particularly those

four firms, why do firms engage in these

programs and what are their objectives. And

what we found is that companies start

engaging in these types of programs because

they want to make social impact. They feel

that it's part of their corporate social

responsibility to engage in providing

opportunities because they can. And many of

them will talk about certain core values that

the organizations hold that makes these types
of programs consistent with what they should
do.

For example, Microsoft talks about
accessibility as a core value and it's
important for their organization as a
culture, but also it's important for the
kinds of products that they produce that they
should be accessible. That's an important one
and it's really important for organizations
to understand why they're doing these kinds
of programs and how consistent these programs
can be and what kinds of methods they will
integrate so that they can be consistent and
effective.

The other aspect, which becomes
important especially for the sustainability
and the scalability of the program is what
are the business benefits of these programs.
This is where they took a strengths-based

perspective. There are talents in the community that can meet needs that the organizations have and the technology industry that – is clear. There are a lot of jobs that go unfilled. We found that and some research identified that. There's a percentage, about 16 percent of college student pursuing technology degrees that are on the spectrum.

There's a talent pool that is really important to engage in the community that becomes an opportunity for these organizations that they emphasized over and over again as an important catalyst for creating these programs where we can meet talents with needs as well.

The other thing that as programs matured, one of the things that these organizations found – when they're competing with talent particularly the millennials.

Millennials want to engage in companies and
want to work for companies that have a
positive social impact. And a number of firms
were told that when certain employees are
deciding between two offers when all things
are equal, if a company has a program like
autism hiring and they will actually
reference it specifically, they will choose
the company that has it for a variety of
needs.

One, they want companies that are
socially responsible, but also there are a
number of individuals that have personal
experiences with family members or then
themselves are on the spectrum that they feel
this is a company that has similar values to
mine and that's why I'm going to join this.
It's becoming a very important part of the
employer reputation and brand and it's

becoming an important part that they are competing on.

Other instances as these programs are new. SAP, for example, have been around since 2013, Microsoft 2015. So they're really – but we do have anecdotal evidence of improvements for productivity and innovation.

The fact that you have different perspectives, different cognitive perspective of exploring problems, exploring processes, looking at products from an accessibility perspective. When you have a neurodiverse team, you could actually provide alternative designs that have been productive for members of industry so they actually point to a number of instances within their organizations where that actually happened.

A very important catalyst for whether a program will surface or not. This is actually very different than most other diversity and

inclusion efforts that I study for other underserved populations. Companies decide whether they can do this effort or not if the ecosystem, the community has the right resources, if the state has the right policies and agencies that can contribute, if the community members are involved and supportive of these efforts. The ecosystem becomes really important for whether a firm will engage in these programs or not. And with large multi-national organizations, their choice to scale it to different locales within the US and outside of the US because remember these could be catalysts for change across the world. A lot of them sometimes say well we can't do it here because we don't have the supports, the local supports for whether it's coaching or other supports for members. That becomes really important that has been discussed.

But there are a lot of questions that remain around catalysts and objectives for these programs. One of the biggest questions that everybody has now is how do I scale the program from 72 individuals within one locale or one state or two states to across the US. Even though I have 200,000 employees and I have offices across the world, how do I scale it? How do I invest in this program? How do I find the supports for it in the community? And sometimes how do I find employees that will meet the demands of the different communities? That's one that keeps coming up.

More importantly, how do we scale these programs so that we can serve within our organization? People have a variety of needs and abilities so across the spectrum and not just where many of these programs are.

And also how to do this in collaboration with existing programs around diversity

inclusions that already exist in the organization. Those are a lot of the questions that remain around catalyst and objectives, why people are doing this and what are their goals around this.

The second aspect, which is maybe a little bit longer, but what methods and practices do they use. What is really important? The first thing is leadership support is the most important and in fact the most successful companies are the ones where these initiatives are even initiated by some of the executives and why they do that because it's more consistent with the core values and becomes better supported and funded a swell. They talk about that quite a bit.

But leadership support is not just sign off. When you're changing culture and when you're changing the whole system of an

organization, sending the messages of this is something we value and here's how we will behave and here's how we will include and here's how we will create equal opportunity that comes from the leadership. It reinforces that culture. It says here's what we expect you to do and behave as. It starts changing the knowledge and attitudes around who should work alongside of me. That becomes really important and it doesn't start just at the beginning. You have to do it continuously and we'll talk about that.

Another important dimension is all these programs look different and they look different across organizations because they have to be aligned with organizational values, culture, the way the business model is being delivered, how they do their business. There's a lot of variety and that's by need. So designing a program has to be

fitting within the company and it has to be
very systematic about how we assess what will
work and what won't work and how we measure
it.

And the other very important set of
practices is around building a culture of
diversity, educating employees around what
autism is and how you might engage
productively and improve supervisory
relationship.

I'm going to talk just quickly about
improved supervisory relationship because
it's probably the most significant factor and
it's also the most significant factor across
a variety of underserved communities that I
study across industry.

When managers are trained on effective
practices in leading a team and creating
collaboration across the team between
neurotypical members and neurodiverse

members. When they do that well, those
universal practices or those practices become
universal good managerial practices.

One of the things that these
organizations say when I have managers go
through the autism awareness and the autism
culture training, they become better managers
across the board. We are seeing a spillover
effect where these managers are better
managers for people on the spectrum, but
they're better managers for their entire
team. But they're better managers for the
organization. And how these practices change
becomes really important so that's a really
important dimension where those programs are
catalysts for really good change across the
organization as well.

The other thing that is an important
best practice is providing accommodation and
in a continuous pattern where when an

individual engages in these programs and they have their coach from VDR for the first couple of months or six months depending on the needs, it's really important to create a systematic process where you reassess and reengage in accommodations and understand that accommodations will vary across the community. Building those mechanisms in a systematic and continuous way along the lifespan of the program and the employee becomes really important.

In some cases, some of those accommodations whether it's the changing of the interview or noise cancelling headphones or stand up and down desks become really important practices where some organizations, for example, Microsoft, is providing for all employees that come into the organization now. When you start your job, you come into a desk that is stand up and stand down and has

noise cancelling headphones because they are
effective. They are starting to use some of
these practices in what we think of as
mainstream practices as well.

And the last thing and this is where
these programs really differ and they're
innovative. The way recruitment and
onboarding is developed is very different and
I'll talk about that in a minute.

They think about the lifespan or the
life cycle of an employee. How do we prepare
the employee or how do we engage with
educational institutions to prepare them for
the workplace? What are the more effective
mechanisms around recruiting and onboarding
and how do we retain and onboard them?

And a critical piece and this is a
little similar to what everyone has talked
about so far is really thinking about the
employee as having a support circle within

the company. They provide them with a variety of support personnel. And some of these – everybody has a manager, mainstream as well. Most organizations have mentors in place. Most organizations have teams that they collaborate or are embedded in. But there's also a job coach that can help bridge the gap between a person's personal life circle and the supports they get there and their needs with internal. Thinking about this effort is really important, but also thinking about the privacy concerns when you have an employee and their parents or their external and personal support circle wants to engage with the manager and how you balance that. Those are some of the challenges that the organizations face because you have to respect the privacy and the independence of the employee depending on their needs.

Understanding that life cycle both personal and professional is really challenging. I only have a minute so I'm going to go fast through that.

And, again, the ecosystem that Erik talked about is something that is really important, understanding how you can develop partnerships internal to your organization with the community, your local community and also the external community and how you balance those values and those pressures.

A lot of questions remain. We have more questions than we have answers. We haven't studied these programs yet because they're all new and it's really difficult to study and I'll talk about that in a second. I'm not going to go through all of these questions, but they are there for you to review if you're interested in the slides.

Lastly, how do you establish and systematically measure the impact of these programs on the employees especially an integrated employment model where you're not going to necessarily measure anything differently than mainstream because of all kinds of HR regulations as well. Those are things that companies struggle with. How do we measure and how do we communicate these metrics and what specific metrics? How are they consistent and how do we balance the social impact and the improved performance? Those are some of the tensions around value and cultures of the type of organization. And when you're talking about performance in some instances around job rules, you're seeing that individuals who come through the autism hiring program are exceeding performance expectations in terms of the averages of what they produce and what does that mean for

their neurotypical colleagues who are not meeting the same kinds of metrics in productivity. And what does that mean for the team dynamics and how do you manage that? And how do you talk about those different expectations because there are skill sets that might be more suitable for these jobs? Those are some of the questions that we're having in industry. A lot of open ones.

One really important question when we talk about performance metrics in organizations is how do you engage self-advocates and employees to really explain and talk about here's what success means for us and how do you embed that in organizations.

One of the really important parts for all of us researchers is how do we engage companies and partner with them in the current – 20 more seconds and I'll be complete. When we are trying to engage and

really study the practices and the impact of

these programs on individuals who are already

employed, there are some legal liability

issues around gaining access to data or

gaining access to members that are

participating. That makes it difficult for

academics. Risk of confidentiality of members

of the organization. Practical implications

for industry partners is really high.

But a really important one is how to

include the voice of self-advocates in this

research. I study women with autism that work

in the technology industry in particular and

have identified a number of individuals, but

they get asked to participate in these

studies over and over again. There is a

fatigue of studies around people who are

engaging in these programs. Those are some

things that we're trying to figure out some

of these challenges around studying
employment from the employer's side.

For me, I will conclude with saying
great potential for these programs. And when
I talk to the employers and I collaborate
with them, there is real excitement and a
real intentionality to create effective
programs.

The challenge is from a resource
perspective, these kinds of studies are
really hard to fund, for example, because
they're qualitative. They focus on a few
companies. There are only a few people in
these companies. The largest has 150. How do
we understand what's happening, what are the
effects of that and how do we share best
practices across the board is the challenge,
but there's a lot of energy around it. Thank
you.

(Applause)

DR. TAYLOR: I'm not sure how much time we have left, but do we have time for discussion or are we going to wrap up?

DR. GORDON: We have a while for discussion if necessary. We are due to take a break around – 3:55 is when we're due – so we have plenty of time for discussion.

Larry and then John.

DR. WEXLER: Thank you for the presentation. Just a general question. It may apply more to Paul. Were any of these participants on SSI before they started? If they were, what happened?

DR. WEHMAN: Some of them were on SSI. The real question that I thought you were going to ask is how many hours did they work and they ran right into the Social Security cliff. Many of them could've been working 25 to 30 to 32 hours. They almost all stopped at 23 hours. In five and seven years out unless

they've been moved all the way up to 35 to 37
or 40 hours, they stopped at 23 hours. You
pick up your 745 from Social Security from
Social Security and you pick up your 900
because now most of them are making between
$10 and $13 an hour and you're making between
1500 and 1700 dollars a month. Of course,
then they've got their benefits.

I've had communications with people
directly in Congress and their aides. My
theory has been let them earn as much as they
want and keep their SSI. 98 percent are on
SSI anyhow. Let them work and build a work
ethic. And then at some point later in life
if they really have a career to develop then
you can start easing off SSI. But SSI is
always going to be notwithstanding the
benefit counseling, tax incentives that are
out there. There are incentives to work
longer, but that is – I've given up fighting

that. I focus more really on the inclusionary aspects of it.

DR. WEXLER: I ask because we are pretty much completed the Promise Grants, which have 13,000 families in it and that was the whole point of them from Congress. We don't really have the results, but my guess is they won't be very much different than yours.

DR. WEHMAN: It was interesting because I've had the opportunity recently to be comparing, for example, the Wisconsin Promise Grant versus the New York one, dramatically different. The Wisconsin outcomes were incredible. The New York ones were less incredible. And SSI aspect played a major role in both of those just kind of a sidebar, but I'm with you.

DR. GORDON: John.

MR. ROBISON: I guess I have a little bit of a contrarian point of view being an

advisor to some of the Autism at Work efforts myself. One of the things that you didn't mention and nobody really wants to talk about at Autism at Work is that the whole program in all these companies is founded upon the assumption that these autistic people will be helped into the workplace by government-funded vocational counseling. They talk about all these things the employer does to make the employee successful and it's easy to get the impression that that's the good will of the employer, but it's not. It's the government agency stepping in and providing that to make it possible. I can't fault the employers for taking what they are able to get from the government.

But what I hear from people who don't become Autism at Work interns is that they don't want the stigma because to qualify for Autism at Work, you have to qualify for voc

rehab or disability services support from your state. And when I look at young people who are coming out of college programs like ours, they say to me – they say, John, I was in special ed for all those years in school and I am so proud I made it into a mainstream college and there is no way in the world I'm going to go back to the state and say now I'm disabled. Help me do this.

What that leads me to wonder then is I suspect a very large fraction of the autistic population who is able to go to college feels exactly as I just said.

And my question for Larry is is there a possibility that education and labor could work together so that we could qualify young adults who had special ed diagnoses in high school to receive some level of benefit or treatment when they go into employment without them having to go seek full

disability support and maybe that's a time-
limited thing. Disability support isn't
normally time limited, but I think there are
a lot of people who fall through the cracks
because they're just too proud and they are
unwilling to go ask for those supports. But
at the same time, they don't quite have the
skills to make it fully and it falls apart
for them.

DR. WEXLER: Well John, first of all,
when students move into college, the services
of college are based on self-identification.
Once a kid graduates high school, they're out
of our realm 100 percent. It's VR or it's
labor or it's SSI. There's actually not much
we can do. We work closely with VR on a
number of – because they're actually in our
office – on a number of initiatives. But
that's a tough nut to crack in terms of
getting SSI to sort of drop the requirement

to be identified as a person with a

disability in order to get services. I don't

know. You're kind of putting me on the spot.

Paul's laughing up there. He might have

the answers.

DR. WEHMAN: I'm not laughing at all.

What I'm really thinking about the incredible

spectrum of different people. I've been in

ceremonies in Princeton – one at MIT and

these are people who I have met who are

professors that would never need anybody from

any government to help them. They're

brilliant.

But then I'm also thinking about a very

large technology bank company that is all

over the place and came to us and they wanted

us to send them interns that they could

onboard and then hire. Six months later, the

phone rings. People are doing great at work,

but they have A, B, and C challenges. Can you come on over and help? I do workshops.

I was at a workshop not long ago at Children's Hospital in Philadelphia. The mother comes up with two sons. One has a major in physics and one in chemistry. They tried to get work. Worked for a while. Got the brain power to do it. Can't get adjusted – I'm not completely sure that you can divorce the government subsidized activity, but when Hala was talking about this and I want you to jump in on this. I believe – she had a lot packed in there.

The real solution to scaling this thing up and this would get to your point is if these companies are serious about hiring people across the spectrum then they need to hire staff within their own HR departments that are trained like some of those ladies that I showed up on my screen there. Because

every now and then the majority of people on

the autism spectrum are not like the people

that you saw on the screen. They're not. They

have more capacity across the board. But

periodically, there are going to be

challenges just like there are with other

employees. HR gets called in with other

employees for drinking or depression or

whatever. Why shouldn't they be also called

in for some of the same issues? I screwed up

your name, but would you answer that too?

    DR. ANNABI: No, you said it perfectly. A

couple of things I will say are the hiring

programs are the bridge to connect candidates

and to really break down the interview

barriers. I think that is one dimension. I

understand that including my students.

    I run a preparation program at the

University of Washington for technology

students so that those who don't want to go

through the hiring program can ask for special accommodations around interviewing and going through a mainstream process with just a few modifications. Not everyone has to or can or should go through a specific program, but what these organizations are trying to do and particularly some that are more advanced is trying to understand how they can change some of the mainstream processes to be more inclusive and so an individual who might not want to go through the specific program and have less needs can succeed.

Some of the practices we're talking about are helpful and spillover to individuals who already exist in these organizations that are on the spectrum that do not disclose. We actually hear this quite a bit from current employees that might actually disclose to their managers at that

point, but talk about how some of the changes

in managerial behaviors and also raising the

awareness and changing the attitudes around

who can work and who can contribute and in

what ways and having agency and having

members of the community, the autism

community feedback to how you can change

these programs is really important. It's

changing the fabric of organizations. Yes,

there is a dependence initially in the early

phases to create what I call bridges through

the employment process, the onboarding

process that is helpful and necessary might

change over time.

But I think these programs are not just

about creating – or utilizing federal support

for employment. It's really about helping the

organization change and building capacity

within the organization. Over time, maybe

that capacity is preparing specific

individuals to provide that training, but I think it's a lot more than that.

DR. WEHMAN: John, you are exactly right. It's just that you're too early. We are at the first phase of actually showing that people with autism not only can work such as I showed in our videos, but can really make huge contributions and become part of the fabric of the organization so it isn't just a diversity program. That's the first phase.

The next phase is for some of these corporations like – we have Randy Lewis coming in from Walgreens and he's going to help us the Dominion meeting. And they've done some tremendous things at Walgreens. But I don't think that they have still reached the point where all of their regional retail HR offices have got people who are specialists in dealing with challenging forms of different types of disabilities that maybe

neurotypical, not just autism spectrum

disorders, but others. If you want to move

away from having – if you don't move away

from having the government being involved

every time in it, you'll never get to the

second and the third phase because there's

not enough government programs that are all

going to get together. It's the corporations

that really have to take over and run on this

thing. We're a little bit too early in that

yet. It's still not happening yet.

DR. ANNABI: I will add one other

example. One of the things we're seeing with

one company that is a little bit more

advanced – our individuals who are hired

through the program are now carrying out some

of the training. A person on the spectrum is

carrying out the awareness training and the

managerial training because they've been

through the program.

DR. WEHMAN: They are mentors.

DR. ANNABI: Not just mentors. They're actually doing the training for managers of how to manage a neurodiverse team. That's very powerful.

DR. GORDON: I want to make sure – there's a bunch of people who want to make comments and question. I want to make sure we move on to hear them. Alison, you're next.

MS. SINGER: I have a question first of all about how we conduct this research and then I wanted to introduce another data point. It seems to me that when we're looking at employment research, we are looking at individuals with autism who receive a certain training intervention versus individuals with autism who don't receive that intervention. But why are we not comparing individuals with autism to typically developing individuals?

For example, Erik, you quote a statistic where you said only 38 percent of adults with autism who are four years out of high school report that they like their job very much. I would be interested to know how many typically developing 22yearolds report that they like their job very much. Why is that not the control group?

DR. CARTER: There are some datasets and studies that do reference both of those. The particular dataset that I was referencing didn't have the comparable data included in that. I think one is looking at the datasets where this is being collected and making sure there are representative samples of others who don't have disabilities in those as well. We've been looking at and partly we're doing this in our state-level data. We have two reference points. What are the employment rates for people with disabilities and where

we can subdivide those and then what are the

rates for people without disabilities, not

just globally, but at the level of different

counties because those also vary? So picking

your reference point locally becomes really

important. I think that's an important place.

Some of the research that we have in

queue is trying to collect both of that

information and then say one comparison is

other individuals and their satisfaction, but

ultimately we're still concerned about an

individual who has a job and they're not

satisfied with it. They also are their own

point of reference if that makes sense.

DR. WEHMAN: In our two studies, we were

taking youth in their last year of high

school. It was not a case of looking at

comparable non-labeled individuals with

autism who had been out of school for a

number of years. These were all individuals

who were in their last year and they opted
out of their last year of high school to be
in this nine-month internship program. But
your point is extremely well taken.

MS. SINGER: One concern that I have
honestly about this whole area is that we are
setting homogeneous expectations and
homogeneous goals for a heterogeneous
population. For example, in data that are
going to be reported at the upcoming INSAR –
actually, Susan talked earlier about the
upcoming INSAR policy brief on suicidality.
But the first policy brief was on employment
and data were collected in the US by Matt
Lerner at Stony Brook and Alycia Halladay
from the Autism Science Foundation in
collaboration with the Karolinska Institutet
in Stockholm and Curtin University in
Australia.

And there were some really interesting –
as part of this, they conducted in-person
groups and they did a survey of adults with
autism and a survey of employers. And one of
the things that they found surveying the
adults was that over one-third of the
individuals with autism reported that having
a full-time job would negatively impact their
quality of life.

This idea that everyone with autism has
to strive for full-time employment or that –
I think a comparable analogy would be in
housing. We somehow accept the idea that our
non-disabled children may graduate from
college and have to move home for a few years
as they're getting their career off the
ground. But somehow when our young adults
with autism have to live at home, that's
considered failure.

I want to make sure that we are not
setting goals that are not necessarily
appropriate given the heterogeneity of our
population.

DR. CARTER: I think just to comment on
that, that logic is embedded in the whole
transition focus that we do. At one level,
it's nice to know where outcomes for people
with disabilities are relative to people in
their community who don't have labels. But
ultimately, the best barometer for the
success of transition services, the
transition to adulthood is what were that
individual's personal goals in the area of
working, learning, living, and did they
attain those personal goal. That actually is
the way you would evaluate whether someone
has a successful transition. Did they attain
the goals that were important for them that
were set?

But the metrics that we use to evaluate whether special education is effective or our indicators don't account for what the desired outcome is. They just present globally what are employment rates or college rates.

What I hear you calling for is a consideration of does the person's aspirations actually become realized and are we collecting data on that as well.

MS. SINGER: According to this data that's going to be presented next month, a third of the individuals don't share the goal that full-time employment is necessarily going to improve their quality of life. Other things that they reported were that they are not necessarily interested in promotions or moving from part-time work to full-time work. That they are happy with part-time work. The increase number of hours that we use as a metric does not necessarily apply to what

individuals with autism is reporting is how
they measure their quality of life.

I'm just concerned about how we are
measuring our success here and whether or not
we are just applying goals that are not
necessarily the goals of the individuals
themselves.

DR. WEHMAN: I hear you in that. I think
we live in a democracy. We live in an
opportunity for people to have free will to
work if they choose. Our job, my job is to
make that an opportunity because in the world
I live in people with autism - nobody thinks
they can work. The people that I work with
the level of autism. When moms and dads hear
that that is an opportunity to work even if
it is part time because of the Social
Security cliff, they're fighting to get into
it.

Now, once you get to be 30 or 40 or 50
and you're like no, I don't want to work
anymore. Free will. Figure out how you're
going to change your lifestyle if you don't
have money coming in. Figure out how you're
going to change your lifestyle if you don't
have other hobbies. If I don't work, I'm in
real trouble. I have no other friends. I have
to work. But if I play poker and golf and all
the things that I'm sure Erik does all the
time then I'm sure that I would be wanting to
work 20 percent of the time.

I don't disagree with you. It's just
that this is a panel about how to get people
to work. Opportunities. What are the
opportunities?

DR. GORDON: I think we should probably
avoid arguing about whether free will exists
or not, but it is a panel. It's a panel about
maximizing opportunity to work. I think these

other ethical questions about if we can get
people to work whether we should require them
economically, if you will, to get them to
work. That's a different story. I think we
want to stay away from that.

Sam, I believe you had your hand up
next. Are you interested in making a comment
or a question?

MS. CRANE: I had a couple of small
points. One, I just want to get back to the
really surprising findings about gender and
independence. I don't think I caught – this
is a question. I don't think I caught how you
operationalize the – how do you measure
independence. I think that that might be
interesting.

DR. TAYLOR: I'm happy to talk more about
that. That was a really long process. We had
a lot of narrative information about what
people were doing for 400 people over ten

years. To take that and put that into
something that you could actually make apples
to apples and oranges to oranges comparison
actually was a significant amount of work.
What happens a lot of the time is it gets
collapsed down to employed or not employed,
but that combines somebody who is working 30
hours a week independently with somebody who
is in a more segregated setting. That was
complicated too.

We basically developed this nine-point
rating scale with how independent the
position was, but the most independent being
working in the community without any supports
or being in a post-secondary educational
program. If they were doing those things, but
for really minimal hours, it was kind of down
one point. Supported employment was below
that. In that sample, a lot of different
variations of sheltered work. Some people

were in sheltered positions and also working out in the community. That got a higher score than somebody who was only in sheltered positions and then at the very bottom where people who had no activities at all. We went through this incredibly excruciating process to take all these activities and put them on a scale. It was basically the amount of independence inherent in that.

But the gender findings were a surprise to us and after we published that work, we were able to get a small grant, an RO3, to dig into some large datasets that had enough women to actually pull them out and see if we could get some ideas about what might be going on that then we could down the road look at in a more hypothesis-driven way. We found a couple of things that I think are interesting.

Using data from the Interactive Autism Network dataset, we found that men and women were working at the same rates. But when people were not working, the women were three times more likely than the men to say that it was because they were choosing not to work and that was the case even if you took out families who have women and men who had children living at home. In the general population, that would account for that difference typically, but it didn't seem to among the women with autism.

And then we're also finding when we look at autism symptom scores if we look at raw scores of symptoms among – this is another dataset – among adolescents, the raw symptom scores are the same, but the sex and age norm scores are really different. Women on raw scores look really similar to the men, but when you compare them to – norm them to their

typically developing peers, they look much more impaired than the men do relative to their typically developing peers.

Then you can think about what might the impacts of that be over the life course if the same autism symptoms make a person look really different from their peers. We have some hypotheses about these where we were looking at actually electronic health records too and we're showing that there might be some higher rates of disease and burden of disease among women with autism relative to –

We are really – I think right now, we are mining a lot of datasets to try to put a picture together and develop some hypotheses for what the unique needs might be.

MS. CRANE: I was actually going to say that it might be health issues and that connects to what Alison was talking about.

Just anecdotally, I know a lot of autistic women who develop pretty significant health challenges as they age and they might decide I'm too tired to work. It's not that I can't – it's not that I'm not skilled. It's not that I'm not able to access the workplace, but I'm just tired. And maybe I don't work full time or I don't want to work at all.

The point you made about comparison to peers, it's possible people are getting discouraged as they see their peers moving up the ladder in various ways in the work place and they don't. I think those are – I'm really glad you're looking into that more and I really would look forward to hearing what you find.

DR. GORDON: I'm curious if the panelists – actually, before I say anything, let me ask

– anybody on the phone who has questions or comments. Okay.

I'm curious if the panelists each might comment on issues of sustainability and of cost effectiveness, if you will. Clearly, when we heard from SAP, that makes sense for a company. They're getting high value out of these technologically savvy, but socially impaired individuals who come to work for them. And if they can find a way to get them into the right place then that's a very high value proposition. That's a very different question from supported employment in a library or something like that. Of course, there's a spectrum in between those.

But I'm wondering if you have some thoughts about sustainability in each of the different models that you might comment on.

DR. ANNABI: Maybe I'll start on the types of companies that I'm working with. I

think that is the critical question that even the technology firms are grappling with because sustainability and scalability as you increase the number of employees and across such a diversity of countries and offices that building capacity within the organization to work effectively and to design the work effectively is still pretty high. That's still an empirical question, an open question of how you do that.

Some of the models I'm seeing evolve from the more mature programs is how do self-advocates become more involved in training. How do some of the HR personnel that already exist is cross trained across a diversity of scale sets and populations and serving underserved employees.

One of the other elements in the questions that I have even preparing the organization to support challenges with

mental health and physical health. And one question came about regarding what other services can we provide. In my interviews with – I study females on the spectrum in the technology industry and a number of them said I choose some of my companies around the companies that have a lot of services like food and all of these other things that are already provided like the Google example.

Companies are really looking at for scalability and sustainability of the program. Two things. One, you have to create the business case like Jose mentioned. But the other thing is building internal capacity of individuals that are cross trained to serve a broader population and to embed it potentially with the broader diversity inclusion efforts as well. I think that is essential for sustainability.

I would add, and this is another empirical question, identifying those universal principles across the organization that serves a large population.

DR. WEHMAN: I think the short answer again because there really is such a wide range of issues and challenges that people with autism spectrum disorder face across the whole spectrum to say that there's one size kind of fits all is difficult.

But the closest thing that I can see that would follow up on what Hala said was that I really think that probably a peer-to-peer, meaning business-to-business communication, about which models are working the best for them is the long-term way to move into what I guess I would call the second phase.

This phase that we're in now – let's say it's in the first two or three innings of hey

look what we did. We're able to do this. This is great. We couldn't do it 20 years ago. Now, we can do it. We need to give moms and dads hope. We can give families hope. And those people who want to work we can give them hope and we can give them some ideas of champions. But how do you get to the fourth to the seventh or the fifth to the eighth inning? I think it's like having Randy Lewis from Walgreens come in and talk with the people at Bon Secours like he did in 2010 and he's going to come in tomorrow for the second time to talk to Dominion Power. That will be the first utility company that would really be buying into this in a big way for their roll out, which is starting tomorrow.

Now if Dominion can do it then maybe some other utility companies will do it. It still doesn't get at the solution to John's question now. And I cannot get away from the

fact that if you do not get companies to staff their HR departments in such a way that they know how to deal with people who are different and everybody is different. That's the thing. I'd like to say people – autism have the corner on it. They don't. If you talk to any employers at the senior manager, certainly at the first line of supervisor level, they'll all tell you – they'll give you every story in the world. They will say the last thing we're concerned about is the fact that this person makes some strange noises or does something once in a while. The workplace environment will often define how a person is going to be accepted or not.

Really ultimately to get to the second phase of your question, the companies are going to have to communicate with each other and then use the resources in the community that are funded selectively. When you put up

your slide at the end and you had those

graphics on one side and all the graphics in

the middle and you had external job coach,

really the external job coach should be –

they should become employment consultants.

They should be called in periodically. They

shouldn't be running everything. This comes

from somebody that – I've been pushing this

for 25 or 30 years and I'm convinced it will

never work this way. You have to get the

companies bought in. I am seeing some

companies buying in, but nowhere near to the

level that we hope.

DR. ANNABI: Can I respond to that?

DR. GORDON: I'd really like to hear from

Erik first because he runs a statewide system

that's really trying to do this.

DR. CARTER: We're turning this question

back to local communities, communities that

don't have large corporations that can't turn

to a service system or grant funding or anything that requires eligibility requirements to figure out how you do this at a local community with the assets you already have. How do you engage your chambers of commerce and your affinity groups and your Lions and Rotary Clubs and your faith communities and others to figure out how you make it happen when there is no external funding or no autism at work project or corporation.

When you bring the right people in, people outside of these circles who are not going to think in terms of solutions, of service systems or eligibility or what diagnosis you have to have to get help, but a community that knows people. It's surprising how they are able to figure things out.

I think both of these have to happen concurrently, but for us, we're trying to

figure out how to get employment outcomes to
go up when there is no service system that's
going to support it really well. I think
that's where we also need innovations as
well. That's the community conversation
approach we're using.

DR. GORDON: Hala, go ahead.

DR. ANNABI: Just to clarify. The
external coach is temporary. It's only for
the first phase for onboarding unless there
is a need later on. And that's especially
federally supported is only depending on the
needs is only temporary. And the
organizations are taking a lot of the
responsibility internally and building the
internal capacity.

The employer roundtable that I mentioned
does – and the intention of that is just
that, to exchange best practices and to help
newer companies that are interested. For

example, you see IBM on there. IBM is a new

program. It has only been around for a year.

And the way that was designed and established

is by support from existing firms like SAP

and Microsoft and others as well as some

providers and I don't know who they use

specifically to do that design and build the

internal capacity.

I think that model – I agree with you

wholeheartedly, Paul, that it has to be the

change and the capacity built within the

organization and we're starting to see that.

But I think there are a lot of unanswered

questions that also the academic community

has to engage in to see what are the best

practices that are working and what are some

that are not working.

DR. WEHMAN: Here is the challenge. A lot

of these companies will onboard and they want

to recruit and they want to bring people in.

And then they hire them and then they can't get past what I call the red zone. The red zone is the first 90 days to 100 days. The yellow zone is past 6 to 8 months. At 12 months, you're flying. They've got that problem of not having to report.

DR. GORDON: So that gets to my question about sustainability and cost effectiveness. If you have someone who is going to go on again work in tech or work in some other high value industry, pull down a salary of 100K a year, it makes total and absolute sense for a company to invest tens of thousands of dollars and even $100,000 in onboarding someone like that given how valuable that employee can be over time.

But if you're talking about folks who are working for minimum wage in a hospital system or something like that, that's a whole different economic proposition. And there you

need to make the case either to the people

that are paying for it, the hospital or the

corporation, or to the government that is

putting out the dollars because yes, we want

to make sure that individuals with autism

reach their maximum capacity to contribute to

society from the perspective of enabling them

to live fulfilling and meaningful lives for

themselves. Absolutely we want to do that.

But if you want to make the case to

society, to corporations, to governments that

supported employment or supported transitions

into employment or getting them past the red

zone or into the eighth inning or whatever

sports metaphor you want to use is something

that we want to invest in that cost

effectiveness has to be there. It doesn't

have to be big, but it has to be there.

DR. WEHMAN: Well, consider the

alternative. If you don't go to work, you're

going to go ultimately into an $18,000 a year day program.

DR. GORDON: The math – my point in saying that is the math is usually in your favor even for minimum wage if you can manage your transition so they don't – as you said, the coaches – but we need to establish the evidence base for it just like we do for cost-effective treatments when we want to offer them and have the health insurance or CMS pay for them. Lewis.

DR. REICHARDT: I just had a brief question to whether you've given any thought to resiliency at a time. This is a time when the economy is good. Unemployment is generally good. I guess this will not last forever, we know.

The second question is when you're dealing with a whole state, do you find that acceptability and buy-in depends on what the

unemployment level – Tennessee, I think, has
probably wildly different unemployment levels
in different parts of the state.

DR. WEHMAN: I will let you answer the
state. We do know that whenever we've had the
economic downturns, 1990, 2000, 2008, we can
almost always see a drop of the general
population with disabilities are going –
they're going to earn less. They will be
among the first to lose jobs frequently at
least that's the current way we are right
now. That's what I've seen nationally.

DR. CARTER: We tracked our state data
over the last ten years and the pattern of
employment for people with and without
disabilities. The gap between the two is
exactly the same as it rises and falls. We're
seeing that exactly. While our employment
rates are up now for people with disability
so they are for everyone else. We are

beginning to look at county by county where
that gap has elevated whether that we're
seeing slower movement around disability than
those --

DR. WEHMAN: The real question is can we
disrupt that. Can we disrupt that? In other
words, I can tell you right now that the
people that I showed you, a number of them
have been employed now for several years.
They're not going to be the first ones out.
They have better productivity rates. You have
a whole pharmacy where if you identify – if
you don't identify which are the expired
drugs, somebody will die because they get
Vancomycin and it's expired. They pay
attention to the value of some of the people
that I was showing up there and they make
their decisions on that basis. That's in the
minority. That's minority. We're in the early

innings on this. We're very much in the early innings on this.

DR. GORDON: Alright, we are going to have to take a break. Thank you so much to the panelists for their really scintillating discussions on this incredibly important issue. And thank you as usual members of the committee for your questions and comments.

I think, as we move forward, it will be important for us to think about recommendations that IACC wants to make in this topic area as we think about next year's updates. Thank you very much.

We are going to take a 15-minute break and come back at 4:15. We'll be running just five minutes behind schedule. We should be able to make that up before 5 o'clock. Please be back here at 4:15 sharp.

(Whereupon, the Committee took a brief break at 4:00 p.m., and reconvened at 4:15 p.m.)

DR. GORDON: I want to thank the panel and the committee for an outstanding discussion on employment.

Next up we have an update from our National Autism Coordinator Dr. Ann Wagner.

DR. WAGNER: Thank you everybody. I'm going to make this brief. Just as a context and a reminder, I'm not going to go through all of this, but we have a Federal Interagency Workgroup on ASD, which we call FIWA, with lots of representation from the Department of Health and Human Services, other federal departments and agencies. I'm not going to go through this, but I just wanted you to have this in your materials in case you're curious about who is participating.

And then I wanted to take a few minutes to update you on a couple of things that we have been doing. One of them is a meeting on outcome measures for transitioning youth and adults with ASD and Susan alluded to that a little bit earlier. A lot of the things that we heard in this meeting were reflecting things that we were hearing today in this meeting.

You're familiar with the 2017 Report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorders. This report identified a gap, which is a need for survey or other kinds of research results on the outcomes of transitioning youth and adults with ASD. But also noted that in order to have good data coming from that kind of research and those kinds of surveys, we really need outcome measures in order to evaluate any potential changes in programs

and support services that we have. And the
need is in addressing what the report refers
to broadly as quality of life. But the point
was that it's not – we don't need more – they
were not talking specifically about measures
of symptoms, for instance, or counts of who
has a job and who doesn't have a job, but how
satisfied people are with the way their life
is turning out and how integrated they are in
their community.

In our discussion in the FIWA meeting
about these gaps and this need, we identified
some researchers working in this area who are
supported by grants in our programs. We
identified some people supported by the
Department of Defense, the Administration on
Community Living and NIH. This was by no
means meant to represent everybody working in
this area, but because we knew these folks,
we invited them to a special meeting of the

FIWA subcommittee on March 19. We had a special meeting in which we heard about their current efforts and their ideas about what needs to happen next.

These are the presenters. These were the people who came to talk with us. Two of them, Christina Nicolaidis and Nancy Cheak-Zamora, come from the health services research areas. Gale Whiteneck and Mark Salzer come from the rehabilitation community integration research areas. These are sort of two fields that don't necessarily interact and talk with each other so they had very different perspectives, very different approaches, but a lot of common ground. It was a very interesting meeting and discussion. The results would not be a surprise to anybody. We need more work in this area.

It talks about special challenges to measuring outcomes and satisfaction with

outcomes in the population related to

heterogeneity, communication problems, things

that we've been talking about today as well

as the need to have input from people on the

spectrum in terms of developing and adapting

measures.

We're following up with this group

because we want them to disseminate their

recommendations and their ideas more widely.

There's a plan to put together a document

probably in the form of a white paper, a

publication so that we can get the word out

to the field that we're interested. And

following up on this meeting will be on the

agenda of our next FIWA meeting so that we

can talk internally about ways that we might

facilitate research in this area.

And then the other thing that I just

wanted to note that there is a lot of

interest in the government now in supporting

transition of adolescents to adulthood
smoothly very broadly across the population.
This has afforded us some opportunity to
collaborate with some other groups and
partners, which I think is really important
and they're going to help us avoid
duplication leverage, existing or ongoing
efforts and also get the unique needs of the
ASD community considered among these larger
efforts.

Three of them that I wanted to mention.
There is the Federal Partners in Transition
group that has been in existence since 2005.
This group is led by the Department of Labor,
Social Security and the Department of
Education. There is a lot of overlap between
the FIWA, between the IACC and between some
of these groups in terms of the departments
and agencies represented. And sometimes they
are the same people, but not always.

But this group, the Federal Partners in Transition, is guided by their 2020 Federal Youth Transition Plan and their goal is to improve transition outcomes for youth with disabilities.

One of the things that they were talking about in a recent meeting was efforts to facilitate and support the development of internship programs, for instance. That also was relevant to things that we've been talking about today.

Then within NIH since last year, there's a Trans-NIH Pediatric Research Consortium that is led by NICHD. I believe Diana Bianchi is co-chair or chair. And they're looking at pediatric research broadly so it's a very broad mission. But they have a subgroup recently, focusing on adolescent transition to adulthood. We learned of this because of one of our FIWA members gave a presentation

to that group and let them know about our outcomes measures meeting. They asked if they could send people to the meeting. There's a lot of opportunity for partnering there as well.

And then finally, within HHS, there's a recent effort to coordinate the efforts on youth in transition within HHS. Elizabeth Shay at the Administration for Community Living has initiated a meeting to coordinate cross HHS activities and that they will be focusing on health care transition for youth and particularly those with disabilities and special health care needs. That's a third.

I think these are really good opportunities again to coordinate, leverage things that are ongoing now and make sure that the unique needs of ASD community are on the table in these larger efforts. Thank you.

DR. GORDON: Okay. Are there questions for Ann or comments? Any on the phone?

We'll move into the next segment. The next segment is back to committee business, in particular, the 2019 Summary of Advances Nominations. If you recall at each meeting, we go over the nominations that were sent in by you over the preceding – since the last meeting. These are from January through April. These are preliminary presentations brief of any particular nominated papers that you would like to highlight and then as you know, next January, assuming we exist by then, we will compile those results and select a number of them, 20, to submit to Congress.

With no further ado, we'll move right into the consideration. There are no questions submitted in Question 1. Sorry. No papers submitted for Question 1.

For Question 2, which was the underlying biology, there were two of them. One of them was by me regarding the role of Shank3, which is a known high-risk, high-impact gene that predisposes to autism and its role in sleep and circadian rhythm. I think this is important because the biological mechanisms of sleep are definitively translational. They are operated across multiple species. And of course sleep architecture effects can have multiple effects on neural function and neural development. That's why I nominated that one.

Walter and Alison both nominated the next one, the Schafer article. I don't know if you care to make any comments about it. Dr. Koroshetz, you are deferred to.

DR. KOROSHETZ: I thought this was pretty interesting in the sense that they took iPS cells from the folks who --

DR. GORDON: iPS cells are stem cells derived from adult tissues.

DR. KOROSHETZ: Right so like skin or blood. They took it from people who had this increased growth pattern that you see in the brain over the first couple of years in some folks with autism.

What they demonstrated is that in their organoid cultures they saw basically over exuberance of growth of processes and cells. It was replicated in the organoid, which is basically you take the iPS cells, you put them in a dish and you let them grow and organize themselves.

But then they - but the really, more interesting part was they did the analysis of the transcriptome at different stages in their control iPS cells and in the iPS cells taken from folks with autism. They demonstrate that in the very early stages of

differentiation the cells from folks with

autism are basically getting into patterns

that should not be occurring at the early

point in time. This is occurring at a stage

before the cells even become neurons. It is

at the neural stem cell stage, which if – and

in those genes that they see in these early

stages that are abnormally expressed in the

folks with autism, they see a lot of genes

that came from the GWAS studies of autism.

Those genes are enriched for what we think

are autism genes.

    If the story holds water, what it's

pointing to is a defect at the very early

stage of development of brain and also

whether it will see that in other patients of

autism without the large brain, larger brain,

is yet to be seen.

    And the other thing they did was they

used another process where they moved the iPS

cells straight to neurons and skip this early

stage. And there, there's no difference

between autism cell and the controls.

Again, there's a lot of mathematics in

this one. You have to always look for

somebody else to replicate it. But if what

they say is true, it's pretty amazing.

DR. REICHARDT: I wouldn't say the

differences all disappear, but they were

clearly much – the differences were – the

cells were much more normal if they were

directly differentiated to neurons as opposed

to going through all the precursor stages,

which I thought was the most interesting

thing.

DR. GORDON: That suggests that there is

some development course that is programmed or

that unfolds through development that is

actually responsible for the changes that are

associated with autism as opposed to

something that takes place in neurons by themselves.

And Question 3. There were a number of submissions. One by David Amaral, one by myself, one by Linda Birnbaum and another by Geri Dawson. I'm the only one here. I'll comment on that and if anybody wants to comment on the other ones.

This is the study that I referred to earlier in the day when talking about the many definitive epidemiological studies. This is a nationwide cohort study showing that MMR vaccine does not increase the risk for autism. It's another of the many dozens of nails in the coffin. But whether or not it will make a difference in convincing the skeptics, the fact is it's another strong piece of evidence refuting the vaccine hypothesis.

Are there any comments about the other three? Again, they can still be considered of course next year.

Actually, Geri, are you on the phone? Do you want to talk about that?

DR. DAWSON: Sure. The slides that I see over the web are slightly behind everything so I'm hearing your speech before the slides. But you'll have to tell me exactly what's showing.

DR. GORDON: So it's the Septier paper that we're asking you to comment on. Increased risk of ADHD in families with ASD.

DR. DAWSON: Yes. Got it. This is just an interesting study because families who have a member with ADHD show an increased risk for autism in younger siblings and vice versa. It just points to the very interesting and shared genetic overlap between the two conditions. I think it's also important just

in terms of talking to families potentially about risks for one versus the other in the family. And also I think when you see both in the family, you can point to this kind of study to show that indeed there is some shared genetic risk. Genetic and environmental even, not just genetics, but they also talk about environmental factors that could be shared with both disorders.

DR. GORDON: Great. Thanks Geri. But don't go away. You also submitted Question 4, treatments and interventions.

DR. LAWLER: Hold on. I can talk about the other one.

DR. GORDON: I'm sorry. Pause Geri. We'll come back to you. Which one did you want to talk about?

DR. LAWLER: The prenatal vitamin use with autism risk. What's new here is looking at the association between prenatal vitamins

and autism risk in a susceptible subpopulation. The study population was the MARBLES study and this is where moms with an existing child with autism are enrolled when they are planning to become pregnant or in the early stages of pregnancy. They are followed during the pregnancy and the babies up to the age of 3. Not only is it a very efficient study design, but this really reduces the risk of recon bias because you're collecting data in real time from these moms well before the baby is born before there is any clinical evaluation of the baby.

In this setting, investigators found that prenatal vitamin use in the first month of pregnancy had a big impact on reducing the autism risk in that new baby.

They also found an association between prenatal vitamin use and the severity of autism symptoms and also cognitive scores.

There were some separate analyses looking at
the amount of folic acid in prenatal
vitamins. That's a big component. And those
analyses suggested that folic acid may be
driving this association and of course there
is biologic plausibility to this.

I really liked this study because many
of the studies that NIHS support are looking
at environmental chemicals that are harmful
and that increase risk. This is a great
example of a modifiable risk factor and
exposure that can be protective.

DR. GORDON: Do you know, did they look
at the B12 component that also has been
advanced as a theory for --

DR. LAWLER: They don't report those
analyses. They looked at iron as well. I
believed they looked at them, but they just
didn't include them. It's a fairly small

sample size so they may not have had enough variation in some of those other components.

DR. GORDON: I think and if so, I'd like to point it out that they used a dimensional readout essentially. They looked at autism severity scores as opposed to just the categorical did the individuals get a diagnosis of autism. Is that right?

DR. LAWLER: Right. They did both.

DR. GORDON: And I think that's important because it suggests that you might have effects across the spectrum, if you will, and not just at those who are near the borderline of whether you're going to get a diagnosis so it's probably a good thing for everyone.

DR. LAWLER: Yes.

DR GORDON: Thank you.

Now, we'll go back to you, Geri. You submitted for Question 4, the Rogers et al.,

a multisite randomized controlled two-phase trial of the Early Start Denver Model compared to treatment as usual. This is in the treatments and interventions category.

DR. DAWSON: Right. This is the first randomized multisite clinical trial of an intensive comprehensive early intervention. This is the Early Start Denver Model. It started out with a brief phase of parent training, followed by two years of intensive treatment with the Early Start Denver Model.

The primary outcome for this study was language ability as assessed by a standardized test. You have to actually show higher rates of language acquisition relative to what you would expect for normal development in order to get a significant increase on a standard score. This was on the Mullen Scales of receptive and expressive language.

And the secondary outcomes were IQ so the full-scale IQ score on the Mullen and also ADOS symptoms. It was found that there was a treatment by time interaction, in other words, for the primary endpoint, which was language. There was an advantage in terms of language development for children who had received the Early Start Denver Model as compared to intervention in the community. And the community children by the way did receive high levels of intervention in terms of hours of intervention. There wasn't a huge difference. It was just a model.

Looking at two other outcomes that were reported in the original study that was published in 2010 at a single site, there was a significant increase in IQ and a decrease in autism symptoms, but in both groups so both the community group and the Early Start Denver Model group. It showed significant

improvements in their IQ and reductions in ADOS scores. The average improvement in IQ was similar to the 2010 study.

The study was done where the raters who conducted all the tests were blind to whether the child had received an ESDM versus community treatment and the analyses were conducted independently at a data coordinating center.

DR. GORDON: Thank you, Geri. I have a couple of questions for you. First, is this a truly independent replication of the earlier study so these are different investigators?

DR. DAWSON: I was a PI on the original study and Sally - and Annette (indiscernible) who was involved in this study. I would not say it was independent investigators.

DR. GORDON: Okay. And then the second is what's the sample size in this one.

DR. DAWSON: It started out with an intent to treat with 118 children and then there were 81 children who fully completed the two years. But the analysis was done as an intent to treat analysis that included children who had been lost.

DR. GORDON: Gotcha.

DR. DAWSON: By the way, the primary loss in terms of attrition was the transition from the living from just the parent training into the intensive.

DR. GORDON: Finally, just so that everyone is on the same page and particularly our listeners out there in radio land, the Early Start Denver Model – what is the principal mode of treatment that it uses?

DR. DAWSON: Right. So the Early Start Denver Model is a comprehensive model. That means that it's not targeted just on one domain such as social communication, but it

really targets all the means of early

behavioral development. It integrates

principles of applied behavior analysis with

developmental and relationship-based

principles.

DR. GORDON: Thank you very much. The

next one is one that we at NIMH put forward,

treatment patterns in children with autism in

the United States. This is less a trial, but

more a description of what individuals are

getting. I think one of the important results

is that many – half of the caregivers of

individuals of children with ASD reported at

least one barrier to treatment such as

waiting list for treatment or lack of

coverage for treatment. It signifies the

importance of advocating for coverage for

individuals with autism still even though the

evidence base for those treatments has been

improving, witness the previous paper. Still
work to be done.

Question 6. There were three submissions
for lifespan issues. The first one again was
done by NIMH and it was a 20-year study of
suicide death in a statewide autism
population. I can't see what state it was in.
Do you remember? It was in Utah. And the risk
of suicide death in individuals with ASD was
increased over time just like it did in the
general population for 2013 and 2017.
Interestingly, counter to the phenomenon in
the general population, females with ASD were
three times as likely to die from suicide –
sorry. I take that back. Females with ASD
were three times as likely to die from
suicide as females without ASD, but I believe
also they were more likely to die than males
with ASD. You don't think so, Julie.

DR. TAYLOR: No, same.

DR. GORDON: Same. Whereas in the population, the rate of death by suicide in males is two to three times that in females depending upon the age range. In ASD, we're seeing much more death from suicide in females compared to males relatively and more suicide overall in this one state. That speaks to the importance of this as we've been talking about before. Under recognized problem.

David Mandell – did he step out? He had to leave unfortunately, but he presented a paper on vocational rehabilitation. And Jennifer Johnson submitted a paper on competitive employment for transition-aged youth.

DR. CAPLAN: I can, do you want me to do that?

DR. GORDON: Go ahead.

DR. CAPLAN: The Competitive Employment for Transition-Aged Youth is actually the study that Dr. Wehman just presented, the outline of. The study included young adults with ASD aged 18 to 21 who were enrolled in public special education. One group of students received regular special ed services and the other group spent their last year of high school, as he said, in a specialized internship program. It provided employment experiences, specialized instructions and supports for people with ASD as well as other activities to support employment in four Virginia hospitals. You've seen the major results on the screen. I think that should do it, but that's this one.

DR. GORDON: Thank you. And I just want to point although I don't want to – let me ask the question. Was this research or the initiative – is that something that grew out

of either recommendations of this committee
some years ago to start focusing on
transition-aged youth or is this something
you think was existent before that?

DR. CAPLAN: It actually started before
that. This is his second cycle of this line
of work.

DR. GORDON: Thank you. So those are the
nominations. Please – we'll of course be
keeping them in mind as we go to voting on
the ones that we want to put forward next
year at least those of us who are still on
the committee by then.

Finally, the next order of business is a
round robin. We have about 15 minutes left in
the meeting if people have things that they'd
like to share with the group from their
institutional organization. I'll just look
around the table and then we'll go to the
phone. Go ahead, Stuart.

DR. SHAPIRA: From the CDC, I have two
things to inform the group about and the
group may already know one or both of these.
The first has to do with morbidity and
mortality weekly report that was published
earlier this month. Folks may know that in
2010 that CDC began population-based
surveillance for ASD among 4-year-old
children living in communities across the
United States. And these communities are a
subset of those sites participating in the
regular ADDM Network, which is surveillance
on 8-year-old children. The subset is known
as Early ADDM and the MMWR was publishing
results from Early ADDM.

There are seven sites from the ADDM
Network who participated in Early ADDM
surveillance for at least one year during
2010 and 2012 and 2014 and among them, three
of the sites had data for all three of those

years and consistent data sources and
catchment areas. And the estimated prevalence
was higher in 2014 than in 2010 for one of
these sites for New Jersey, but it was stable
for the other two sites for Arizona and
Missouri.

Now the interesting information and I
think the very relevant information is
looking at age of diagnosis of autism in 4-
year-old children and the age of first
developmental evaluation because the goal is
to get developmental evaluations as early as
possible before 36 months and diagnosis by 4
years of age with ASD.

Unfortunately, the data show that there
has been no change over time in the age. It
still remained. The proportion who is
diagnosed after four years of age or who have
their first developmental evaluation after 36
months still remains the same.

The bottom line is that autism continues to affect many children and families and services and support are critical now and as children grow of course into adolescence and adulthood. And the surveillance summary reinforces that more needs to be done to ensure that the signs of potential developmental delay need to be recognized early and the children evaluated early through once developmental concerns are recognized.

The second item to mention is that in March CDC and the Association of University Centers on Disability with support from HRSA's Maternal and Child Health Bureau announced a new cohort of what are called Act Early Ambassadors. The Act Early Ambassadors work with CDC's Learn the Signs Act Early Program to improve early identification of developmental delays and disabilities,

including autism. There are now ambassadors

in 47 states in DC and in three territories.

What the ambassadors do is they serve as

a state or territorial representative of

CDC's National Learn the Signs Act Early

Program and they promote the adoption and

integration of Learn the Signs Act Early

resources and materials to support

developmental monitoring in systems that

serve young children and families such as the

WIC program and Early Childhood Services.

DR. GORDON: Thank you, Stuart.

DR. LAWLER: Really quickly, NIEHS has an

upcoming event next Wednesday at Eastern noon

as part of our Partnerships for Environmental

Public Health. We'll be hosting a webinar

that features two of our autism grantees,

talking about the state of the science and as

importantly, the challenges that scientists

face in communicating environmental risk factors for autism.

Craig Newschaffer, who is now at Penn State, and Anny Xiang, who is at Kaiser Permanente, will be our guest speakers. I've provided Susan with a link to the registration and more information about that. You can find it on the IACC website.

DR. GORDON: Thank you very much.

DR. RONYAK: Good afternoon, this is Marci Ronyak with Indian Health Service. I just wanted to thank IACC, Dr. Daniels, Dr. Wagner for helping support the Interagency Roundtable. Dr. Shapira. We had a variety of our federal agencies that are part of IACC with that. We will be making that another event next year on April 2 so please mark your calendars for April 2, 2020. It should be an afternoon webinar. I am excited to say that as we started last year with the

inaugural one. This year we actually had

approximately 80 folks attend. We've had a

lot of folks provide follow-up emails, ask

for resources. And I would really like to

extend a special thank you to Autism Speaks

for providing an excellent presentation and

discussion. Please look forward to that and

please share the invites as widely as

possible. Thank you.

DR. GORDON: Thank you. Alison, I believe

you had something.

MS. SINGER: So the Autism Science

Foundation held is Sixth Annual Day of

Learning two and a half weeks ago. All of the

videos from all of the presentations are now

available on our website for free, including

the presentation from IACC chair, Dr. Gordon,

as well as presentations on incorporating

wearable technologies into research,

understanding the autism recurrence risk rate

and the offspring of unaffected siblings, the role of the microbiome, reducing suicidality, communicating research to the public and reducing self-injury and aggression in people with autism. Those are all on our website.

Our next day of learning is going to be on October 17. It will be in San Francisco. The keynote will be delivered by former IACC chair, Dr. Tom Insel, and will also feature IACC member, who is not there anymore, David Mandell.

And also we just announced our spring round of pre and postdoctoral fellowships. Those are also – if you want to read about these really incredibly, exciting and talented up and coming young investigators, they can all be found on our website as well.

DR. GORDON: Thank you. On the phone, are there any updates from anyone on the phone?

DR. DAWSON: I just wanted to mention the INSAR meeting in Montreal, which will be May 1 through 4. If you want to understand some of the detail in terms of the presentations that will be made, you can go to the INSAR website and there is a beginning schedule up and you can look at the keynotes. I think it's going to be a very exciting meeting.

There is also an autism neuroimaging workshop that is going to be held in Montreal right before INSAR and in partnership with INSAR. Information about that is also on the INSAR website. I encourage everyone to come. It's just a wide range of topics from very basic research to treatment and dissemination work.

DR. GORDON: Thank you. Can you just for again the viewer at home – what is INSAR?

DR. DAWSON: I'm sorry. International Society for Autism Research. This will be in

Montreal, Canada this year. The date is May 1 through 4.

DR. GORDON: Thanks. I have a couple of updates. First, I wanted to make you all aware of a program. I've spoken here before as have others about the ABCD program, the Adolescent Brain Cognitive Developmental program, which is actually quite a large research effort that spans multiple NIH institutes to study the neurodevelopment in children ages 9 to 19. We're very excited. It's going like gang busters. The data are already available for public – for researchers from around the world to access and study and in fact, there have been already a number of publications with some interesting results.

But relavent to this group, the NIH is beginning to plan. I should say is well into the planning stages of a complimentary

initiative that would start at or around birth and extend up through age 10 doing the same thing, studying neurodevelopmental from a neuroscience perspective, from a behavioral perspective, and looking at the effects of adverse experience and also of substances particularly with an interest in looking at the effects prenatal opiate exposures.

I'm very pleased to say that the announcement was well received by the community. It received a very large number of applications for the first round of planning grants and so we're very hopeful that this will get off to a flying start within the next few months and that you'll begin to see the structure of it and we'll begin to hear what it's going to look like over the coming year or two as those planning grants get executed.

The next thing I want to say is as we've been talking about several times through the day, the IACC is authorized by Autism CARES Act. As you know – as you've heard, this Act expires September 30 of this year. We know, however, that Congress is hard at work on the next revision of it. There is language that is publicly available somewhere. You should be able to find the language and look at it and see what they're working on. There are some differences, but compared to what was existed before, but they are proposing to reinstate the IACC.

When the IACC gets reinstated though, we will have to re-enroll members. Pay attention to when that gets passed and to calls for nominations for members from the public. Of course, the Secretary of Health and Human Services is the one who determines the

membership. Isn't that correct? We will need to be reconstituting the committee.

As soon as that law is passed and we get authorization from the Secretary and we get the nominations and the members approved, we will be having another meeting. We will try to get it going as rapidly as possible hopefully without missing one, but it does take some time to get people on board.

With that, I'll turn it over to Susan for the conclusion.

DR. DANIELS: Okay. I have a few little announcements. With regard to the legislation at the July meeting, I will give you an update on the legislation at that time and that will be the last planned full committee meeting for this iteration of the IACC unless we have other business that we need to conduct and we could always call an extra meeting if we needed to or do something on

the phone. But the plan is to have our last
meeting on July 24 here in Rockville and it
will be here in this building, the same
location.

Some other upcoming items that I
mentioned to your earlier. There is a Mental
Health Workshop sponsored by the IACC. That's
May 21. Everyone is welcome to come to that
or to watch the webcast. And the Housing
Working Group will be holding an event
probably in June 2019. Stay tuned for that as
well.

I wanted to give just a very brief plug
for NIMH having a couple more Autism
Awareness Month events or items that are
coming up, but they are not fully announced
yet. The podcast that will be coming up and
then Dr. Gordon will be also sending out a
message.

DR. GORDON: Yes. There will be a Director's Message. It's in the final stages of being edited. Hopefully, it will be out by the end of this week or early next. It is on – actually, it's on the topic of where we've come in the last 20 years and where we might look forward to in the next 20 years in autism findings.

I have to give a shout out to all the staff in the autism research, but particularly Ann Wagner and Lisa Gilotty because they provided the outline and many of the ideas that are expressed.

DR. DANIELS: Great. Those items will be on the IACC website on our Autism Awareness page as well.

We also – I think those are all of my announcements.

DR. GORDON: What about the event next week?

DR. DANIELS: And just to remind you of course. Next Tuesday is our Annual Autism Awareness Month event, A Woman's Voice: Understanding the Autistic Experience. That will be here at NIH on the main campus in the Porter Building. You're welcome to watch it on the webcast or to attend in person. We'll be sending out more reminders about that one. I think that's my last announcement.

Thank you so much for a really productive and stimulating meeting and thank you to our special guests who have been here with us today. It has been very nice to have you here to help recognize Autism Awareness Month, all the contributions of everyone in the community and around the table who are working to make everyone's lives better in the autism community. Thank you.

DR. GORDON: Thank you to those on the phone. Bye bye now.

(Whereupon, at 4:56 p.m., the Committee adjourned.)