INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JANUARY 24, 2024

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 10:00 a.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

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AGENDA

PROCEEDINGS

DR. JOSHUA GORDON: Morning and welcome. If I could have all members of the IACC take their seats. Thank you everyone for being here bright early this morning. My name is Joshua Gordon. I'm the director of the National Institute of Mental Health and the chair of this body, the Interagency Autism Coordinating Committee.

It's my pleasure to welcome members of the Interagency Autism Committee in Rockville, Maryland at the NIMH Neuroscience Center, as well as members of the Committee who are online joining us today. Also, I'm pleased to welcome members of the public, both seated here and as well as both those who are watching video cast.

It's my pleasure to give you an update on what we are going to do today. I'm going to introduce some new members of the IACC that are sitting around the table. And then I'll turn it over to you, Dr. Susan Daniels, the executive secretary for IACC, who will take us through the Committee's business.

Before we do that, I'll welcome some of the IACC members who are new and ask them to just briefly introduce themselves. First is Dr. Brooke Mount, who comes to us from the Department of Justice. We're really pleased to have a representative from the Department of Justice join us on the IACC. Would you like to say a few words to introduce yourself, Brooke?

DR. BROOKE MOUNT: Good morning, everyone. And thank you so much for having me here. I'm incredibly excited to be part of this group. I recently joined the Department of Justice at the Bureau of Justice Assistance, where I oversee the criminal justice and behavioral grant portfolios. So, we do a lot of work bridging law enforcement and behavioral health cross collaboration systems. Thank you so much.

DR. GORDON: Thank you, Brooke. And thank you for being an excellent demonstrator of how to use the mic. Just make sure you press the button and make sure it turns green and speak directly into the microphone.

DR. GORDON: That's so that not only people in the room can hear you, but also, of course, our members and the public online. I want to also thank Maria Fryer, who previously represented the Department of Justice on the IACC.

Next, I'd like to introduce Dr. Christy Kavulic from the Department of Education. Dr. Christy, would you like to introduce yourself? We'll ask Christy to introduce herself later on when she comes.

DR. SUSAN DANIELS: Oh, Christy is right here.

DR. GORDON: Oh, sorry.

DR. CHRISTY KAVULIC: It's okay. I'm sorry.

DR. GORDON: Oh, that's perfect timing. I think you're seated over there. But while you're doing that, I'll acknowledge Dr. Larry Wexler. Most of us around the table know him very well because he is the longest serving member of the IACC. He retired just a few months ago after the last meeting.

And I'm really disappointed I didn't get to acknowledge that at the last meeting, Larry had been a really valuable member of this Committee. But in the meantime, Christy Kavulic is as I'm sure an equally valuable members of the Committee. Would you like to introduce yourself to the group?

DR. KAVULIC: Sure. I'm Christy Kavulic and I am in the Office of Special Education Programs within the Department of Education. And I served as the alternate under Dr. Wexler prior.

DR. GORDON: Nice to have you join us today. Another recent addition to the IACC is Ms. Camille Proctor. Camille was here at our last meeting, but didn't have any chance to introduce herself. Camille, would you like to say anything else?

DR. GORDON: Okay. She'll be here. We'll have her introduce herself later. There is another new member of the Committee sitting to my right, Dr. Monica Bertagnolli, who's the director of the National Institutes of Health, recently appointed. Really pleased to have her join us today.

Usually, the NIH director is represented by an alternate. But Dr. Bertagnolli really wanted to come meet you all and address you this morning. So, she'll introduce herself in just a few minutes. But before that, I acknowledge we have some Committee member news to share. Dr. Matt Siegel, who's not here today, has been appointed to a dual leadership position as the Chief of Clinical Enterprise in the Department of Psychiatry and Behavioral Sciences at Boston Children's Hospital, as well as the Chief Behavioral Health Officer at Franciscan Children's. He will begin his new position next week. But he's not here today. We wish him the best in his new role.

Before turning it over to Susan for the morning's business, I just want to acknowledge we have an exciting agenda for the rest of the day. We're going to hear a presentation from the Federal Interagency Workgroup on Autism.

That is the group that Susan in her capacity as the National Autism Coordinator convenes to make sure that our federal agencies follow up on the recommendations of this organization.

They’re going to be presenting on their various agency's activities in the autism space, and on how this group works together to achieve the goals that you all set forth for us.

We're also going to discuss Committee business this morning. And this afternoon, we'll have public comments as usual, discuss them, and then have a panel on justice and law enforcement issues.

With that, I'm going to turn it over to Susan who's going to take us through the minutes, make some housekeeping announcements before we begin with the program. Go ahead, Susan.

DR. DANIELS: Good morning and welcome. It's great to see so many of you here. And thank you for joining us in-person and live online for some our members, and also to the public watching us. So, we are looking forward to today's meeting, exciting agenda that we have prepared for you if you're with us all day.

So, next I'm going to take attendance officially so that we can know who's here. So, I will go through the attendance list. And you can just say "here" or "hello." Joshua Gordon?

DR. GORDON: Here or hello.

DR. DANIELS: Monica Bertagnolli?

DR. MONICA BERTAGNOLLI: Hello.

DR. DANIELS: Diana Bianchi?

DR. ALICE KAU: Here. Alice attending on behalf of Dr. Bianchi.

DR. DANIELS: Thank you, Alice. Amanda Bryans from the Administration for Community Living -- Children and Families?

MS. AMANDA BRYANS: Here.

DR. DANIELS: Anita Everett or alternate Mitchell Berger from SAMHSA?

MR. MITCHELL BERGER: Yes, this is Mitchell Berger.

DR. DANIELS: Oh, I didn't hear you very well, Mitchell. But thank you.

MR. BERGER: Yes, I'm here.

DR. DANIELS: Tiffany Farchione, FDA?

DR. TIFFANY FARCHIONE: Hi, this is Tiffany Farchione. I'm the division director in the Division of Psychiatry at FDA. And also, I'll be in and out today. So, my alternate Martine Solages is on the line as well.

DR. MARTINE SOLAGES: Hi, everyone. This is Martine Solages. I'll be here when Dr. Farchione steps away.

DR. DANIELS: Thank you, Martine and Tiffany. Elaine Cohen Hubal from EPA?

DR. ELAINE HUBAL: Hi. Good morning, all.

DR. DANIELS: Good morning. Jennifer Johnson from ACL or Amanda Reichard? They are going to be joining us virtual later in the day. Kristi Hardy for NINDS?

DR. KRISTINA HARDY: Hi, Susan. I'm here for Dr. Koroshetz.

DR. DANIELS: Thank you. Everyone, if you're speaking into the mic, move it kind of close to you because I think it doesn't go as far. Leah Lozier? Leah is going to join us in a little bit. Alison Marvin, SSA?

DR. ALISON MARVIN: Good morning. Alison Marvin, SSA here. And I would also like to mention that we have a new alternate, Heather Gomez-Bendaña. Dr. Gomez-Bendaña, who will be my new alternate, and she is listening in. But I will be here the whole meeting. But I just wanted at least to acknowledge her and welcome her.

DR. DANIELS: Yes, and we welcome her. Thank you so much. I believe that the VA, Scott Patterson, the gentleman was not able to be here due to some last-minute issue. But the VA is also represented by Miller. Kamila Mistry from AHRQ or alternate Justin Mills? I believe his mic has gone virtual. Brooke

Mount?

DR. MOUNT: Here.

DR. DANIELS: Karyl Rattay?

DR. KARYL RATTAY: Good morning.

DR. DANIELS: Lauren Ramos?

DR. LAUREN RAMOS: Here. Good morning.

DR. DANIELS: Good morning. Barbara Roland from IHS?

MS. BOBBY PELTIER: Bobby Peltier, sitting in for Barbara Roland for IHS.

DR. DANIELS: Thank you. Jodie Sumeracki for CMS? Jodie is joining us on virtual. Deb Tucci from NIDCD? And Judith Cooper? I know Judith is in the room. She's way over there. Christy Kavulic?

DR. KAVULIC: Present.

DR. DANIELS: Nicole Williams from ARP?

DR. NICOLE WILLIAMS: Yeah. Hi. Good morning, everybody.

DR. DANIELS: Morning. Scott Michael Robertson for Department of Labor?

DR. SCOTT ROBERTSON: Good morning, everybody. Scott Michael Robertson from the

Office of Disability Employment Policy. Thanks.

DR. DANIELS: Thank you. Taryn Mackenzie Williams and Rick Woychik from NIEHS?

DR. RICHARD WOYCHIK: Yes, I'm here. Rick Woychik, director of NIEHS. And I'm joined by my colleague, Cindy Lawler. And unfortunately, I'm -- I made a commitment to give a presentation at the NIDCR Council, so I'll have to step out. But Cindy will be here and will be briefing me on the meeting.

DR. DANIELS: Thank you so much. And now we'll go through public members. Alice Carter?

DR. ALICE CARTER: Here.

DR. DANIELS: Thank you. Sam Crane?

DR. SAM CRANE: Hi. I am here. I'm joining from home because I had a bad disability day today. I'm online.

DR. DANIELS: Well, thank you so much. Glad you're here. Aisha Dickerson? May be arriving a little bit later. Tom Frazier?

DR. THOMAS FRAZIER: Here.

DR. DANIELS: Dena Gassner?

MS. DENA GASSNER: Good morning. I'm here.

DR. DANIELS: Morenike Giwa-Onaiwu?

MR. ISAACSON: Morenike’s here.

DR. DANIELS: Alycia Halladay?

DR. ALYCIA HALLADAY: Good morning. I'm here.

DR. DANIELS: Craig Johnson?

MR. CRAIG JOHNSON: Good morning. I'm here.

DR. DANIELS: Good morning. Yetta Myrick?

MS. YETTA MYRICK: Good morning, everyone. Present.

DR. DANIELS: Lindsey Nebeker?

MS. LINDSEY NEBEKER: Good morning. I'm here.

DR. DANIELS: Jenny Mai Phan?

DR. JENNY PHAN: Can you hear me? Good morning.

DR. DANIELS: JaLynn Prince?

DR. JALYNN PRINCE: Good morning.

DR. DANIELS: Camille Proctor may still

be on her way. But I know that she's here. Susan Rivera?

DR. SUSAN RIVERA: Present. Good morning, everyone.

DR. DANIELS: Matt Siegel was not able to join us today. Ivanova Smith?

MS. IVANOVA SMITH: Good morning. This is Ivanova Smith. I apologize my camera's not working. I am here.

DR. DANIELS: No problem. Thank you, Ivanova.

DR. DANIELS: Hari Srinivasan?

MR. HARI SRINIVASAN: Hi.

DR. DANIELS: Hi, Hari. Good to see you, Hari. Helen Tager-Flusberg?

DR. HELEN TAGER-FLUSBERG: Good morning, everyone.

DR. DANIELS: Good morning. And Julie Taylor?

DR. JULIE TAYLOR: Present.

DR. DANIELS: Thank you. And last, Paul Wang?

DR. PAUL WANG: Hi, good morning.

DR. DANIELS: Okay. Is there anybody that I didn't read off on the list?

DR. LEAH LOZIER: Good morning. This is Leah Lozier from the Department of Housing and Urban Development. I think I was called earlier, but I'm just having some trouble with my audio.

DR. DANIELS: No problem. Thank you, Leah. And I see Aisha Dickerson getting in. So, say good morning.

DR. DICKERSON: Do you want me to say good morning?

DR. DANIELS: Yes.

DR. DICKERSON: Didn't light up. Here we go. Aisha Dickerson. I'm an assistant professor in the Department of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. So, good morning.

DR. DANIELS: Good morning. Thank you. And I'm sorry that I didn't take the time to read everyone's titles. It's just it's a big Committee. And Dr. Bertagnolli only being new. There are 44 members of this Committee.

So, everybody's online though, and you can see all the information there. So, it's a fantastic group of people that have dedicated their time to serving the autism communities. We really appreciate that.

Next, I would like to turn our attention to the minutes from last meeting on October 11th. And we provided this for meeting materials. Does anyone have any comments about the draft? Is there anything that we left out? Yes.

MS. MYRICK: This is Yetta Myrick. So, on one of the round-robin notes where we talked about the Family Voices Project that I worked on, it says D.C. Family Voices and Family Voices is national. So, I just want to make sure that that is corrected on the notes.

DR. DANIELS: Okay. Thank you so much. Somebody from our team will make sure that's corrected before this goes to -- anything else? Okay. Well, hearing no further comments on the minutes, can I get a motion on the floor to accept the minutes?

MS. YETTA MYRICK: This is Yetta. I can put a motion forward.

DR. DANIELS: All in favor of accepting that motion? Are there any opposed to accepting these minutes with the correction? And anyone abstaining from voting on the minutes?

All right. Well, with that it looks like we have a majority accepting the minutes. And we'll make the post to the website as soon as the meeting's over. And if anything else comes up, any minor corrections, please just contact the office and we'll get it taken care of. Thank you so much.

All right. So, then with that we have some housekeeping announcements. Just letting people know use your mic when you're speaking and when you're not speaking, turn it off so that it doesn't create any feedback. And those online, keep your microphone and your camera off unless you're speaking.

And we will having the same process we've had before for anyone who wants to communicate via writing versus orally, you can use Zoom for the members only. You can use Zoom to write in the chat to the name called "Send Comments Here," which is Mr. Steven Isaacson from my team.

And he will receive your chat and he will read it for you. But you can also, when you want to be acknowledged, you can "Raise Hand" in Zoom. And if the chat is sent to Steven, then he will raise his hand, if you would like that. And let us know anything else that you might need in terms of support for today? We want to make sure everyone feels comfortable.

DR. KAVULIC: Susan?

DR. DANIELS: Yes.

DR. KAVULIC: We're hearing that the people on the phone are getting a lot of rebounding. So, it's very important that we get right on top of the mic for them because they're getting erratic feedback. It is now, but it wasn't before. You have to really lean in.

DR. DANIELS: All right. So, I think that is all that I have. And I am going to turn it back over to Dr. Gordon.

DR. GORDON: Thank you, Susan. And thank you, again, all. Moving over to welcome Dr. Monica Bertagnolli to the Committee today. As I mentioned before, as the 17th director of the National Institutes of Health, Dr. Bertagnolli assumes a seat in this Committee.

Although most of the time, including later today, her duties will require her to be elsewhere. She insisted. She had the opportunity to come today and hear a little bit of the business that we do and also speak to you about her role here.

Dr. Bertagnolli is an amazing surgical oncologist and scientist who's made fantastic contributions to reducing the burden of cancers. She's also been a tremendous contributor in the area of clinical trials more generally.

And for a year more, served as the director of the National Cancer Institute before President Biden asked her to take on the role of director of the National Institutes of Health. And I'm not going to take any more of her time. I'm going to leave her to introduce herself.

DR. BERTAGNOLLI: Thank you so much, Dr. Gordon. And morning, everyone. I am really thrilled to be here and for this kind introduction. And I would say I have the tremendous honor of being the 17th director of the National Institutes of Health.

But I have another tremendous honor in that I am the very proud mother of an autistic son. My son's name is Ben. He is 27 years old. He lives with his father and me, and he is a very happy guy, very mischievous character, and is a much-loved member of our community. And I am so lucky to be Ben's mom.

As you all know, every person with autism is unique and every family's experience is unique. Our story has been one of great challenge. Ben has some significant medical problems, but also great joy. We've been so fortunate that our experience overall, has been very positive.

And as NIH director, I want to strive to have that experience be truthful. NIH has long played an important role in federal efforts to identify priorities for autism research and services. The National Institute of Mental Health leads and manages this Interagency Autism Coordinating Committee and also supports the activities of our National Autism Coordinator.

I want to thank Dr. Joshua Gordon for his service as the IACC chair and Dr. Susan Daniels for serving as the IACC executive secretary and HHS National Autism Coordinator.

As the Director of the NIH, I'm also very pleased to be appointed as an official member of this important committee. I may not be able to attend every meeting, but I will always have someone here on my behalf to represent the Office of the Director and keep me informed about the committee's work.

NIH is the largest funder of autism research in the United States and we are proud of the important advances that have resulted from our investments so far.

Couple of updates. A major goal has been to improve autism screening. NIH-funded studies have helped translate findings about early emergency signs of autism into practical screening tools that can be implemented widely.

For example, we are supporting the development of tools that can screen for autism in toddlers and the preschool age children by tele appointments and even a tablet-based screening app. As a parent who had to go through the challenges of screening 25 years ago -- 26 years ago, I really say that this is a tremendous advance.

NIH supportive research has also found that multi-stage screening and early intervention programs appears to increase autism spectrum diagnosis by as much as 60 percent compared with standard care. With the most significant improvement in detection of Spanish-speaking families.

We are hopeful that such screening will improve early detection and reduce health disparities, which we also know are critical -- of critical importance to this community. Our research has also helped -- helping with what we know about the biological mechanisms that underlie autism.

We support research to examine link across genes, cells, brain circuitry, and behavior. We support longitudinal studies of brain development in children with autism in efforts to develop reliable and objective biomarkers for autism.

And measures of social function and communication, which is really important because having such reliable measures are critical for testing new interventions to improve the lives of autistic individuals. NIH is also proud to support improved training and services for autistic adults and for youth transitioning to adulthood.

In short, there is so much to do on so many fronts. The research laboratory, the clinic, the community, the single, and even the individual family and homes. We want to partner with the breadth of people with autism and their families and communities in ways that are helpful and address the issues that are most pressing to them, to all of us.

NIH funds researchers and interdisciplinary teams of autism researchers and the inclusion of varied perspectives in the research process. And we are committed to important research that advances understanding of autism across the spectrum and across the entire lifespan.

We continue to seek input from the autism community, including autistic self-advocates. And we will continue to work with all other federal agencies to help improve health and wellbeing of autistic individuals and their families.

As NIH director, I am committed to a relationship with those we serve, which is defined by the phrase "Nothing About Us Without Us." I don't expect my son, Ben, will ever be able to live independently. But I am hopeful that he will live his best life, the life that brings him purpose and satisfaction.

Every person with autism should be able to choose their own life and to have the support that is needed to achieve. At NIH, we will do our best to listen to this community, to partner with this community. Because this is the only way we will be able to deliver our best efforts to this community.

Thank you so much for being here today. I am so honored to be a member of the community of love and support for autistic people everywhere. And I look forward to working with you to make their best lives possible. Thank you.

DR. GORDON: Turn it back over now to Susan Daniels, who is going to give us the National Autism Coordinator Updates.

DR. DANIELS: Thank you so much. And we

really appreciate those comments, Dr. Bertagnolli. Thank you so much for being here. So, now I'm going to give the National Autism Coordinator Update, which is going to be the shortest one you've had since this new Committee started because we have a special presentation for you today.

So, first National Autism Coordinator update I wanted to share with you that we recently completed this 2022 Report to Congress on Supportive Services for Individuals with Autism. And it was sent to Congress earlier, but it takes us a while to get the version up online for you. So, now it's available online.

And this is a Report to Congress that was based on report language that was provided to us. And the Report covers supportive services in the healthcare sector that have proven beneficial for individuals on the autism spectrum. And provides some information about many different modalities of services that can be provided.

And also, coverage policies, which is part of the request. And it highlights needs and opportunities for strengthening the system. And I encourage you all to read the Report, especially Committee members, to see what is in there.

And this Report was coordinated by my office and with the cooperation of 20 different federal agencies and departments. And so, we really appreciate everyone's cooperation on this report. It's available on the website. Thank you.

This slide just shows the list of some of the different types of services that are covered in the Report. And so, you can look through that. And we did try to be as comprehensive as we could with different kinds of services.

And some of the recommendations were the areas in the Report that were identified as ways to strengthen the service system with the increased focus on family navigation or services navigation, as the system sometimes can be across many different areas and it's difficult for us to navigate as individuals. And so, navigation is a great opportunity.

Continuity of coverage. Workforce shortages. Diagnostic services. Shortening waitlists. And the opportunities provided by telehealth. So, we encourage you, again, to look at this Report when you have a chance.

DR. GORDON: If I could just interrupt for a moment, Susan.

DR. DANIELS: Sure.

DR. GORDON: I just want to make an editorial comment here. Officially, this body, right, is advisory to the Secretary. And officially, the National Autism Coordinator tries to take what this body suggests and get all the different federal agencies to incorporate that into their policies. That's the purpose of FIWA as you'll hear from her later.

This Report represented an opportunity for this body, unofficially through the National Autism Coordinator, to present those recommendations to Congress. And Congress asked for this Report so that they can figure out what they need to do legislatively to support these services.

So, this was a tremendous opportunity for Susan, for the Office, for the Secretary, and for you all to send a message directly to Congress. So, I really appreciate the hard work that you've done over the last several years because a lot of the things that we've talked about in this room, as you could see just from that presentation, are in this Report as recommendations to Congress. So, thanks. And thank you, Susan, for putting it together.

DR. DANIELS: Thank you. So, that is the main portion of this National Autism Coordinator Update. This time, we did prepare the full listing of all the different activities across federal agencies in a document that is on the web. And I neglected to tell everyone, once we're tuning in online, all of our materials are on the web.

You can access them there. So, I'd encourage you after the meeting to look through the National Autism Coordinator Update after the meeting.

But now, I'm going to turn to the second presentation that we have from members of the Federal Interagency Workgroup on Autism, which is the group that I chair as National Autism Coordinator.

And this group has a number of different things. It is a group that meets in a non-public fashion because we are able to, with pride, to work on initiatives that are being planned and discuss in public. And we're able to take into consideration the recommendations of the IACC and how those could be implemented across the federal agencies.

So, this all-federal working group was initially started several years ago in 2018, and now is named the FIWA. And we meet three times a year, as well as have special needs like we involved to talk about initiatives.

And we -- this is the body that I use to carry out my responsibilities as National Autism Coordinator to help implement what the IACC has recommended.

And the information that's exchanged in the FIWA also helps us prevent duplication of effort, which is also marked in the Autism CARES Act as one of our responsibilities.

And the information that the FIWA generates does come back to you through the National Autism Coordinator Updates through reports that are put together by an HHS and FIWA Office and in the other ways we try to disseminate information.

So, we really appreciate the cooperation across federal agencies. FIWA is a voluntary group and we have excellent membership. And the next slide.

So, this is a listing of all the different federal agencies that are part of the FIWA. And many people who are on the IACC who are federal members also are on FIWA. We also have some additional agencies in the departments that are not on the IACC who are here on FIWA.

So, with that, I'm going to have this presentation today, which is going to be an opportunity for federal agency officials to share some of their various strategy for addressing the IACC strategic plan and autism through their disability and autism programs.

And we can't have all the members of the FIWA speak this morning. So, we're going to have some speak today and some in April. So, we are going to hear from Christy Kavulic from the Department of Education. And later from Matthew Maenner from CDC, Lisa Gilotty from NIMH, on behalf of NIH. Scott Robertson from the Department of Labor.

Jennifer Johnson from the Administration for Community Living, Leah Lozier from HUD, Alison Marvin from the Social Security Administration. And Rob Ochsendorf who represents the National Science Foundation, which is not a member of the IACC or FIWA, but collaborates very closely with us.

And so, with that, I'm going to turn it over to our first speaker, which is Christy Kavulic. Each of you feel free to introduce yourselves as you start your message.

DR. KAVULIC: Thank you. My name is Christy Kavulic within the U.S. Department of Education. And I am in the Office of Special Education. And I am in the Office of Special Education Programs, which is part of the Office of Special Education and Rehabilitative Services.

Within the department, OSERS, the Office of Special Education Rehabilitative Services, and the Institute for Education Sciences, is where a large part of our work around people with disabilities and people with autism is situated. Within OSERS, we have two offices; the Office of Special Education Programs, and then the Rehabilitative Services Administration.

RSA administers Title IV of the Workforce Innovation and Opportunity Act. And then OSEP, where I'm from, administers the Individuals with Disabilities Education Act, or IDEA. Which is the act that provides services to infants, toddlers, children, and youth with disabilities, birth through 21.

I'm going to focus today on some of the work of the Office of Special Education Program, as well as the work of the Institute of Education Sciences under the umbrella of the IDEA.

So, the IDEA serves about 900,000 children with autism in addition to infants, toddlers, and preschool children with autism in their families.

The topics we focus on through national activities funding are research, technical assistance and dissemination, personnel preparation, educational technology and media, and parent programs. These national activities are funded under Part D of the IDEA. Next slide, please.

I wanted to focus specifically on a few areas that we are focused on in OSEP this fiscal year within the personnel preparation line item and then within our technology and media line item.

Across the early intervention and special education systems, we have a shortage of workforce who are prepared to support children with disabilities and their families, including children with autism. And so, our investments are trying to address the shortage of the workforce.

We offer on the screen this coming fiscal year, these various programs. And a large part of them are preparation programs. So, universities apply for funding, and that funding then goes to support scholars in completing their bachelor's, master's, certificate, educational specialist, clinical doctorate, or research doctorate to work within the early intervention, special education, or related services fields.

If someone receives their degree funded through an OSEP grant, they then owe years of service to the field. So, that's the way to try to support people both entering in the field and then working in the field.

We have a specific focus within OSEP on trying to increase the diversity of the workforce in early intervention and special education. And some of our investments this upcoming year, are specifically geared towards minor minority-serving institutions, including HBCUs, historically Black colleges and universities and tribal colleges as well.

The other area I just -- and so, how we have those programs set up is that applicants indicate who they will be preparing within their applications. And some of these applicants specifically identify that they will be preparing personnel to work in the field that have a specialization of working with children with autism.

Not all the grants do, but across the -- all these areas, there are grants that specifically focus on supporting children with autism.

Our educational technology program, the -- this is an area that we're focused on supporting educational technologies to be implemented within early intervention in school systems. And so, the Stepping Up Technology Implementation takes an existing technology and supports the implementation of it in a real-world educational setting.

And then we are going to be funding this year, the National Center on Digital Access in Education to support more accessible educational materials for children. The next slide, please.

I wanted to just highlight where the Institute for Educational Sciences, the National Center for Special Education Research, NCSER is what we call it for short, what they will be competing for this upcoming year.

NCSER funds special education research across four types of research projects; exploration, development and innovation, impact, and measurement. The way this is structured is that it's field-initiated. So, those who come in propose a project. And some of the projects can be -- are -- proposed are specific to supporting children with autism in one of these areas.

The other program that NCSER funds on an annual basis are training programs in special education to prepare individuals to conduct rigorous and relevant special education and early intervention research.

So, these generally go to new faculty that are entering the field. So, early career faculty, those in postdoctoral programs so that they can start developing their area of research and specialization. And, again, it's field-initiated. So, applicants may propose research that targets research around autism.

And then a new grant that NCSER is funding for this upcoming year, again, with a focus on the workforce because we know there are such shortages, is a center on the K-12 Special Education Workforce Grant. And it's to fund a research and development center to try to learn additional research on the Special Education Workforce and how to support them.

And then the last slide I just wanted to highlight was a document that the Department of Education released in collaboration with the Department of Health and Human Services that might be of interest to the committee. It's a Policy Statement on the Inclusion of Children with Disabilities in Early Childhood Programs.

And this statement is a revision of a statement released in 2015. And the vision of the statement is that we set the expectation that all young children with disabilities should have access to high-quality inclusive early childhood programs that provide individualized and appropriate support so they can fully participate alongside their peers without disabilities. Meet high expectations and achieve their full potential.

So, this policy statement offers recommendations to states and local programs of how to look at their systems across different areas to increase inclusive early childhood programs for children with disabilities. Thank you.

DR. DANIELS: Thank you so much for that Dr. Kavulic. And now, we'll hear from Matthew Maenner from CDC.

DR. MATTHEW MAENNER: Hey, good morning. I'm Matt Maenner and I'm the chief of the Child Development and Disability Branch at CDC. Next slide. Oh, one -- just the one in between there [laughs]. There we go. Thank you.

So, CDC is a public health agency with a broad public health mission. And more specific to autism, CDC's autism programs and activities were first described in the Children's Health Act of 2000 and more recently in the Autism CARES Act.

CDC autism programs includes; surveillance including tracking autism through the Autism and Developmental Disabilities Monitoring Network, or ADDM Network. Conducting research through the Study to Explore Early Development, or SEED.

And promoting developmental monitoring and early identification of autism through the Learn the Signs. Act Early Program.

While some of these programs have existed for, you know, more than a decade, CDC has increased its focus on autism across the lifespan and addressing disparities through public health surveillance and research.

And I just want to mention, I didn't have time to focus on the SEED research study this morning. But wanted to mention that in this past year, SEED launched its in-the-field data collection for its current longitudinal phase, which is going to follow up on previous SEED participants who are now adolescents or young adults. Next slide.

To highlight some of the recent activities from our surveillance program, the Autism and Developmental Disabilities Monitoring Network, or ADDM Network, it tracks the prevalence of autism among children aged 8, progress and early identification among children aged 4.

And seeks to better understand the needs of adolescents on the spectrum as they prepare to transition to adulthood and post high school exit.

So, last April, CDC presented to the IACC on the latest ADDM data, which included updated prevalence estimates and also showed disruptions to early identification that coincided with the onset of the COVID-19 pandemic.

And at the beginning of this last year, CDC also received a budget increase to expand ADDM. And the team has worked to establish five new ADDM sites to increase the number of sites that are collecting data on adolescents. And CDC was also directed to use the ADDM infrastructure to reestablish cerebral palsy surveillance.

Also, in 2023, the first publications from the ADDM adolescent activities came out. And so, there were two papers that focused on the health and co-occurring conditions of children aged 16. And then a second publication looked at services and supports indicated in IEPs and transition planning goals. Next slide.

So, the Learn the Signs. Act Early Program encourages early, ongoing, and family-engaged developmental monitoring of all children and early identification of developmental delays so that children and their families can receive the services and supports they need.

They do this through a variety of different activities, including producing and providing free tools and resources such as the Milestone Tracker app for families and professionals who serve them.

We learned earlier this week, that the Milestone Tracker app is probably going to cross the 2 million download threshold any day now. So, we think by Monday we could see 2 million.

CDC has also supported seven cohorts of Act Early ambassadors since 2011. Ambassadors are state or territorial leaders working to increase collaboration and coordination among early childhood programs and embed Learn the Signs. Act Early into early childhood programs.

And so, as of last October, the program has grown to 60 ambassadors. They're in 49 states, Washington D.C., four territories, and three tribal communities. And both individually and as a group, they are just amazing, amazing people.

The Learn the Signs. Act Early Program has also established partnerships to integrate the developmental monitoring into programs and systems that serve young children and their families particularly focusing on reaching low-resource families through partnerships with the USDA, WIC program.

They provide technical assistance and collaborative learning opportunities that are being provided through WIC staff in 23 states and two territories. And they also are collaborating with the AAP to target messaging to pediatric healthcare providers about the importance of developmental monitoring, screening, referral, and follow up.

And we are now working closely with HRSA to embed these resources with their health center grantees who have been recently funded to focus on early childhood development. And I think that's it for me. Thank you.

DR. DANIELS: Thank you so much, Dr. Maenner. And next, we will hear from Lisa Gilotty from the NIMH.

DR. LISA GILOTTY: Hello. Good morning. My name is Lisa Gilotty. I'm a program officer with NIMH. And I'll be highlighting just a couple of NIH initiatives that may be of interest to the Committee or that you may not be aware of. Next slide. Okay.

The first is the NIH Autism Centers of Excellence. The ACE program supports research on autism throughout the lifespan, including innovative and cost-effective services and interventions. The award support research at individual centers, which feature collaborations between a team of experts. And also at research networks, which involve multiple institutions.

Each ACE has adopted a specific Plan for Enhancing Diverse Perspectives, or PEDP, that outlines strategies to increase the number of individuals from traditionally underrepresented backgrounds in the autism biomedical, behavioral, and clinical workforce. As well as to increase the participation of underrepresented populations in autism research.

These centers are supported by a number of NIH institutes, including NICHD, NIDCD, NIEHS, NIMH, and NINDS. And at the bottom of the slide, you can see some information about the funding and the scope of the awards.

The current group of awards will be active until 2027. And there's also a link to get more specific information about each of the ACE centers. Next slide. Next slide. Oh, yes, that one. Thank you.

The next is the Intellectual and Developmental Disabilities Research Centers. These were established in 1963. The NIH-supported IDDRCs are located at 15 universities and children's hospitals across the U.S. to provide support for state-of-the-art research in intellectual or developmental disabilities, including autism, using multidisciplinary, collaborative, and integrated approaches to advance the development of services and interventions for IDDs.

The research projects include approaches to increase understanding of risk and resilience, use of novel technologies to improve assessment and treatment, and development of interventions for management of co-occurring mental health conditions.

There’s, again, some information about the funding and scope. The current group of IDDRCs will be active until 2025. And at the bottom, there's a link for information about the announcement. Next slide. Okay.

And finally, the Rare Disease Clinical Research Networks, the RDCRN program. Oh, and I should say upfront that this program is led by the National Center for Advancing Translational Sciences, or NCATS. The program is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing.

Through a network of consortia, scientists from multiple disciplines at hundreds of sites around the world, work in partnership with patients and patient advocacy groups to study more than 280 rare diseases.

The current group of RDCRNs include 20 active consortia working on multi-site longitudinal studies, as well as pilot and feasibility projects, to advance treatment for rare diseases, including Phelan-McDermid Syndrome, which is associated with autism.

These are all cooperative agreements.

And, again, at the bottom you can see a little bit of information. These are supported across multiple institutes, including NCATS, NICHD, NIMH, and NINDS. And there's also a link where you can get some additional information about the centers. And that's it for me.

DR. DANIELS: Thanks so much Dr. Gilotty. Next, we're going to hear from Scott Michael Robertson.

DR. ROBERTSON: Thank you, Dr. Daniels. I am Dr. Scott Michael Robertson. I am an autistic white man with blue eyes, brown hair, and glasses, wearing a red shirt and a dark jacket. I believe it's navy with lines.

And I've got the Office of Disability Employment Policy background behind me at the U.S. Department of Labor. And we are an agency that focuses on increasing access to employment and career pathways for diverse people with disabilities.

Our mission specifically focuses on

activities to develop and influence policies and practices that can increase the number and quality of employment opportunities for people with disabilities. Again, from diverse backgrounds, diverse disability experiences, all different types of disabilities.

We place a cross disability emphasis in our work. And we also focus on other specific areas of disability, such as support for empowerment of neurodivergent people and fostering neurodiversity at work and fostering and aligning with priorities under the Federal Autism CARES Act and supporting the other work of our sister agencies, especially in regard to improving access to employment in government and in industry.

And so, our portfolio focus emphasis is on employment and careers, specifically competitive integrated employment, access for people with disabilities, career pathways, and currently the Federal Good Jobs Initiative across the federal government that the Department of Labor is taking a lead on.

And driving greater support for diversity, equity, inclusion, and accessibility, or DEIA, priorities under federal executive orders. And other key executive policies and practices.

And at the bottom of the slide, I have the Office of Disability Employment Policy, or ODEP's, our home agency logo. And next to that is the recently celebrated 50th anniversary for the Rehabilitation Act of 1973 that we had celebrated in the last several months and have the logo for that there. Could we flip to next slide?

So, I wanted to focus specifically on our work around autism. We do a lot of other processability work as well. So, you could find that at our website, dol.gov/agency/odep. But I wanted to concentrate on the autism work just today.

And our main work around autism is our research project that is called the Research Support Services for Employment of Young Adults on the Autism Spectrum. We often call that REYAAS for short because it is, you know, long.

And the emphasis for that work is on youth and young adults because that is the charge that we had from Congress in Congressional Appropriations that asked us to do this project.

It is by far the largest investment in autism from our agency's history in more than 20 years as an agency. Specifically, what are we, 23 years as an agency? And the goal for this project, the REYAAS project, is to increase access and expand access to inclusive employment and career paths for autistic youth and young adults.

And also, this has greater implications actually across the life course as well in terms of what works well for us youth and young adults, works well for all our autistic people at all different spots of the age range.

And the funding for this project is under a contract with Mathematica -- a partnership with Mathematica. It's almost a $3 million project. It's $2.9 million to be precise. Launched a few years ago in fiscal year 2021. And the project has been engaged in doing data analysis, running listing sessions, especially with autistic youth and young adults.

We, in our listing sessions with autistic youth and young adults, we had about I believe it was about 96 autistic youth and young adults and then many other constituents.

Literature reviews, other forms of data analysis. We've already released many different project reports from this project. And I just wanted to highlight a few on "Programs, Models, and Strategies" from the research literature.

"Evidence on the Effectiveness of Programs, Models, and Strategies." "Barriers and Facilitators to Employment and Careers." This is a report that came out of -- directly out of our listing sessions.

And the most recent report on "Vocational Rehabilitation Characteristics, Service Use, and Outcomes." This was an analysis that Mathematica had done on the VR system especially the years leading up to right before the COVID-19 pandemic.

And we are also planning a survey right now of autistic youth and young adults. It's sort of in the planning development stage. I can't share too many specifics. I'll be able to share more specifics down the line.

But this is going to be an activity that will be looking at surveying autistic youth and young adults directly about experiences and perspectives with employment and careers and barriers experienced, for instance.

And the point of context for all these project activities is David Rosenblum, who is our federal project manager for this REYAAS project. And then I am a point subject matter expert for neurodiversity at work helping assist the project and its activities going throughout since it launched in FY 2021.

And there are links to all these reports on the slide that you can see later on. And can we flip to the next slide?

And finally, I'd like to also share some related neurodiversity at work activities that we have at ODEP. We, for instance, have an employer TA center, the Employer Assistance and Resource Network on Disability Inclusion, or EARN for short -- at -- EARN for short, askearn.org.

This technical assistance and policy development center has released a neurodiversity and workplace guide, as well as a toolkit for supporting workplace mental health. And had also hosted a webinar previously on Hiring and Supporting Neurodivergent Workers: Strategies for Success.

This webinar is archived online. And you'll see also in our round-robin notes sort of late breaking news. We have a couple of sessions that were recorded and posted online recently that I can mention in the round-robin session related to neurodiversity at work and mental health.

And also, our Job Accommodation Network, askjan.org, which is another technical assistance center funded by ODEP, has a neurodiversity at work webpage. And has previously hosted a webinar on Accommodation Solutions for Neurodivergent Workers.

As noted in our round-robin, we also have another webinar coming up in that space. It also has specific webpages for accommodations in the workplace for awesome mental health conditions, intellectual disability, many other disabilities in the A-to-Z library for work accommodations.

And then JAN staff are also available to provide free expert and confidential assistance on demand on work accommodations and supports. They have teams for specific types of disabilities, including, for instance, the Cognitive and Neurological Team.

In the end, this is all free expert,

confidential assistance, your taxpayer dollars at work, if you will. Anybody can connect with JAN, including job seekers, workers with disabilities, employer, service providers, family members, anybody who is interested in learning more about different ideas for addressing barriers through work accommodations and supports and services. Especially, those aligned with the Americans with Disabilities Act and the Rehabilitation Act of 1973. And I think that's -- yeah, that's it for us. Thank you.

DR. DANIELS: Thank you for the update, Dr. Robertson. Next, we're going to hear from Dr. Jennifer Johnson from the Administration for Community Living. Jennifer, are you able to access? Okay. We'll come back to Jennifer. She might be having some technical difficulties. So, I'll skip ahead to Leah Lozier -- Dr. Leah Lozier from the U.S. Department of Housing & Urban Development.

DR. LOZIER: Hi. Good morning. My name is Leah Lozier. And I'm a social science analyst in the office of policy development and research at the U.S. Department of Housing and Urban Development, or HUD. And I'm both an IACC and a FIWA member. Next, please. HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all.

HUD is working to strengthen the housing market, to bolster the economy and protect consumers, meet the need for quality, affordable rental homes, utilize housing as a platform for improving quality of life, build inclusive and sustainable communities free from discrimination, and transform the way HUD does business.

Now, HUD does not have autism-specific programs, but it does serve persons with disabilities through all of its housing programs, including programs specifically for those with disabilities. Among the 4.6 million households that HUD served through its rental assistance programs in 2023, 34 percent were headed by a non-elderly person with a disability. Which includes about 30 percent of public housing households, and 35 percent of voucher households.

So, we're really serving folks in all of our programs. But the focus of today's very brief presentation, I want to highlight four programs specifically for persons with disabilities. Next, please.

So, the first is the Section 811 Supportive Housing Program. I'm sort of referring to this as the traditional program. This program provides interest-free capital advances, essentially, funding to build, and operating subsidies for nonprofit developers of affordable housing for persons with disabilities.

The program is available for very low-income households, meaning those with an income of less than 50 percent of the area median income. A related program is the Section 811 Project Rental Assistance, or PRA program. And really, the key difference here is integrated units.

So, under this program, state housing agencies that have entered into a partnership with state Medicaid and Health and Human Services agencies can apply for grants that subsidize rent for people with disabilities in affordable housing developments. The program subsidizes up to 25 percent of units in a property to ensure that people with disabilities are fully integrated into the community.

Participants must have extremely low income in this program, which is at or below 30 percent of the median income. They must be 18 to 61 years old at the time of admission into the program. And they must be eligible for Medicaid or other Health and Human Services. Next, please.

So, two other smaller and somewhat lesser known programs are mainstream vouchers and NED vouchers. NED stands for Non-Elderly Disabled. Vouchers are a type of rental assistance that enables a household to rent in the private market and pay approximately

30 percent of their income in rent.

So, for mainstream vouchers, this is specifically rental assistance for non-elderly persons with disabilities. It follows the policies of our regular housing choice voucher program. And in this program, at least one adult member of the household must have a disability.

As for NED vouchers, this is also rental assistance for non-elderly people with disabilities. But a key difference here is that the head of household must have a disability. And this comes in essentially two categories.

The first is for non-elderly people with disabilities to access affordable housing in the rental market, just very similar to our voucher program. And the second one, the key difference here is this is for people with disabilities transitioning from nursing homes and other healthcare institutions back into the community. So, that's it for me. Thank you.

DR. DANIELS: Thanks so much, Dr. Lozier. Next, we're going to hear from Dr. Alison Marvin from Social Security Administration.

DR. MARVIN: Hi. Hello. Good morning. I'm Alison Marvin, Social Security Administration. And I'm a statistician and researcher in the Division of the Analytics Center of Excellence at the Social Security Administration. And I'm both a FIWA and IACC member.

And we at SSA, we do not have autism specific programs, but our programs do serve those on the autism spectrum. And we have two disability programs. One is SSDI, which pays benefits to insured, disabled individuals and certain family members.

And when we say insured, that's when people pay in from their payroll or their paycheck. Part of that goes towards that. And we also have SSI, Supplemental Security Income. And that's for those with limited income and resources. That is funded by the general tax revenues. I'm just going to touch on three areas where SSA does help in addition to having these support programs.

One is employment support, where we have policies in place to help our beneficiaries return to work by protecting their cash and medical benefits. The fear of losing medical benefits is a major concern and often prevents people from trying to step back into the work world.

And we also have employment services, notably, our Ticket to Work Program. And these are programs which help beneficiaries return to work and try and help them really succeed in the labor force. Ticket to Work is a free and voluntary program that connects individuals with free employment services, for example.

Next slide, please. The second area is we are research and demonstrations. So, as I've noted here, demonstrations are temporary initiatives to identify services, supports, and policies to support people with disabilities. So, we try and see what works, and try to see what lessons we learn. And you can also try and see what lessons we've learned, if you see that first bullet.

This is a link to our State of the Science Meeting on lessons learned from past demonstrations. This is a really, really interesting site. And you can download, for free, the book in PDF form, which contains all the presentations at that meeting. And you can learn a lot about the demonstrations. And you can learn a lot about what we learned from exploring what we've learned at these demonstrations. So, really recommend that.

And we also just completed our Supported Employment Demonstration project. And I wrote that up in last -- the last meeting's round-robin documents. So, you can read all about that there and, obviously, in this link. And we evaluated our PROMISE project as well recently.

Other -- and we have lots of research and analysis. We have our own journal, Social Security Bulletin. We have data and surveys.

We have public use files for people can use for their own statistical analyses. And if you want to look at the data from the SED project I just mentioned, those public use files are currently available.

And we also have statistics. We have statistical books. So, which you -- for example, SSI and SSDI. And it's often broken down by diagnosis, including autism. So, you can actually go in there and there's mounds of data which could be downloaded in multiple formats. So, that's all available for people to use. Next, please.

I'm just going to mention, this is the last point I wanted to talk about, was research funding opportunities. We have the ICAP, Interventional Cooperative Agreement Program. This allows SSA -- there's a legal -- it's a legal way to allow SSA to partner with non-federal groups on research relating to SSA.

And we have just made an announcement about this. And you can read about those in our current round-robin document. I wrote that up. And you can see, we have two awards. And one of the awards is actually about the -- it's on the ABLE accounts, Achieving a Better Life Experience accounts, which are tax advantage savings accounts for individuals disabilities and their families.

And I've pushed them in previous meetings, but there is a specific project relating to helping people, encouraging people to, you know, the -- an uptake in ABLE accounts. As far as of a time to disability research consortium, those agreements were announced at September. And I mentioned those at the previous meeting. And you can read up about those in the previous round-robin document.

We also have an annual stipend program for graduate students, the ARDRAW program. And this was in hiatus while we looked for a new administrative partner. But this is one of the places where we have students who have specifically completed projects on autism.

So, this is where we actually have our autism specific research. And we've had some wonderful autism specific research from the graduate students.

And I will let you know when we have the new awards up and ready to go. So, we're looking forward to encouraging more students to apply for this program when it's up and running again. Thank you so much. And that's it from the Social Security Administration.

DR. DANIELS: Thank you so much, Dr. Marvin. I'm going to move back to Jennifer Johnson from ACL, if Jennifer is on.

DR. JENNIFER JOHNSON: Hi. Yes, I'm on. Can you hear me?

DR. DANIELS: Yes, we can.

DR. JOHNSON: Okay. Thank you. And then my apologies for having to step away for a minute. As was mentioned, I'm Jennifer Johnson. And I'm the deputy commissioner for the Administration on Disabilities, which is a center within the Administration for Community Living.

For those of you who aren't familiar with the Administration for Community Living, or ACL for short, we are part of the U.S. Department of Health and Human Services, or HHS. And we fund disability and aging organizations that help support people with disabilities. And older adults to live, work, and participate in their communities and also, prevent them from going into institutions. Next slide, please.

So, I want to briefly highlight some of ACL's leading priorities. First, talking about our work on expanding home and community-based services, or HCBS. And addressing the institutional bias to support people to age in place, and also, to divert people from going into institutional settings. As well as safely transitioning them back into the community from institutional settings.

So, a big part of that work has been focused on what we call the HCBS settings role, which in March of this year will be one year since the end of the transition to the HCBS settings role. So, again, we've done a lot of work in collaboration with CMS on the implementation and doing visits to states on the implementation of the settings role.

Next, I wanted to briefly highlight the work that we are doing on supporting caregivers and building the caregiving economy. I think for members of this team, everybody is very familiar with the real crisis we have in the direct care workforce that supports people with disabilities to live in the community, as well as older adults. And that a lot of care is -- then ends up being provided by family members because of the real lack of direct care workers that we have right now.

So, we have a number of, and activities and initiatives that we're working on to address the caregiver crisis. We have a significant investment and a grant to the National Council on Aging on the direct care workforce. And that is a project that is not only addressing the caregiving needs of older adults, but also, the caregiving needs of people with disabilities across the lifespan.

We also have the National Caregiver Support Program and the Lifespan Respite Program. Also, within ACL, we have Oversight and Support the RAISE Family Caregiver Act and the RAISE Committee that's authorized under that act, as well as the Supporting Grandparents Raising Grandchildren Act. And through those two committees, we have issued a national strategy on caregiving to address, again, the caregiving crisis.

And also, help support the caregivers that are providing care to individuals with disabilities and older adults. I want to just last touch on our priority around advancing equity to address the needs of marginalized populations. And we really look at that from an intersectional perspective. And this priority really is reflected in everything that we do.

So, in just the work and initiatives

that I just described, as an example, you know, in the implementation and addressing those, we are taking equity lens and an intersectional lens to all of that work. Next slide, please.

I now want to move to briefly highlight priorities within the Administration on Disabilities. While we have other disability related work that we do in ACL, including through the National Institute on Disability Independent Living and Rehabilitation Research, I'm just going to, because of the short time that we have, highlight the work that we are doing within AOD. The first being on investments that we have around health equity to really promote health equity for people with disabilities.

And so, we have a number of initiatives and investments. And on the slide, there are several links to more information about these projects. We don't have websites for everything because some of these are new, like the peer supports for augmentative and assistive communication devices.

So, another one that I just want to highlight that I know has been of interest to this committee is the I/DD counts. Which is work that we're doing to fill gaps in data that we have on the I/DD population, which would include people with disabilities. Next slide, please.

The next one I want to highlight -- the next priority is achieving economic security and mobility. And a lot of this work is focused on career trajectories for people with disabilities and supporting competitive integrated employment. We have state grants that -- we're in seven states with grants called Community Collaborations for Employment to support coordination and collaboration to facilitate youth transitioning to post-secondary life.

And then we also -- just to highlight another project that we have is a longitudinal study that looks at the trends in competitive integrated employment for people with intellectual and developmental disabilities. Next slide.

Very important to our work is protecting rights and preventing abuse. And we have had, over the years, investment in a number of grants -- eight grants specifically, for what we call, in brief, Living Well grants that are just really looking at health and safety in the community and better use of data to mitigate incidences of abuse and neglect.

So, we have just come to the close of those projects. Some of them are finishing up their activities. But we're continuing evaluation of that and using those findings to help inform how we can best improve health and safety in the community.

And then we also have the Center for Youth Voice Youth Choice, which is addressing the school to guardianship pipeline. So that as youth are transitioning out of school, they get more information and families get more information about alternatives to guardianship. Next slide, please.

So, the next one -- the last one that I want to highlight is empowering individuals, families, and communities. And this one is also very important to the work that we do and very core to what we do.

And so, we have a number of projects that we are funding that are intended really to build self-advocacy, self-determination skills for individuals with disabilities. And also, raise awareness and help others understand how to support that within individuals. So, that is my last slide. I'm ready to turn it to the next presenter. Thank you.

DR. DANIELS: Thank you so much, Dr. Johnson.

DR. DANIELS: And last, we're going to hear from Dr. Robert Ochsendorf from NSF.

DR. ROBERT OCHSENDORF: Thank you, Susan. Good morning, everybody. Rob Ochsendorf with the National Science Foundation. Happy to be here. Next slide. So, NSF is located in Alexandria, Virginia, with the mission of, to promote the progress of science, advance the national health, prosperity and welfare, and to secure the national defense through research, essentially. Next slide.

So, NSF was founded as a federal agency in 1950 and supports curiosity-driven, use-inspired, basic and fundamental research in all STEM disciplines. NSF is the main public funder of academic research in areas not supported by NIH, and also, NASA.

NSF is divided into multiple funding directorates, including math and physical sciences, computer and information sciences, engineering, geosciences, biology, social and behavioral sciences, STEM education, where I reside. I'm a program director in the STEM Education Directorate. And there's a brand new directorate focused on technology, innovation, and partnerships which began last year.

Pictured on this slide are some examples of notable areas of investment made by NSF over the last 70 years. So, here, you can see areas related to astronomy, computer science, material science.

NSF likes to tout that the early search algorithm developed by the founders of Google was a doctoral research grant to Stanford University, where those two individuals were graduate students. And they had this great idea about how they could more efficiently and effectively search this new thing called the internet. And that then gave rise to Google.

NSF has a strong tradition of broadening participation in STEM, long committed to expanding opportunities to STEM for people of all racial, ethnic, geographic and socioeconomic backgrounds, sexual orientations, gender identities, and to persons with disabilities.

Some recent initiatives and funding activities at NSF that I'd like to highlight, just last year, NSF, along with IES at the Department of Education, funded a $20 million National Artificial Intelligence Institute focused on speech and language therapies. That's at the University of Buffalo. This AI institute focuses on transforming education for children with speech and language processing challenges.

The team aims to address these challenges using an AI-enabled screener and an AI orchestrator, they call it. The goals are to use AI to more rapidly and effectively screen young children for speech and language difficulties. And then deploy the AI-enabled orchestrator to deliver evidence-based and customized speech language interventions to students in need in pre-K-12 classrooms.

If you know anything about the speech language area, you know that there's a severe shortage of therapists who are able to meet the needs that exists in U.S. classrooms. And so, the idea here is to leverage advances in AI, large language models, natural language processing, to, hopefully, screen more kids and deliver stronger interventions.

In addition, NSF has recently funded

six, what we call convergence accelerator projects, focused on individuals with disabilities. Within these projects, NSF is investing in research solutions to address challenges faced by persons with disabilities. Including the development of assistive and rehabilitative technologies to enhance their quality of life and provide greater opportunities to gainful employment.

With this $30 million investment, NSF has selected six multidisciplinary research teams to advance a convergence approach between researchers, innovators, and persons with disabilities, spanning organizations and communities across multiple sectors. This work is crucial to ensure these NSF funded solutions address barriers to employment, freedom of movement, and quality of life for persons with disabilities.

Related to the IACC, NSF projects continue to be represented in the IACC autism research database. Just in the last several years, NSF has funded hundreds of research projects focused on STEM learning and workforce development issues. And broadening participation research for individuals on the autism spectrum.

Next slide, please. And I'll just conclude here. So, these are some of the prominent areas in which NSF funds autism-related research. So, you can see my area, mostly in K-12 STEM education.

But also, a lot of work we support in undergraduate STEM education, individuals with autism on college campuses. How are we helping universities' faculty to be supportive of individuals on the spectrum who are pursuing STEM education degrees? Informal STEM education, which refers to sort of outside of school opportunities. So, think about museums, science centers, podcasts, children's television.

We fund quite a bit in that space that has an autism focus. Accessibility and accommodation, technology and small business innovation. I was -- I don't work in these areas, but NSF funds a lot in small business innovation. Think about wearable tech, small business startups interested in wearable technologies to assist people on the spectrum. STEM workforce development issues.

We fund cognitive and behavioral research looking at opportunities, challenges related to STEM learning for individuals on the spectrum. And then we also support a variety of convenings and workshops on this topic as well. So, thank you. Happy to be here.

DR. DANIELS: Thank you, Dr. Ochsendorf. So, you've heard from a selection of our FIWA members. And really appreciate hearing about their programs. We follow very closely and meet on a regular basis. So, in addition to these IACC meetings that you see online, we also are working with these agencies to implement autism related programs across the federal government.

So, now, we have a few minutes. We have about 10 minutes to complete some questions from the committee, I see we have some. And we'll probably go for our bio and networking break at 11:35 a.m. So, Yetta Myrick.

MS. MYRICK: Thank you. Can you all hear me? Okay. Thank you. So, I want to thank everyone who presented today across the multiple agencies.

MS. MYRICK: Oh, yeah. Okay. Oh, let me take the mask off. Okay. So, thank you for everyone who presented and for all your hard work. Really excited about the work group. I do have a question that is concerning, as I think about how this work is being translated out into the larger autism community.

So, there are a lot of great initiatives that I heard about today, some of which I already knew about. Some that I'm learning about, right? But like, what is the sustainability plan of these various initiatives? How is it reaching the larger autism community? That is what I'm concerned about.

We are privileged here to be at this

table, right? And having these conversations and learning about what's happening. But I'm thinking about autistic individuals, their family members, right, caregivers who do not have access to this information.

And so, how is it -- like, what is being done to ensure that this is getting out to the larger masses? Like, that is just -- this is something that just keeps coming up for me, right? And so, I would love -- I don't think we have time to hear from everyone.

What I would invite you all to do is if you -- we do not have the time to maybe write something up to share with the committee because I think it's really important to highlight how this work is translating out in the community. What is the dissemination plan? How are we sustaining this?

DR. GORDON: I think that's a great question. And I wonder if there are any members who would like to take just a moment to address that. I'm thinking in particular, CDC, who in particular mentioned, 2 million people have downloaded that app as maybe one example of reasonably successful dissemination. But if there are others who would like to speak about how they try to ensure that--.

MS. MYRICK: Really quickly, if I can just jump in and say, I am one of those Act Early ambassadors . I'm the D.C.'s Act Early ambassador. And it takes a lot of hard work for us to get information out to the community, right? There are you know, a lot of -- I'm just going to speak for D.C. for a moment and say, there's been a lot of turnover, right?

We've heard a lot about workforce across all these different agencies and how we're really trying to reach folks. But there are a group of us. There are 60 of us. We're all across the country and we're doing this work. So, maybe that is something that needs to be taken into consideration as you are funding these various initiatives.

So, I just wanted to throw that out and

say that this is something that's like we're constantly working on. So, I don't necessarily think that everyone's going to have the answer right now, right?

But I think we really need to be thinking about this because the numbers are going up, right, which is amazing. Because now, people are getting the help that they need, if we can access it. If there is, individuals would have the skills to support the community.

DR. GORDON: I just wanted to just mention they have a dissemination. Go ahead and move on to the next. So, there's Morénike has a comment.

MR. STEVEN ISAACSON: Yes. Good morning. Morénike, in the comments section--Morénike, in the comments said, they fully agree with what Yetta has stated regarding dissemination.

DR. GORDON: Thanks. Scott?

DR. ROBERTSON: Yeah. And I -- by the way, I'm sorry that I forgot to mention that

I'm a senior policy advisor at ODEP. So, I forgot to mention my title earlier. So, sorry about that.

But, yeah, we take sustainability fully in mind with our REYAAS project and our other activities. And it's helping inform a longer-term work to empower neuro divergent people, including autistic people. And drive greater support for neurodiversity work through long-term policies and practices.

Sustainability is always a part of our work, employment of course partly because we take the long game, if you will. Because policy development takes many years off into shape and enhance. But I'm glad that that was emphasized.

And it's something that if other -- of -- our sister agencies, for instance, have other ideas for supporting our sustainability and scalability, we're always open to suggestions for enhancing that focus in our work on increasing access to employment and careers.

DR. DANIELS: Thank you so much, Scott. I also want to say something as National Autism coordinator and as exec sec of the IACC, that we do see IACC to amplify what agencies are doing. Every agency that is planning their program has some plans for their own dissemination. And they have their own audiences through their social media and other means.

But we also amplify that by having this presented in a public meeting. And as you know, our website is pretty extensive. There's a lot of information there. We have a newsletter, et cetera.

But if members of the committee have suggestions on specific kinds of dissemination that might be able to be accomplished through the IACC, you're welcome to just talk with me about it and we can look into that. But we do try to amplify the work of our agencies as well. Next --

DR. GORDON: JaLynn.

DR. DANIELS: JaLynn?

MS. PRINCE: Thank you. Can you hear me?

DR. DANIELS: We do.

MS. PRINCE: This is a very relevant conversation. I've been talking with some care providers and others through a big project we're working on with Madison House. And one of the big questions is dissemination and being able to get information. And we were wondering if there wouldn't be a possibility of a public-private situation so that things from various agencies could have an identification perhaps on a website, and also, private things that are being done.

There would be a need for curatorial work on certain things that are on there are sound. But there is a huge need and people wanting information, people may turn to IACC and there are wonderful things.

But there are some other innovations and different types of things that are happening across the country that others would like to hear about. Because we see a lot of good things happening in one area that should be shared in other areas. And there's not really mechanism and taking the knowledge base that somebody in one location has found that may be helpful across the country. Thank you.

DR. GORDON: Thanks. I think what we'll do now -- Dena is it quick?

MS. GASSNER: No.

DR. GORDON: I think we'll take our break now. There may be opportunities for continued conversation after the break. So, we're going to break now until 11:50 a.m.

(Short Break.)

DR. GORDON: We're going to go ahead and get started in one minute. If people in the room could take their seats, please. Again, if people could take their seats, please. We're going to get started. All right. Continued. Good morning to everyone.

The next section of our agenda today is for us to address outstanding IACC committee business. I'm going to turn things over to Susan to introduce our discussion for this morning.

DR. DANIELS: Wonderful. Thank you so much, Josh. I am going to start by giving Camille Proctor a chance to introduce herself. And I know that you just sat down, Camille, but we would love to hear from you as one of our newest IACC members.

MS. CAMILLE PROCTOR: Hello, everyone. My name -- sorry, sorry, sorry. Hello.

DR. DANIELS: Close to the mic.

MS. PROCTOR: All right. Hello, everyone. My name is Camille Proctor. I'm the founder and executive director of the Color of Autism Foundation. The Color of Autism Foundation, we support families and individuals in underserved communities throughout the United States. Our focus is building efficacy within the families as well as supporting autistic individuals on their pathways to their voices and choices.

DR. DANIELS: Fantastic. And do you want to say anything about your lived experience as well?

MS. PROCTOR: Well, certainly. I forgot

that part. I am a mother of a soon to be 18-year-old autistic young man. And I founded the Color of Autism Foundation because there was no organizations that looked like me. And there were no -- and when I say look like me, that could address the unique issues that were very prevalent within my community.

And I really got -- the best way for me to say this is that I got tired of them taking the one minority that was in their organizations and using them as a trope or a prop to kind of glaze over some of the issues that we do have in urban communities.

So, effectively, that's how and why the Color of Autism Foundation was founded. Because there's a definite need. There will continue to be a need. There's not enough minorities at the table. And so, I just decided -- excuse my expression -- to bring my own damn seat.

DR. DANIELS: Thank you so much, Camille. So, we appreciate having you on the committee. And also, we've had you as a speaker a couple of times on some of our panels. And you'll be contributing today as well. And we appreciate that perspective. So, we're going to move into committee business.

See if -- sorry. The -- it doesn't like me, I don't think. So, we -- I'm going to tell you some ONAC staff updates and talk about some of the documents that we've had that we've worked on recently, and our upcoming activities, as well as a summary of advances. Oh, there's a question from Morénike.

MR. ISAACSON: Morénike just added a comment as Shirley Chisholm says, "Bring a folding chair."

DR. DANIELS: Thank you, Morénike. So, next slide. So, the ONAC staff updates are; we have a new person on board on our team. Ana Cappuccio, who is also by training, an attorney, has joined the ONAC as our new operations coordinator. And will be assisting with administrative duties in the office along with Angelice Mitrakas, who most of you know, who is our management analyst. And they're going to be working on our administrative issues. So, you will be, I'm sure, in communication with Ana.

And also, I wanted to announce that Steven Isaacson, who's been on our team for a while now, recently got his master's degree in social work and --

[applause]

-- which is a wonderful accomplishment. And congratulations, Steven. And he's taken on a new role in the ONAC as our first Neurodiversity Liaison. He will be assisting ONAC with community outreach and projects that are related to issues related to neurodiversity, such as neurodiversity at work.

And we've really appreciated Steven's contributions to the IACC and our office's work. And wanted to really prioritize that outreach and connection with the community. So, thank you, Steven, for serving in that role.

Next, I want to share with you that the 2022 IACC Summary of Advances was published recently. And this was required by the Autism CARES Act of 2019. It provides lay-friendly summaries of the top 20 most significant advances in ASD/autism, biomedical and services research that were selected by the IACC. And includes articles addressing all seven areas of the strategic plan.

The full report can be found at the link that is provided on the slide and it's up on our website. It's in the carousel when you first log onto the website. And also, there's an easy-read version of the report found on the link below. And we did receive a public comment that mentioned that they didn't feel that the easy-read was easy enough to read.

We did boil each research paper down to one sentence and tried to use words that are readable by at least one sixth grader. I know my sixth grader could read it and understand it. We did not have a way to condense it into pictures. That was requested that it be depicted in pictures. But I think most research papers are very difficult to summarize in a photo or a picture.

So, that's the best we feel that we can do on taking a scientific publication down to a more condensed version, but we hope that it will be helpful. And I know I've received a lot of public comments as well that have been very positive and supportive of that. So, thank you so much.

Next, we have our upcoming activities, which we talked about at the last meeting. So, in October 2023, the IACC voted to focus on co-occurring physical and mental health conditions and their impacts on health outcomes for the 2024 IACC strategic plan update. Because we are required by law to provide some type of update. And we're going to do a deep dive into this particular area.

And the draft report on co-occurring conditions was actually initiated by the previous committee and will be used as the foundation for this report. As decided in

2023 by the current IACC, ONAC is going to work with the working group chair, Dr. Julie Taylor, to update the draft before it comes back to the IACC for review.

And in addition, ONAC has published a formal request for public comments on co-occurring conditions on behalf of the IACC per your request. And the results of that request for information will be shared at the next IACC meeting. And the IACC will have an opportunity to review the comments. And the final report, our goal is to get it out in 2024.

Next slide. So, this is a slide on the request for public comments. And it is open until February 14th. And there is a web form where you can submit your comments. To date, we have received 678 completed submissions. And we also have 247 incomplete submissions, where someone may not have pressed submit at the end or maybe they're still thinking or working on this.

We will reach out to those individuals

to try to get them to complete their comments. We have already captured the information in our database, but we don't want to count it as complete until the person has indicated that they're wanting to submit it. So, we will reach back out to them. You can still submit comments.

If you're having any kind of technical issues or difficulty with submissions, please write to our office and we can get you a personal assistance to help you submit your comment. And this is also in the federal register. And please feel free to share this with your networks widely.

If you need any kind of materials, like the email that we sent out, you need a copy of that so you can forward it by email, or if you need a social media graphic, let us know. We can help you out with that. But we would love to get as much input as possible so we can get the most timely update to this issue in our next strategic plan update.

So, steps forward with this include that

ONAC is going to categorize the feedback that was provided from this request for public comments and get it back to you in April. We will also work on updating the draft report and incorporating feedback from the request for public comments. And IACC members will be receiving the opportunity to review the draft and review the public comments.

And we will work toward this to finalize the report during this year. So, that's the end of committee business, which is pretty short. We did finish our big strategic plan update last fall and that has gone out already. We've completed the 2022 Summary of Advances. We are working toward 2023 which is the next item of business. But maybe I'll take a pause here before we move into the Summary of Advances to ask if there are any questions.

MS. PROCTOR: Sorry. I have another question. When you all look at the public comments, are you keeping track of what states and territories are actually submitting comments from?

DR. DANIELS: We have some voluntary information that is provided. We didn't ask them their states or territories. We asked for whether they might be an individual with autism, a parent, an advocate, a researcher, et cetera. So, we will have that information. They can voluntarily provide their name and organization if they wish. But I doubt that we'll probably have states and territories.

MS. PROCTOR: Yeah. Now, that I'm thinking about the form, I'm like, no, you wouldn't have it. So, sorry, about that question.

DR. DANIELS: It's also --

MS. PROCTOR: I'm just curious to know.

DR. DANIELS: -- in terms of privacy for us to collect too much demographic information on the person. So, if the person voluntarily gives us at least their name and their affiliation -- many people we found in the autism community like to have their names shared with their public comments. So, we want to give that opportunity for acknowledgment. Privacy is not always the desire of the presenter of the comment.

MS. PROCTOR: Yeah.

DR. DANIELS: But we also do want to protect the privacy of individuals that don't want their information shared. So, we will have that demographic breakdown for you in terms of how many autistic individuals may have submitted, et cetera, based on whoever voluntarily fills that part out.

MS. PROCTOR: Thank you, Susan.

DR. DANIELS: Anything else? All right. Well, we wanted to reserve a good amount of time for the 2023 Summary of Advances. Because last time, we weren't able to do that. Next slide. And I'm just going to go over the process before we move on. And I will hand it over to Josh.

So, the IACC members have been in the process of nominating articles that represent January 2023, to January -- well, December 2023. And today, you're going to discuss those nominations. And after this meeting is over, once you've discussed the nominations and decided if you're eliminating anything, adding anything, or have any comments on it, after this meeting, we'll give you the opportunity to vote on the top 20 articles to be presented in the publication. And all the remaining nominations will be listed in the back of the publication.

Our office, the ONAC, will work on preparing summaries of the articles and the draft publication. And IACC members will have a chance to preview it before it's published. And we look forward to helping you get this published out -- publication out in spring to summer 2024. So, thank you. And I'll turn it over to Josh.

DR. GORDON: Thanks, Susan. And thank all of you for your nominations. We have a grand total of 76 nominations, so 76 contributions to the scientific literature on advances relevant to autism. And I think virtually all of them represent absolutely wonderful contributions to that literature.

And our task here is to try to identify 20 that we will collectively put forth, as is our responsibility under the Autism CARES Act, to Congress, and to the public, as being representative of the kinds of advances that will change things on the ground for individuals, families, and communities with autism.

The process that we are tasked with today is not to go through each and every one of them. We can't make it through 76 if we wanted to discuss each of them. But what we're going to do is in each of the seven categories, is give you an opportunity to do one of three things for any of the nominations in that category that you feel it's necessary to bring up to this group.

So, we're going to assume at baseline that you can read and get a sense of the topic and the importance and the quality of the work from the abstract. So, I would like to say let's hear about three different types of categories. One, if there's an article that based upon our criteria, which is that, you know, it should be an advancement that's that worthy of expressing to the public.

It should be well powered with a well done rigorous study. And it should be primary research, not reviews of other literature. These are the criteria that we've agreed on, although we have made exceptions in the past.

If based on this criteria you feel it doesn't belong on this list, we should not be voting for it. Please raise that with us today. If there's an exceptional study in here -- they're all exceptional studies. But that, for whatever reason, the abstract doesn't convey that and you really think it's important to make a brief comment in support of that article, please do.

And similarly, a brief comment against inclusion in the final 20 on any of what you feel, again, isn't expressed well in the abstract, and you really need to make that comment.

So, let me open it up for comments on the body of nominations that are in the first category, screening and diagnosis, which is nominations one through eight on pages two to five of the document. Let me just open it up if there are any individuals on the committee who'd like to make a comment in one of those three areas. Dena?

MS. GASSNER: I just have a question for Dr. Frazier about his --

DR. GORDON: A little closer to the mic, please.

MS. GASSNER: Dr. Frazier's nomination for the eye tracking study. Do you have any idea what the sample size was for that?

DR. FRAZIER: It was well powered. I don't have enough --

DR. GORDON: Microphone. Sorry.

DR. FRAZIER: Yeah. It was well powered. This is the JAMA publication, I think. I don't --

DR. GORDON: Jones, Klaiman, et cetera --

DR. FRAZIER: Yeah.

DR. GORDON: Social visual engagement.

DR. FRAZIER: That's Ami Klin's work. You know, they've been doing this for a long time. It's very well powered. It was -- it's a preregistered study. I mean, they really did everything right in this work. Yeah. Go ahead, Alycia.

DR. HALLADAY: I'll add to say that there was an original study, and there was a replication study. In the replication study, there was a validation study that went to the FDA. It was across, I believe, at least four sites and almost 500 people.

MS. GASSNER: My problem is, I don't know how many people are in a site. That's why I'm asking.

DR. HALLADAY: I'm happy to send --

DR. GORDON: -- 199 enrolled children.

MS. GASSNER: Okay. That's what I was looking for. Thank you. Thank you, everybody.

DR. PAUL WANG: Yeah. Just in case others aren't aware, the PMIDs are clickable, I think, on all of these, so it goes through to the articles. So, the answers to Dena's question and many others might be able to be found that way.

I just want to make the point that there are two articles here from Jones, Klaiman, Richardson, and last author, Klin. The one that Tom nominated is number three. And that is the more recent, more mature, if you will, representation of the project. So, I would certainly favor number three over number four, which is earlier work from the same group.

DR. GORDON: I feel comfortable actually then withdrawing number four given the NIMH nominated it. And that number three, you're saying, is the more comprehensive example of that work. Okay. So, we will withdraw number four. We won't vote on that one.

Any others? I would like to just make a very quick comment about Pham et al., number seven on the list. This is obviously a really important area for coverage in the sense that it's about equity and inclusion of underrepresented groups in care models.

And the Get SET Early program is an evidence-based approach to the screen, evaluate, and treat model that we heard about a little bit earlier today as something that we think can really change the course for treatment in early autism. So, I just wanted to highlight that to make sure we understood this. This study addresses many issues that have been raised before this body in the past.

Okay. So, we'll move on then to the next set of nominations in the biology section, which goes from page 5 to page 11. Nominations number 9 through -- wow, 9 through 21. So, about 12 nominations in that area. Any comments, highlights? Any that you suggest might need to be withdrawn?

All right. Hearing none, we'll move on to the next section. Sorry. Go ahead, Paul.

DR. WANG: Sorry to be slow on the draw. A number of the articles nominated in this section represent work in animal models or in other kinds of experimental models, not in people. I wonder if you, Dr. Gordon, have any comments on the suitability of those papers for our voting?

DR. GORDON: Yeah. I think that's a really good point. There are a few in there, like number 18, that are done in humans. But when we're talking about biology, what we're looking for here -- from my perspective -- in this group and in appealing to the public -- it's one thing -- we're not trying to appeal to other scientists here and say, "Oh, this is a hot area of advancement or cool technology. What I'm trying to look at -- as I read these nominations -- is which ones are the ones that we should know about because they have yield the potential for translation.

And sometimes that's going to be in an animal model, because we can get at the mechanisms better. We can get down to potential targets for treatment. So, again, not to bias you in any way, but if I'm looking at one of the human studies by Schwartz et al. on Auditory Evoked Potentials in Adolescents with Autism, this is a step forward in terms of being able to potentially develop biomarkers. But it doesn't have the ability to then go in and ask, "Well, what are the molecular or cellular elements that we could target with a therapy, be it a drug or a stimulation paradigm?"

So, there are different advantages to the different types. So, I would be looking at those abstracts and trying to say, you know, which ones have the potential to develop into something that would be of use. That's how I would try to evaluate. And I think that can happen from animal or human. That's my own bias. Others happy to comment? Morénike, please?

MR. ISAACSON: Good afternoon. Morénike says in the comments, "Excellent question regarding the animal models. Thank you for asking as this is something that has been discussed in the community with varying opinions."

DR. GORDON: Okay. Is there no other questions or comments on the biology section? Yes, go ahead, Susan.

DR. RIVERA: So, I actually just want to follow up on this. And I'm glad Paul raised it. I think we need to look really carefully at the animal studies. I think there's at least one that I'm looking at, which is number 10, which is really using an animal knockout model of autism, and looking at behaviors in the mice that mimic or mirror behaviors we see in children, or individuals who are autistic. And I think that we need to take -- that's not that, that work isn't important, but is it one of the findings that's really moving the field in a different direction? I think I would argue that if you're looking at behaviors that you're trying to find in rodent models that we know are present in autistic individuals, that may not be one of the ones that we want to highlight on our list for that.

DR. GORDON: Thank you, Susan. I appreciate that. So, this is the Chen et al. article on aversive responses to touch in mice. And I agree with you that it's very important to understand that behavior in a mouse is very, very different from any human, and that you need some evidence of translatability at different levels other than behavior to be able to interpret much from the studies.

I think the strength of that particular study is the use of, in this case, a bona fide mutation, which we know in humans does lead to increased risk for autism. That's the fragile x mutation. But as you point out, the reliance on a behavioral readout, which can be challenging to translate from rodents to humans, social touch means something potentially very, very different in a mouse than it does in a human being. And I think we have to remember that.

Thank you for that discussion. So, as you go through those nominations, you can keep these ideas in mind, whether you wish to endorse any of those studies. We'll move on to the next set of nominations in the area of genetic and environmental risk factors for -- I should say factors, because it's not just risk. It's risk and resilience, which is on pages 11 to 14 comprising numbers 22 through 28. Any comments along the line, or questions on any of those nominations? Go ahead, Elaine.

DR. HUBAL: Yes. I just -- unfortunately, I haven't had the time to go through this thoroughly. But I do notice -- I do have some concern that some of these probably should not be promoted as -- you know, in this package, you know? So, even just the number 22, the PFAS one, excellent research group. And their findings, you know, are sort of -- they very clearly say they're a bit equivocal. So, I'm not -- I sort of -- in this area, especially when we're talking about some of the environmental exposures and chemical ones in particular, and the PM and things, since I'm not sure how it informs people's decisions or policies, especially when the findings are not, you know, so clear -- I guess I just want to sort of have that in the front of people's minds as they're looking at these. And I'll look more closely.

DR. GORDON: Thank you. I mean, I'm looking at the abstract right now as quoted in here -- not the abstract, the description of it. And it is -- does sound equivocal. "Blood levels were not strongly linked to any changes in SRS score. The sex differences in exposure was not robust." And the conclusion, "The need for further investigation could suggest that it's not ready for primetime."

DR. HUBAL: Yes, exactly.

DR. GORDON: Alycia, did you want to comment on this particular article, or do you want to raise a different one?

DR. HALLADAY: Well, it has to do with this particular --

DR. GORDON: Please, go ahead.

DR. HALLADAY: -- article, and the

question that was raised. So, I think, number one, you know, we get caught up. I want to warn us against voting down negative findings, right, so -- besides this. So, this can stand on its own, but it does have to do with equivocal findings, right? So, they didn't find an effect. Does that make it non-important because it wasn't a positive effect? It was a lack of an effect.

So, I think we need to, you know, kind of think about that. And then I did -- and I didn't know if her concerns were more because the outcome was autistic traits, not necessarily an autism diagnosis, per se. So, I -- you know, maybe you can provide some guidance about, is there a line, or do we use our own judgment about the line between autistic traits and an autism diagnosis?

DR. GORDON: Well, I think it's a great question. We're trying to determine whether, you know, we want to reject this outright, or just now you've heard some things about a weakness of the paper and maybe, you know, it's a recommendation that you not vote, but you can make your own mind up. And I think we're trying to figure that out just now. Let me just say that I think there is -- I agree with you 100 percent on negative findings, right?

There are some really important negative findings in this field, right, that can help reassure people, and that can guide policy decision making. I think the comment and question here is whether this is a negative finding, or what we would call an equivocal finding, meaning a finding that we cannot make conclusions from. And while those findings are important in the sense that it does say we need more research, do we want to put one of those equivocal findings, one that we can't make conclusions from forward as an advance, as opposed to recognize that it's important contribution we're not ready yet? Aisha, were you raising your hand?

DR. DICKERSON: Yes. Yes, I am.

DR. GORDON: Go right ahead.

DR. DICKERSON: Yep. Thanks. So, as somebody who works with the ECHO group, I can say that they were purposeful in using autism traits instead of an autism diagnosis, because they listened to autism advocates in saying that they don't want people to look at risk factors for autism, but instead, look at autism symptomology. So, they purposely looked at autism traits in an effort to work collaboratively with the autism community. So, I want to say that it's not we're avoiding looking at autism so much as we're trying to look at symptomology instead, because that's what has been requested from the community.

DR. GORDON: I saw another hand over here. I missed it. Was it Jenny, did you have a comment or question? Okay. We'll get you next. Let me just ask -- I'm not hearing a very strong consensus that we should remove this, right? Okay. But you've all heard some concerns about this.

Take that into account, of course, when

you make your decisions as to which to vote for. I do want to just ask if the -- since NICHD nominated it, whether Alice Kau, the representative for NICHD today has anything to say about the article Ames et al., number 22? Is there another alternate for NICHD on the phone?

DR. KAU: Hi, Dr. Gordon.

DR. GORDON: Yes.

DR. KAU: This is Alice.

DR. GORDON: Oh, yeah.

DR. KAU: No. We just saw it's a well powered study, and it's worth bringing up for IACC Committee's consideration, but --

DR. GORDON: Thank you.

DR. KAU: -- I definitely understand the issues raised and discussed just now.

DR. GORDON: Okay.

DR. KAU: Kathy, do you have anything to add to it?

DR. KATHY KOEPKE: No. Nothing to add.

DR. KAU: Good.

DR. GORDON: Okay. We'll move on then to

the next session -- section. Oh, sorry, Morénike, you did have a question or comment?

MR. ISAACSON: Yes. Hello. Morénike has two comments. They say, "We are not mice." And they also say, "I appreciate the term -- the use of the term traits, and the intentional efforts to be respectful in wording."

DR. GORDON: Thank you. Okay. And I agree with both of those comments as well. We will move on then to the next section, which is on interventions, which is located on page 14 through 17 of the document that you received. Nominations 29 through -- I can't find page 17, there it is -- through 36. Any comments or questions? Jenny, go ahead and start us off.

DR. MAI PHAN: Hi. For number 30, First Author Che, the intervention study doesn't look like it's specifically to autism, but neurodevelopmental disabilities in general, although autism was mentioned. But I'm wondering if the committee feels that this study is just too broad and not specifically autism.

DR. GORDON: That's number 30, Che. Is that correct? Yeah. Okay. Any comments or responses to Jenny's point? Are you suggesting that we might want to withdraw it, or just making the case? Okay. So, there's a suggestion that we should withdraw this because it's not specific to autism. Are there objections to withdrawing it? Go ahead, Susan.

DR. RIVERA: I don't have a specific objection to withdrawing it. And I think that's a very good point that Jenny brings out. Let me try this. Is it better?

Okay. Sorry. I don't have a specific objection to withdrawing it. I'm really glad that Jenny brought this up, because I think it's more of a -- sort of a policy issue for us to consider. I do want to just point out that the focus of the article is one that is potentially very practical advice for the public regarding diet, and its effect on neurodivergent populations.

But if we have a policy of choosing articles to -- you know, for this briefing that are only going to be about autism, I think we should save that policy and sort of keep that in mind when we are recommending them. If we don't have that policy, then I think, you know, that's a different question.

DR. GORDON: I don't think we have expressed that policy explicitly in the past.

DR. DANIELS: So, in past discussions, we have talked about trying to stick with autism. Just because if we started considering all different neurodevelopmental disabilities, it would potentially open it up to something very broad and would not be specific to autism. So, we have had those discussions, maybe not in this iteration of the committee, but it's happened before.

DR. GORDON: I might suggest, Jenny, that we go ahead and leave this one in -- with the recognition that -- and the point that you've made that it is not specific to autism and includes, in particular, ADHD, as well as other developmental disabilities, which might make the conclusions less broad. And if you're considering voting for it, you might actually look and see whether there was evidence that the subset of individuals -- that the risk of autism was lowered by the diet or not. And I'm guessing we probably can't make that conclusion from the paper, but I haven't read it myself to know.

DR. DICKERSON: I did look at -- I looked at the paper. And they do parse out the results by autism and ADHD and other known developmental disabilities. So, the details --

DR. GORDON: A little -- sorry. A little closer, Aisha, please.

DR. DICKERSON: Sorry. The --

DR. GORDON: Please.

DR. DICKERSON: -- details in the paper, they are stratified by specific neurodevelopmental disorders, including autism. So, the details are in the paper.

They're not in this description or in the abstract, but it's in the paper. Just in my glance about it.

DR. GORDON: And do you recall whether the effect was similar, stronger, or weaker in the autism subgroup?

DR. DICKERSON: Let's see. I can scroll down and look and tell you.

DR. GORDON: Okay.

DR. DICKERSON: It looks like the results were overall null, so no asssociation. But no associations are still important.

DR. GORDON: Okay. I'm sorry. I'm sorry, I'm not sure who nominated this one. But if the group that nominated it would like to speak up? HRSA?

MS. RAMOS: Nothing to add. But I think, in general, it's great. This group's gotten more and more thoughtful about the articles that are being submitted. And we're submitting more and more articles, which is I think making it harder probably to hold down to 20.

And so, if there are more common things that we should consider as we're nominating, that could be helpful going forward to. So, whether it's the sample size, whether it's the specificity to autism -- I think there's a range of things that, as nominators, could be helpful for us to consider.

DR. GORDON: That's a good suggestion. We'll work on some of that. I want to know if it's on this because, otherwise, I have Julie in front of you. But Dena, is it on this one?

MS. GASSNER: Put Julie.

DR. GORDON: Okay. Julie, you're next and then Dena?

DR. TAYLOR: My comment is not on this one. So, if Dena has a comment on this article, per se, we can do that one first.

DR. GORDON: No. They're new comments. Go ahead, Julie.

DR. TAYLOR: Okay. So, I had a comment on number 33, the Hatfield study, which is super cool. It's like looking at sort of exercise gaming to increase physical health, but it is a very small sample study, preliminary study. It looks like the n is five.

So, although I am really excited to see where this goes, I'm not sure that this study is definitive enough to be on the list. I wanted to know what everybody else thought. So, it's number 33, Hatfield, GamerFit-ASD beta test.

DR. GORDON: Any comments on that? Sorry. Is your mic on? I can't quite hear you.

MS. GASSNER: I would have to say that it might be helpful for us to create a criteria of the information that we need in this document to review this, because the vast majority of us are either not researchers, or we are at tiny, cheap universities that won't give us access to a meaningful library.

And so, I think I'd love to help you guys come up with like, what is the sample size? We need to know what the breakdown was by gender if we have it by -- you know, whatever those small criteria are. In this one, what's missing is the outcome.

So, that's probably in the article, but it's not here. And for those of us who don't have library access, that's a barrier. So -- but that was my concern along with Julie's about the sample size, you know? They didn't really put in this, at least here, what the outcome was. Was their improvement? It just said, "We did this," so --

DR. GORDON: All right.

DR. WANG: Dena, your concern is spot on. The outcome is not in the paper. They're merely saying that they adapted it to an age group. So, I agree with Julie's concern.

DR. RIVERA: I agree too. It was a feasibility study, essentially. So, echoing Dena, I think we need to be very mindful when we are nominating these articles and a list of criteria that we are made to stick to would be helpful to all of us, I think.

DR. GORDON: Absolutely. In the past, we have emphasized the need to include sample size, but perhaps we haven't done that enough. Would HRSA like to make a comment?

MS. RAMOS: No. It's -- that's fine.

DR. GORDON: Okay. So, I think we're going to withdraw Hatfield based on the small sample size, and the fact that it is a feasibility study as opposed to reporting out a result. We don't have a rule against feasibility studies, just to let you know.

But those two combinations, I agree with the consensus around the room that, that would be withdrawn. Paul, is it on this one or -- no. So, Dena, I'm going to go to you. And then we'll go to Paul. Okay. Paul?

DR. WANG: A comment on 35, and a question on 36. Thirty-five is a report of a study comparing two different intervention approaches, discrete trial therapy and JASPER. I think it's really unusual and -- but good to see direct comparisons of different therapeutic approaches. And it's something that's just extremely rare.

These studies don't get proposed. They don't get done. And it's great to see this published. As people can see in the abstract based on, I think, the primary outcomes, they didn't really see a difference between the two, which is a null result but interesting. But potentially, one of the therapies or the other was better for certain subpopulations.

So, I think this is actually an -- very important study from the perspective of sort of the sociology of science, let alone the results.

DR. GORDON: Can I just -- before you move on to your second one, I want to emphasize that, again, this is a topic which has come up in the past. I don't remember if this IACC or the previous incarnation with the notion that we need to be able to compare across available treatments to know which ones work better or equivalently or et cetera. So, thanks, Paul, for bringing that up. You had another one?

DR. WANG: My question about number 36 is whether it belongs in the next category, service and supports, rather than here? It does not report on the benefits or lack of benefit of an intervention. But it really seems to be talking about who gets behavioral therapies, you know, like sort of like the delivery of that particular kind of intervention.

DR. GORDON: I think that's a good point. It can be easily moved. Any other comments or questions from this section? Okay. Thank you very much. We'll move on --

DR. FRAZIER: A quick one, sorry, Josh.

DR. GORDON: Sorry. Go ahead, Tom.

DR. FRAZIER: Thirty-four is an example, in my opinion, of a study that has a modest sample size, but you really need to dig into the details and realize that this is a very unique subgroup with a really particular challenge.

And so, having 70 kids with 6000-plus aggressive behaviors observed is -- I just -- when people think about these things, I don't want them to just think about them very simplistically about what the number of people are necessarily, because this is a really important study that can't be done in thousands of people.

DR. GORDON: Yes. So, this is a study for those who are just looking at this for now, where they studied individuals with extreme, aggressive behaviors, and found that they were able to predict three minutes before the aggressive behavior was found based on biosensors those individuals wear when it would occur. And I think that, you know, we can all set for ourselves that we think that's a major advance. But, of course, studying individuals with aggressive behavior is another priority that was identified. We had a whole panel on it at the IACC, very compelling.

DR. HALLADAY: I just want to add that, yes, 70. But again, this was a study that was -- those 70 were basically pulled from multiple sites. So, this was a study where they really tried -- they really tried to get. And also, people that would -- there was -- you know, one thing that doesn't pop out, but should be addressed, is that there was a percentage of people that started the study that weren't able to wear the sensor. That doesn't mean this is a bad study. It doesn't mean that it won't help anybody.

And actually, I think this is one of the first to show that it was, in fact, effective, rather than just being a preliminary, what can happen?

DR. GORDON: Okay. Thank you very much. We will move on to services and supports, which is on page 17 to 28. A lot of nominations here. And that covers nominations number 37 to -- I don't see the split here -- to 23. Sorry, to page 23, 37 to 47. Dena, go ahead.

MS. GASSNER: I already apologized if I didn't read it thoroughly enough. But item number 38, it's looking at the disruption -- the pandemic disruption that people experienced in getting treatment and care. And my question is -- they found that autistic children were more likely to have unmet needs. I guess my question is, did they compare that to non-disabled kids?

I mean, didn't -- most of us defer medical care or dental care during COVID because of the risk factor. So, as a standalone without the comparativeness, I'm not sure what we're going to be able to get from it?

DR. GORDON: Would anyone from NIMH or SSA respond?

MS. GASSNER: It's article 38.

DR. GORDON: Yeah. I mean, my read of it is that it says that they compared to non-autistic children, but it's in the NIMH description. I'm not sure it's in the SSA one. But I haven't --

DR. CARTER: They did compare to non-autistic children from the article. Sorry, it’s Alice.

DR. GORDON: Thank you, Alice. Okay?

MS. GASSNER: Thank you.

DR. GORDON: Any other -- sorry. Morénike?

MR. ISAACSON: No comments on this section. On the last section, Morénike on Dena's point said, "Thank you for that point. Some of us are limited by paywalls at times."

DR. DANIELS: I just like to point out, the PMID is a hyperlink there that goes straight to the abstract on PubMed, which is a public website. So, you can at least get the abstract from there. But anytime you want the papers -- when we send it out for voting, we actually do send you the papers themselves.

But we can send it to you anytime you want if you just write to the office. We have all of those, but we don't want to flood your inbox with lots and lots of stuff. But the abstract is there. Next time, instead of putting PMID with a bunch of numbers, we're just going to write abstract here and make that the hyperlink to make it more obvious.

DR. DICKERSON: But also, a lot of the papers that are funded by NIH have a PMCID, where you can get access to the paper for free.

DR. GORDON: Okay. If there are no other commments, I just wanted to, again, highlight one that is in my mind responsive to the IACC input, and that's number 40, the Feinberg et al. paper. In fact, it came up today [laughs], the importance of family navigators.

So, family navigators are often desired and often advocated for. And NIMH and other of the NIH institutes are trying to develop the evidence base to support that. This is one paper that attempts to do that with a decent sample size of 339 families. Paul, did you want to comment on that?

DR. WANG: Yeah. I just have to educate myself on this paper, because I liked very much our 2021 Summary of Advances winner from the same authors. And it seems like it's the same project. So, I would just want to read very carefully what's new in this one.

DR. GORDON: Thanks. If you could let us know, we can promulgate that too. Okay. Then we'll move on to the next section, which is on lifespan. And it goes from page 23 to 32, and articles number 48 to 69. Any comments questions or points on any of those articles on lifespan? It's wonderful to see so many of them. Go ahead.

DR. RATTAY: While it may seem a little self-serving, I want to give a shout out to our colleagues Hughes et al. at CDC. As Matt Maenner said today --

DR. GORDON: Sorry, which number is it?

DR. RATTAY: Sorry, 53. Fifty-three, which this year has really been our first -- the first time we've been able to look forward in the ADDM Network, youth and young adults. And this one specifically looks at education, transition planning for youth and young adults using the ADDM Network. So, we think it's a really helpful contribution.

DR. GORDON: Thank you. Scott?

DR. ROBERTSON: Yeah. Thank you. Question and couple of comments about ones that I nominate. Where's the boundary also between supports and services and lifespan, because I put mine for employment into the lifespan? I wasn't sure in terms of sometimes where the dividing lines are on that. And I also just wanted to just highlight a couple of the ones that I nominated.

One was on -- one of my five was on masking, which I think has come up a lot recently in terms of committee's focuses and discussions on things related to socialization and communication and other aspects of life experiences. And this was quite groundbreaking in terms of looking at masking in the employment context is the only study that's ever done that, and has a pretty significant sample size. And looked at masking not --

DR. GORDON: Scott, can you tell us what number you're talking about?

DR. ROBERTSON: Oh, I'm sorry. That's number -- I believe, 61. It's the article by -- I'm bad with names, but Pryke -- what is it? Pryke --

DR. GORDON: Pryke-Hobbes.

DR. ROBERTSON: Pryke-Hobbes, The Workplace Masking Experiences of Autistic, Non-autistic, Neurodivergent, and Neurotypical Adults in the U.K. And the sample size was 472 folks, so that's pretty significant, including of that group 285 autistic people. And the rest were other neurodivergent folks and non-autistic people.

And that was very eye opening from the qualitative research perspective in that study. And the findings are really helpful in terms of I was learning about barriers that stem from masking, and how it impacts folk's mental and physical health and well-being.

And the other article that I wanted to highlight too was the unrelated kind of social kind of aspect of things, the number 66, on Szechy, I think, S-Z-E-C-H-Y. I don't know how you pronounced it? Is that Szechy? That talks about the double empathy problem and perceptions in the workplace.

And this was especially meaningful, but

only because that there's a growing literature on the double empathy problem in terms of that communication, social issues stem. Not just from autistic people's difficulties, but differences in perception and processing among autistic people and non-autistic people. And that creates a lot of the barriers experience.

But the fact also that it highlighted how autistic people are often better sometimes at reading into certain situations, and the storyline -- the big net that they had, that's actually the result that was found in this study. That autistic people actually understood the perspective better of the autistic person in the workplace than non-autistic people.

And that shows in terms of differences in terms of perception, empathy, in terms of processing that situation comparatively. And it's good evidence base for advancing that double empathy problem in regard to the workplace and just overall.

DR. GORDON: Thanks, Scott. And then answer to your first question, these categories are meant to be applied to our -- the categories in our strategic plan for autism research and services. So, you know, I think this one, for example, the empathy one is -- you know, one that is -- particular in this case, two adults with autism, although there may be similar effects in children.

So, I think it's appropriate to the lifespan. But that's what I would look if you're trying to figure out which area to nominate in. Does it apply to issues raised in which chapter, if you will, of our strategic plan. Julie?

DR. TAYLOR: Hi, again, everybody. I have two papers that I just wanted to say a really quick word about. The first is number 52, the Hong paper. And in full disclosure, I was involved in this paper, although sort of as a minor role. But I think it's really important that I just want to sort of make clear.

So, this is looking at sort of

development and change over time among adolescents and adults using data collected over 22 years -- a longitudinal study of 22 years. The youngest people were 10 at the start of the study, and the oldest people were 69 at the end of the study.

So, we used an accelerated longitudinal design to characterize trajectories over -- what is that -- 40, 50 years of the lives of autistic adults in the sample. And what we found is that there are some worsening of some developmental trajectories across some areas when we get into midlife and in early old age.

So, most of what we know about development in autistic adults is from early adults and early adulthood. And so, starting to understand how things may change when people move into older adulthood, and what the needs of older adults who are autistic, may -- what needs they may have, I think, is something that we don't know much about. That this starts to tell us a little bit. So, I just wanted to mention that.

And then 68 is a study that I nominated, but I was not involved in. And this is looking at employment outcomes for autistic college graduates. And the reason why I thought this was important is because I hear people throwing around statistics all the time about the rates of employment for autistic college graduates. And I don't know of a single study before this one that actually has looked at that in a rigorous way.

In fact, when I tried to trace it back, recently, I traced it back to a blog post that somebody had, that now people are kind of citing. Oftentimes are saying 80 percent of autistic college graduates are unemployed. So, this study actually has some pretty rigorous data -- population based data on the employment rate of autistic college graduates.

It finds that unemployment is high. It's not 80 percent. But I think it starts to give us a feel for what this transition from college into employment looks like for this group, and where the needs might be. And maybe there's another study that's looked at this, but I haven't come across it. So, I thought it was important.

DR. GORDON: Thank you, Julie. Jenny?

DR. MAI PHAN: May I make suggestion when organizing the papers for us to decide on? Can we organize it by maybe age group, starting with adolescence, then transitions, and then adults and then maybe the -- like, the study that Julie mentioned, where it includes the entire lifespan almost, because that will really help with deciding, you know, selecting the 20 articles to be included. Thank you.

DR. GORDON: Thanks. That's a good suggestion. Dena?

MS. GASSNER: I want to go back to Julie's study. That she was just talking about 52 about the changes over the lifespan. And I just want to say, from a policy standpoint -- from a policy standpoint, we really need to hold on to this kind of an article.

Because it reflects that while a person in early adulthood may have had some cognitive capacity, leaning toward more self-sufficiency, that can be held against them in seeking community-based interventions later on, when we hit that deep well in the bottom.

I'm not one of those people hitting that deep well. I'm 65 and just finished my PhD. But I've had reporting from a lot of autistic adults, who find that between burnout and then just constant onslaught of demand for self-sufficiency and independent living skills, they really, really struggled to sustain that.

So, I think, from a policy standpoint, we need to figure out how can we increase services, or provide services to people who may not previously have needed them? I think this research article support us asking for better and enhanced outcomes there.

DR. GORDON: Thank you. Morénike?

MR. ISAACSON: Yes. Good afternooN. Morénike says, "They wholeheartedly agree with Jenny's remark. Additionally, what Dena stated is very true of many individuals in the community."

DR. GORDON: Thank you.

MS. GASSNER: One more quickie. On 56, the article about self-harm, I just want to really point out the inordinate rates of self-harm around autistic females in this study. I don't think it's rare. I think it's the rule rather than the exception. And I think delineating this kind of self-harm separate from self-injurious behavior is probably not helpful.

If you're hurting yourself, you're hurting yourself. And those categories of separating and delineating it out, don't seem to be particularly helpful. But I appreciate this. I want to champion this article, because I think that number is really life altering, 86 percent is inordinate.

DR. GORDON: Sorry. Just so you know, it's 83 percent increased likelihood, not an 82 percent overall likelihood. That's still tremendous. It's nearly a doubling. And it is a doubling of suicide deaths for females. So, these are big numbers. Paul?

DR. WANG: Just looking for guidance from you again, Dr. Gordon and Dr. Daniels. A number of these studies are from outside of United States. Sweden, United Kingdom, Canada, Australia, do we need to take that into account as -- at all as we think about this, or no, we can simply ignore that fact?

DR. DANIELS: So, in terms of our charge from Congress, it's really to identify scientific advances. So, it doesn't say only from the United States or funded by U.S. funders. So, I believe that you can nominate anything that you think is a really important advance you think Congress and the public needs to know about.

MS. GASSNER: In addition to that, we have to recognize the difference in the educational systems internationally. Voc rehab doesn't exist in many of these countries.

Not going to college is very common, for example, in the U.K., among the regular population, as compared to the U.S. where it's almost expected. So, as we weigh international studies to include -- I think we need to weigh all those extra factors.

DR. GORDON: Yeah. And if I could just generalize from those particulars to the -- what we would not want to do is vote for, or put forth applications that we don't think are generally applicable, whether we talking about that generality being on a global scale, or in the United States. Alycia?

DR. HALLADAY: I want to put in a plug for number 52, again, for a different reason, though. Because if we want to kind of like promote to the higher up, so to speak, the type of research that we need to do -- and this isn't the short -- that isn't the short game. This is a long game. This is longitudinal studies.

This is tracking individuals over time for an extended period of time, which is hard to do. It's expensive, but it's incredibly valuable. And it's not that -- it's not -- you know, it's not that other studies shouldn't be done, it's that this is the sort of study that we need to continue to invest in, the longitudinal design. So, for that reason, I would check.

DR. GORDON: Okay. Thank you. We're going to move on. Scott -- we're a little bit worried about time, so please keep your remarks brief. But go ahead, Scott.

DR. ROBERTSON: Yeah. Just very briefly, I just wanted to note that the -- I suggest that we keep the focus allowing for international research. Because I think if we had to restrict only the American, like U.S. funded research, then it would really hinders a lot, for instance, on the lifespan area.

A lot of the research on employment Community living focuses does come out of the

U.K. and Australia and other countries. And we have a gap sometimes in some of that research here in the U.S. So, I think it would really hinder us a lot if we weren't able to have those studies from outside the U.S. Thanks.

DR. GORDON: Thank you. Aisha?

DR. DICKERSON: Green then it turned red? There we go. Okay. So, I also wanted to point out that a lot of studies outside the United States are still funded by NIH. My studies are in Denmark. They're funded by NIH. So, I don't think that we should discount studies just because they're outside the United States.

Also, I want to put in the plug for the biological studies this year. Because last year, you all just kind of toss those out. And they're important to me. So, if you all would just consider the biological studies this year, I would really appreciate it. Thank you.

DR. GORDON: Thank you, Aisha. All right.

We are on to the last section, which is the infrastructure and prevalence, pages 32 through the end, numbers 70 through number 76. Any comments, points to bring up in that collection. Dena?

MS. GASSNER: I want to talk about article number 72. And I just want to point out one specific point. I'm sorry, there's no paragraphs for me to help refer. But it says, "The largest increase in Medicaid uptake. over the nine years they study was in the 25- to 34-year-old range."

And I think that's significant, because that's the age -- as somebody who helps people get on social security disability, that's when parents say, "This isn't working. We tried college. It didn't work. We tried employment. It hasn't worked." And that's the age around 25 is the point where a lot of people have to defer to systems.

And so, I think that's a significant statistical piece of evidence there for us to weigh in regard to policy and accessibility.

DR. GORDON: Thank you. You know, I want to point out one thing. You know, this is the increase in the prevalence of autism amongst Medicaid-enrolled adults. So, I think I don't want to be too pollyannaish. But it does suggest that whatever we're doing is working if more of them are getting into Medicaid. May not be working enough, but it's working.

In particularly, absolutely -- I don't see a state by state analysis here. We have other research that NIMH has done that showed where Medicaid has been expanded in those states. We see better accessibility of mental healthcare. And I don't know if those subanalyses are in this paper. But that's something to think about. JaLynn?

MS. PRINCE: Thank you. Number 70 is rather important, I think, at least these steps, because it goes into what you're talking about longitudinal studies, because the terminology of profound autism right now is becoming much more in the conversation.

But we don't have any idea about what

happens with children. And for lack of a better term, do people mature or grow out of particular types of behaviors? And is that because of physical or emotional or brain functions? We don't know.

And it's hard to treat something and provide resources unless we understand more about it. So, I think things like this and then going into longitudinal areas, so we can understand what the implications are for the individual through lifespan. Thank you.

DR. GORDON: Thank you. Morénike, did you have another comment? I see a hand up.

MR. ISAACSON: Morénike thanks Aisha Dickerson for their insights. Also, concurred with Dena's past comment about self-injury. And they also clarified their name. It's Morénike.

DR. GORDON: Thank you, Morénike. Any other comments? Okay. Thank you very, very much for your considered discussion of these nominations. And as Susan mentioned, our next task will be to vote on them.

So, please, if you've been taking notes or listening carefully, jot things down now, so you can take these comments into consideration. I know I've been doing it and -- when you do file your votes in the next couple of weeks. I'm going to turn it back over to Susan to close out the committee business section and tell us about lunch.

DR. DANIELS: Thank you so much for a great discussion on the nominations. And we were carefully listening to feedback. We will do our best to try to incorporate feedback where it's possible, and, of course, to try to make things as accessible as they can be.

So, next, we have lunch, which is everyone's favorite session. We have the Pike & Rose across the street, where there are restaurants for those who don't have a lunch. There are some people who ordered your lunch, and that's being delivered here.

So, if you're waiting for that, you can probably go up to one of the staff, or out to the front. And they will be able to help you with that.

And I've been told we're allowed to eat in here. We're also allowed to eat in some of the rooms in this corridor if you would like to use that. Anything else that I need to mention?

DR. GORDON: I would just say that, at 1:45 p.m., please be back promptly because we have three oral comments, as well as a review of the written comments. And we want to leave plenty of time for discussion of those comments. And I look forward to seeing you back here at 1:45 p.m.

DR. DANIELS: Thank you, everybody.

(Whereupon, the Subcommittee recessed for lunch and resumed at 1:45 p.m.)

DR. GORDON: We're going to get started. It is 1:45 p.m. If people can come take their seats -- we would appreciate it -- to make sure we have a full time for oral comments. Again, if people could please take their seats.

All right. So, we are now going to

proceed into our oral public comment session. We will have three oral commenters, as well as a summary of the written comments and committee discussions. I want to welcome our oral commenters. Are they going to -- are we going to have them come up to the podium or -- they are virtual. They are all online. Okay.

We are going to ask each of you to make your comments. And please hold your comments to three minutes to make sure that each of our commenters have time to speak. And then, we hear our written comments, and we have time for the IACC to dicuss.

Again, the three commenters we have are: Nicole Corrado, Anthony Tucci, and Jordyn Jensen. And I hope I'm pronouncing those correctly. And we're going to start with Ms. Corrado.

MS. NICOLE CORRADO: Hi.

DR. GORDON: Hello. Go right ahead.

MS. CORRADO: Okay. Hi, I'm Nicole Corrado, and I'm based in Montreal, Quebec, Canada. I am autistic, and have personal lived with elopement behavior and the missing persons system.

I was so frustrated with the system when I lived back in Toronto, that I joined the Toronto Police Service's Missing and Missed Implementation team as a civilian adviser. And I am now working on a study regarding elopement behavior with the University of Waterloo.

I hope to keep in touch with the IACC on information regarding autism, justice and major case management situations like missing person cases.

Most research on autism and missing persons regards hyperactive children wondering off, and does not interview autistic persons on their perspectives. As a result, data is little to non-existent regarding missing persons in the neurodiversity. I am researching this very subject and would like to keep in touch with you on this data.

My main frustration with how my missing persons file and bulletin were handled in 2016 was in regards to mental age theory. Mental age theory must be avoided at all cost, and it can be replaced with more respectful terms like, support needs. And Ivanova Smith has a great YouTube video on that very subject.

It is essential that a person's privacy be respected when reporting a missing person. No one wants to have their entire personal profile googled after ten or twenty years associated with the worst day of their live.

Toronto has a first names, no gender model, which is very useful for people who only have first names. Like, some Indigenous people only have first names by their own cultural choice.

Their first name, no gender models started after missing transgender persons where being misidentified as the wrong gender. And I am happy that Toronto is moving forward on this.

And I had said before, there are far too many police programs that talk to agencies but not autistic people. Please, contact autistic persons whenever possible when developing police public safety policies.

And people go missing for many, many reasons. Some people go missing because of abuse at home. And one of the things I should point out is that women shelters must be made sensory friendly, and allow animals. Many women do not want to leave an abusive situation because they're concerned about their animal's safety.

So, there is a project in Chatham Kent called, Purple Leash Project. That's in Canada. But they have similar things in the United States. I also mentioned that many parts in Canada and the United States have vulnerable persons registries. There are different views on such registries. I choose to be on them but some people don't want to be.

Not being on a registry should not cause a missing person to be deprioritized. Vulnerable person registries must be fully voluntary whenever possible, free, have easy self registration for people with a lot of autonomy, and be separate from incident report software. So, they need to be written in plain language and --

DR. GORDON: Ms. Corrado, can I ask you to wrap up your comments? Thank you so much. But can I ask you to wrap up?

MS. CORRADO: Thank you. Yes. I would love to discuss more with you guys on this topic and --

DR. GORDON: Thank you. And we very much appreciate your input.

MS. CORRADO: You're welcome.

DR. GORDON: Next, I will ask Anthony Tucci to unmute. Thank you very much. Please, go ahead and proceed.

MR. ANTHONY TUCCI: Thank you for the opportunity to present the oral comments today. I'm the parent of a 20-year-old son who has autism, and is a nonspeaker. My comments today will focus on the appropriate interplay between communication science advocacy and the advocacy for the protection of communication rights.

This topic had become highly relevant due to the fact that disagreements among some members of the scientific community have given rise to an unbounded form of scientific advocacy, that attacks individuals with autism who use communication methods that advocates claim to lack scientific validation.

To protect the human and civil rights of individuals, speech and language professionals are compelled to master how science can properly enlighten the field of autism without compromising communication rights.

In exploring this challenge, I will begin by highlighting the essential role that scientific research plays in helping to promote and advance effective communication interventions.

Commmunication is a fundamental feature of humanity. Scientific research continues to develop affective approaches and technologies to help individuals with severe communication challenges.

However, research process is slow. Many research gaps continue to exist. To meaningfully addresss this shortcomings, the communication science industry should colloborate, and engage in cross-disciplinary research with a broad array of medical disciplines to replace research gaps with genuine wisdom that will stem from this required integrative approach.

The recent NIDCD Conference that focused on exploring research directions for the promotion of speech and language, represents a great step in this direction.

Next, I want to showcase how unbounded scientific advocacy has compromised and impaired the human and civil rights of individuals with autism. Conventional wisdom allows us reasonably conclude that the application of science, and the great potential for scientific progress will lead to improvements of the human condition.

However, unbounded scientific advocacy limits communication rights, deprives individuals of their dignity and autonomy, and represents a form of science and it's greatest dicontents.

A select group of so-called scientific advocates blazingly interfere in the lives of certain minimally verbal and nonspeakers that have merely selected a preferred mode of communication that opponents do not support, such as spelling to communicate.

And claim that these methods do not qualify to be protected as human rights. Because one, they lack sufficient validation. And two, are prompt dependent, and will not result in independent communication.

However, these requirements are not supported by the human rights convention, are discriminatory, and violate the American with Disabilities Act. Simply stated, the scientific community is not the appropriate gatekeeper of human and civil rights.

They do not possess the knowledge, or the legal authority to define or redefine the parameters that individuals with autism must satisfy to be permitted to exercise their communication rights.

A world leading expert on disability law and policy has opined that every provision under the U.N. Convention on the Rights of Persons with Disability "is aimed at expanding person with disabilities available options, not circumscribing that, and that demanding respect for their choices, not overriding that." In the same spirit --

DR. GORDON: Thank you. Can --

MR. TUCCI: -- the ADA serves to ensure that disabled individuals enjoy an effective mode of communication that is equal to that enjoyed by non-disabled individuals.

And specifically requires that primary consideration be given to a disabled individual's communication choices and preferences. I offer the following recommendations --

DR. GORDON: Thank you. Please, could you just quickly -- excuse me.

MR. ANTHONY TUCCI: -- to help the community work together.

DR. JOSHUA GORDON: Yeah. Mr. Tucci, if you could wrap up please. Thank you.

MR. ANTHONY TUCCI: Yes, I will. The formation of workshops and communities to foster legal and scientific communities to work together.

I proposed additional regulatory guidance by the justice department that will compell the scientific community, including speech and language professionals to properly and fully disclose all communication rights.

Thank you for the opportunity to speak. And I appreciate all your advocacy on behalf of individuals with autism.

DR. JOSHUA GORDON: Thank you very much for your comments. Finally, I'll ask Jordyn Jensen to unmute, and to present your comments.

MS. JORDYN JENSEN: All right. Hi, my name is Jordyn Jensen. I'm the executive director of the Center for Racial and Disability Justice at Northwestern Pritzker School of Law. Our center is entirely disablity led.

So, in response to the IACC's 2021 to 2023 Strategic Plan and the scope of this meeting, we submitted a public comment letter regarding interactions of autistic individuals with law enforcement.

We'd like to share evidence-based research to inform a responsible and equitable approach to addressing the committee’s priorities at the intersection of race and disability, moving forward.

Disabled people, especially, autistic people face high rates of victimization, which increases the likelihood that they will interact with law enforcement, and the criminal justice system.

In interactions with law enforcement,

autistic people may demonstrate non-normative behaviors, which can be interpreted as resistance or non-compliance. This can cause police to perceive a situation as threatening, or dangerous, leading to the use of excessive force.

And quoting our faculty director, Jamelia Morgan, and particularly her paper on Disability's Fourth Amendment, "Disability related behaviors create pathways to excessive force by police."

This is true when for instance disability is coded as threatening and potentially dangerous, not because of any actual threat or danger, but rather because officers interpret disabled people as exhibiting behaviors that do not align with the dominant social norms.

You'll surely recognize racial disparities in policing. Black Americans are five times as likely to report unfairly stopped by police than white people. And police disproportionately threaten or use force against communities of color.

It's also important to take into consideration, the social and historical context within which this discussion is taking place.

Police have a long and complicated history when it comes to interactions based on race and disability, respectively, and especially, where they intersect. Througout history, police have been used as a form of race-based social control. And we see this element of social control exhibited today.

Concerns regarding autistic tendencies such as wondering, elopement are responded to with policing, and surveillance. Yet, inadeqaute consideration is made to the relational power dynamics inherent in these interactions.

So, going back to interactions between police and disabled people, 50 percent of people killed by police officers are disabled. And when people of color, autistic people, and those at the intersection are killed at the hands of police, jurisdictions tend to respond by pushing for more police training.

Similarly, in conversations around autism and safety, autism-specific training for law enforcement is seen as the key solution. But despite police departments' increasing disability and unconscious bias trainings, autistic people, especially autistic people of color, continue to be met by police with force, coercion, and even death.

So, we need to shift away from advocating for more police training and toward investing in communities and amplifying the voices of autistic people of color. Additionally, law enforcement training can actually serve to reinforce stereotypes and inadvertently heighten biases. Encounters with police can be traumatizing for anyone, but autistic people in particular, especially autistic people of color.

So, instead of relying on and

encouraging more police training, we urge the IACC to prioritize the perspectives and voices of disabled people of color and involve them more in these meetings and discussions. For any conversation happening about autistic people, they should be recognized as the experts on issues that are directly impacting them.

We also recognize that concerns for autistic people's safety are real and important, but believe that other solutions should be prioritized, given the extensive literature and conversations around police training, causing more harm than good. It is essential to recognize the --

DR. GORDON: Thank you. Ms. Jensen, can I ask you to wrap up please? Thank you.

MS. JENSEN: It is essential to recognize the history of these systems and instead invest resources in the communities and organizations led by disabled people of color. We recommend reading our whole letter, which was submitted. Thank you.

DR. GORDON: Thank you very, very much. Thank you very much, Ms. Jensen, and to all three of our oral commenters. I'm now going to turn it over to Susan for a presentation of the written comments which you each have received in the file sent in events and to you.

DR. DANIELS: Yes, and I'm going to have Dr. Oni Celestin from ONAC share the written public comments with you.

DR. ONI CELESTIN: Good afternoon, everyone. We received 13 written public comments for this meeting on the following topics. We received three comments on justice and law enforcement; two comments on research services and supports for adults with autism; two comments on research and service needs, resources, and policy implications.

Two comments on addressing the needs of autistic individuals with high support needs; one comment on mental health research services and treatment; one comment on concerns about medical practices; one comment about increasing autism acceptance and reducing stigma; and one comment on the needs of the direct support professional workforce.

And again, all the comments can be found on our website. Thank you.

DR. DANIELS: Thank you. Yes, in the materials section, you can find the full text of the comments for anyone who wants to look at them.

DR. GORDON: Okay. We're now going to open it up to the committee to discuss the comments made. You may discuss any of the written or oral comments. And please raise your hand or -- yes, go ahead, Yetta.

MS. MYRICK: Okay, it's on now. I'd like to thank everyone who has provided both oral and written comments. I want to highlight for the group Rose Baumann's comment, the written comment, where they express that "Our has family has needed to call 911 more than once for helping keeping everyone and everything in the home safe during an aggressive episode.

Unfortunately, law enforcement is often ill-equipped to handle individuals with disabilities, causing them to be dysregulated." So, I just want to highlight that comment, because this is something that is being talked about in the community and my local community, in the community at large.

And so, I really just want to say that it's going to take everyone working together, and I'm really excited about the presentation later. Laurie Reyes, I know about your work in Montgomery County, so I'm really excited to hear what you have to say specifically. But yeah, it's going to take all of us to work together to get this together, right?

Because we can't have folks dying because they have behaviors, and it just -- it sickens me, right? And so, yeah, I'm just really excited we're having this conversation today. Thanks.

DR. GORDON: Thank you, Yetta. Dena.

MS. GASSNER: I just wanted to bring up or emphasize Nicole LeBlanc's crisp, explicit comment. We need support for HCBS adults who do not have nursing level of care. Autism is a dynamic condition. The support --

DR. GORDON: Sorry, Dena. Can I just ask you to spell out that acronym?

DR. DANIELS: Home and community-based services.

DR. GORDON: Thank you.

MS. GASSNER: Yay. Again, autism is a dynamic condition, and the needs for support services ebb and flow. I have a colleague who recently relocated for the dream job of her lifetime. And the process of simply relocating and unpacking and trying to move some of those services to a new state is on the edge of costing her her job.

And so, the we need to switch our ideas about nursing level of care to episodic and intermittent needs. I think, from a policy standpoint, we're going to be getting many, many people off the rolls of unemployment and out of social services if we can switch to the idea of episodic support.

You know, I'm about to relocate. I'm going to hire people to do that. It's going to put me in debt to do that. And I'm living on $900 a month, right? We can't continue to keep people out of the workplace and out of opportunities because we just assume that their needs are constant. Thank you.

DR. GORDON: Other comments, people online, people on the Zoom can raise your hands, and I can see you. Go ahead, Alycia.

DR. HALLADAY: I'll let someone on the Zoom jump in first.

DR. GORDON: All right. Sam, but I've got you next.

DR. HALLADAY: Okay.

DR. GORDON: Go ahead, Sam.

MS. CRANE: Yeah. I wanted to talk a little bit about the commenter who was discussing communication supports, because this is something that I have seen in practice, and it really can cause issues on an individual level.

There are researchers who, without, you

know, evaluating or interacting with individual people who use typing to communicate, engage in sort of public denunciations, and, like, harassment of individual people who use typing to communicate.

I think that's really inappropriate and I think that it it blurs the distinction between what I would say is sort of the research focus, which is, you know, replicability, you know, ensuring that we see things happening at scale, predictive -- you know, getting -- understanding things at a population level versus individuals who I think are are more -- when you want to look at whether an individual has valid form of communication.

Where, in fact, they are communicating, the questions end up being different. And I think it would be really useful for -- in the communication sphere, getting a coalition of researchers and stakeholders together to determine best practices for addressing whether an individual is communicating in a way that is authentic.

I've seen people communicating in ways that are completely idiosyncratic and special only to them.

And so, if we had a norm where, you know, we're only recognizing communication that looks exactly like a form of communication that's in a peer-reviewed study, we are going to have negative outcomes and we're going to be ignoring communication from individuals who are communicating.

So, you know, getting a more nuanced look into individual communication and developing guidelines for determining whether an individual is showing authentic communication would be a really important topic, I think.

DR. GORDON: Thank you, Sam. I like the way you put that. I think there is a challenge here, and it's a challenge which affects even the work that we do at the IACC.

The challenge is that we want to

advocate for investments and services for individuals with autism that work for them, for their families, for their communities. Yet we recognize, of course, that there's not unlimited resources to provide those services.

In fact, we need lots more resources, even for the services that we know absolutely work for everybody, or at least a lot of people. And so, there is, if you will, a competition -- a de facto competition, unfortunately, for scarce resources in this area. And I think what you therefore rely on is some evidence that things work in order for the public to invest in those services.

At the same time, Sam, you're 100 percent correct in that -- and this is something that's faced across medicine for individualized precision medicine, is we need ways to understand whether things that work for a small group of individuals can actually work for that small group of individuals, and can even, more importantly, as you pointed out, be tailored to specific things for specific individuals.

And I think this is a tension that we face. And it may be something we need to come back to as an IACC, although I also appreciate the recognition that institutions like NIDCD, the National Institute on Deafness and Communicative Disorders, which is very interested in communicative assistance devices for individuals with autism and funds research in that area.

I think for them to hold meetings like the one that was lauded are steps in that right direction. So, I really appreciate that comment, Sam. I want to -- yes, Alycia, I want to go back to you.

DR. HALLADAY: Sorry. So, for -- is Mr. Tucci still on the line?

DR. GORDON: I don't know, but go ahead.

DR. HALLADAY: Or was that a pre-recorded message? Well, his comment and then also his statement referred to something called scientific advocacy.

So, I wanted to get maybe a clear sense of what he was talking about. In the spirit of open communication, I wanted to get kind of more of a clear definition. What does he mean by scientific advocacy, and what -- why is -- there seems to be something I'm missing.

DR. GORDON: Mr. Tucci, can you unmute and respond? No, he's not on anymore. Let me make an attempt, unless someone else around the table would like to sort of suggest what might be meant by that term, or online --

MS. CRANE: If he's not still on the line, I am pretty sure I know what he's talking about.

DR. GORDON: Go ahead, Sam.

MS. CRANE: Yeah, there's -- you know, it's a specific -- I don't want to, you know, call anyone out. But there are specific people who, you know, do research in this field, who, who, who also sort of then go into policy advocacy.

So, not -- and I really appreciated the

way that Dr. Gordon was phrasing the distinction between, you know, deciding what we want to invest in with limited dollars to support supports, versus making, you know, let's say clinical or rights decisions about an individual person who's found something that works for them.

And I have definitely seen individual researchers who go beyond advocacy around what needs to be supported. And into like, specifically, you know, if a person was trying to gain a reasonable accommodation at school or at work or even in a court case, they will insert themselves into that controversy.

And advocate against access to that form of communication based on their understanding of whether the form of communication is research-based. And I do have concerns about that.

DR. HALLADAY: So, I don't want to belabor this conversation, but I would argue that the term "scientific advocacy" is inappropriate. So, we have scientific evidence, and then -- but -- and evidence that's used for advocacy, but I'm a little confused about the term scientific advocacy. So, I just want to put that on the record.

DR. GORDON: Thank you very much, Alycia. Scott, you have your hand up.

MR. TUCCI: Yeah. I'll --

DR. GORDON: Oh, sorry, Mr. Tucci, did you want --

MR. TUCCI: Yeah, sure. It would be my pleasure.

DR. GORDON: But perhaps keep it brief. Very brief, please.

MR. TUCCI: Yes, it would be my pleasure. Yeah. Basically, the term "scientific advocacy" that I'm referring to is a concept that individuals who are taking the position that they are adhering to the scientific model, the evidence-based practice model, that they're not going to say that we're promoting interventions that meet the best evidence rule.

And my position is that individuals that are going to advance that claim are going to ultimately go beyond the scope of just being limited to, "Well, you have a technique that we believe doesn't meet our interpretation of best evidence.

And as a result of that, we're going one step further in saying that if you don't meet what we consider to be best evidence, you don't qualify for certain communication rights."

So, what I'm suggesting is that these individuals that are -- with their scientific hat, are basically failing to see the distinction between, "Well, what does it mean if our argument is there's no scientific support for this intervention."

Whereby, the individuals that are using, for example, in this case, a method of communication that has worked for them, and they have -- there's disagreements amongst experts.

Some experts say there is science

supporting this intervention. Other experts say that there aren't any. Then it becomes a question, well, because --

DR. GORDON: Thank you, Mr. Tucci.

DR. HALLADAY: We have a lot of public comments, so I'm not going to belabor this. But we can come up with a different term than scientific advocacy.

MR. TUCCI: Okay.

DR. GORDON: Thank you very much. Really appreciate the input and the discussion. One last comment, and then we should move on is Scott Robertson.

DR. ROBERTSON: Yeah. Thanks, Dr. Gordon. I just wanted to comment on the last of the written comments in the -- Nicole's comment -- public written comment on the needs of the direct support professional workforce, how it highlighted a program in Canada to employ neurodivergent people, including autistic people, as patients in medical simulations to help educate medical students.

I wondered if NIH and some of your

sister agencies could maybe help with supporting practices like this for medical schools here in the U.S., given that a lot of medical students don't receive a lot of education about neurodivergent people, including autistic people.

This has come up previously at prior IACC meetings, so I'm glad this was highlighted in the comment.

DR. GORDON: Thank you, Scott. All right. We're going to now move into the main event for the afternoon, which is the justice and law enforcement presentations and panel discussion. This afternoon's topic is one that has come up innumerable times in this body, as well as in many other discussions that we've had -- and we meaning collectively, all of us -- in the autism community.

We've, in the past, held discussions that have been focused, for example, on wandering, and that has also brought in the role of law enforcement in ensuring the safety of individuals on the autism spectrum in those specific situations.

But today, we're going to have the opportunity to hear about a broader range of justice-related issues, including the interactions of autistic individuals with law enforcement and the judicial system, and programs that are emerging in this space to develop best practices that will increase safety and protect the rights of people with autism and other intellectual and developmental disabilities.

Today's presentations will highlight the important work that governments and other organizations are doing to address some of these issues, and raise, I'm sure, many interesting areas for discussion. We have two separate parts to this afternoon's events.

First, we're going to hear a series of presentations on current programs to address justice and law enforcement issues for individuals on the spectrum. Then we're going to hear a panel that includes several people sharing their lived and professional experiences in this area.

I'm going to go ahead first now and introduce our first speaker, Mr. Steve Gordon, an assistant U.S. attorney and civil rights enforcement coordinator for the U.S. Department of Justice, who will present a brief overview and discuss his work in the Department of Justice. Steve?

MR. GORDON: Thank you, Dr. Gordon. I appreciate that.

DR. GORDON: There you are.

MR. GORDON: And I'm going to start off here. Little introduction. Are folks able to hear me okay? Is this better? Okay, perfect. So, as we've already heard from some of the folks here, individuals with autism, like any other person in society, are likely to encounter law enforcement officers at some point. Sometimes, as a crime victim, a suspect, or a witness.

And unfortunately, because of the lack of understanding of autism in the law enforcement community, sometimes, these interactions end badly. And without proper training, criminal justice personnel may misinterpret the conduct of individuals with autism as intentional disrespect or disobedience, which may escalate encounters and lead to unnecessary criminal justice involvement.

An important tool for addressing lack of knowledge is providing law enforcement with training to increase cultural competency and cultural humility for people with autism. And this afternoon, you will hear from people who have worked with law enforcement agencies to increase cultural competency and cultural humility for people with intellectual and developmental disabilities, including autism.

So, my presentation on the Americans with Disabilities Act is an appetizer. It's hard to do justice to one of the most important civil rights statutes in the amount of time that I have, and would probably take a full day, if not a full semester, to cover how the Americans with Disabilities Act intersects with law enforcement.

So, the Americans with Disabilities Act is a civil rights statute that prohibits discrimination based on disability. It affords similar protections against discrimination to people with disabilities as the Civil Rights Act of 1964, which prohibited discrimination based on race, color, religion, sex, and national origin.

A really important resource for everyone is ada.gov. It's the Department of Justice's website, and it is a huge resource of information. You can find the statutory language, regulations, technical assistance, and settlement agreements, as well as briefs and complaints that the department has filed. Many people are familiar with the archive version.

I myself enjoy using that version over the new version, and you can find that at archive.ada.gov. There are two technical assistance publications that are really important. And when you see the blue hypertext link when you get this presentation later, you can click on that, and it will go right to the DOJ technical assistance publication.

One is commonly asked questions about the ADA and law enforcement, and the other is examples and resources to support criminal justice entities in compliance with Title II of the ADA.

So, the ADA covers all state and local entities, including those in the criminal justice system. We're going to talk a lot about law enforcement agencies today, but it also covers courts, jails, community corrections, public defender services, prosecutors, state and local service agencies (social service agencies), that assist the criminal justice system.

In Virginia, we call those community service boards. And everything that law enforcement or entities in the criminal justice system engage in is covered by the

ADA. It includes the operation of 911 and now 988 emergency centers; law enforcement on the street interactions, including taking and responding to complaints, interviews and questioning witnesses, victims, or suspects, assessing individuals for diversion programs, arresting, booking, holding suspects, and setting conditions for probation or parole, providing emergency medical services, and enforcing the law.

So, all aspects of the criminal justice system are covered. So, what are examples of what the ADA requires? Okay. So, if a law enforcement agency fails to make reasonable modifications in policies, practices, or procedures when necessary to avoid disability discrimination, that is a possible violation of the ADA.

Failing to conduct individualized assessments to determine how to ensure equal access, failing to communicate in a way that an individual with a disability can understand -- effective communication is a core principle of the ADA. Screening out people with disabilities from programs -- so a correctional facility that says you have autism. You can't participate in a early release program. That's a potential violation.

Really important, under the ADA, one-size solutions do not fit all. And as you can see from this illustration, not everyone is going to fit on the same size bicycle. So, it's really important that we aim not for equality, the same size bicycle, but equity. And this is a core principle under the ADA. As you can see in the first panel, we have equality. No curb cut. No audio for what the traffic signals are announcing. And that is not equity.

And if you look at the second panel, you will see equity. Okay. Everyone gets what they need, understanding the barriers, circumstances, and conditions. And it's the same thing when we're talking about autism or other intellectual and developmental disabilities. You have to aim for equity, not just equality.

And the ADA prohibits discrimination not just based on affirmative animus, but also based on thoughtlessness, apathy, and stereotypes about people with disabilities. So, examples of failure to modify policies, practices, or procedures, really important. Failing to deploy alternate responses for behavioral health calls and failing to coordinate with community mental health agencies.

And if you look at the Department of Justice's letter of finding in the investigation of Louisville, Kentucky, which involved Breonna Taylor, you will see there's a nine-page discussion of the Americans with Disabilities Act and the whole issue of failing to modify their practices.

Denying a request for a support person to assist an individual with intellectual or developmental disabilities during an interrogation, very important. We know that people with autism are more likely just to be very agreeable. And that can get them into a lot of trouble, including false confessions.

A prison GED program that fails to modify the curriculum for people with intellectual disabilities, very important in corrections. Everything needs to be modified to ensure that people with disabilities get equity.

So, in the Department of Justice's letter of finding, it explained that the Louisville Metro could modify their policies and procedures and training program and deploy community-based provider-operated mobile crisis teams to behavioral health calls, both initial calls for service and encounters when an officer determines that a police response is not necessary.

And DOJ pointed out that when someone was in cardiac arrest, EMS and a trained medical professional would come. But what Louisville was doing when someone was having a behavioral health crisis was they were sending out police with tasers and guns, as opposed to people who were trained in a medical response.

A behavioral health focus response should be available to people who experience behavioral health issues instead of traditional law enforcement response when appropriate. Again, this is from the department's letter of finding. Systemic considerations are really important in this area. And that's the plan ahead stuff, the proactive stuff.

And that means doing things like training criminal justice personnel, conducting reviews of policies and procedures. Very important for law enforcement to look at their policies and procedures.

And IACP is going to be on this panel and talk about some model policies that they have. Collaborating with mental health and disability service providers, and that's a topic that's discussed in the Louisville program. And you're going to also see what

The Arc of Northern Virginia and The Arc of Loudoun are doing. And Leigh Anne is going to talk about the Arc's program generally as well. So, what are examples of how to ensure accessibility? Train law enforcement officers that when responding to a person in mental health crisis who does not pose a significant safety threat, that they should consider providing time and space to calm the situation, de-escalation.

In a court, requiring court staff to explore reasonable modifications to allow qualified individuals with autism to participate in diversion and probation programs and specialty courts.

In corrections, implement policies that encourage correction staff to seek assistance from crisis intervention teams and mental health professionals when interacting with inmates that exhibit negative or disruptive behaviors.

Train correctional staff in the use of

de-escalation techniques and to forego discipline and provide treatment where it is apparent that a prisoner's behavior was related to a disability.

Collaboration. Okay. So, increased collaboration and improved resource allocation between criminal justice agencies and disability service systems can also help reduce disparities with people who have disabilities. Actions required by the ADA are not special privileges -- this is a myth that a lot of people believe -- but instead measures to ensure equity and accessibility.

Another thing I want to point out, it's important to recognize that people with disability are -- disabilities are more likely to be the victims of serious crime like rape and sexual assault, three times more likely.

So, it's very important that law enforcement take seriously the complaints of people with IDD, including autism. Those with cognitive disabilities had the highest rate of total violent victimization among disability types measured. 21 percent of unreported violence against persons with disabilities was not reported because the victim did not think the police would help.

So, there is a thought process out there that would be helpful if we all could work on. Okay. Community engagement has been really important for my office, the U.S. Attorney's Office for the Eastern District of Virginia. And we have worked with the Arc of Loudoun's Disability and Justice Coalition. And you can see here a photograph of a meeting that we held.

And the previous U.S. attorney is in the photo, and you'll see the sheriff's department is there. Folks from the public defender's office were there. The commonwealth attorney's office, which is the local prosecutor, is now on this as well, and many staff members from the Arc of Loudoun.

Alright, I gave a presentation to the Disability and Justice Coalition on the ADA requirements, the long-form version of this presentation, which was about two hours. And you can see, this was at the community service board mental health agency. I've also given presentations to the Virginia Department of Corrections. They have an annual ADA coordinators training. And I've done it also for the Public Defender's Conference in Virginia.

And this past October, at the International Association of Chiefs of Police, I again gave my long-form presentation on the ADA and law enforcement. Why is this important we're out in the community discussing these issues?

So, it's not just an academic discussion or discussion for this particular agency. It's important for the people where the rubber meets the road to hear this stuff. It's important for us all to find ways to collaborate. And it's amazing the relationships that we can build and that I've seen Leigh Anne and The Arc of the United

States build in communities.

So, it's really important. I've also spoken, by the way, with the Virginia Sheriffs' Association. 86 of the 136 sheriffs' departments in Virginia do on-the-street law enforcement, and all of them have some interaction with corrections. They either operate it or their partners. So, really important.

All right. I also want to show you, this is a flyer that the Arc of Northern Virginia put out for one of their programs where they do mock traffic stops. And the police get together with people with intellectual and developmental disabilities.

And sometimes, this is the first opportunity for people with intellectual and developmental disabilities to be in a non-threatening situation with police departments. It's also an opportunity for the police departments to get to know people in the community. And it's really important and it's a great program.

And I know that Montgomery County, Laurie, is going to talk, I think, about what they do in a similar vein. I welcome hearing from folks. Please feel free to contact me. This is a very important topic for me. I'll reveal that I have a sister with intellectual and developmental disabilities, and this has been a lifelong concern.

And I've been a lifelong advocate in this area. Thank you. And I know we have some other speakers as well.

DR. GORDON: Thank you very much. We're going to move along and we'll take questions at the end, I think. Yeah. So, Susan, did you want to make a comment first?

DR. DANIELS: Yes, we were -- just wanted to make a comment that we are talking about police law enforcement situations. And if anyone feels very sensitive about that, we do have a sensory room. You can step away or you can feel free to step away from the meeting if you need a break. But we will be talking potentially about some sensitive issues.

Thank you.

DR. GORDON: Okay. Our next speaker is Ms. Carlean Ponder. I hope I'm getting --

MS. CARLEAN PONDER: Carlean, yes.

DR. GORDON: Carlean. Thank you for that. Ms. Carlean Ponder from the Autism Society of America, and she'll be speaking about the Autism Center for Empowerment, Advocacy, and Justice, of which she is the director.

MS. PONDER: Thank you. Hello, everybody. Yep, Carlean Ponder again. And the Autism Justice Center is a brand-new initiative for the Autism Society.

And it's funny, because we've actually changed our name, Dr. Gordon, to the Autism Justice Center, because people felt that was directly to the point of what we're doing. Just a little bit about my background.

I'm an attorney. I did cross-disability work from a regulatory perspective for many years with the Social Security Administration. I've done federal policy work with my good colleague and friend Leigh Anne.

And I've done a lot of work around the intersection of disability, particularly mental health disabilities, and policing in the local community, the topic of crisis response. And how we respond to people in mental health crises is near and dear.

So, just little bit. The Autism Justice Center, which is, again, a brand-new initiative for the Autism Society, serves as a resource for autistic people, family members, and advocates who are impacted by all forms of discrimination. Criminal justice is one form.

We're hoping to also move into other areas around housing and healthcare and employment as we go along, and in the education system. But we're starting with the criminal legal system because of its impact on people and the severity.

So, who we are. The Autism Justice Center has a fantastic task force. On that task force, we have directly impacted individuals. So, that means individuals who have had some experience with the criminal legal system, where their autism did, in fact, interact with particular situations.

We have lawyers. We have professional advocates. What we've been able to do in a very short amount of time is actually come together and provide expertise to people and their families who are encountering some aspect of the criminal legal system at this particular moment.

For example, I got a call from a family yesterday whose son was in a car accident. There were some criminal charges attached to that car accident. And they were very concerned about the legal representation that their son was getting, because they didn't feel that the attorney understood autism and the impact that autism may have had on their son's reaction to the car accident. And I was able to share some resources with them.

So, just briefly, what I'm going to talk about, I'm going to talk about the -- about autism and the justice system. I'm going to talk a little bit about race and autism, from what we have seen and are currently seeing, some of the issues that we're covering at the Autism Justice Center, and some of our recommendations to make improvements.

So, autism and the justice center, here are some of the statistics that are out there. Autistic people, seven times more likely to interact with the criminal system than people who are not autistic. This comes from being victimized more often, and it also comes from just interactions with police officers more often. It also comes from having mental health issues.

For example, I think the figure is 70 percent of autistic people experience anxiety. There are, you know, other forms of mental health, behavioral health needs that could increase an autistic person's likelihood of coming in contact with the law enforcement. Steven Gordon covered some of that.

An overreliance on having to call 911

and having an armed law enforcement response to what's really a mental health need is one way that that happens. Autistic children experience disproportionate levels of school discipline. I think most of us have seen reports of restraints and seclusion being used far too often in our schools to deal with our kids who have behavioral health needs.

Sometimes, schools also have an overreliance upon police officers to intervene in those situations, even with children as young as five or seven. We've seen that happen as well.

Sometimes, you know, we see law enforcement encounters, because there is a need for some assistance, either from a caregiver, a parent, a, you know, teacher, who really does need some support and assistance when there is physical aggression happening or possible.

So, that also increases the likelihood of coming into contact with the criminal legal system. There are some statistics showing that places such as group homes and day programs are actually frequent callers to 911.

So, at the Autism Justice Center, another issue that we're seeing happens to relate to conduct around sexual behavior. That could either be in person, or it could be online behavior, and it is leading to increase contact with the criminal legal system.

So, race and autism. We know that fewer Black and Latino children are diagnosed as autistic, although, you know, that is changing now, which is a good thing due to access and awareness that wasn't there previously. Asian children happen to have the highest diagnosis rate.

And we're not -- I think the studies are saying they're not quite sure if that's accurate or if that's an overdiagnosis or what's going on there. Black autistic individuals are more likely to be hurt or killed during police encounters, and that just tracks what we know about Black people in general during police encounters.

So, Black autistic individuals disproportionately held in jails and sentenced to longer prison terms. And again, that is really a reflection of what we know about Black people in the criminal justice system.

And so, when you add on autism or another disability, you get the same disproportionate rates there. Couple of examples. At the Autism Justice Center, we're proud to have Neli Latson serve as our ambassador. You may know him.

Neli was 19 years old. In Virginia, when he was sitting outside of a library, someone made a phone call saying that they saw a suspicious person. I think they identified him as a suspicious Black person. I think they also said that there was a gun present.

When the police officer arrived, Neli and the police officer had a difficult interaction. Neli experienced a reaction -- you know, a fight or flight reaction, which is also common. And he asked to be left alone. That didn't happen.

There was a physical altercation. Neli was arrested, charged with several different crimes, and had a terrible experience of being incarcerated, I think for more than 10 years or around 10 years. Long periods of that were spent in solitary confinement, or other forms of confinement that were, quite frankly, just torturous.

And so, due to a lot of advocacy from the disability rights community, and just the social justice community at large, he was finally released. And he got a conditional pardon from the prior governor of Virginia. And we work with him because he is a wonderful advocate and tells his story so well. And that's part of what he's giving back to society now.

Another incident that struck me was Matthew Rushin, a young Black man also in

Virginia who had been in a car accident. He injured people, and he himself was injured. But what struck me about that particular case was that he was taken to jail immediately. So, not to a hospital or somewhere where he could get medical care, but to jail.

And he was questioned for hours without an advocate, without a parent, without an attorney. When I saw the video, he was bleeding, and it was clear to me that this young man was disoriented. And so, you know, I have a lot of questions about how well our ADA enforcements are being -- our ADA protections are being enforced.

So, that's a large part of the work that we want to do, why we started the justice center. So, some of the issues that we're seeing in particular at the justice center, a lot of it has to do with difficulties in the judicial system when it comes to distinguishing mental illness from autism.

We're seeing difficulties where autistic people do not have intellectual deficits that are -- or that are noticeable when they are coming in contact with the judicial system. There's some bias issues there. We're also seeing lots of problems around strict liability laws.

And it prevents -- I said a legal conundrum for the developmentally disabled, because with strict liability laws, if you did the thing, you're guilty. And it's very hard to add in a mitigating defense or to add in a reason that might explain that behavior.

So, autism in the courts, distinguishing mental illness. We know that autism is a neurologically based developmental disability. It's a spectrum, lots of different symptoms. People could be absolutely anywhere on the spectrum, but it mostly impairs social learning, communication, that kind of thing.

That can be very difficult to explain to somebody who is not familiar with disability, who's not familiar with autism. You know, if you are a defendant in a case, if you did something, there's a criminal, you know, charge attached, and you go before a court.

It's very -- and if you present -- you know, if you present as if you understand perfectly, you know what's happening, and you're not somebody who has an obvious disability, well, there may be some bias there. The court, you know, may think that disability isn't present, or that it's just not that relevant to whatever the issues were that led to the criminal charge.

And so, that's a hurdle that we're facing. Intellectual versus social limitations, that's another one, because it -- you know, when you're being charged with a crime and you are having to defend yourself and your actions, and you want to talk about, you know, maybe a stimuli -- stimulus that that occurred that was disability-related that led to that action, if you're able to do that well, that actually might be a bias.

Because again, you know, the court sort of looks at it and the prosecutor sort of looks at it as you're conveniently using disability, right, like, as an excuse in this case, where, you know, if you're able to come here and if you're able to talk to me and if you're able to explain what happened, I don't see how disability is a factor.

So, you know, conveying compromised adaptive functioning, conveying that somebody may be -- you know, may be perfectly capable of functioning in one area, but have significant limitations in another is hard. It is difficult. And I think we have a long ways to go in terms of making sure that our judicial system has a grasp or firm understanding of autism in that sense. Strict liability laws.

So, with a strict liability law, the prosecution doesn't need to prove that a defendant intended to do something that's illegal, or nor that the defendant was reckless or negligent. It's enough for a conviction to just prove that the act was committed, and that the defendant did it, which is difficult.

When we're trying to say, "Yes, but here's the background that led to that person getting there. There was some information missing, some education that they never received." And I'll give you an example. I'll give you an example of, like, where that comes in.

At the Autism Justice Center, we see this most in criminal cases involving sexual interactions either online or in person. So, for people who have trouble communicating or forming social bonds, you know, just outside in the community, online activity can be attractive. People can spend excessive amount of time online if you're in chat rooms or whatever.

And, you know, one feature of autism can be the tendency to sort of collect things. So, if you happen to be downloading images, and some of them involve underage people, whether you saw that, didn't see it, whether you knew it or you didn't know it, if you have it, if you possess it, you're liable for breaking strict liability laws around sex offense and exploitation.

And so, we have lots of examples of this coming to us. And in a lot of the cases, I've heard people say, "I had no idea," you know, that one or two images out of, I don't know, 100, 200, 500 images that this person downloaded happened to contain this information. They just -- they didn't know, or they had difficulty distinguishing ages or faces, because that's not what they were looking at. They were focused on a particular feature.

What we're seeing is people are being prosecuted, and they're being prosecuted quite heavily. We're seeing people get plea deals, sometimes for five years, sometimes for more. A lot of these particular strict liability statutes come with -- you know, you get 30 years in prison, maybe even a lifetime in prison.

Significant. In one particular case that we're helping with, this young person had just turned 18 over the summer and had friends who were younger. They were girls. They engaged in a, you know, sexual relationship. They did what is common for a lot of young people today with disability or no disability, and did a recording, you know, on their phones, took pictures on their phones, uploaded it.

Images got spread around the community. Parents were upset. Charges were pressed. This young autistic person is still in jail, facing significant charges as a result of that. The prosecutor has said that life imprisonment is on the table.

Okay, I'm running out of time, I'm learning. But -- so, just to give you an idea, part of what we want to do is some training and education for our judicial system around these issues.

Because when you have something like these strict liability laws, and you have social communication deficits, and very, very lonely people who might be more prone to excessive online behavior, it's just a perfect conundrum, right, to lead to very significant legal criminal entanglement. And we've got to do more. And what we recommend is diversion. I'll stop there.

DR. GORDON: Okay. So, we're going to start with the first one. Next, we have Leigh Anne McKingsley, the senior director of Criminal Justice Initiatives at the Arc of the United States.

MS. MCKINGSLEY: All right. Hello, everyone. Let me see if I can -- here we go. I just want to make sure everyone can hear me okay, and before I get started, just say thank you so much to Susan for inviting us here to have this important discussion around justice issues. It's incredibly important.

And oftentimes, being in this field for a few years now, I've noticed that sometimes, it doesn't make the cut in terms of priority issues until there's a crisis, and then people want to talk about it.

So, the goal that I think we're bringing here today as a panel too is to say we need to get in front of that. And we all are working together to do that. So, we're just so excited to have this opportunity to talk to you today about it.

Just a little bit about myself, I started with the Arc of the United States 27 years ago. It was really because of the Americans with Disabilities Act that was passed only four years prior to me joining the Arc that we got a grant through the Department of Justice to create materials for law enforcement courts, people with intellectual and developmental disabilities, on this very topic.

And I learned that how many people with intellectual disability were being executed. I could not believe what I found out. I had met with advocates that -- and not very many, I would say, throughout the country, doing this work.

And I thought nobody knows this. How can we not know this? And then you cannot unsee that. And so, I never looked back after that. I started discovering through other data -- which we didn't have until later on -- just how often people were victimized as well. And I realized that there's so much people don't understand about this population.

And so, whether it's autism, fetal alcohol spectrum disorder, all these different types of developmental disabilities, we have to make sure we don't choose to unsee what we know today, and that we make decisions differently moving forward.

And that is a little bit about why we -- whoops, I went the wrong way -- why we started the center, and why we can't stop advocating. So, I have two pictures on the screen here. One is of Ethan Saylor. That was one of the cases we worked on early on in the center when the center started.

And he was a person with Down syndrome who died when he wanted to see a second showing of a movie. He went to -- without a ticket, he went back into the movie theater, and there was off-duty police there. And so, they were called over.

Long story short, they ended up taking him down, and he died due to asphyxiation. And that happened in Maryland, and his mother then began a crusade to make sure that everyone understood what happened to her son, Ethan, and that it did not happen again.

And we started working just about the same time, so we worked together on this issue. We worked in Maryland to provide police training. But that -- the reason I bring up his story is because just in 2020, another similar situation happened. And this one was with Eric Parsa, who you see on the screen, and his mother with him.

And this one was particularly heartbreaking, because Eric died with his mother holding his hand with police there. And also, he died for the same reasons when he was held too long. And there was a lawsuit.

And so, now that the lawsuit is done, they're able to speak out about this. And this family is an amazing family that I got to meet just last -- well, at our last convention in New Orleans -- and speak with them at length about what their experience has been, how they try to do everything right, and how just a few months before this situation, they had an encounter with police that went great. Everything went great.

So, what is the issue here? Why can't it be consistent? What's going on? What do we need to learn from Eric's story? And they are bound and determined to make sure that we learn from this, that Eric is honored through the situation.

And so, I know she's listening today, so I want to say thank you so much to Daren and Donna for sharing your story with us. You've heard some of the statistics. I always want to start with the actual stories, because that's what really matters. But the statistics is what gets us the attention for the grants and for the money to support this issue.

And you've heard some of those today, but I do want to bring to your attention that we do have data from the Bureau of Justice Statistics. And that is the data -- actually, money from the BJA is what allowed us to create these infographics.

And this shows you that 2 in 10 prisoners and 3 in 10 jail inmates reported having a cognitive disability. That is the most commonly reported type of disability, because they looked at different types of disabilities, and they saw that cognitive was the most commonly reported.

So, I wanted to bring that out. But then if you look at crime victims, we know the same thing is true. So, again, the Bureau of Justice Statistics looked at how often people with cognitive disabilities are victimized, and they found, for example, that they were seven times more likely to experience sexual violence.

So, whether you look at it on the suspect/defendant side or the victim side, cognitive disabilities, they are most likely to be overrepresented in the system.

And so, we can't just say, "Okay, we're going to look at it from this angle or we're going to look at it from this angle." And unfortunately, that's how the funding streams work. And we're not able to bring the two together and say, "How are these things interacting?"

So, it's very important that we think about that when we're looking at solutions, policies, and that kind of thing. So, because there's so many different diverse issues around this. The Arc started the National Center on Criminal Justice and Disability, as I said, 10 years ago.

And thank you so much to the Bureau of Justice Assistance, BJA, for helping create the seed money so that we could start the center, and we could also provide training. But not training that just does a one-off training but actually creates community-based solutions. And I'll say a little bit more about that in a second.

But this is what we've been working on in the past 10 years is to provide training and technical assistance. Information and referral, we provide nationwide information and referral. So, if it's a person who's an attorney, a person with a disability, family members, whoever is needing, looking for support or assistance, we provide that.

And I will just mention that many of our calls as well, like Carlean was talking about, does deal with sexual offense. That's been true ever since I've been at the Arc. We get so many calls around that.

There's many, many issues that I like to unpack with you that will take too long to go into that discussion. But please, please know that that is a huge need out there in the community that we continue to try to address. And then resource collection and, of course, education.

I did want to mention, too, that race and disability has to be key at every conversation around this issue. We do have some data showing that young people with disabilities are 13 percent more likely to be arrested than their peers without disability. But if you look at Black youth, that figure jumps to 17 percent. And then people with disabilities overall -- have an overall 43 percent chance of arrest, but a disproportionate amount of that does fall on young Black men.

And so, we cannot have this conversation without making sure that we're centering these issues in every single thing we're thinking about, whether it's policy, training, whatever it is. That has to be key.

And then I had mentioned the data from -- oh, we're going the wrong way again, sorry about that -- from BJS. I wanted to mention also the story of James Meadours who's a survivor of sexual violence.

He's probably had -- he's -- he told me, seven different incidents of sexual-related violence throughout his life. That's not uncommon. We know from some of the research studies that it's highly common for people with intellectual developmental disabilities, including autism, to have some type of sexual violence in their lives.

I actually met James when I started at the Arc when I was 24. He was on the board of directors. And we found out that we both had sexual assault in our background. We started talking about how in the world is the Arc not talking about this or other people not talking about this if we know this is common?

But, you know, actually, we didn't have the data yet. It wasn't until later that we got the category of disability added to the National Crime Victim Survey. Before that, we just heard about it, and we saw the data from Canada. So, we knew this was an issue. As a survivor, I knew it was an issue because I knew the numbers in the general population.

Well, my gosh, if it's happening at the

disability community, we have to raise awareness around this. And so, James and I started talking about how do we do it. And his story is just an amazing one and that he's gone through so many different seasons in his life. But knowing that one of the things he really wanted to do is talk about this issue.

And he has raised awareness throughout the country about crime victims with disabilities and what he wants to see happen and what changes he wants to see happen. And so, I applaud him. And I always want to mention just his story. He now is with the President's Committee on Intellectual Developmental Disabilities, really trying to bring this issue at that level.

So, these are just some of the projects and initiatives that the center has been working on. We currently have a grant that we were just awarded through the COPS Office. That's the Community-Oriented Policing Services Office. And they focus on community policing within within law enforcement.

We'll be creating what's called Just Policing. It'll be online, as well as in-person training for law enforcement. We're focusing on intersectionality issues in this curriculum, as well as making sure that we're not missing youth with IDD and autism.

Another one is language access barriers to justice among victims with IDD, working with the University of Cincinnati, as well as the University of South Florida. And we're looking at how can we increase access to victims, specifically looking at all types of victimization.

And I won't go through all of those. But if you do have any questions about these other projects that we're working on, I know I've got some -- Kelly with IACP. She'll be telling you more about some of these projects that we're working on together.

I will mention -- earlier, you all were talking about the need for looking at international research. And I would applaud that effort. We've been doing more work internationally, working through Open Society Foundation, provided some money, and over the past seven years, we've been looking at other countries to see what they're doing in this area and how we can learn from each other.

So, I think that's really important, especially when you're finding a lack of research and solidarity around these issues in your own country. So, we've been building ways to learn from each other in that way.

This is one I wanted to mention that when we started the national center, this was the key training that we created called Pathways to Justice. And this is a one-day training that involves law enforcement, attorneys, victim service providers, people with disabilities, and disability advocates.

But what's different in this training is that we, basically, have set out a way to ensure that the entire community that is involved in this will help co-train, as well as create a plan moving forward.

So, we've heard today that it's more -- it's important to not just think about this as training, but how do we build that long-term approach? So, we created what's called Disability Response Teams, number one. And we work with that community to say, "You have to have at least these folks on your team." And we have to think beyond the training day.

What is it in your community that is most needed? What do you have access to? What data do you have? Where is it that you know that you can maybe make a difference here, but then think about long-term how to plan for that?

And so, our principles are: nothing about us, without us unless be community-based, multidisciplinary teams, and then relationship-oriented. And what I'm excited about is that we're talking to different universities now to really start doing a more thorough investigation and evaluation, not just to the training, but of these teams to say, "If we put teams in place, how can they really make the difference long-term in these communities?"

We also use what's called the Pathways to Justice model. And if you ever -- okay. If you have ever heard of the SIM map, which is Sequential Intercept Mapping, we basically took that and overlaid intellectual developmental disability. But this is a great tool when you're thinking about, as a community or when we're thinking about policy development, it goes through the entire criminal justice system.

And we're looking at each step along the way: are we identifying disability? Are we providing accommodations? Which ones? And then how are we providing long-time -- long-term support at each stage of the system? We can't just look at one and think we've solved it. And we can't just involve law enforcement and think that's it. We've got to involve everyone who comes in contact with someone with autism or developmental disabilities.

This is where we've had Pathways so far.

We've been talking to -- actually, we went to South Korea where they're looking at wanting to develop their own National Center on Criminal Justice and bringing more training in their countries. So, we really see the desire for this, not just in our country but other countries as well.

Here's some of the resources that we'll provide through this -- to Susan for you to take a look at later on. Some of the things that I mentioned today, plus we just had a video come out through Comcast Newsmakers on disability rights and criminal justice. It's a short video. So, you can take a look at that and share it with others who might be interested.

And then that I wanted mention, too, we have staff that aren't here today. But Josh Branch is an attorney, as well as Jessica Oppenheim who worked at our national center. And we've got a link to the Pathways to Justice as well. So, thank you so much. And I'll pass it onto Kelly.

DR. GORDON: Thank you. So, next, we have Brooke Mount and Kelly Burke. Brooke is the senior policy advisor at the Bureau of Justice Assistance at the U.S. Department of Justice. And Kelly is a senior program manager at the International Association of Chiefs of Police.

DR. BROOKE MOUNT: Hello, everyone, and good afternoon. My name is Brooke Mount. I am a very proud mom of a 13-year-old son who has autism. And I also work at the United States Department of Justice within the Bureau of Justice Assistance as a senior policy advisor.

My portfolio includes grants that provide funding to criminal justice and behavioral health to develop programming, including programs like the Justice and Mental Health Collaboration Program, Connect & Protect, which provides funding for law enforcement and behavioral health cross collaboration, including the 988 Lifeline, and the Collaborative Crisis Response

Intervention Training Program, which you're going to be hearing more about shortly.

BJA is located within the Office of Justice Programs and is one of three grant-making components with DOJ. The Bureau of Justice Assistance was created in 1984. And the goal is really to reduce crime, create safer communities, and reform our nation's criminal justice system.

Our work really focuses on providing funding through programs, transferring knowledge through training and technical assistance, developing guidance and resources, and engaging with partners and stakeholders all across the country.

Today, you're going to hear more about some of the incredible work that BJA has been supporting, along with our partners at the International Association of Chiefs of Police, specifically including the development of training and resources to raise awareness in the law enforcement community, such as the use of evidence-based best practices in police responses for people with behavioral health conditions and intellectual and developmental disabilities.

I'm going to turn this over to Kelly Burke, so she can really get into the details regarding these programs. But thank you so much.

MS. KELLY BURKE: Thank you, Brooke. Good afternoon. My name is Kelly Burke. I am with the International Association of Chiefs of Police. For those of you that may not be familiar with us, we are an international nonprofit membership organization made up of police professionals of all ranks from around the world. We have about 33,000 members, and we focus on education and training and advocacy and engagement.

One of the aspects of our work is we have grant-funded initiatives to develop training and resources for law enforcement and their multidisciplinary partners on a number of issues. And -- let's see. The first one I'm going to talk about is the Academic

Training to Inform Police Responses Initiative. That is a BJA-funded initiative, led by the University of Cincinnati in partnership with IACP, the Arc of the United States, Policy Research Associates, and the National Policing Institute.

The academic training initiative was started in 2020 to provide training and technical assistance to develop evidence-informed and best practices in crisis response and police engagement with individuals with mental health, substance use -- or mental health conditions, substance use disorders, as well as individuals with intellectual or developmental disabilities.

And this initiative led the development of a 40-hour training curriculum, the Crisis Response and Intervention Training. And we call it CRIT. It's a toolkit I'll get into in a moment. It was designed to prepare officers to respond effectively to people in crisis. The overall philosophy for this curriculum is officer safety, public safety, and diversion from the criminal justice system whenever possible.

The goals of the Crisis Response and Intervention Training curriculum and toolkit are to expand knowledge of mental health conditions, substance use disorders, and intellectual and developmental disabilities, as well as to create connections with people with lived experience, enhance awareness of community services, and emphasize the de-escalation of crisis situations while supporting officer safety and wellness.

The curriculum is based on the Memphis Model of Crisis Intervention Training. You may have heard of CIT training that was developed over 30 years ago across the country. This curriculum is -- was based on that 40-hour curriculum, but is significantly modified and enhanced to include content throughout the whole 40 hours on individuals with intellectual or developmental disabilities.

I think it's important that -- to note

that the curriculum focuses on behavior and not diagnosis, specifically the behavior that officers encounter in the field. There's a heavy practical component of roleplaying and de-escalation.

The training and the tools that accompany the training curriculum are designed to complement the development and implementation of local crisis response programs development at the local level. It prepares officers to recognize individuals experiencing crisis related to behavioral health conditions or intellectual or developmental disabilities; employ tactics to effectively manage crisis situations, including de-escalation techniques; and access local resources to divert individuals away from the criminal justice system.

And it prepares officers to enhance the safety of the individuals in crisis, the officers, as well as community members. And this resource was developed because typically, Crisis Intervention Training did not include any content or only limited content on intellectual or developmental disabilities.

So, this curriculum is unique because of that aspect to provide the content and the skills and strategies throughout the entire curriculum for effective police response. It explores perceptions and attitudes on disabilities, disability culture, and community. It provides content on identifying characteristics of intellectual and developmental disabilities, identification tips for officers, and strategies for responding more effectively as a police officer.

The curriculum encourages the inclusion of people with intellectual and developmental disabilities in the Family and Peer Perspectives Panel. Sorry. Oh, I skipped ahead. One second. It provides recommendations and guidance on integrating site visits to local places that deliver services to individuals with intellectual and developmental disabilities and provides opportunities for participants to interact with individuals with IDD.

It includes content on laws and policies specific to the disabilities rights for -- as it applies to law enforcement officer interactions. It encourages inclusion of representatives from the IDD service system to describe their services to the local officers and what is available. And it provides participants with specific de-escalation skills and includes roleplaying scenarios for responding to people with IDD.

In addition to this training curriculum, which is fully downloadable, and it's customizable to the local community, it can also be used for various different types of crisis response programming at the local level. In addition, the Academic Training to Improve Police Response has also developed a number of resources specific to law enforcement.

There are two I'll highlight here are we have a resource on mental health conditions and developmental disabilities and knowing the difference that is specifically targeted to law enforcement, as well as another resource on developmental disabilities, what officers need to know. And this resource specifically discusses how understanding more about disabilities leads to safe and effective interactions and provides examples of possible behaviors of people with developmental disabilities and recommended responses.

I'd really like to highlight this resource that was developed with all the partners on the academic training. It's the Law Enforcement Response to People with Developmental Disabilities: Steps for Deflection and Pre-Arrest Diversion. This is a multipage guide, and it offers insights into the developmental disability community, offers suggestions for successful interactions, and outlines options for safe and effective deflection and pre-arrest diversion when people with IDD encounter law enforcement and may be experiencing a crisis or otherwise in need of services.

It describes the four key steps officers can take to support deflection and pre-arrest diversion: identification, communication, accommodation, and support. And this was all adapted from the stages of the Arc's Pathways to Justice model. Also, I'd really want to highlight that this includes lot of examples of accommodations for individuals with IDD to assist in communication efforts and seek supporters and other resources.

And I want to also let you know that this effort is continuing. We have the -- IACP now leads a new BJA-funded effort to expand on this CRIT training and technical assistance that was awarded just in 2023. And this includes enhancing interactions between law enforcement, but it also includes correctional officers and people with IDD.

This is in partnership with the Arc of the United States, Policy Research

Associates, the National Police Institute, and the American Correctional Association, to further develop resources to, and training and technical assistance to, specifically, 39 communities that are funded by the Bureau of Justice Assistance around the country and receive grant funding directly from BJA.

I do want to briefly mention that the IACP is also working with BJA who has provided funding and support to develop resources around reducing injuries and deaths of individuals who go missing due to their -- either developmental disability or dementia such as Alzheimer's and such.

We've developed a number of resources with the Arc and the National Center for Missing & Exploited Children, as well as the Autism Society of America. And I will just describe a few of them here. We've just developed that specifically. And you can click on the link to see those resources as well.

And an easy -- we created a QR code. So, if you just point your phone there in the presentation, you can go directly to download all those resources. So -- and thank you for inviting me to share these resources with you today.

DR. GORDON: Thank you very much, Brooke and Kelly, both. Our final presenter for this session is Officer Laurie Reyes from the Montgomery County Police Department here in Maryland, in this very county we're in right now. Officer Reyes will be discussing the Montgomery County Police Autism/IDD Unit.

OFFICER LAURIE REYES: Hello, everyone. I am very excited to be here. As -- so, it's more than just exciting, right? I see familiar faces in this audience that I've known for 20 years, working here, right? And we love each other, and we're a family. And I've called upon many people in this room and said, "Holy moly, I need some help with something." And they've all been here.

So, I want to share that that this is more than just Officer Reyes or Laurie presenting. I really have -- I have to say thank you, right? Because I've called upon a lot of you guys to help me out on this journey when someone says, "Well, what is Laurie Reyes? What does she know about autism? What does she know?" So, it's because of all of you that that's why I get the chance to stand up here and be a voice. So, thank you so much.

All right, Officer Laurie Reyes. It's very hard for me to sit here at a podium. As my fellow officer in the back knows, I walk around a lot. So, I basically have to attach myself to the podium so that I'm not walking around. I've been a police officer for 26 years. I have run the Montgomery County Police Autism/IDD Unit for 20 years.

It started in 2004. It started when officers, you would teach them, and they'd say, "Autism, what's that," right? And that was 20 years ago. So, the name of the program, it's the longest titled program in Montgomery County. But I don't give a flick.

You know why? Because when you do a Google search and you're a parent of a child who has autism and you're looking for resources in the police community, it's going to pull up. It's going to say, "Okay. You know what, I may live in Nevada, but Officer Laurie Reyes in Montgomery County might be able to help me out."

So, the name of the program is the Montgomery County Police Autism/IDD -- I also do the Alzheimer's and dementia side, too -- Outreach Unit. Again, it started in 2004. We provide training and education to all of our officers since about 2010. We started teaching officers. Again, people would say, "What does Laurie Reyes know? Where did you get your education?"

Do you know where I got my education? From the parents that are sitting here and looking like -- right back at me, from Stuart, you know, from JaLynn, from all these people that have given me their own journeys and said, "Laurie, this is what our officers need to know."

So, training and education, outreach, empowerment, right? Awarding a family that maybe we've searched for their son three times, but they're willing to get on the news and say, "Call 911. They'll help you." That's empowerment.

Follow up, what my fellow officer of also 26 years who's sitting back there that would just about die if I told her to come up here right now. Follow up. So, also -- and then most important, the most important, response. You cannot tell a family to call 911 if you're in need and then not provide a great response, right? You can't do that.

So, the unit, that's kind of it in a nutshell as far as what we provide. Now, I know even making up a slide like this, I'm preaching to the choir. You all know these statistics. We know that. I share this with you because this is what we also teach our officers, too.

Just today, myself and Amy taught our

CIT officers. That's the officers that are receiving a week-long class on mental health. And we made sure that autism IDD was included in that. So, we teach that.

But why does statistics matter, right? When you're teaching officers before lunch, they're like, "Oh, my gosh. A whole slide on statistics. She's got to amp it up a little bit." Why do I share this with all of you? Because this is what we're seeing in law enforcement.

2004, I started this unit. It was one in 150 births. And right now, where are we at? One in 39 in Maryland? One in 44? So, why does that matter? Because when I started the unit in 2004, most of the calls we were handling were for our little peanuts. They were little guys on the autism spectrum.

So, when you teach officers, and you say, "Why does it matter?" Because who is responding to a call for a five-year-old in the middle of Midcounty Highway? Who's responding? All of you are responding.

My mom -- I always laugh. My mom, in her Ford Focus, she is stopping her car at 83 years old to help the five-year-old in the middle of Midcounty Highway. Now, fast forward and we have a 25-year-old in the middle of Midcounty Highway. Who are they calling? Amy and I can raise our hands. They're calling the police because they don't know.

So, why do these stats matter to police officers? It matters because there's an increase in age and prevalancy. That is what we're facing in law enforcement. So, that's why the stats matter, and that's why we share them with police officers.

And here's the thing as we talk about training police officers. It is not just about training. What we have created in Montgomery County is a culture of what we once said was awareness -- forget about awareness. I don't care about awareness. It's action. It's a culture of action. That's what we've created by educating our officers.

What started as just a simple class of, "Hey, here's some behaviors," or "Here's what you might encounter with wandering," or "Here's what you might encounter with someone in crisis," it's gone on to officers not leaving that call without trying to provide individuals with other resources. And being an officer, that's looking out beyond that first call. Beyond that first call. So, again, the stats matter.

All right. So -- and many of you know this young man on this slide right here. And maybe his mom is on this, right? Maybe Stuart, maybe his mom might be on this call. So, what we're seeing in law enforcement, we are seeing -- so, in Montgomery County, we average three to eight finds a week. Three to eight finds a week where we locate an individual who has autism usually, that has wandered that we locate before caregivers have contacted us. Three to eight a week.

We also handle about two calls a day for individuals who are on the autism spectrum.

In one week, in just one calculation from my sergeant, we had 27 calls for service for individuals on the autism spectrum. So, what we're seeing -- and I know I say this challenge. It's a challenge in law enforcement because we're seeing calls of a more serious nature, not beyond wandering and elopement, for individuals who are in crisis, true crisis, parents, caregivers who are in crisis that need services and resources.

And oftentimes, it is me, it is Amy, it's the patrol officers who are providing them these resources. We're also seeing an increase -- and as I stand here at NIH and say, we are seeing an increase in co-occurring conditions. Not only that, co-occurring conditions in our young guys, right, where we're seeing autism in significant mental health crisis.

So, as I say and I categorize it as a challenge for law enforcement. That's what it is. Couple that with increase in age, increase in prevalency, increase in co-occurring conditions. These are all things that we need to scream from the rooftops that we're going to need more services.

When we have an individual with autism that's in crisis, and the only place we can go is to a hospital on an emergency petition where they're released 30 minutes later; well, that's what we've got to do because maybe that -- maybe that's what the parent needed at that time. That's not okay. We need better services.

So, I will say that we, Montgomery County, what are we doing in response to that? So, again, poor Amy, sitting in the back of the room, she's going to be put on the spot. We started to do follow-ups with the families.

So, after a call for either wandering and elopement or somebody in crisis, if we can't respond, we call the family. "Hey, not only did officers -- are we asking -- did officers do everything right? Could we have done something better, done something different? What would you have wanted?"

But we also say, "Hey, are you aware of this organization? Are you on the autism waiver yet? Are you reaching out to DDA?" And we can tell you, sometimes families aren't there. They're not there. So, last year, it was 600 follow-ups, 600 follow-ups from Amy and I calling families and saying, "What do you need? What do you need from us?"

But also, in this era where we understand that law enforcement does not always get it right, when you create a culture of action and awareness, it begins to be more than just training. Right? And that happens through a process. And I believe that's what -- you know, that's what we've done here. But it has to be all involved. It can't just be law enforcement.

So, what are we doing? Hold on. I want to skip forward. What are we doing? One initiative that I'm probably most proud of is the work that we do in schools, the work we do with individuals who are navigating autism and their way to independence, whatever that may be. Amy and I presenting to individuals. This is how you're creating the whole community, understanding what needs to happen. We're in the schools. We're talking to individuals and saying, "How can you have a positive interaction with law enforcement?"

And I get the controversy of that. Police should know. But we need -- this has to be a total approach. And I know everyone has said that. It has to be a total approach. So, we are in the schools. It's the best part of our job, it truly is, from elementary all the way up to high school. And I invite anyone who would ever want to see us. We'll be at Damascus High School. That's always fun. So, please, if you're ever interested in, "Hey, what's the program doing," please come out and see.

All right. I'll go back real quick. So, just some of our resources, some other things that we're doing. We do the Traffic Stop class where it's a two-part, a webinar and then an in-person traffic stop for passengers and for drivers. We also --I know there's another picture of the schools. I had a young lady -- the picture is too small.

I had a young lady with autism who wandered from her home, and she stole a horse. You can't make up some of the stories that we have here. As God is my witness, my girl, she was like, Pippi Longstocking. She stole a horse, took it down Beach Drive. I swear. Officers did a fantastic job.

But here's where the other part comes in. We're not upset with her. We're not upset with her mom. Swear to you. She also -- I have a picture of this. Not only did she steal the horse the second time, the first time, she brought the horse to her front yard. God is my witness. So, what do you do with that? You empower her and you say, "Hey, Park Police Mounted Unit, this young lady loves her some horses."

So, maybe she needs to see horses and learn about, you know, what -- not stealing them but, you know, learn that we're not mad at her. She's navigating her journey, and we're not mad at her. And we're not mad at her mom. Because, you know, how can you possibly keep your eye on someone all the time?

Okay. So, more of our actions and interactions. And let's see here. Oh, there you go. So, Amy and I, one other thing that I'm proud of -- I know I'm short on time, but I've got to tell you -- the school presentations. We go into the schools, and we do a presentation for the general population of students, all students in the school and have a whole school assembly on why Montgomery County Police has an Autism/IDD unit.

And I do call it "Looking Out for the Underdog," not because of the negative connotation of being an underdog, but doggone it, you yourself could be the underdog. I could be the underdog. So, maybe look out for those. Be kind. Don't be the bully.

So, that's one of our presentations that kind of couples with us having the presentation for individuals who have disabilities and making sure that everyone knows that they're not alone on this journey. And there's more of our traffic stop classes.

This is a young man, Harrison Porter. Harrison Porter is a young man who has autism, and he is also navigating this world and has worked with me as a self-advocate. But he's applying to colleges now. So, that's pretty awesome, and we'll be helping him on that route too.

And more importantly, we work a lot with self-disclosure, kind of describing why self-disclosure can be important. A personal journey, that is a personal choice. But we do let officers know that people may self-disclose their disability to them. Why it's important when you're driving, or why it's important when you have an interaction with law enforcement. We cover that. And we let our officers know that you could have an individual that approaches you in the community.

And -- okay. So, quick -- I told you it was quick. So, you know what's funny? I think I stood up here just to show off and say how much I love my job and how proud I am of the officers in Montgomery County. So, that's all I have. I love seeing all these faces. And there's my email. You could email me today, and myself and Amy will get back to you. Okay? Mwah. Thank you, guys. Thank you.

DR. GORDON: I want to thank you, Officer Reyes and all of the presenters. We are running behind. So, in an effort to make that up, we're going to take a short break. Let's see how far -- we're going to take -- we'll start up at 10 of. So, we'll take a 10-minute break. We'll be five minutes late after that point. And we will hold the discussion until after the afternoon's panel.

So, if you've got questions or comments you want to make, jot them down, so you don't forget. And we'll see you back here in ten minutes.

(Short Break)

DR. GORDON: We're going to get started, please. If we could have seats. If everyone could take a seat, please, we're going to get started.

Thank you all for coming back so quickly after our short break. But we want to make sure that we have plenty of time to hear from our next panel and to also get a chance to discuss amongst ourselves the implications of what we've heard today. So, with no further ado, I'm going to turn it over to Susan who's going to be conducting -- orchestrating the next group.

DR. DANIELS: Thank you so much. Well, we're really looking forward to this community panel that will complement our earlier panel that was formal presentations. We're going to be doing this in a Q&A fashion. And we have some wonderful presenter panelists on this panel.

So, our first panelist is Dr. Maria

Mercedes Avila who's a member of the IACC and a professor of Pediatrics at the University of Vermont and director of the Vermont LEND program. And she's also the mother of a son on the autism spectrum and will be on virtually with us today.

Our next panelist is Ms. Lindsay Naeder, vice president of Services and Supports and Community Impact for Autism Speaks, and she's the sibling of an autistic person.

Our third panelist is Ms. Camille Proctor, who's a member of the IACC, as well as the founder of The Color of Autism Foundation, and as you heard earlier today, is also mother of a son on the autism spectrum.

Next is Ms. Amanda Wroten, the director of Safety on the Spectrum for Autism Society and is also neuro-divergent.

And our final panelist is Mr. Greg Robinson, the deputy director of Public Policy for the Autistic Self-Advocacy Network. And he is an autistic self-advocate.

And you can also feel free to share additional details that you'd like. I just wanted to give that quick overview of who's on the panel.

And I'm going to conduct this by asking a series of three questions. And I'll just call on each person. And our panelists are over here and on the screen. So, we will start with the questions.

So, my first question for the panelists, and I'm going to -- the order I'm going in is Maria Mercedes Avila, Lindsay Naeder, Camille Proctor, Amanda Wroten, and Greg Robinson. And I'll just keep it the same the whole time. So, to Maria Mercedes Avila, hi. I see you on the screen. What are the most important law enforcement and criminal justice issues that you feel affect the autism community?

DR. MARIA MERCEDES AVILA: Thank you, Dr. Daniels and the Committee for including the work that we're doing here in Vermont. So, for the first question of most important issues or pressing issues, I think here in the previous panel, they talked a lot about training, and I think that's one of the key areas that we need to continue looking at.

So, I would say the lack of law enforcement training, but meaningful training connected to child development, ASD, looking at racial disparity, but also the intersection of health and mental health disparities when they connect with other systems of oppression.

The other, lack of training connects to lack of knowledge of social and historical context in our society, so looking at the history of systemic racism and other isms and how these interact with issues impacting our communities.

I live in Vermont. So, this is one of the Whitest states in the country. And it's a small state. So, we all know each other when we work with law enforcement, like I do. And sometimes I hear people in Vermont say, for example, "Well, what happened in this state doesn't happen here."

And this is an important comment that we need to keep in mind. Because it doesn't matter whether we are in Vermont or in a more diverse or larger state in the country, everybody has to have knowledge about issues that took place in our country that are impacting the community. So, that's something that is important to highlight related to education.

And most importantly, working with families, with children, with ASD and other IDD, we hear constantly that families are eager to share their stories and experiences, interacting with law enforcement. And I think that's something that we need to continue doing, hearing the voices of the communities in a meaningful way and affect change and improve systems connected to those experiences. So, thank you for this first question.

DR. DANIELS: Thank you so much, Mercedes. Next, I will go to Lindsay Naeder, the same question. If you need me to repeat the question, just ask.

MS. LINDSAY NAEDER: Thank you, Susan, and Committee. You know, the highest profile -- there we go. Again, thank you, Susan and Committee. We know for sure the highest profile cases -- how's that? All right. We're in there now. Everyone's got me. Okay.

Thank you again, Susan and Committee. We know for sure the highest profile cases make the news. But at Autism Speaks, our autism response team, which is our information and referral resource, receives and fields thousands of requests seeking safety resources every single year.

The top needs that we see with those requests very, very frequently involve the need for first responder training resources. The most common request that we're getting are from parents and caregivers actually asking the question, "In my zip code, are the first responders trained? Do they know about autism?"

It's a very, very difficult question to answer. We can do our best. And if they're lucky, they live in a county like Montgomery County and have Officer Reyes at their disposal. But very, very often, they do not have those resources.

Progress absolutely has been made. We're seeing, you know, promising practices and best practices popping up in communities. But it's very often led by advocates, individuals that are passionately committed, parents themselves, community organizations, my colleagues here doing really great work.

But we haven't seen it scaled so that I can report that my team is answering a question from every single zip code, saying that there are standards and that there are trained officers in the community.

DR. DANIELS: Thank you. Camille Proctor.

MS. CAMILLE PROCTOR: So, for me, the most pressing issue, honestly, is the killing of Black people by the hands of the police. Officer Reyes, no offense, you're a gem. If I could get you wet and feed you after midnight, you'd be a gremlin and multiply. But unfortunately, you are just one person.

And until we address the systemic racism that's rampant in this country, we cannot protect these vulnerable people, people who are at risk daily because of the color of their skin. And then it's compounded because they are autistic. They have sensory issues and a myriad of other things.

And we keep saying, "Train the police." And I do respect the police. But I think that some of this money that you're throwing at training the police, you should be throwing at these grassroots organizations who are in these communities working with these families.

We need to be training these young Black people how to interact -- Black and Brown people how to interact with the police. No one's talked about that. We keep talking about training the police. They have that available to them. It's been available to them forever. Whether or not they're using it or utilizing it, that's on them.

All I know is that Avarius Thompson in Chicago, in November, he was walking home from the store. He fit the description of a perp. He got tazed in his own backyard. Stephon Watts got killed in his own house.

And the other important issue to me is that we stop -- that the people who are listening to this and the people in this room, you all need to come together and fight to have crisis intervention units in all of your communities. Because the police aren't crisis interventionalists. So, that's my statement.

DR. DANIELS: Thank you so much, Camille. Amanda Wroten.

MS. AMANDA WROTEN: Hi. Thank you so much for having me. I think when I look at this question on behalf of the Autism Society of America, I really think about this quote from Sir Edmund Hillary where he said, "It's not the mountain you trip over. It's the pebbles." It's those little things. And it's not one thing. It's not law enforcement training. It's not 988. It's all of the things working in unison together. Because a rising tide lifts all boats.

And for me, it's looking at those things and understanding that individuals with autism are seven times more likely to be a victim of a crime, 12 times more likely to be involved in the criminal justice system without intent. And that's before we add a racial component, to Camille's point. So, yes, it is the training, but it's also that culture that goes around it.

For me -- I'll share my story just briefly because I know we are short on time. I stand squarely in the center of this if anybody is wondering. My husband is a career police officer. My job before this was the executive director of a police foundation in Virginia, and I'm on the spectrum.

When I started having meltdowns as a masked female, I thought the most prepared person in the world stood in front of me. And he was completely helpless, despite Virginia's one-hour requirement on autism training.

But I can tell you firsthand, when we started doing autism-informed approaches to it, to de-escalating just a simple meltdown in our house that didn't involve law enforcement, it changed, and the perspective changed too. And that information and that culture that was built around it was so powerful for us as a family.

And I know that's just one experience of autism, but it can't be just one answer or just one training or just one number or just one thing we're looking at. It's got to be Camille's point about bringing in racial disparities. It's got to be training. It's got to be 988. It's got to be all of the things to get us there.

DR. DANIELS: Thank you so much, Amanda. Greg Robinson.

MR. GREG ROBINSON: Thank you so much

for having me today. I do want to echo a lot of what my fellow panelists have said. I do want to also say that I think, when we approach this, one thing we have to recognize is that many times, the real safety risk is posed by police interaction for many people on the spectrum and that we do need to -- one way that we can minimize the impact of police violence is by minimizing interaction with the police in many cases.

So, when there are -- putting in place alternatives to police for behavioral health crises can be a very critical role in this conversation. I think there are -- we also have some very outstanding questions about the validity of CIT and co-response models, whether those models actually do reduce the use of force in police interactions.

DR. GORDON: Greg, sorry, can you just move the mic closer to you?

MR. ROBINSON: Sorry.

DR. GORDON: You can move it closer to you.

MR. ROBINSON: Yeah. We have a lot of questions about whether CIT and co-response models do actually reduce the incidence of use of force. We basically have great concerns where police are present that one of the fundamental rules of police -- again, Officer Reyes, you do seem amazing. I do respect the work you do.

I also want to note, you are here, armed, because you are on duty. And that is part of the police presence is when you are present on a scene, the possibility of use of force is present with you. And that is something that I think we do need to engage with when we approach these and talk about how we can find alternatives to policing.

Another thing I want to raise here, is another issue that has been raised to us by the community around policing and safety is the use of ID markers and databases to -- as a form of disclosure that poses as a safety tool. But I think there are very profound privacy concerns that our community has raised around both how those databases are maintained and used by state agencies, in addition to the fact that when it's an ID marker, it is an automatic disclosure every time somebody does present themselves in the community in a case where they would show ID.

Given that many of our communities are also on the LGBTQ spectrum, there are also concerns that this information can be used to deny medical care and other circumstances or otherwise deny agency and rights.

So, this is something that has been raised to our organization through many venues, and it's something that we're actively looking at related to law enforcement as well.

DR. DANIELS: Thank you so much. So, my second question for the panel is, what is your organization doing to help address some of these issues? And I'll start with Maria Mercedes Avila.

DR. AVILA: Thank you for that second question. And I can share briefly that we were able to adapt a training model that was created for health and mental health providers into what is today the Fair and Impartial Policing Training in the state of Vermont. The model includes the history of systemic racism, looking at intersecting issues of having a disability and being from a racially diverse background, looking at child development.

Some of the issue that we identified working with law enforcement was that there was a lack of knowledge related to some of the federal laws related to accessibility and also a lack of knowledge of Executive Order 13166, which is the Language Access legislation related to providing interpretation and translation services for limited English-proficient population. That's one of the key findings that we have through our work, and we incorporate that training into our work.

Through this training model, we were able to train all law enforcement agencies in the state of Vermont, and we collected pre- and post-test data related to the training that we offer. Seven years ago, we also created a cultural brokering program, which are community leaders who work with law enforcement and our programs to be able to bridge that cultural divide that exists between organizations and the communities that we're trying to reach. And through these programs, we were able to reduce and prevent arrests in many of the communities that we work with.

And finally, we also interviewed more than 100 community members related to their experience with law enforcement and the criminal justice system, including the community justice centers in our state, and we were able to identify recommendations. What we found was that there is a lack of knowledge from the community around the role of law enforcement and the limitations of law enforcement, including not understanding juvenile law, for example, for many of the communities. And then from law enforcement, there was also a lack of knowledge related to the communities, the cultural perspectives of the community that we serve, and also, that disconnect created a bigger disconnect between communities and law enforcement. Thank you.

DR. DANIELS: Thank you. Next, Lindsay?

MS. NAEDER: Yes, thank you. At Autism Speaks, we have two main approaches to promoting our safety work. The first is broadly to increase access to safety resources, services, funding streams at the state level, federal level, so that individual unique needs can be met.

There are no two people with autism that have the same safety needs. We're talking about many trends today, but there's a lot of individualized needs that must be met at the family level through the school system and through other services. Part and parcel would be then to talk about increasing First Responder Training, but also broadening our concept and definition of who first responders are.

We're talking a lot today about law enforcement agencies and officers, and that is absolutely something that we need to make sure that we're addressing, whether it's through crisis interactions -- we saw the statistics today -- whether it's five times or seven times more likely to interact with law enforcement.

But we also need to think about school resource officers, emergency room personnel, EMTs, 911 telecom operators, all of these folks, and so many others. I'm sure every single person has another sector that's popping into their mind right now that has to operate for our community as first responders. So, we're really making sure that we have resources and tools that can increase overall understanding and knowledge around autism, but also putting that through the lens of safety needs.

DR. DANIELS: Thank you. Camille?

MS. PROCTOR: So, one of the things that we, at our organization and -- we encourage those who are in law enforcement to participate in our programming, to be volunteers. And we had a program -- and we'll probably start it again -- where we had law enforcement and some of our youth work on projects together, and we had them do this for six weeks.

The reason we put them together in this manner is because we wanted to humanize our boys and girls. We wanted them to be people to these officers. We didn't want them to be a list of, may not make eye contact, may not do this. We wanted them to get to know those individuals so that when they were out working, if they saw someone that reminded them of Jeff or Cindy or whomever, they would understand and respond differently.

And what we got in regard to the feedback is that's exactly what is happening. They don't look at this list of maybe this, maybe that. They look at the individual, what they're doing, their body language. And I hope that what we're doing will work long-term and give law enforcement a better ideal that autism isn't linear, and it's not a one-size-fits-all. But we want them just to, again, stop being reactionary.

DR. DANIELS: Thank you. Amanda.

MS. WROTTEN: You're going to hear a theme from me. Earlier, I said it's not one thing, right? It's all of the things. So, what we're doing at the Autism Society of America is trying to build that culture of practice. And to that end, if you are a caregiver and you're in law enforcement, please call our helpline at 1-800-3autism and connect with me. Because our ideal trainer for something like this is a caregiver that has autism that can bridge that space in both communities.

So, we're building that culture of practice. It's not a quick-build, I'll tell you. And we need everybody in this room to help us. We want to be a part of your efforts, and we want you to help with ours. But uplifting those voices of individuals, caregivers, parents and, again, as I mentioned, those who are involved in law enforcement that have a connection to autism. Our saying here is, "The connection is you," and we really mean that.

In addition to that, I'd be remiss if I didn't speak to what we're doing with the Kevin & Avonte Grant. Leigh Anne from the Arc and IACP are our sub-recipients on that grant. We're lead TTA providers. And I've got to tell you, that's an interesting experience. Because we work with about 60 sites across the country, and many of them are law enforcement agencies. And they experience the difference in community where they have trouble getting tracking devices out because of the mistrust.

So, we're trying to bridge that gap and really build a true community of practice. But if you ask me for a one-sentence about what we're doing, we're trying to make sure everyone goes home safe at night. Whether it's Officer Reyes, whether it's Camille's son, whether it's me, whether it's my husband, we're trying to make sure that everybody goes home safe at night because that's what community means and that's what we want to be a part of.

DR. DANIELS: Thank you. Greg?

MR. ROBINSON: So, we engage in a lot of work related to this through many of the coalitions that we participate in, civil rights coalitions, both with the disability community through Consortium and Constituents with Disabilities, as well as the Leadership Conference.

A lot of our work really is aimed at bridging the disability rights and disability justice communities and the broader civil rights communities to make sure that we are really rowing in the same direction on issues of police violence and making sure that the disability community is well-represented, that we are addressing these issues, and that we are making sure that response systems like 988 are fully accessible to our communities including those who use text-to-speech or may need other alternative routes to contact.

In addition, we produce resources for community members around the criminal legal system and police violence. We have resources on the criminal legal system broadly, police violence, the school-to-prison pipeline, autism and safety, and sexual violence. So, this is an area where we also put priority in producing resources that can educate our community, both about the issues broadly and ways to advocate for what can best serve their needs. So --

DR. DANIELS: Thank you. And my third question for the panel, and we'll start with Mercedes is, what are some ways that you feel the federal government or state and local agencies and organizations can help address these issues?

DR. AVILA: Thank you. I want to start by saying that language matters. And in our interactions with law enforcement and in our work, we have found that even manuals and training procedures include language to describe disability, mental health conditions, immigration status that are very oppressive for the community that we serve.

So, language is one of the key areas that needs to be addressed and updated to be inclusive. I have gone with families who have children with special needs and with ASD and hearing a police officer or the criminal justice ask a question using a word that is very oppressive for the child, that breaks the connection between the community and law enforcement.

We talk about training. I would say I advocate for best practice training model that builds upon knowledge. Every year, I've seen in many law enforcement agencies that they use training models that are the same training every single year. So, nothing is being learned new with these models. Advocating for funding that encourages partnerships with communities to be able to hear the voices of the communities.

And finally, I would say we need leadership buy-in, not in words, but in actions. We need actions from leadership to advocate for change, and we also need funding allocated to advance this work in our communities. Thank you.

MS. NAEDER: Yes, thank you. At Autism Speaks we supported Kevin and Avonte's law to be passed initially and continue to lobby for continued funding, obviously, to make sure that this program can continue and hopefully, in the future, expand.

We'd like to see similar efforts include more community partners and more of the promising practices that the recipients of those funding streams are receiving. We do see a really great opportunity for some of this intersectional work, whether it's with mental health partners through the racial lens, through other disabilities, that can come together.

And when you're convening a stakeholder group, you can identify universal practices that can be applied to the crisis intervention training model that could then be applied and scaled nationally.

We also have seen really great success in either supporting existing community-based models, something as simple as a safety fair, where you're gathering those stakeholders on the ground, in communities where you can have autistic people, their families, their caregivers, bring their safety plans. You know, we've got great resources you can download to create crisis plans and to create safety plans that will grow along with you throughout the lifespan.

We know a child's needs are not going to be the same as an adult's needs. You don't necessarily outgrow your autism. And even if your child has been raised in a community and you feel comfortable that local law enforcement knows who they are, as they grow and change, maybe they're going to drive.

Maybe they're going to be living independently. Maybe they're just going to have a tough time in a grocery store.

Promoting and funding opportunities that highlight those community-centered programs will really sort out some of the opportunities that we need to see in leveraging these intersectional programs.

DR. DANIELS: Thank you. Camille.

MS. PROCTOR: So, I'm just going to reiterate some of the things my colleagues said. I do think that it's very important that we work with community organizations. But I also would like to gently remind people that the Disability Movement was birthed from the Civil Rights Movement. And for some reason we've forgotten all about that.

And so, you have this section of people, they're Black, and they're not being served. And we keep forgetting about them. And I'm not trying to change the subject, but I think it's very important that we take a look at ourselves, and we go back to, where did we come from? Again, we came from the Civil Rights Movement. And there's no reason why a Black child is being born right now, and his father or mother will be talking to him as an infant telling him what he cannot do in this United States.

So, I think that it's important that we do take a look at these underserved communities and work towards creating better programs because they are the ones who are the most adversely affected. Yes, I care about everyone's life, but when I tell you, statistically, people with disabilities who are dead because of a misunderstanding, are people of Color.

Very rarely do you -- and when you do hear about someone that is not a person of Color, it is magnified. It is magnified. And that makes me angry often because for that one child, there are probably 10 Black or Brown children that experienced something similar or worse.

DR. DANIELS: Thank you, Camille. Amanda.

MS. WROTEN: Thank you. I'll say, Dr. Daniels, this chair is a nice start. If you ask me what the federal government can do, it's nice to be included in these conversations. You know, we greatly value it at the Autism Society of America, but I think, you know, my subrecipients at the Arc or IACP would also love to participate in these conversations more. It's a great platform, so thank you.

You know, there's a couple of areas, and I think we've heard them throughout the day. One is just a general lack of data. I come from a PR background. So, I'm prepping talking points and looking for data, and it doesn't exist. So, I asked my husband who's a police officer, and he said, "Well, it's not listed on the Uniform Crime reporting."

When we look at a 1-in-36 diagnosis rate and we look at racial information that's tracked on uniform crime reporting, we should be getting disability and autism-related information. But if it's not on uniform crime reporting, we're not going to see it because that's the FBI gold standard.

So, there's a lack of just data about how deep that problem is, and until there's support to collect that data at a federal level that departments follow, we will not have that data.

You know, beyond that, funding state-developed high crisis units, we've talked about that, like cahoots. But I want to echo that also with we have to continue that community of practice. The Police Foundation around -- in Newport News had a call for service over the holidays that resulted in a fatal shooting. It was not autism-related, but it was a mental health phone call.

And at the time, the chief listed in the paper, he called for the Marcus Act, all the things through the community service board. And they didn't come to help because they didn't feel qualified. So that kicks the ball back in their court. And that's what I mean by it's not one thing. It's all of the things. So, if we only did a mobile health crisis unit and we don't train officers, what happens when that falls apart?

And then like everybody else, we need more money. You know, everything is underfunded. We need not just money to provide training and autism-specific training and meaningful training, but to work with departments that don't have an Officer Reyes, to implement a program there and actually pilot it and give families an opportunity to know what they're supposed to do in a traffic stop, which is a very stressful situation for anybody regardless of autism.

And supporting things like the Safe Interactions Act requiring officers to receive meaningful training that includes autism-specific de-escalation practices. And then the last thing for me is 988. But it's a two-way street, not just knowing that 988 exists but having the support on 988 to know what to do next so that training goes both ways.

DR. DANIELS: Thank you. Greg.

MR. ROBINSON: So first off, I want to thank my fellow panelists for raising the issues of all parties involved, all sectors involved when it comes to training.

I do think at the dispatch level is when -- where a lot of decisions are made in terms of who responds and how they respond, that really impact how people experience emergencies. And that can range from whether police are appropriate for dispatch, but also whether lights and sirens are appropriate. So, I think that is a critical piece.

I also want to sort of back up a bit and talk about -- again, police violence, I think impacts people's ability to live in the community, both very directly in their ability to move about their community, to interact with their community, and feel safe. We've talked about other cases.

I also want to mention the case of Charles Kinsey, a support worker, and Arnaldo Rios Soto, where -- this was a case where Mr.

Soto was in a group home, left the group home, and the support worker found him. But in the meantime, there was a police report that the metal train he had in his hand was reported as a gun. There was a police response. And while Mr. Soto was not harmed, it wasn't for lack of trying. The police shot the care worker in the leg accidentally.

So, I think understanding -- again, this speaks to who's part of the response team and what they are, what they know and how they -- and the competency both in dispatch and in response. I think addressing wandering also makes me want to really back up and talk about community living more broadly. I think we need a more robust support system, including much more robust funding from home community services to ensure that people have the direct support they need. If they need one-on-one support, that they have that support. And that itself can prevent some of this wandering.

I think we need to ensure that people

have the resources they need across -- system-wide. And this is another place where we need more funding. But we also need more data about where that unmet need currently exists. And I think that's a place where we have significant gaps.

And I think the other thing we have not talked on this panel as much about access to justice, but I do think one critical piece when we're talking about justice systems is making sure that people have the resources they need to -- for assessment and accommodation if they are justice-involved, that while we did go over the statistics around people in prison and jail, there's also an under-diagnosis problem in those systems.

And that we have a public defense system that is radically underfunded, under-resourced, and often don't have time to get people assessed and accommodated appropriately. And that really does impede people's ability to defend themselves in court if they are justice-involved. And I think that for us is a huge issue.

I would also like to say, as my time wraps up here, that I also think one thing -- one fear that we have around segregated legal systems but also around even within 988 and crisis response, is making sure that those don't track into institutionalization, that if people are getting emergency crisis responses, that does not become indefinite hospitalization.

One last incident I'll raise here. I am a gamer, so this is something that came on my radar through video games. But there was somebody who -- in the U.K. -- who hacked and released development footage of an upcoming video game that is a very big deal, and he was sentenced to indefinite secure hospital confinement. And the reason given was his profound autism.

This denies him a great deal of due process. And this is a case where -- this is somebody who did something I wouldn't even know -- beginning to know how to do, and he clearly is able to communicate because he has said that he absolutely would do it again.

And that, to me, I read the Lancet article, I don't understand how that meets the definition of profound autism. And it makes me very worried about how some of those definitions are used, if they are used to track people into institutional responses. That is also a cause of concern that I have. So --

DR. DANIELS: Thank you so much and thank you so much to our panelists for answering some of these thought-provoking questions. And we look forward to interacting with you in the Q&A, and also with previous panelists as well, since we didn't have time for Q&A earlier. So, thank you so much, and I will turn it over to Dr. Gordon to help moderate it, but I will also assist.

DR. GORDON: So, thank you. We're going to open it up now for comments or questions from members of the committee and -- go ahead, yeah.

MS. YETTA MYRICK: Thanks to everyone who presented today. It was really a rich conversation. It gave me a lot to think about, as I'm sure many other members of the committee. I love this idea of a proactive approach versus a reactive approach, right? In terms of the criminal justice system, I'm going to quote you and say, "It's not one thing, it's all the things." Right, Amanda?

And so, in thinking about that, right, there was a lot of conversation about -- there was a lot of conversation about training officers, which is great, right? Everybody has said that's a great thing, but how do we -- like, what are the other steps that we need to take, right? We heard a lot of things that were shared here.

So, my question to -- I would love to hear from everyone. I don't know if there's time. But what is the key takeaway that you want individuals and their families to know as they learn more about navigating the criminal justice system?

Like if someone is just starting to -- okay, I'm thinking about my son who's now 20, right? Like, one of the things that I did for him was I had an IEP goal that was set up that, literally, he learned how to take his ID out of his wallet, right, and literally say, you know, before he touches it, you know, "I have my ID. Can I show you?" Right? Like, this is something that we did individually.

And so, I'm really thinking about, yes, we need an approach all over, but I'm thinking about individual families right now that need help right now in this moment, individuals that need help right now in this moment. So, thinking about what you shared today and all the amazing resources and the thoughts, what is one key takeaway that individuals and families can utilize right now?

DR. GORDON: Thanks for that question, Yetta. I'm going to use the chair's prerogative to ask specific people to answer that. And if I could, Laurie, can I get you up there, and can you answer it in like two sentences? If not, that's fine.

OFFICER REYES: So, to answer your question quickly -- everyone knows I'm long-winded. So, this is really challenging for me, just want to let you know. That's already my two sentences.

All right. So, what we do is -- and I'm with you, I think more needs to be done in the area of interactions with individuals on having that interaction with law enforcement.

We talk about self-disclosure. If you have an interaction with law enforcement, what should you do? Calm hands and to get the -- here's the thing though. I get pushback on, "Why are you teaching individuals? You should be teaching officers." And I say, "No, no, no, it has to be everybody. It has to be the caregiver that has that conversation, the police officer, everybody has to be a part of it."

So, yeah, I mean, I'm game. Whatever you want to do, let's do it. I'm happy to invite you to hear me speak to one of our groups. Come as a big group and come watch us when we present to individuals about having interactions with law enforcement.

DR. GORDON: I'm going to ask also -- Maria, I don't know if you're doing that in Vermont. Do you have something to add?

DR. AVILA: Briefly, I would say that what we generally tell communities and families is to be able to connect immediately with an advocate. I think many times, when there are stressful situations, it's very hard for families to even be able to make a decision at that moment. So, be able to reach out to one of us, to one of the cultural brokers, to somebody who is in the community working with law informant to make that bridge, so we can advocate on their behalf. Because stressful situations are very hard for families. So, we get calls all the time, and I will keep advocating for having advocates with them.

DR. GORDON: Anyone else who has a strong one-sentence answer? Come on up to the table.

MS. LEIGH ANNE McKINGSLEY: It's Leigh Ann with the Arc U.S. And one of the things we've been talking about is creating a certification program for justice advocates that would be part of our network.

There are things like this in other countries, like the Appropriate Adult in the U.K. where they have something in place so that there can be someone there, that you were just talking about, to provide that advocacy right at the front. And so that's something we've never had in this country. And, it's about time we get more organized on that front. So, I just wanted to mention that.

DR. GORDON: Thank you. In the interest, I'm going to move on from now, and we can come back to that if there's some time at the end, I've got you down JaLynn. I'm going to turn to Ivanova now on the virtual. Ivanova, do you have a question or comment?

MS. SMITH: Hi, this is Ivanova Smith, and my comment for a question is for officers. Have you had any positive interactions with autistic people, and are there ways that officers could help autistic people solve the problem that -- and one example is, I actually had a police interaction. I've had several. I had one that was very negative where a police officer was kind of dragging me around and yelling at me, and that was really scary.

But I had a different interaction that was very positive, and I was able -- they actually were able to help me get to my next bus stop. I had a meltdown because I missed my bus. And that officer, instead of like trying to arrest me or anything, was very -- was like, "I can help you get to your next bus stop. I'll just drive you to your next bus stop." And that was really helpful.

And so, I'm wondering if there's more

ways that officers could like troubleshoot with that autistic individual and help them when they're in that meltdown and say, “Hey, maybe there's a solution. Like let me --" talk slowly to the person and say, “Hey, I just want to help you. And, you know, what's the problem here,” and -- kind of thing like that? Like, try to think of a positive way that you could help the person.

And I've had an officer do that, and it's been a very positive. And so, I'm wondering if there's more ways that we can do that? Also to train officers in non-speaking communication and behaviours communication. Because I think that is what training is lacking is when you have individuals that are non-speaking and cannot tell you what their name is or things like that.

Like, you should be able to train officers in being able to know if a person is non-speaking, and get a hold of the caregiver. Thank you.

DR. GORDON: Thank you, Ivanova. Would

anyone care to respond to that? Please go ahead. And then --

OFFICER REYES: So, thank you so much for sharing that. And here's the thing. I'll be quick. Thank you so much. I know it's hard to share the good and the bad, right? And I'll tell you that just this morning we taught about 35 officers about how to have positive interactions with those who are speaking and non-speaking and gave them a great overview.

And we've trained, I guess, over, I don't know, 5,000 officers over the course of, you know, 20 years. But I invite you that if you ever have an interaction, and you want to reach out to me, and you want to ask, you know, "Why did this happen," I'm here for you. You know, we're here for you. You can reach out to me. My email is right there. If you wanted to talk about what happened, the good and the bad, I'll take what you share, and I'll pass it on. Promise. Okay? Thank you, love. Thank you.

DR. GORDON: Amanda and then Craig, and

then we'll take another question.

MS. WROTEN: Sure. Thank you for sharing that. I really value you sharing both sides of that story with us so that we can make the world a little bit better.

I just want to let people know from the non-speaking perspective, if you go to the resources that are on the IACC website for this meeting, the Autism Society of America has our first responder communication boards up in English and in Spanish.

They are free. Make copies. If you are a law enforcement officer on this phone call, if you know another law enforcement officer in another jurisdiction, if you're a chief, if you have a friend that's a cop, send them the link to the file because it's a great tool to pull out. And it supports many needs.

So, it could be somebody with Alzheimer's. It could be somebody with dementia. It could be somebody with just a language barrier in general. But specifically for autism, it has photos related to what law enforcement might need to ask or information they might need.

And I know it's a lot to carry around, all of our different things. I have three pairs of headphones in that bag over there. But you can also print it out for yourself.

I have verbal shutdown during a meltdown and having that at your disposal, if the officer doesn't have it, that you can pull out and point to, can start bridge that gap with communication.

So, it's on the IACC website with all the resources that we send in, in English and Spanish. You can also call us at 1800-3-autism and I will send it to you. It's a free resource. It's our first responder communication board in English and Spanish.

MR. ROBINSON: Great. I'm going to be super duper quick, but I did want to say I really appreciated Officer Reyes in your presentation, that you, featured ID bracelets. Because I think, when we talk about -- I mentioned earlier sort of ID flags and things that have been proposed, I think that's one alternative that works for people who don't speak, who don't need to reach for their wallet, which can be potentially perceived as threatening, and allows them to communicate information, without speaking.

So, I think that is --I was really gratified to see that as an example in your presentation. Because that was something that is also something that has come up for us that we've discussed and recommended in the past. So --

DR. GORDON: Scott.

DR. ROBERTSON: Yeah. Thanks Dr. Gordon. So I had a question to -- with regards to federal law enforcement, the federal justice system. I wondered if any of the panelists might have any suggestions, ideas, recommendations for how we could apply lessons learned from local and state law enforcement perspectives to the federal system.

And I ask partly because we do not have

any universal requirements for the federal justice system for improving accessibility, including access for autistic people and supporting programs and practices. And the federal court system actually is not required under any statute to provide accommodations for people with disabilities other than communication supports like sign language interpretation, CART systems, and FM systems.

So, there's a large gap with regard to the federal law enforcement system and state and local system. So, I wondered if there's anything that could transfer over from what we're learning from the state local system. Thanks.

DR. GORDON: Thank you, Scott. Any of the panelists, care to respond? Well, that's telling.

MS. NAEDER: I can jump in.

DR. GORDON: Oh, go ahead, Lindsey.

MS. NAEDER: This is just very specific, but, you know, I have clocked a couple hundred hours of -- in partnership with the

National Center for Missing and Exploited Children, delivering first responder training that is autism-specific. Some of the feedback we got at the local and state level was including command-level leadership in the training and developing a training that is train-the-trainer module so that you're not just targeting an increasing knowledge base with, you know, patrol or people that are fresh out of the academy, but that you're building it within the institution that's a community.

You're leveling up the autism knowledge of that structure. And we know the challenge -- is it 1 million law enforcement officers in the United States, something like that? The structure within that is so complicated. There's hundreds of different branches at the state level. But I would say that making sure including command-level leadership in the training will also incentivize those positive interactions. You can create opportunities to not only think through when things go wrong, how could we do better, but to celebrate and to really make space for making sure that those positive examples are becoming policy and procedure and not just one-offs.

DR. GORDON: Thank you. We're going to turn to a comment from Morenike.

MR. ISAACSON: Yes. Hello. Morenike has this comment to share. "It is extremely frightening that people are trying to weaponize profound autism as a reason for regressive and problematic policies and practices under the guise of choice.

"Things like institutionalization and segregated housing are being labeled as safe, disability-equipped alternatives or so-called communities of choice when they know the term 'community of choice' means something completely different, things, for example, like sub-minimum wage and restraints.

"They say those aren't specialized innovations. They're inhumane and unjust ways to throw people away. Who is going to be hurt the most by these things? People who look like me and my kids. They say they shudder at the cluelessness and privilege of those who claim these things are necessary.

"As a person with a graduate degree in special education and a Black disabled mom whose intellectually disabled son has experienced institutionalization in polypharmacy, they say they're not just talking semantics.

"The things being pushed by certain groups and similarly minded individuals are the things that get my people killed. Black and Brown people with level three autism live in the real world, and that world is hella ableist and hella racist."

DR. GORDON: Thank you, Morenike. I'm going to put you down on the list unless there's a direct response to what Morenike is saying. Okay. Dena?

MS. GASSNER: Thank you. I just wanted to reiterate what Graig had to say about underdiagnosis. In my work as a social worker, every single individual that I have had dealings with law enforcement got their diagnosis after the dealings with law enforcement.

So, getting people properly diagnosed so that they can get a medical alert bracelet or whatever is just critically important. I have the same concerns Craig discussed about the ID card. It's not the card, it's the reaching for the wallet that terrifies me.

So, my son wears a medic alert dog tag, and we taught him to say, “I need my mom. I'm autistic,” and to just tap that dog tag because then all the hands are visible, right? And so, I totally agree with you, Officer, that we absolutely have to start teaching our people how to interact, how to show their hands, how to do those things.

Sadly, most people of Color get that talk way early on. But they're still disproportionately represented in these interactions. Our kids who are not kids of Color don't get any of this training. And parents are so afraid they're going to be scared of police that they don't teach them anything. And that doesn't work either. So, thanks for listening to that.

I did just want to bring up one really, really important point. I love your traffic stop idea. We think that if you can drive a car, you can drive a car. But if you can't deal with the law enforcement officer who wasn't trained, when they stop you, you're not ready to drive.

The last thing I want to say is I'm unfortunately going to have to tell you that the Ohio State Senate just overrode the governor's veto to deny transgender access to healthcare for our people who are transgender. We haven't talked about transgender. We kind of talked about LGBTQ and intersectionality. But the highest risk factor for law enforcement interaction is being a Black male transgender person transitioning to female. They have the highest exposure risk of all.

So, I really do hope that all we've

talked about today in terms of training law enforcement people, we're also emphasizing the massively higher percentage of neurodivergent people who are part of the transgender community because they're dying rampantly all through the country. And I hope we can do better on that. So, I'm sorry, I didn't have a question. I had to preach for a minute.

DR. GORDON: It's okay. I see that Greg wanted to respond to that. And also --

MR. ROBINSON: I just wanted to follow up because I did mention when I talked about one of the concerns we have around IDs that is a concern that the trans members of our community have raised, is that if there's a database, that possibly a parent, possibly a guardian, possibly some third party put you in years ago, that can be used to deny you care too.

And we've seen a number of states that have targeted disability status, specifically autism, to say that autistic people are not capable of making -- of knowing who they are and making these decisions and seeking trans-affirming care.

So, that's a very active concern for our community that we have, and I think that intersects very closely with some of the concerns we have around how disability ID flags in, whether 911 databases or DMV databases, how that information's used. Because that is a place where that is a really, really serious concern.

MS. PROCTOR: Yeah, I just wanted to make a -- tell a short story, which is this, my son who is autistic, his special interest is travel. So, last year we were in Paris at New Year's. And they blocked off all the streets and our route back to our hotel.

He's a creature, I mean, of habit, I mean, the route back to the hotel, the streets were blocked off. And right in front of our hotel, they had it blocked. And we were trying to talk to the officers to let them know that we're staying in the hotel right there.

And my son decided that he was just going to break the blockade. And he took off running. And I said --like you see in the movies where it's like, “No.” And, I screamed, I'm like, “He's autistic.” And the cops looked at each other. And then the one cop grabbed him by the shirt like this. He said, “Monsieur, you can't run off like that because you made your mother upset.”

Now, I'm thinking to myself, that never would've happened at America because all they would've seen was a Black man running down the street and disobeying what they were being told. But when I said, “He's autistic --" well, I don't even know what I said really. I'm just making up what I thought maybe I said because I was in just like such a panic. I was in such a panic.

And then when that officer -- and then he -- I guess he told the other officer, and he's walking back with him. And he goes, “Now, we don't want to do that. We have to listen to our mother.” And he's just lecturing him on listen to his mother, and you have to -- you can't do this. And I'm just like, ”Where am I?” And I go, “ Oh, yeah, I'm not in America.”

So I just -- I wanted to leave you all with that because that -- it's frightening. And I don't want you to say, “Well, she keeps talking about racial stuff.” But you know, that's who I am. And that's my identity. And everything that's been said here, I think it's going to take a collective on all fronts in order to change the way that we protect our individuals who are part of our community.

You know, autistic people are part of our community. So, we need to protect our community members. And that's just first and foremost from me. We need to protect our community members. We all need to do better, right? We need to do better. We need to speak up. Parents need to be able to go to the lawmakers and say, “Here's what I need for my child.”

You can't sit at home on your couch and be a couch cheerleader or internet cheerleader. If you're not going to get off that couch and go to your state capitol and say, you need this change and why you need this change and why your child matters, and it doesn't matter what color they are, you're useless to me. So I'm going to need everybody to get up, put pen to paper, and do what you've got to do.

DR. GORDON: JaLynn.

MS. PRINCE: Thank you. There's a couple of other levels, if we're going to be looking at this comprehensively, and Scott, you brought up a couple of issues. One is we had encountered a situation where there was an attorney that was representing an autistic man, but his specialty in disability law happened to be surgical malpractice and causing disabilities.

So, he really did not know anything about autism, but yet he was defending somebody with autism, which takes it to the next level of a friend of ours who is a federal court judge. And I said, "What would you change in the system if you could?" And he said, “Education of judges on all levels to understand autism and disabilities.”

And that's something that we have not covered here yet. But it is an important thing because a judge may have the discretion of making a longer sentence or a shorter sentence or modifying things. So, that is an element that even if there are excellent people in law enforcement. And Laurie, I wanted to mention some things, here. It has been amazing to see her team in action.

The last one, last situation was that our son was at a shopping center not too far from here, with a Black man who has been an absolutely amazing caregiver. He went to get a pizza, got out of the car to get the pizza at the door that was being delivered by curbside. Our son escaped from the back of the car because he was mischievous and disappeared. And this fellow was panicked. He has been with Madison for years.

And he started looking for him, couldn't find him, called us. We called Montgomery County Police and said, "No sirens. And this is what the situation is." I was concerned for two reasons. One, that we had a Black man at 10:30 p.m., possibly going through houses near there or through parking lots where cars were parked, searching for our son.

Meanwhile, it took five officers and about 15 minutes to locate our son who had gone up to the movie theater because he wanted popcorn. And we had not looked there. We'd looked every place else. But they were so cool that they said, “Madison, you seem to like us. Would you like a picture taken with us?" And so Madison has that on his counter that he has had a positive encounter with officers.

DR. GORDON: Thank you, JaLynn. I'm going to have to cut you off. I'm sorry. Because there are three more people, and we've got five minutes on [inaudible].

MS. PRINCE: All right. They have done wonderful things that she --

DR. GORDON: Thank you.

MS. PRINCE: -- has not been able to tell you that there's a long list that people can do in their community, including first responders --

DR. GORDON: Thank you,JaLynn.

MS. PRINCE: -- and autism.

DR. GORDON: Thank you. I'm going to ask Steve if you would want to make a brief comment about judges since JaLynn brought that up.

MR. GORDON: Yes. State court judges are covered by the Americans with Disabilities Act. I have done training, for state court judges in Virginia. And I'll tell you right now, the Justice Department is suing the Pennsylvania judicial system because there are judges that are refusing to allow people who are -- have opioid use disorder from taking methadone and Suboxone.

The Department of Justice has done things in this space, and I've done training and education. The Virginia judicial system also has a very good ADA coordinator, and we have a settlement agreement with the Virginia system for failing to provide sign language interpreters to people who are deaf.

So they, as a part of that, set up a good ADA coordinator system, and they're required to have ADA coordinators as well, which are in-house people who understand how the ADA works. So --

DR. GORDON: Thank you, Steven. Jenny, I have you next.

DR. JENNY MAI PHAN: Thank you panelists. And thank you to all the speakers for sharing this really important resource for our broader community. I have a question, if anyone who's spoken today have interfaced with schools or educators or school administrators to share the resources and trainings that you've done in the broader community? Because our kids spend hours in school and that would be a perfect setting for this education and then to invite parents and caregivers to participate in this education?

DR. GORDON: Anyone? Go ahead, Laurie.

OFFICER REYES: So, yes, I started about 10 years ago presenting to paraeducators, principals, all school staff, and then that kind of led into the general assemblies, to the general population on having them have an understanding of autism and other disabilities.

And, of course, our push to teach every single class in Montgomery County, all of our classes were trying to have my partner in the back be able to do that. But yes, we work, we work a lot. We're in schools all the time. We were in schools when folks maybe didn't want us in schools. And I said, “I'm going in.” Because my kids need me. And these kids need to hear about having interactions with law enforcement.

Because we were seeing our officers have interactions. And I wasn't going to take that I wasn't wanted in the school as an excuse. Because I know my kids. I know my kids need us. And I have seen our officers say, "Yeah, we had a young man who was in complete crisis. But he said, 'Officer Laurie told me to keep my hands here, or Officer Laurie did this, or Officer Laurie said something.'"

So, please, please, please, the importance of police officers looking like me in full uniform because that's what they're going to see in crisis, in uniform, having that interaction and saying what they should do in a police interaction needs to be supported. It's important.

DR. GORDON: Alycia, you're still back there? You also had a question or comment.

DR. DICKERSON: She was trying to get your attention for me.

DR. GORDON: I'm sorry. You're blocked by the camera, Aisha. Go right ahead.

DR. DICKERSON: Well, the person that I was hoping would answer my question left. My question was around the training. Because as everybody has said, Dr. Reyes is awesome, but coming from Alabama and living in Baltimore, it's not something that I often experience.

Similarly, as Ms. Proctor mentioned, as a Black person, that my interactions with the police haven't always been that great. Regardless of what kind of training is available and my wonderful education, my interactions are still not always that great. So, I just avoid the police like they're COVID.

But what I was hoping -- oh, she's back. Yes. Okay. So my question was, given that we have this wonderful training that you do here in Montgomery County, I'm wondering what are the barriers to making these kinds of trainings more of a nationwide thing?

I mean, we train the police on how to shoot accurately, right, like precision and all that stuff. How can we weave in training for de-escalation? Because even then, like I said, at my education level, I've had to de-escalate with the police when I wasn't doing anything.

So, how can we -- what are the barriers to making these kinds of trainings more on a nationwide level? Is it a funding issue? Is it a willingness issue? Is it a time issue? And I was hoping that Ms. Burke, since you're back, do you have any perspective on that? Because you -- I'm thinking that you have more interaction with a large variety of jurisdiction. So, what have you seen to be the biggest barrier to these kinds of trainings?

MS. BURKE: Oh, sorry. How much time do you have [laugh]? I would say there are 18,000 law enforcement agencies around the country. Sorry. There are 18,000 law enforcement agencies around the country. And state-level -- state mandates the actual training at the accreditation of officers at the local level. So, there's no one policy in the United States that mandates training for, you know, all police officers. It's at the local and state level.

You know, the availability of training, you know, evidence-based training materials, there's the availability of training time. There's a lot of demand for getting officers in training on a lot of different, you know, important topics and that kind of thing. And, you know, the recruitment and retention issues in law enforcement and taking officers off the streets to go into training.

There are, you know, some compounding factors that relate to -- that impact on getting this type of training out, across the country. But I would say that the state level accreditation, for mandating what officers need, that is, you know, one avenue. Like Amanda mentioned that in Virginia, it's one hour of training that is required, but it's different in every state.

DR. GORDON: Well, thank you very much. I want to thank all of the panel members from both, the earlier panel and at the later panel this afternoon. I want to thank all of the committee members for really what was a stimulating discussion.

I think we heard a lot. We heard a lot about training, about community engagement, about training both sides, about thinking about it comprehensively. We heard some about obstacles in the -- whether it be with -- regarding to federal system of enforcement and judges, whether it be about the Balkanized system. For someone who deals with trying to influence medical practice, mental health practices throughout the United States, this is a familiar story, right?

The federal government actually doesn't, often, in these cases, set standards, right? That's really left up to various other organizations, including state and local government. And so -- but thinking about ways that we might recommend some of this work to be done in a national way could be productive.

So, thank you very much for engaging on these topics and for engaging as well with the public comments and with this morning's topics as well. Susan, what other closing remarks do we have?

DR. DANIELS: Well, just want to thank you again for wonderful panels this afternoon. We really appreciated all these insights and such an important topic. I'm glad that we were able to take this on and have such a great discussion. So, thank you very much. And I know that through the Department of Justice, there are a lot of different coordination activities going on. We'll continue to engage on that. So, thank you.

DR. GORDON: And by way of closing out the meeting, we will dispense, out of time interest, with the oral recitation of the round-robin updates from the different agencies and organizations around the table. But they have been provided in writing.

And all the materials that I've said, "Oh, that's in writing, or you got it before," whatever, that's all on our website.

It's all publicly available. And so, anyone listening in who wants more information, wants to be able to take a picture of that QR code or click on any of the links, you should be able to get that on our website.

Thank you very,very much. And our next meeting is scheduled for --

DR. DANIELS: April 17th. And I also want to give you a heads-up that we're tentatively planning for April 16th to be our special event. It's not totally planned yet, but -- and so I didn't put it on the slide -- but you're hearing it. And we will let you know the final date for that.

We'll also have our office be in touch about the summary of advances and voting for that and follow-ups with the new report that we're going to be doing on co-occurring conditions. So, we really appreciate everyone's engagement today and wish everyone safe travels home and hope that you have a wonderful evening.

DR. GORDON: And once more, thank you to

all the ONAC staff who are sitting around the outside of the room. Give them a good thanks. Give them a round of applause. And everyone who travelled here, have safe travels back.

[Meeting ajourned]