INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, APRIL 04, 2023

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

PRESENT:

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

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

COURTNEY FERRELL AKLIN, Ph.D., National Institutes of Health (NIH) (representing Lawrence Tabak, D.D.S., Ph.D.)

MARIA MERCEDES AVILA, Ph.D., M.S.W., M.Ed., University of Vermont

SKYE BASS, L.C.S.W., TeleBehavioral Health Center of Excellence, Division of Behavioral Health, Indian Health Service

MITCHELL BERGER, M.P.H., Substance Abuse and Mental Health Services Administration (representing Dr. Anita Everett, M.D., D.F.A.P.A.)

AMANDA B. BRYANS, M.S., Office of Early Childhood Development, Administration for Children and Families

PRESENT: (continued)

ALICE CARTER, Ph.D., University of
Massachusetts Boston

JUDITH A. COOPER, Ph.D., National Institute
on Deafness and Other Communication
Disorders

SAM CRANE, J.D., Quality Trust for
Individuals with Disabilities

AISHA DICKERSON, Ph.D., Johns Hopkins University

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

MARIA FRYER, M.S., U.S. Department of Justice

DENA GASSNER, M.S.W., Adelphi University

ALYCIA HALLADAY, Ph.D., Autism Science
Foundation

ELAINE COHEN HUBAL, Ph.D., Center for
Public Health and Environmental Assessment
U.S. Environmental Protection Agency (EPA)

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

WALTER J. KOROSHETZ, M.D., National Institute
of Neurological Disorders and Stroke

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

LEAH LOZIER, Ph.D., U.S. Department of
Housing and Urban Development (HUD)

ALISON R. MARVIN, Ph.D., Social Security
Administration (SSA)

PRESENT: (continued)

KAMILA MISTRY, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ)

YETTA MYRICK, B.A., D.C. Autism Parents

LINDSEY NEBEKER, B.A.

MORENIKE GIWA ONAIWU, Ph.D., Rice University

SCOTT PATTERSON, Ph.D., H.S.P.P., U.S. Department of Veterans Affairs (representing Matthew Miller, Ph.D., M.P.H.)

JENNY MAI PHAN, Ph.D., Children's National Hospital

JOSEPH PIVEN, M.D., University of North Carolina-Chapel Hill

JALYNN R. PRINCE, B.F.A., Madison House Autism Foundation

LAUREN RASKIN RAMOS, M.P.H., Health Resources and Services Administration

KARYL RATTAY, M.D., M.S., F.A.A.P., Centers for Disease Control and Prevention (CDC)

AMANDA REICHARD, Ph.D., Administration for Community Living (ACL)

SUSAN RIVERA, Ph.D., University of California, Davis

SCOTT MICHAEL ROBERTSON, Ph.D., U.S. Department of Labor

IVANOVA SMITH, B.A., University of Washington

MATTHEW SIEGEL, M.D., Tufts University

PRESENT: (continued)

HARI SRINIVASAN, Ph.D. Candidate, PD Soros Fellow, Vanderbilt University

HELEN TAGER-FLUSBERG, Ph.D., Boston University

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

DEBARA L. TUCCI, M.D., M.S., M.B.A., F.A.C.S., National Institute on Deafness and Other Communication Disorders

PAUL WANG, M.D., Simons Foundation

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

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

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PROCEEDINGS

DR. JOSHUA GORDON: Well, welcome, everyone. Thank you for joining us today. My name is Joshua Gordon. I'm the Director of the National Institute of Mental Health, and Chair of the Interagency Autism Coordinating Committee. I'm very pleased that you can be joining us today for this meeting of our committee. It is Autism Awareness Month where we take time to recognize the contributions of people on the autism spectrum to our communities. We spent a lot of time in recent committee meetings discussing the needs of autistic people across the spectrum and across the lifespan. I want to assure you that what we do at NIMH, as well as on this committee, is strive to improve health and wellbeing for all autistic people and their families. A little bit later during this meeting, you'll hear about several special events happening across the government for Autism Awareness Month, and you'll have lots of other opportunities for a wonderful agenda, which I'll be describing in a little bit. Before I do that though, I want to mention some committee member updates. Ms. Dayana Garcia, who has represented the Administration for Children and Families in the recent past, has accepted a new position outside of federal government, so she won't be serving on the IACC. The alternate member from ACF is Amanda Bryans who will continue to serve until a permanent replacement is made. Mr. Stephen Whitlow, who has served as a public member of the committee, has also stepped down from the IACC in March, as he recently announced his run for the Louisiana State Legislature, where he would continue to support efforts to improve the lives of people with disabilities if elected. Both Dayana and Stephen express their appreciation for the opportunity to serve on the IACC and we wish them well in their future endeavors. Dr. Joseph Piven has also let us know that he'll be stepping down from the committee in the coming weeks. Joe, would you like to say a few words?

DR. JOSEPH PIVEN: Great. Thanks, Josh. Yeah, I just wanted to thank all of you and the leadership for this opportunity to be part of this committee over the last two years. Especially to thank, Susan Daniels and her incredible team for all the hard work they've done and contributions to the autism community. I wish we'd been able to get together face to face and so we could have further developed our relationships. But hopefully, my path will cross some of you in the future, and I thank you again for this opportunity.

DR. GORDON: Well, thank you, Joe for your contributions to the IACC over the past two years, and for your continuing contributions to scholarship and to making the world a better place for individuals on the spectrum. We wish you well. Joseph also brought up the fact that we're not meeting in-person today, and I'll just say that we would've liked to do so. The meeting space that we rely on is currently under renovation, and so we hope to be able to have that open and ready for our next meeting in the fall. Finally, I'd like to recognize the newly minted Dr. Morenike Giwa Onaiwu on the completion of her doctoral studies. Morenike recently received her Ph.D from the University of East Anglia. Her dissertation entitled Bringing Fire to the People: Activist Scholarship, Creative Collaboration, and International Advocacy Through the Lens of Black Disability Studies is really a wonderful contribution to scholarship and to the field. Congratulations to you, Morenike. I'm sorry to say that I'm going to be stepping off of this meeting for a few hours. I'll rejoin you for the public comment section of the meeting. I've had an unfortunate family emergency that I need to attend to throughout the day. In my place, I want to introduce Dr. Shelli Avenevoli, who's the Deputy Director of NIMH, and will be filling in for me along of course with Dr.

Susan Daniels, who is of course the Director of the office of the IACC and the Executive Secretary for the IACC. Shelli, would you turn on your video and just briefly say hi?

DR. SHELLI AVENEVOLI: Hi. Good morning, everyone. It's my pleasure to join you today. I look forward to the rest of the meeting and welcome.

DR. GORDON: Before I depart, I do want to give you a review of the agenda. We have some really wonderful presentations for you today. First, we'll hear from the Centers for Disease Control and Prevention, which has recently updated their autism prevalence estimate. They do that on an annual basis. We'll also hear an update from the National Autism Coordinator and discuss the IACC committee business this morning. In the afternoon, I'll rejoin you as I mentioned, for the public comment section, and then we'll have a panel presentation on increasing racial equity and improving disparities in autism outcomes. With that, I'm going to say farewell from now and turn it over to Susan, for her own opening remarks. We'll do the roll call and approval of minutes. Susan, take it away.

DR. SUSAN DANIELS: Thank you, Josh. Welcome, everyone to our April IACC meeting and our time to recognize Autism Awareness Month. A time that we promote acceptance and inclusion of all autistic people and take action to address the needs of autistic individuals and their families with the goal of improving outcomes. As Dr. Gordon said, we have a full agenda today with updates from the CDC, federal agencies and partner organizations, committee business, and a discussion this afternoon on race and autism. We look forward to hearing from all of our speakers and our public commenters today. So I’ll make a few housekeeping announcements. We want to remind committee members to keep your microphones off unless you're speaking, and also to keep your cameras off during the presentations and the breaks. You're welcome to turn on your cameras during committee discussions or when you're raising your hand to speak. If you are a committee member or federal alternate you would like to contribute our written comment during our discussion periods, please use the Zoom Raise Hand function to let us know that you'd like to comment and/or send a chat to Send Comments Here within the Zoom chat. That comment will be picked up by a member of our staff, Mr. Steven Isaacson, who you've all seen at our previous meetings, who will read your chat into the meeting for us so that everyone on NIH VideoCast can also hear what the comment is. Now, I'd like to go through a roll call just so we know who's all here today. We just saw Dr. Joshua Gordon and Dr. Shelli Avenevoli for NIMH. Next, I'd like to call on Skye Bass from the Indian Health Service.

DR. SKYE BASS: I'm here. Good morning, everyone.

DR. DANIELS: Good morning. Alice Kau for

NICHD.

DR. ALICE KAU: Here.

DR. DANIELS: Thank you. Amanda Bryans for ACF.

MS. AMANDA BRYANS: Hi thank you for the nice welcome. I'm very glad to be here.

DR. DANIELS: Thank you, Amanda. We're glad to have you with us. Mitchell Berger, Alternate for Anita Everett at SAMHSA.

DR. MITCHELL BERGER: Yes, I am here.

DR. DANIELS: Thank you Mitchell. Tiffany Farchione with FDA.

DR. TIFFANY FARCHIONE: Good morning. I'm here.

DR. DANIELS: Thank you. Maria Fryer from Department of Justice.

MS. MARIA FRYER: Good morning, everyone. Thank you. I'm here. Good for you. Thank you.

DR. DANIELS: Thank you. Elaine Hubal from EPA.

DR. ELAINE HUBAL: Good morning. Thank you for having me.

DR. DANIELS: Thank you. Amanda Reichard, the alternate for ACL.

DR. AMANDA REICHARD: Good morning. I'm here.

DR. DANIELS: Thank you. Dr. Kristie Hardy, alternate for NINDS. Or Dr. Koroshetz for NINDS. I think that Dr. Koroshetz is going to be here part of the day. Maybe not logged on yet. Leah Lozier from HUD.

DR. LEAH LOZIER: Good morning.

DR. DANIELS: Oh hi, Leah. Thyria will be joining us later as well?

DR. LOZIER: Yes, that's correct.

DR. DANIELS: Great. Thank you.

DR. WALTER KOROSHETZ: Oh, hi. This is Walter Koroshetz from NINDS. Sorry, I just had a trouble finding the right buttons.

DR. DANIELS: Glad you're here, Walter.

DR. KOROSHETZ: Thank you.

DR. DANIELS: Alison Marvin from SSA.

DR. ALISON MARVIN: Good morning. Thank you for having us.

DR. DANIELS: Thank you, Alison. Matthew Miller.

DR. SCOTT PATTERSON: Scott Patterson here for Matt Miller.

DR. DANIELS: Oh, Scott Patterson from the VA. Thank you. Kamila Mistry?

DR. KAMILA MISTRY: Here. Thanks.

DR. DANIELS: Thank you. Lauren Raskin Ramos.

MS. LAUREN RAMOS: Good morning. I'm here.

DR. DANIELS: Thank you. Karyl Rattay.

DR. KARYL RATTAY: Hello, everyone.

DR. DANIELS: Sorry. Oh, hi, Karyl. Jodie Sumeracki.

MS. JODIE SUMERACKI: Hi. Good morning.

DR. DANIELS: Good morning. From CMS. Courtney Ferrell Aklin from NIH Office of the Director. I have a note that Courtney's going to be here part of the day, so might not be logged on yet. Judith Cooper for NIDCD.

DR. JUDITH COOPER: Yes, I'm here, but I think Deb is also here.

DR. DEBARA TUCCI: Oh, yes. Hello. Good morning, everyone.

DR. DANIELS: Deb, nice to see you. Thank you, Debara Tucci. Larry Wexler from Department of Education.

DR. LARRY WEXLER: Good morning. Yes, I'm here.

DR. DANIELS: Good morning, Larry. Nicole Williams from the Department of Defense. I believe Nicole is here because we were emailing earlier, but might not have her sound working or something right now. Scott Michael Robertson for Department of Labor.

DR. SCOTT ROBERTSON: Good morning. Happy National Autism Month.

DR. DANIELS: Thank you.

DR. ROBERTSON: Thanks.

DR. DANIELS: Same to you. Cindy Lawler for NIEHS.

DR. CINDY LAWLER: Hi, everyone. I'm here today.

DR. DANIELS: Thank you. Then we're going to go through the public member list. Maria Mercedes Avila.

DR. AVILA: Good morning. I'm here.

DR. DANIELS: Thank you. Alice Carter.

DR. ALICE CARTER: Here. Good morning.

DR. DANIELS: Good morning. Sam Crane. I think that I don't have a note that she's planning to be here. She might had something else come up. Aisha Dickerson.

DR. AISHA DICKERSON: Good morning. I'm here.

DR. DANIELS: Good morning. Dena Gassner.

MS. DENA GASSNER: I'm here. Thanks.

DR. DANIELS: Thank you. Morenike Giwa Onaiwu.

MR. STEVEN ISAACSON: They said they're here.

DR. DANIELS: Thank you. Alicia Halladay. Alicia is actually planning to log on from an airplane, so may not be speaking. Might be texting more throughout the meeting. Yetta Myrick.

MS. YETTA MYRICK: Good morning, everyone. I'm present.

DR. DANIELS: Thank you. Lindsey Nebeker.

MS. LINDSEY NEBEKER: Hi. Good morning

everyone. I'm here.

DR. DANIELS: Good morning. Jenny Mai Phan.

DR. JENNY PHAN: I'm here. Good morning, everyone.

DR. DANIELS: Good morning. Joseph Piven.

DR. PIVEN: Good morning.

DR. DANIELS: Good morning. JaLynn Prince.

MS. JALYNN PRINCE: Good morning from the Washington DC area on a beautiful spring day.

DR. DANIELS: Thank you so much, JaLynn. Welcome. Susan Rivera.

DR. RIVERA: Good morning. Here.

DR. DANIELS: Good to see you. Matthew Siegel.

DR. MATTHEW SIEGEL: Here.

DR. DANIELS: Hello. Ivanova Smith.

IVANOVA SMITH: Hello. Ivanova Smith. I am here.

DR. DANIELS: Thank you, Ivanova. Hari Srinivasan.

MR. SRINIVASAN: Hi.

DR. DANIELS: Hi, Hari. Helen Tager-Flusberg.

DR. TAGER-FLUSBERG: Thanks for a terrific program for the day.

DR. DANIELS: Oh, well, looking forward to it. Thank you. Julie Lounds Taylor.

DR. JULIE TAYLOR: Good morning, everybody.

DR. DANIELS: Good morning. Lastly, Paul Wang.

DR. PAUL WANG: Good morning, Susan. Good morning, all.

DR. DANIELS: Good Morning. Did I miss anybody? That concludes the roll call, and now we'll move on to the approval of the minutes from the January 2023 meeting. The draft minutes were posted on the web and sent out to members of the committee, and I wanted to know if we have somebody that would like to put a motion on the floor to approve the minutes. Or if there are any comments or questions about the minutes, any changes that are needed. Which also you can feel free to send them too if you need to, if they're minor.

DR. AVENEVOLI: There's a motion in the comment, Susan.

DR. DANIELS: Wonderful. Thank you. I didn't see it.

DR. LAWLER: I second the motion.

DR. DANIELS: Oh, perfect. All in favor, can you please raise your hand in Zoom? Members of our team will just watch for that. Are we good there with the team? Is there anyone who's opposed? You can put your hands down and then we will ask if anyone's opposed to accepting the minutes. Debara, is your hands still up from before or is it opposed? Oh, it's down. Is anyone opposed to accepting the minutes? I don't see any hands. Is anyone abstaining from commenting on the minutes or voting for the minutes? No. It looks like a majority has voted to accept the minutes. Oh, Ivanova, you're abstaining. There's one abstention.

MS. SMITH: No, I'm not. I'm supporting.

I'm supporting.

DR. DANIELS: Oh, you're supporting it.

MS. SMITH: Sorry.

DR. DANIELS: Oh, that's okay.

MS. SMITH: I thought that was the word I was supposed to press. I'm sorry.

DR. DANIELS: That's okay. I know it's a little bit challenging in Zoom sometimes. It looks like the majority of the committee has voted to accept the minutes. We're going to approve the minutes. If there are any other little minor changes, you can always send them our way, but we will get the final minutes posted on the website after this meeting. Thank you. Now, I will turn it back to Dr. Avenevoli to introduce our speakers for the morning.

DR. AVENEVOLI: Wonderful. Thanks so much, Susan. Let's get started with our agenda. As many of you know, the CDC ADDM Network has been monitoring autism prevalence across the United States since 2000. Last month, the CDC released updated estimates of autism prevalence in eight-year-old and four-year-old children. Here to discuss the latest findings with us today is Dr. Karyl Rattay, Director of the Division of Human Development and Disability, and an IACC member. Joining Dr. Rattay are two members of the ADDM team. Dr. Matthew Maenner, Chief of the Child Development and Disability Branch, and Dr. Kelly Shaw, Acting Lead of the Surveillance Team and the Child Development and Disability Branch. Welcome to you all. We look forward to hearing from you. I'll also note that our presentation will be about 40 to 45 minutes today, and then we'll allow about 15 to 20 minutes for Q&A. We want to save time for question and answers. Thank you all. Thanks, Karyl.

DR. RATTAY: Thank you so much, Shelli. I have the great pleasure of really getting to kick us off with this discussion. I am really happy to get to introduce you to two amazing members of the CDC team. As many of you know, I've just joined CDC in October, but am incredibly impressed and proud of the work that they have done around ADDM over the past few years, especially the last five years. Well, I've known Dr. Matt Maenner enough in the last five months to know he's not the type to brag about his own work. I really wanted to highlight a tremendous milestone of this recent release, which many of you I think are aware of the work this team has done to decrease the time it takes to get the data published into the public. The big milestone here is, through the work of this team and changing the methods, they've been able to shave off an entire year. From the end of the year of data collection to the time it makes it out to the public, which is really tremendous. Going back in time, five years, when the team was hearing, and I know some of you were involved in the discussions, they were hearing that there was a need to get the information out more quickly, which really drove discussions and thinking around a change in methodology and using more administrative data that were available like education data and claims data, health data, rather than requiring every child in the system to have an individual provider in the ADDM system diagnosing them. There were concerns as they were thinking through this, and just really proud of how all of the partners, again including many of you, came together to understand the changes in methods and what it meant. As the team was doing this work, they were able to validate that the change in methods were showing very similar results, but also showing much increased efficiency, so 50% decrease in efforts to collect the data, which is also not only decreased the time for publication, but also very importantly opening the doors to enable whether it's expansion in age groups. I think Matt will talk a little bit about 16-year-old publication, which is now possible. Increase in geographic areas or numbers of kids being able to be included. Also now we're well positioned to increase the number of ADDM sites and number of conditions as well. I'm just really proud of this team. I'm glad to have an opportunity to brag about them. Very, very grateful for all of your input. Your partnerships in this work is really important. As we go forward, we're really interested to know how you all use these data and how these data are helpful to you for action, for policy, for additional research, et cetera. I just saw someone in the Chat ask, what is ADDM? I think Matt will probably talk in more detail about ADDM, but ADDM is our nation's autism surveillance network. Currently, it's in 11 sites. Through ADDM, for well over a decade now we've been collecting data on with kids at age 8. But to better understand prevalence of autism, but also some of the characteristics, demographic information as well. With that, thank you for that question, and I am going to hand it off to our two great leaders and brilliant scientists. Dr. Matt Maenner and Kelly Shaw.

DR. MATTHEW MAENNER: Well, thank you

very much, and I don't know if the slides are on their way too.

DR. KELLY SHAW: I'm sure they're.

DR. MAENNER: Yeah, but good morning and thank you for the opportunity to provide and update from CDC's Autism and Developmental Disabilities Monitoring Network, which we call ADDM Network for short. We're here with Dr. Kelly Shaw, who we each led one of the reports, if you go to the next slide. There were two reports that we released a couple weeks ago. It's still fresh for us. One was on early identification of autism and one was on prevalence of autism from the 11 participating communities in the network in 2020. Kelly and I will review the main findings of these reports and also highlight a few other new things that either just came out from that ADDM data or will be coming out any time now as soon as the journals publish them. Next slide, please. If it seems like we were recently here giving an update to the IACC, it's because we did just last year in

January. As Karyl alluded to, we've changed up our timeline a little bit to try to make things faster, and so I thought I'd just take a moment. Just the timing of things is one of the I think more confusing aspects of communicating our work. To orient everybody, we'll talk about what our new timeline looks like. Historically, the surveillance data would typically come out in the fourth year after the surveillance year. There'd be like three years and change of data collection. The 2014 data came out in early 2018, the 2016 data came out in spring of 2020, which I think some people may have missed because there were other things happening that month. But then we implemented some new methods to try to make things more efficient and faster after that. For the 2018 surveillance year, we were able to speed things up a few months and publish the reports at the end of 2021. Then this year we're publishing data on 2020 in March of 2023. Whereas under the old timeline, it would've been March of 2024, so we would've potentially been here a year from today. These changes also afforded us other efficiencies and the ability to do more and to cover more ground. There's certainly no shortage of important data gaps that we could be addressing. By implementing these more efficient methods, we were able to maintain the basic indicators that the network puts out very, very similarly. But we were also able to expand our tracking of early autism detection among four-year-olds to all of the sites rather than just a subset of some of the sites. As Karyl mentioned, we began a new activity, following up adolescents at age 16 to learn more about the needs of adolescents on the spectrum, and to think about transition planning and what might be in store for them after high school. Next slide, please. The ADDM Network it's a population-based surveillance system that monitors autism among children living in multiple geographically defined areas. Here on this map the counties that were included in the most recent reports are shown in green. The ADDM Network has reported autism prevalence among eight-year-old children every two years since the year 2000. This isn't a nationally representative sample, but it does cover a large population, and it has both geographic and demographic diversity in the communities that are included. Next slide, please. The way autism was ascertained, which was the same as the last report as well, is that all children were included if they were the right age and they lived in the surveillance area during the surveillance year, so at any time during 2020. They had documentation of any one of the three of these things. They could have a written autism diagnosis from a qualified professional somewhere in a chart. They could have a special education classification of autism from a school, or an autism of ICD or billing code that it could come from healthcare providers, different administrative service providers. But if they had any one of those three things, they would be counted in the number of children with ASD. Next slide, please. The overall result averaging across all 11 sites was, one in 36 children were identified as having autism in 2020 in the ADDM sites. That's about 2.8%. I think the next slide compares it to the previous report, which included the same 11 communities in 2018, which was one in 44 children, or 2.3%. Next slide. This bar chart, this isn't showing the numbers over time. This is showing the 11 sites in the most recent year for eight-year-old children, and so the height of the bars represents the overall autism prevalence, but then the different colors represent the kind of the level of information that we have on how we know they were identified. The green bars indicate children that had a written statement, indicating they were diagnosed with autism somewhere in their records. The blue reflects children that didn't have that written statement, but were classified at some point as receiving autism services in special education. The purple are children that didn't have the written diagnosis or a special education classification, but did have an autism ICD code associated with their record. About three-quarters of the children had a written diagnostic statement, indicating autism somewhere in their record. You can see there was still some variability between the low and the high from Maryland at about 2.3% to California at 4.5, I want to say percent. But the other sites were really all between the 2.3% and 3%, which is potentially a bit narrower than past years. Next slide. In addition to reporting the prevalence by the state, we also report by different demographic groups. One of the interesting findings from this most recent report is this continuation of racial and ethnic differences in prevalence, especially in the context of what was observed in ADDM reports previously. This shows historical data from the previously published ADDM findings, starting with the 2002 surveillance here. This are just exactly what was published in those reports. The different color dots represent the different racial and ethnic groups. In the first report, just only reported race specific prevalence for non-Hispanic White and non-Hispanic Black children, and then other groups were added over time. But you can see that for the first years of the ADDM Network, there was a pretty consistent difference in that the prevalence was higher among White children than among Black, Hispanic, or Asian Pacific Islander children. That persisted about through the 2014 overall. Next slide shows the next couple years, the gaps started to narrow a little bit. In 2016, there were no overall differences between White and Black children. Then in 2018, there were overall no differences between any of the racial group. But still within some communities that there were some instances, I think particularly with Hispanic children being less likely to be identified. But then the next slide, this year, that pattern has continued where over time all of the groups are increasing. But the prevalence among White children, it was increasing more slowly compared to the other groups. This pattern has continued. Where the gap is closed, they've caught up, and now the direction of the differences has reversed. One thought is that this could indicate more equitable detection of autism among all children, but it's also too early to say exactly what this means just based on this one year of data showing this new pattern. With the next slide, I think we will turn it over to Dr. Shaw to talk about the other report.

DR. SHAW: Sure. Absolutely. As folks who might remember, I think perhaps it was discussed on a prior IACC meeting. The ADDM Network has been moving away from just reporting median age of diagnosis, because as a metric, over time it has a lot of limitations to it. We published an analysis that went into that in excruciating detail, I would say. But what we have started using is cumulative incidents of autism spectrum disorder because what this measure does is it incorporates information about prevalence as well. This graph is showing on the X-axis, age and months, and then we are graphing the cumulative incidents of diagnosis or special education eligibility, which we usually refer to as identification over age. What we're able to do is to compare the children who are four in 2020 to the children who were eight in 2020. We can see the trajectory of how they are accumulating these identifications of ASD over time. What we have seen since we've started using this measure is that each year, the younger group has a higher cumulative incidence of identification by 48 months of age. There are increases in identification over time that we can see with this approach. Then the next slide. What this also enabled us to do, first, I have like a blank graph to hopefully help explain it before just flashing stuff up there. Well, for the 2020 surveillance year, of course, what we wanted to look at was whether we could look at the impacts of COVID. Being able to break apart incidence. But in this case by calendar month and looking over time helped us get at that question of what happened to early identification of autism. What we did was we took, again this comparison of the four-year-olds in 2020, to the eight-year-olds in 2020. We compared the first four years of life to see what was going on when eight-year-olds were in the same age window to four-year-olds. If you go to the next slide. The blue bars indicate more identification. We also did this with evaluations, and it showed very similar pattern. Prior to March of 2020 for the four-year-olds, there were increases, there was much more autism detection going on compared to what eight-year-olds had experienced four years previously. Then on the next slide, here we can see where that progress was really wiped out by the pandemic, and so it just went off a cliff in March of 2020 for the four-year-olds, and they began to see even fewer identifications and evaluations compared to what the eight-year-olds had seen four years prior. We, of course, think this is a really striking finding because of the importance of early identification. Next slide. The data release is not just the reports. I think people often prefer maybe not reading the reports, but having some of the more friendly communications products that we offer. We, of course, update the website with the newest data. The community report for autism is a product that we really appreciate being able to provide for communities because it summarizes all of the findings for folks, but each state has its own page where they pick what they think is the most important for their community. We also have easy-read summaries with the goal of being an even more high level summary of findings so that those have the maximum accessibility of the science for everyone.

There are slides with the data visualizations, many of which you've seen today that are available for researchers and other folks who want to talk about ADDM data. We try to provide visualizations that look nice, that the folks can just plop into their talks too. The data visualization tool allows folks to look at data from four different federal data sources. It includes all communities so they can see what data are available for their communities. Matt, did you want to briefly mention that commentary?

DR. MAENNER: Yeah. One of the new things we did this year was the MMWR. The CDCs publication that publishes these reports has been encouraging this idea of a paired commentary where we can share the drafts to have a commentary come out to accompany it published elsewhere. Rather than going an academic route, we thought this was like a great opportunity to include a community perspective on what these data mean, point out maybe what needs to be done, and really have that participation right from the instant that it was published. We were really pleased to have this accompanying commentary in STAT news by two members of the community that certainly this committee is very familiar with, and it was great to work with them. We're just really glad to be able to have that right at the beginning. I think these data are meant to be used and to help understand what's happening and to ideally help inform good decisions about what needs to be done. We're just really pleased for their collaboration on this.

DR. SHAW: Next slide. We, of course, had the data release, which was a lot of things, but that wasn't even all that was going on. Early in this year, we had a few papers. Suddenly, come through the publication pipeline, some unexpectedly, but it's always nice for that to work out. Next slide. First I'm going to talk about the first ever adolescent data that CDC was able to publish. As Matt mentioned, five of the sites followed up on children who initially came to attention with symptoms or indications of ASD by age 8, and these sites were able to follow them up through age 16 and collect similar information and see what happened over time. There's lots of really good information. In that report, I was just going to highlight one figure. This shows the percent of these children with co-occurring conditions by age eight years, and then by age 16 years. What you can really see here is that these children continued to be identified with these different co-occurring conditions over time. This could be really important and indicate a need for special considerations or particular services as these children age. Especially, in that kind of transition to adulthood period, these could be really important. The next slide, please. Then we also brought some population data. This newly defined profound autism, we wanted to at least describe what that looked like in population data. Both the prior study and this study were led by Michelle Hughes. What she was able to do in this study was she looked over from 2000 to 2016 to see what the population prevalence was of profound autism. What she found was that 27% of children with ASD had met this definition of having an IQ less than 50 or being non or minimally verbal. What this graph shows is what the prevalence looked like over time for both profound and non-profound autism where you can see increases, but there were even greater increases in non-profound autism than profound autism. Data are missing for 2012 and 2014 because verbal status was not collected for those years. This is pending publication any day in Public Health Reports hopefully soon. Next slide. We also published the first statewide and county level ASD estimates. We had seven sites participate in a pilot study where what they did was they combined statewide health data and education data, so they linked those data sets together to provide these estimates. This graph is showing the county level prevalence of ages 3 to 21, which at the county level ranged from 0.5% to 2.9% in this data set. What we thought was really important and also interesting about this as well is we were able to compare within the study areas that were doing the full ADDM methods. For children who were eight, we looked at the prevalence among eight-year-olds from this method and compared that to the full ADDM, and they were very similar for children who were eight. We think that this is a really exciting method that could be useful. The tradeoff is that it doesn't have as much detailed information about co-occurring intellectual disability or age of diagnosis, but it could really potentially help folks when they don't have more resource intensive methods to get data for areas that have never had data before. The next slide. Oh, sorry. I guess that was it. This was the graph when we compared within the study areas, age 8 and age 4. For age 8, I think it was just on average 6% different from what the full ADDM methods described. For age 4, it was a lot more variable, and this likely reflected the different kinds of data that people were bringing in to this project compared to what they used for ADDM. The next slide should be acknowledgements, I think. Did you want to join?

DR. MAENNER: No, we are really privileged in that we can share with you all of this work, but it takes an enormous team and people have worked so hard over the past several years through really challenging circumstances, and we just really appreciate that we get to work with such an amazing and dedicated group of people.

DR. AVENEVOLI: Thank you so much.

DR. SHAW: Yeah.

DR. AVENEVOLI: Absolutely. We really appreciate the time you took and the excellent presentation. Let's dive into questions. Yetta, you had your hand up first.

MS. MYRICK: Good morning. I think Larry

actually had his hand up. Then I'm next, if that's okay. I don't want to skip in line.

DR. AVENEVOLI: I was relying on the computer. Let's have Larry and then we'll come back to Yetta.

MS. MYRICK: Thank you.

DR. AVENEVOLI: Yeah.

DR. WEXLER: You want me to go?

DR. AVENEVOLI: Yes, Larry. You please go first. Thank you.

DR. WEXLER: I would've to deferred to the computer too. First of all, thank you. Those data are so compelling, and I know you all have been engaged in this for decades at this point. You're probably aware I managed the IDEA data and we remain perfectly willing and happy to supply you whatever data you need from our shop.

DR. SHAW: Thank you.

DR. WEXLER: Yeah. Please feel free to contact me. You probably already go directly to my data team, which is fine. The one question I had is, have you all begun to do any comparisons internationally as to where these latest numbers line up? I know South Korea does a pretty good prevalence stuff. I will belabor it, so you get the gist.

DR. SHAW: Yeah.

DR. WEXLER: Thank you.

DR. MAENNER: Well, first of all, thank you for the offer to collaborate. It's something we intend to take you up on. The education system is critically important to serving children with autism. Sometimes it's the only service provider in a certain community that really provides any meaningful support and services, and so we would love to talk more about how we can use what we have to learn what's happening and what's needed. In terms of international comparisons, I actually admit I'm a little bit rusty right now. We haven't gone back and tried to refresh the latest. We do keep a list of autism prevalence studies on the CDC website that we update, I think maybe every quarter or six months. We will go reread that. We've mostly been paying more attention to what the national surveys have been reporting, and of course, they sometimes combine years together. I think with this latest data, certainly with the national surveys it seems like they're in the ballpark, where we're seeing similar things. But of course, every community can be so different too. I think the variability is always there for me the really interesting part rather than just like what the big number is.

DR. WEXLER: Yeah. I think your numbers are much more in line with South Korea's from two or three or four years ago, which were seen as incredibly high and not that ours weren’t. But I think the number approaches South Korea, but I don't know what their absolute latest numbers are, but thank you for your work on this, it’s really remarkable.

DR. SHAW: Thank you.

DR. MAENNER: Thank you.

DR. AVENEVOLI: Yetta.

MS. MYRICK: Thank you. I'll jump in there. Good morning, Drs. Maenner and Shaw. Good to see you both. How many states have been represented across ADDM Network since 2020? You might not know off the top of your head, but I'm just curious.

DR. SHAW: Since 2000.

MS. MYRICK: Oh, is it 2000? Not 2020. Since 2000.

DR. SHAW: Yeah.

DR. MAENNER: Since the beginning.

MS. MYRICK: Yeah, since the beginning. Do you know?

DR. SHAW: Actually, I think 20 states.

DR. MAENNER: Twenty, yeah.

DR. SHAW: Sounds about right. That is on our data visualization website where you can see historically who has been included. That might be the easiest way, but I want to say we did update that number when we were doing the updates this year. I think it's 20.

MS. MYRICK: I was just curious. Thank you. Can you talk about what next steps are to collect data, maybe on a national level? I'm always going to push that, but just want to know if there are any thoughts on the pipeline about that. Then my final question related, but not directly with numbers more nationally or globally is, speaking to why Black children are being diagnosed with co-occurring ID, could you speak to that as well? Thank you.

DR. MAENNER: The first question about what's next, so we have a bunch of stuff coming out this spring. I think we've also learned at the beginning of this calendar year that Congress included additional resources to expand the number of ADDM sites, and then also to incorporate cerebral palsy tracking in a few of them. I think we're just waiting for people to push a button before we can talk about exactly what that'll look like. But the team has been working incredibly hard to do what Congress has asked us to do. In terms of the future, it's hard to predict. But I think that over the past several years, this program has basically overhauled just about every part of how it does its work to be more efficient, that we've been able to scale in adding age groups. Kelly talked about her work being able to get some data for like a whole state for every county in the state. I think we're really well situated to do these things, but then it's just a question of priorities and whether we're asked to do it, and have the resources to do that. Because at the same time, we've taken a very careful approach to think about what are the indicators that people really expect and need from the ADDM Network? That does include things like co-occurring intellectual disability. It does include things like how early are children getting identified with autism, and that still requires more intensive data collection. As things get more electronic or structured, that could change too. But I think we're well poised to do something. It just depends on that tradeoff between depth and breadth and speed and resources. But I think we've shown there's different ways it could be done. In terms of the differences in prevalence and co-occurring intellectual disability, for me, that was one of the surprises in the data this year. Historically, going back on that slide that showed like year over year, the differences were when more White children were identified with autism overall than Black children, it seemed maybe one explanation for that higher co-occurrence of intellectual disability is just that those were the kids that were more likely to come to attention. If there were differences in average, on a group level about access to services, maybe children with intellectual disability would be more likely to be picked up than children without. We do see that in the data when you look at the age of diagnosis. That's one of the few times that we compare ages. Children with intellectual disability tend to be diagnosed at younger ages with autism than children that don't have intellectual disability. But as the more and more children were being detected and the prevalence numbers evened out, and then this year the prevalence of autism among Black children exceeded White children, it was a bit of a surprise to me at least that that proportion with co-occurring intellectual disability didn't really budge. These data tell us what is happening, but they don't always tell us why. There are different ideas about what this could mean. It could mean there's still could be under identification in that group. Among Black children, we don't know what the ceiling would be. Some have proposed it could be a lack of early intervention that could potentially improve their performance on those tests early in life. We don't know, but it's certainly an important finding.

DR. SHAW: Social determinants of health. Upstream factors of maternal health, which we know there are disparities in and can also play a role in intellectual disability. But as Matt says, we can't see in our data the reason why, but it's definitely concerning.

DR. MAENNER: Yeah. Again, there's no biological reason why autism prevalence or co-occurring intellectual disability should be different between these different groups. I think it does warrant consideration of what other factors are at play.

MS. MYRICK: Thank you so much, and I appreciate your work. Good to see you, guys.

DR. MAENNER: Nice to see you.

DR. SHAW: Good to see you. Yeah.

DR. AVENEVOLI: Thank you. Morenike, you're next.

MR. ISAACSON: Good morning. I'll be reading a comment in two parts for Morenike. They say, "communities of color have been shouting from the rooftop for decades that our autistic children have been historically misdiagnosed as having conduct disorder, oppositional defiance disorder, and related diagnoses. Similarly, rather than receiving autism classification by school districts, which would better ensure that they would receive adequate services, our children are more likely to instead be labeled as emotionally disturbed or otherwise mislabeled as they travel on the pre-K to prison population. I see a lot of people jumping on the bandwagon with alarmist rhetoric related to the CDC data, but little to no practical effort nor resources being devoted to culturally affirming care for our kids. It's disgusting. People need to stop using us in their numbers when it's convenient to you while championing services and policies regarding restraint, institutionalization, surveillance, subminimum wage, et cetera, that harm Black and Brown children and adults. We aren’t your tokens.” The second part says, “within the span of under one year, we have seen significant revision of the proposed criteria for profound autism. I would like you to clarify the justification for merging groups of individuals with an alleged IQ under 50 with groups of minimally and non-speaking individuals, particularly given that for many non-speaking individuals, IQ is often improperly calculated. I also wanted to know the difference between individuals who have IQs under 50 who are speaking compared to those who are non-speaking, because intellectual disability isn't synonymous with being non-speaking. It can co-occur with it, but so can average IQ and intellectual giftedness.” They say “conflating the two unnecessarily can create a lot of concerns.”

DR. MAENNER: Well, thank you. We really appreciate the comment. Certainly, like the racial differences in prevalence and the reporting of the disparities in co-occurring intellectual ability, it's something that certainly with co-occurring intellectual disability's been a persistent finding, and it's been something that we have been called to put more emphasis in talking about rather than just setting it aside. There is a lot more to understand and certainly a lot more to do.

DR. SHAW: I would also just say to your point that people have been around. I thought that was definitely the message of the peer commentary in STAT that was written with the release as well. What people in the community know is that it's no surprise. I thought that was also a good point.

DR. MAENNER: The profound autism analysis. I think it's really important to clarify what CDC's role is in terms of setting policies or standards for how children are classified. Our role is really to report data and to contribute data to these conversations and these ideas that are being proposed -- no one from CDC had a role on the Lancet Commission that develop this definition. But it is a potentially important idea about maybe there's a way to define a set of characteristics that apply to some people on the spectrum. We did our best to apply those characteristics to the data we had rather than us deciding what they should be. We took this definition and with the understanding that like a lot of things, including the definition of autism itself, it'll probably be iterative. It'll probably be as people learn about what's useful and what those choices really mean when trying to describe different groups of people for different purposes. It could evolve over time. Our position on this is just that I think this is an area where there was a data gap and we were able to contribute to it, but we aren't taking a position on whether that is a standard the community is. We're not directing the community to use it. We're saying, this is what it looks like if we apply it to the population data we have. All of the issues about the subtleties in trying to measure intellectual ability, nonverbal status, those are really difficult. Even if you're making those assessments in a clinical setting and at a population level, oftentimes the things you're trying to estimate you have to do from less than perfect measurements.

That's actually a big part of our work, and so we can appreciate the comments about how challenging those are to measure.

DR. AVENEVOLI: Thank you. Joe.

DR. PIVEN: Good. Thanks. Well, thanks for a great presentation and for your really great work and obviously hard work. I think you guys were on before, and I may have raised the same issues. Apologies for being a broken record here, but I really want to focus on what potential ascertainment biases exist in this data. Just as an anecdote, I'm a clinician in a rural state and in a tertiary care center, and there's a tremendous push for us to help kids get services in remote areas that don't have services. Often the ticket ends up being a diagnosis of autism. That's unfortunate. I think that's a problem in ascertaining through the schools and I'm not exactly sure what qualified professionals are, but I think that there's some inherent issues there, and I worry that what we're tracking is a another social phenomenon and not necessarily just the actual prevalence. I recall maybe this is before your time, but the landmark ECA studies in the '80s of psychiatric epidemiology. There was one rogue group that instead of using the methods that had been used throughout the ECA, they did a door-to-door, more classic, traditional, epidemiologic study, and their results were quite different. I do worry about that, that I appreciate the need to cut costs and be efficient. But I think at some point, we really do need a traditional door-to-door epidemiologic study to really have some ground truth here.

DR. MAENNER: Yeah. I think that encapsulates a really long-running, almost like philosophical debate in this space. The idea of, are we really measuring true autism? The challenge I think is to say, to what standard? What is the ground truth? Who has done this? Then in order to implement something like that, in any study in which you would need willing participants that there would be issues of consent, issues of scale, how many people in what communities? How would you know what you would see, and would that generalize? If you're going door-to-door in one community, would you get the same result in another state? I guess I wouldn't say it that it's totally in the name of efficiency, but these data do show what the actual practices are in these communities, which is also important. If the idea like you had mentioned is if identifying a child helps get them into services, and I'm assuming everyone is acting in good faith and would say that they need these services and would stand to benefit from them, there is public health utility in understanding those patterns of practices. The idea of what is the actual truth of autism, that would be something that would be very interesting and we'd be very interested in measuring it, but I think we would look to our colleagues with more clinical expertise about what is that objective ground truth.

DR. PIVEN: Great. Thanks very much.

DR. AVENEVOLI: Thank you. We have several hands up and I'm acknowledging that we have about eight-and-a-half minutes. Let's move through as many as we can before the break. Lindsey, you're next.

MS. NEBEKER: Can you see me?

DR. AVENEVOLI: We can hear you now.

MS. NEBEKER: Great. Thank you for a great presentation. I'm going to touch up on a question that has already been brought up before, but I wondered if you can help provide a little bit more specificity on this. As you probably know, our IACC meetings are livestreamed and recorded and they are available to the public. I always feel like even though those of us in the committee have a lot of familiarity with autism and autism research and terminology and being able to have an understanding of how these things work, I also recognize there is a vast majority of our autism community who may not be as familiar with understanding how we come up with criteria for research. My question is to you is: Hypothetically, if I were a person who was just a family member or someone who was not too familiar with how the autism research and criteria work, if you can explain in simple terms, how are the surveillance areas in the specific states selected or have been historically selected for whenever you do the prevalence rates? Also, in capacity for the long-term plan, is there a long-term plan in place to expand the bandwidth and expand the number of states and sites where you do these studies and what are the specific criteria for selecting which sites you're going to use?

DR. MAENNER: Yeah. It's a very good question. If we're talking about the nuts and bolts of how this works, it's also worth pointing out that this isn't even research. Public health surveillance is a different kind of activity that has special provisions under the health code for working with sensitive data. The process for someone to be a site, it's a competitive process. CDC puts out funding announcements that public health authorities can apply to. In our case, it's often people at either health departments or universities that are working on behalf of the health department to augment their capacity to do this activity, and it's competitive. They create a proposal that describes what their geographic coverage is, why they think they would be successful in doing it, their experience, their capacity, the relationships they have in the community, especially with places that serve children with disabilities. That application is then judged by a set of independent reviewers, so it's no one on our team that reviews and scores the applications. It's an objective review panel within CDC. People that know a lot about public health in doing this kind of work, but not directly on our team, they score the applications and then we generally just go right down the line until we run out of resources to fund them. In terms of plans for expansion, there was increase in the president's budget that was signed in January that is affording ADDM to expand and add additional sites in the same capacity that we have the current ones. We've been scurrying since we realized we had additional resources to make that happen, and so the team has been very efficient. There's lots of layers within government of that, working through to where it gets out into the world. But the team here has been incredibly on top of it. I think in the coming days, we'll have something to say about the addition of sites as well.

MS. NEBEKER: Great. Thank you so much.

DR. SHAW: Thanks.

DR. AVENEVOLI: Thank you. I think we have time for maybe one, maybe two questions. Amanda, you're next.

MS. BRYANS: I'm going to go fast. Thank you. I'm also echoing another remark. I know you guys didn't choose the word profound. I have a long history of working with people with developmental disability. That is a loaded term. If there's anything we've learned about people with neurodiversity, it's that judging creates cognitive schema that can be problematic. I've known a young man who is non-verbal and was considered the term low functioning until they figured out he actually can read and has extensive knowledge of the political situation in the United States, which really makes him a genius in my book. I just think we have to be so guarded because when you use words like that, it puts people in compartments that influence how people teach and treat them, and it's a big problem. The other thing is, because I work for the Office of Head Start and I know the data can never be totally up to date. We are seeing very concerning things for people, for families, especially with lower resources in terms of states backing away and districts backing away from multidisciplinary evaluations, so more kids getting diagnosed maybe with speech and language without having a really comprehensive look at how they're doing. We've also heard of districts assigning children to gap time between part C and part B, like a gap year before you go to college. Kids who are still eligible under IDEA are not getting services. Again, these are not families who have access to legal representation. These tend to be low-income families, and we know of another state where they don't have enough speech and language therapists. Children are only getting speech and language as four-year-olds, not as three-year-old. I was surprised and glad to see some of the equity problems may have diminished, but I think they may have gotten worse again during the pandemic. We're going to have to really consider that when we know so much about how much early identification and early intervention matters with autism. Again, thanks for your work. It's provocative and that's really valuable and I appreciate the chance to speak.

DR. MAENNER: Well, thank you for your comment.

DR. AVENEVOLI: Thank you. Jenny, we're going to give you the last question, comment for the day.

DR. PHAN: Hi, Matt. Hi, Kelly. Thank you for being here and for your presentation, and I will be brief. I couldn't help but notice the figure that you put up that showed the prevalence rate and broken by the different racial groups that the Asian and Pacific Islander Group had such wide error bars, so there were bars that were stemming out from those dots. Just to speak to the public and explain what that is. Could you talk more about what that means so that the rest of us can understand what those error bars mean?

DR. MAENNER: Sure. Yeah. Those are 95% confidence intervals. The practical interpretation of it is how precise you think that estimate is. Big error bars mean you probably don't have enough data to really be confident. It could be reasonably within that range. The reason for that is just because, looking at the demographic composition of these communities and the country as a whole, smaller groups have fewer people, which means less precise estimates unless there was a deliberate attempt to overrepresent those groups to create stable estimates. Every data point that we've put in our reports at least now for the last I think three surveillance cycles, we do apply a standard for statistical precision, and we just borrowed one that is widely used by the National Center for Health Statistics. Even though those bars are wide, it's still reasonable to interpret it as a stable estimate. But when that isn't the case, you'll see like a little suppressed symbol if you look in some of the tables within individual sites. It's just a function of how many people are in that group, and that affects the precision of the estimates.

DR. PHAN: Thank you. I appreciate the breakdown.

DR. SHAW: Thanks.

DR. AVENEVOLI: Thank you. I just want to say thank you so much to Karyl and Matthew and Kelly for this excellent presentation. Very informative and the great discussion from the rest of the panel. We're going to take a five minute break. We're going to come back at 11:21 and start the next session. See you all soon.

[Short Break]

Welcome back, everyone from our very brief break. We'll have a longer break soon. But first and most importantly, I'm going to turn it over to Susan Daniels, our National Autism Coordinator, for the update, followed by IACC Business. Susan.

DR. DANIELS: Thank you. I have the National Autism Coordinator update where I'm going to be sharing some highlights from around the government and around the community. First, I'm going to share a few highlights from the White House and Autism Awareness Month Updates. First, from the

White House during Black History Month, which was in February, the White House released a fact sheet on the Biden-Harris Administration's Work to Support Black Disabled Americans. We have a link for you on this slide to that fact sheet, and they noted many different initiatives across the entire federal government where they were working to help Black Americans and people with disabilities thrive in their communities, at work, at home, and at school. The fact sheet covers employment, financial empowerment, access to disability benefits, education, housing, family support, and healthcare. You might want to check out that fact sheet.

Next, just very recently, we had President Biden's Proclamation on World Autism Awareness Day 2023, where he renewed the administration's commitment to equal rights, inclusion and support for people on the autism spectrum. He talked about where the administration has made strides, including home and community-based services, housing, employment, education, safety and law enforcement, healthcare, and also on global human rights. You can see the proclamation on the White House website. We also have some updates about Autism Awareness Month. At the United Nations, over the weekend, UN Secretary, General Antonio Guterres, issued a statement to mark World Autism Awareness Day, focused on building inclusive environments around the world. There also was a special event on Sunday with the global virtual event theme, Transformation Toward a Neuro-Inclusive World for All. You may want to see the video, which is on the UN website and we provided the links here. Also, I would like to welcome and invite you all to join us in about a week and a half or so on Friday, April 14th, from 2:00 to 3:00 PM Eastern. Our office and the NIMH are going to be hosting an Autism Awareness Month Special event, which will feature interviews with four autistic artists. Sheila Benedis, Ronaldo Byrd, David Downes, and Jeremy Sicile-Kira.

You won't want to miss this. It's very colorful, and we have a wonderful webpage up for the event on our website where you can view galleries of the art and get a preview of what they are going to be sharing. This is free and open to the public and will be available on NIH VideoCast. Visit the website and register for that event. Also, wanted to highlight Indian Health Services’ two events for Autism Awareness Month, including American Indian, Alaskan Native parents of children with autism panel that will be taking place on April 12th at 12:00 PM Eastern. Also on April 27th, they will be hosting “The importance of screening for autism spectrum disorder and the use of the M-CHAT.” That's another webinar and we've provided the links here so that you can attend those. In addition, the National Institute of Environmental Health Sciences here at the NIH is going to be hosting on April 20th from 1:00 to 2:00 PM Eastern, a special event for World Autism Awareness

Month, identifying early brain markers in infancy in autism and associated developmental disabilities. It'll feature Dr. Mark Shen from the University of North Carolina Chapel Hill, and so you can register on the webpage that's indicated on this slide. All these slides will be posted after the meeting. In addition, if you want to find out more about different things that are happening around the country and around the world for Autism Awareness and Acceptance Month, please check out our website and we've compiled events there and we will continue to update it throughout the month. We also have a new newsletter that just went out yesterday. The OARC newsletter where we highlight various events and news updates from around country and around the world. Welcome you to see that. If you'd like to subscribe, I've provided the link where you can subscribe to that newsletter. Next, let's talk about federal activities. I will go through some of the other federal advisory committees that we have in the government that overlap a little bit with our subject matter of disability and autism. First, the Interagency Committee on Disability Research. This committee held a Lunch and Learn Webinar on COVID-19 data on Individuals with Intellectual and Developmental Disabilities recently. This webinar featured people from HHS, and so you may want to check that out. There's also a report that they issued in 2021, and we provided the link to the report here on the slide too. With the National Council on Disability, which is a federal agency that works on disability related issues, they held their recent quarterly business meeting on February 16th and issued a notice of funding opportunity that closed on March 22nd, called The Absence of People with Disabilities in Clinical Trials, and I thought that members of this committee might want to know that that was out. The awardee that gets this grant will prepare a final report to provide recommendations and promising practices to increase inclusion of people with disabilities in clinical trials. In addition, on March 23rd, the National Council on Disability issued an update of its health equity framework. That information is also provided here. We heard that the NCD also in collaboration with the National Indian Council on Aging recently released a toolkit called Understanding Disabilities in American Indian and Alaska Native Communities. It shares resources and recommendations on disability services and protections for tribal nations. That is available on the IACC website as well. The Federal Partners in Transition is a federal working group that works on youth with disabilities, and they just held their general committee meeting on March 16th, and they're continuing to work on their new Federal Youth Transition plan, so we will keep you updated on the progress of that plan. SAMHSA's Interdepartmental Serious Mental Illness Coordinating Committee, which works on serious mental illness and serious emotional disturbances, which sometimes overlap with autism as co-occurring condition. Their recent activities include a meeting that happened on March 14th, and they had a presentation from Brandon Staglin, President of One Mind, on The One Mind Initiative: Social Innovation for Better Mental Health. The full agenda and link are here on this slide for you. I'd also like to draw your attention to an upcoming workshop of the NIH and the National Institute of Child Health and Human Development, called Ableism in Medicine and Clinical Research Workshop. This will be taking place later this month from April 27th to 28th and will be a two-day meeting on Ableism in Clinical Care and Biomedical and Behavioral Research. You're welcome to register for that event. I'm sure that several of you will want to attend that. It's free and open to the public. Some additional committees that I've listed here didn't have any new updates, but wanted you to know that we did check. The Raised Family Caregiving Advisory Council, Disability Advisory Committee, President's Committee for People with Intellectual Disabilities, and National Advisory Committee on Individual with Disabilities and Disasters, didn't have updates at the time that we put these slides together, but I think the DAC has just announced a new meeting, and so we'll provide that update for you. We'll probably update the slides before we post them. I just have a few non-governmental activities that I wanted to point out for you. One, that on March 30th, 2023, the Autism Science Foundation, held its Annual Day of Learning that featured talks by researchers and clinicians about topics in autism research and the event videos and information about the event can be found on their event page. In addition, the Kennedy Krieger Research Institute held a conference called Neurodiversity in the Workplace, and they brought together employers, stakeholders, and policy makers committed to improving employment outcomes for the neurodiverse workforce. More information can be found on their website. Also, the AJ Drexel Autism Research Institute recently issued a new report, a National Autism Indicators Report, exploring individual's use of Medicaid across the lifespan. It's called Introduction to Medicaid and Autism, and it is the first report in the Autism Institute's New Policy Insight Series. You can find that information on their website. They also have a very nice at a glance edition that you might want to read. It's like an easy-read edition with a lot of graphics. I think this is my final update, is the International Society for Autism Research is holding its annual meeting in Stockholm, Sweden from May 3rd to 6th. They will be sharing new scientific progress and findings from scientists across the world. Information for that and the registration is found on their webpage and hope that many of you will be able to attend that. With that, I conclude the National Autism Coordinator update, but are there any questions that anyone has for me? I'm not seeing any.

I will transition us then to committee business. We have some items for committee business to discuss today for the IACC, including the IACC Strategic Plan. I'll update you on the status of that. The Health Outcomes Working Group report that I mentioned last time and some updates about the IACC Summary of Advances. The 2021 to 2023 IACC Strategic Plan that this committee approved in January is in the process of being published and we expect it to be published in May. The committee voted to approve it and we are working on that publication. After it is published, we will also transmit it to Congress and the president as required by the Autism CARES Act of 2019. We've also prepared an accessible easy-to-read version that will also be released at the same time. For the Health

Outcomes Working Group Report. This is the report that the committee was working on in the last iteration on co-occurring conditions. I asked the committee last time if the committee was interested in continuing and finishing this report, and the committee did approve work on this report. Our office will be picking up this report as soon as the strategic plan is published and working on this over the summer to get a draft ready for this committee to review, and we will be reaching out to people who are involved earlier in the report and doing some revisions to get it up to date. You can expect to see some emails about this between now and the next meeting of the IACC in October. Julie Lounds Taylor has graciously offered to continue chairing the working group and we will reconvene members of the working group to take another look at the report and help us with the update as well. With the IACC Summary of Advances, I'm very pleased to announce that the 2021 IACC

Summary of Advances was released yesterday, and so many of you probably saw that in the OARC newsletter and on Twitter. This is a report that was required by the Autism CARES Act of 2019, and this committee selected 20 of the most significant advances in ASD biomedical and services research over the course of the work of this committee. The articles cover all seven areas of the strategic plan. The full report can be found at the link provided here, and we also have an easy-read version that was created for this report. Thank you all for your work on this, and we are working toward getting caught up on the summary of advances. Hopefully, we will soon be in the current year only. To give you a status update on the 2022 IACC Summary of Advances. We've already had you nominate articles, discuss the nominations and vote. Now, we're at the stage of our office working with our contractor to prepare summaries of each article and prepare the full draft publication. Once that is prepared, we will give the committee an opportunity to quickly preview it and comment on the draft and then we will prepare it for a final publication over the summer and present it back to you in October. For the 2023 IACC Summary of Advances, we have started the process of nominating articles for this year, for 2023, and today we're going to discuss the nominations that have come in so far and the rest of the process will ensue after that. Are there any questions up to this point? Not hearing or seeing any. I will move us on then to the discussion of the IACC Summary Advances. The goal of today's discussion will be to review the list of 20 nominated articles that if accepted, will eventually appear on the ballot. The selected article should represent significant advances or progress in understanding autism across the seven areas of the strategic plan and the seven areas we expect to cover most likely by the end of the year as we take in all of the different nominations from the committee. During this discussion, you're welcome to share any articles that you find particularly noteworthy if you want to say something about them or if you have any concerns about anything on the list and would like to propose removal of something from the list. Just keep in mind that we do not want to include studies that are too preliminary or have a very small sample size, reviews, commentaries, or workgroup recommendations. This publication is meant for original research findings in both services research and biomedical research. I will share with you the 20 nominations that we received to date. For Question 1, we have four nominations, I believe. Yes, there's just four. We had Differential Performance of Social Communication Questionnaire Items in African-American, Black versus White Children. Predictive Value of Early Autism Detection Models Based on Electronic Health Record Data Collected Before the Age of one

Year. Examination of the impact of the Get SET Early program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder and Level of Attention to Motherese Speech as an Early Marker of Autism Spectrum Disorder. Does anyone have comments about any of these nominations that came in? For anyone who's watching online, we have a listing on our website on the meeting page of all of these nominations as well and for committee members too, there's a packet. The packet shows who nominated the articles as well. Any comments here? I'm not seeing any comments. I will move on to Question 2. We had only two nominations here, Profiles of autism characteristics in 13 genetic syndromes, a machine learning approach, and Sex differences in social and emotional insight in youth with and without autism. Is there any discussion of these items? Either support or concerns? You do have a justification that was provided by the individual or agency that was nominating the article? Ivanova Smith. Do you have a comment?

MS. SMITH: This is Ivanova Smith, and I just want to say I support, I think it's important that there's more research on sexuality of autistic people and supporting autistic people, understanding their own sex and things like that because it's very hard. Autistic people to struggle with that. I think that's really important to look at that. Thank you.

DR. DANIELS: Thank you. Yes, and I think that this article talks about the differences in how people of different sexes, so males and females, interact socially and how much emotional insight they have. But yes, I appreciate that comment. Thank you, Ivanova. Anyone else? I'll move on to Question 3. We didn't have any nominations this time around for Question 3, but stay tuned for October. I'm sure we will have some.

DR. AVENEVOLI: Dena has her hand up now.

DR. DANIELS: Oh, sorry. Dena, would you

like to provide a comment?

MS. GASSNER: I'm sorry. I couldn't get to my button fast enough. The same article that Ivanova is commenting on, I think one of the relative strengths of that is that they're comparing autistic girls to non-autistic girls, which is such an improvement. Much of our research is compromised by the continued comparison of autistic girls to boys. I just wanted to champion that aspect of the study.

DR. DANIELS: Thank you, Dena, and that is true. It wasn't strength of that study. Any other comments on this? For some reason on my screen, I'm not seeing faces. I see at the bottom if somebody has their hand raised, it's like little words. Sorry if I'm almost slow to see that.

DR. AVENEVOLI: I can help you, Susan. I'll look for hands.

DR. DANIELS: Oh, thank you. That would be great, Shelli. Question 4, interventions. We have one nomination, The earlier the better: An RCT of treatment timing effects for toddlers on the autism spectrum. Any comments here?

DR. AVENEVOLI: None so far.

DR. DANIELS: I will move to Question 5. I believe we have just the three, so we have three for Question 5. Preparing Law Enforcement Officers to Engage Successfully with Individuals with Autism Spectrum Disorder: An Evaluation of a Performance-Based Approach. We also have Barriers to service and unmet needs among autistic adolescents and young adults, and Racial and Ethnic Disparities in Geographic Access to Autism Resources Across the US. Are there any comments on those?

DR. MARVIN: Hi. This is Alison Marvin. I'm from Social Security. I just wanted to mention that I had put forward the preparing law enforcement officer's article and it has a comparatively small sample size if they did do a pilot before doing the main study. But it was such I think an important in our area, which has very minimal research behind it, but I thought it was important to include it. That is why I did put in something which did have a smaller sample size than I would normally, normally go for. I just wanted people to have that in mind, but keep it in mind.

DR. DANIELS: Thanks so much for that additional information, Alison.

DR. AVENEVOLI: Maria has her hand

DR. DANIELS: Oh, Maria.

MS. FRYER: Oh, hello. Thank you so much. I just wanted to concur and say thank you so much for this submission. I am forwarding many of the slides and discussion to some of our teams, our technical assistance providers as I'm going these. Because through our Stepping Up initiative we're looking at counties and county collaboratives between public safety, law enforcement, and justice partners in partnership with other service providers and community partnerships. We're trying to look at not only the impact and effectiveness of models, but also talking about the just the racial and ethnic disparities and doing a crosswalk with who is coming into the jail and why. I definitely was taking note through the CDC presentation and some of the numbers there and moving that along to see if we can maybe start a dialogue or create a brief around that. This is really wonderful to see these articles here so that we can talk more about co-occurring disorder and crosswalk that with interactions with law enforcement and just get at some of the reasons behind that and some of the underlying environmental factors and social determinants of health and thinking through like why is that and what can we do to impact change. I'm really happy to see these. Thank you.

DR. DANIELS: Excellent. Thank you so much, Maria.

DR. AVENEVOLI: We have Scott as well with his hand up.

DR. DANIELS: Thank you.

DR. ROBERTSON: Yeah, thank you. Well, I didn't nominate these articles. I think it's great, especially with these research articles that we are looking at like race, ethnicity, geography, gender identity, sexual orientations. These diversity aspects, I think it's really helpful to see this more and more in the research literature as we go through time because I think it's been so much left out over the years and I think that we're getting better coverage now, so that's really great. I'm glad that folks are nominating that. I'll make sure to try to include similar things when I make nominations later on. I hadn't made a nomination for an article yet.

DR. DANIELS: Wonderful. Thank you, Scott.

DR. AVENEVOLI: Yetta.

MS. MYRICK: Thank you. No, I really appreciate the thoughtfulness that was taken to basically put these articles forward. I think that specifically as we talk about law enforcement and other groups, I would say to the whole IACC membership and myself included that we really need to be thinking broadly about all the different groups that are interfacing with the community and really think about putting forth more articles such as this. Alison said it's a small sample, but this is something that has come up in some of the work that I'm doing nationally. Then in terms of thinking about like barriers to service and unmet need, there's been so much focus I think on school age. But as my son is getting older, he's now 19 thinking about what do services look like. As my son ages and becomes an adult is important. Then also to this idea of disparity, depending on where people live. This is another thing that is coming up. I think these three articles are spot on, and I hope that as a group, once we dig a little deeper, these will definitely be included in the large summary. Yeah. Thank you.

DR. DANIELS: Thank you so much, Yetta.

Any other comments on Question 5?

DR. AVENEVOLI: No other hands, Susan.

DR. DANIELS: Thank you so much. We will move on to Question 6. I was trying to remember which ones had multiple. We have four articles for Question 6, including Predictors of sleep quality for autistic people across adulthood, Girls With Social and/or Attention Deficit Re-examined in Young Adulthood: Prospective study of Diagnostic Stability, Daily Life Functioning and Social Situation, and A longitudinal study on cognitive aging in autism, and finally, Psychological, behavioral, and biological factors associated with gastrointestinal symptoms in autistic adults and adults with autistic traits. Any comments here for these four articles? Dena?

MS. GASSNER: I was going through the sleep study article and it does make mention of the use of social service systems as a factor in sleep quality, but I cannot find what that factor is. Is it that having more predictability in their lives due to social services reduces sleep disturbances? I just couldn't seem to find that in the study. Given the difficulties we're having in getting late life services for people who weren't diagnosed before 21, I think that's really significant in terms of looking at service delivery. It's just a question. I don't know if someone else did a better reading and they found the story to that, but yeah.

DR. DANIELS: I don't know if anyone has that answer.

MS. GASSNER: I'll reread it.

DR. DANIELS: Yeah, I guess we can all imagine multiple reasons why someone that isn't getting good services might have trouble with sleep. I don't see any hands raised for that.

MS. GASSNER: Thank you.

DR. DANIELS: Thank you so much. Any other comments?

DR. AVENEVOLI: No hands, Susan.

DR. DANIELS: We will move on then to Question 7, and I know that there are two pages of Question 7. We have Prevalence and treatment of mental, behavioral, and developmental disorders in children with co-occurring autism spectrum disorder and attention-deficit/hyperactivity disorder. We have Adolescents with Autism Spectrum Disorder: Diagnostic Patterns, Co-occurring Conditions, and Transition Planning. We have Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years. Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, which we just heard about. We have Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years, Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, which also was discussed today. Statewide, county-level autism spectrum disorder, prevalence estimates, seven US states and Prevalence and Disparities in the Detection of Autism

Without Intellectual Disability. Those are all our nominations. Do we have any comments or anyone that was a nominator here would like to say anything in support of these articles? Or does anyone have concerns?

DR. AVENEVOLI: Karyl has her hand up.

DR. DANIELS: Oh, go ahead, Karyl.

DR. RATTAY: Obviously, I'm biased from our perspective of the work we do. Two of the papers, Maenner and the first Shaw paper, are the two that were described in detail today. We believe there's just such tremendous value in understanding the change in prevalence, the change in disparities, and also very importantly, early identification, as well as learning how the pandemic impacted identification of four-year-olds. Certainly, we see those as important papers. But the other two I also wanted to highlight as bringing value. The second Shaw that is up there right now, Kelly did talk about that a little bit. I'm seeing this as a bit of a watershed paper because we're taking this in-depth ADDM data using a different methodology and validating the fact that we can do statewide prevalence in an easier way and less resource intense. Of course, we don't get all of the information. But right now many states don't have great autism prevalence data, and so I think that this study brings great value. Then if you go back to the first page on this. Are you able to go up one slide?

DR. DANIELS: Yes. The previous page?

DR. RATTAY: Yeah. The Hughes paper looked at diagnostic patterns. I was able to look at the 16-year-olds that we now have in our system and co-occurring conditions and better understand. For example, they looked at transition plans who had them, who didn't, and found, for example, those with intellectual disabilities were less likely to have transition plans. I think that's really important information. Also, we're able to find that those with co-occurring mental health conditions were, I'm probably going to say this wrong, but had later diagnoses. In other words, there may have been more confusion around what their diagnoses were earlier on, and so that may have led to, this is more of a hypothesis, but may have led to a later diagnosis. I think there's some real valuable information in these and would encourage folks to take a look at them.

DR. DANIELS: Thank you so much, Karyl for that extra information about those papers. Are there other comments that anyone has on these? Just to note for everyone, if you happen to notice Question 7, infrastructure and prevalence, we used to call it infrastructure and surveillance until we got public comments very concerned about surveillance, thinking that that meant Big Brother. We changed it to prevalence to make that a little clearer and a little bit more plain language. That has been a recent change within the last year. I'm not seeing any other comments and you don't see any, Shelli?

DR. AVENEVOLI: No, you're clear.

DR. DANIELS: Let me just give you a summary here. We had a little bit less on committee business today because we didn't have a big project to discuss. Thank you again for all the work that went into the strategic plan. We look forward to releasing that soon. We'd encourage you to continue sending your article nominations to our office to the IACC Summary of Advances, or if you're in the middle of doing something and you don't know where that email is, you can send them to me and we will get them in. We take them all year round and we send you reminders quarterly for those. Did I see? Was there a comment that somebody was trying to make?

DR. AVENEVOLI: I don't see one, Susan.

DR. DANIELS: Something flashed on my screen and I wasn't sure what that was. We also will be discussing new nominations for the IACC Summary of Advances in October and sharing with you the 2022 publication. With that, I believe we can conclude our IACC

Committee Business a little bit early and have a little more time for lunch. We will take a break until one o'clock, and I believe we're right at about noon, so we will have a one-hour break and we'll come back promptly at one o'clock and take our public comments at that time. I hope everyone enjoys your lunch, and thank you so much for your participation in our committee business today. Thank you.

(Whereupon, the Subcommittee recessed for lunch at 12:00 p.m. and resumed at 1:01 p.m.)

DR. DANIELS: Welcome back everyone. It's 1:01 and we are ready to start the public comment session.

DR. GORDON: I want to add my words of welcome. Hi, Susan. I'm back. I want to add my words of welcome and I look forward to the oral comments session, but I'll turn it over to Susan Daniels to introduce each of the public speakers and also what's going to happen during the session.

DR. DANIELS: Thank you so much. We will first start with our oral public comments, and I'll just remind everyone that we want to be very respectful of everyone as they're giving their public comments, and we will listen to all the oral comments first, and then we will do written comments and then have time for discussion. We'll start with Dr. Geraldine Dawson, who's on our list.

DR. GERALDINE DAWSON: Thank you for this opportunity to make public comments at the Interagency Autism Coordinating Committee. I'm Geri Dawson, Professor at Duke University and Director of the Duke Center for Autism and Brain Development. I'd like to draw your attention to a proposal by the Accreditation Council for Graduate and Medical Education, to make two changes to the requirements for pediatric resident training that would negatively impact the care of autistic patients and their families. I provided a link to the proposed changes in my submitted letter. The first change would remove the current requirement to have a developmental behavioral pediatrician among other subspecialists on the faculty of the residency program. The second change would remove the current requirement for ensuring adequate exposure to the spectrum of normal development and the longitudinal care of children with special healthcare needs. The US healthcare system is currently inadequate to meet the healthcare needs of autistic individuals. The primary care pediatrician plays a crucial role in autism screening, referral for a diagnosis, and addressing the substantial health-related challenges that are associated with autism, which include increased neurological, ophthalmological, and gastrointestinal problems, among others. Primary care pediatricians are the medical home for autistic children and the entry point for early detection and referral for evaluation and behavioral and physical health services. Plus, medical training about patients with autism and other neurodevelopmental conditions is essential for our future medical workforce. Research has documented the substantial impact of co-occurring medical conditions on quality of life for autistic individuals and the important role of medical training in addressing the complex healthcare needs of autistic patients. Removing the requirement to provide adequate exposure to patients with neurodevelopmental conditions and other special healthcare needs during medical training would represent a significant step backward from reaching the goal of meeting the healthcare needs of autistic individuals with significant long-term consequences for health, quality of life, and mortality in adulthood. As the national body that oversees research, services, and policy related to improving quality of life for autistic individuals, I urge the IACC to provide comments to the accreditation council about this proposal, which can be submitted directly at the website and I provided this website in my letter. Please note that the deadline for submitting these comments is tomorrow, April 5th, 2023. Thank you again for allowing me to have an opportunity to address the IACC.

DR. DANIELS: Thank you so much, Geri, and I should also mention that Geri's a former member of the IACC and we have two of those today who will be giving oral comments. Thank you so much, Geri for being here. We will wait to have discussion until our discussion period. We will go on the next commenter, which is Dr. Miya Asato.

DR. MIYA ASATO: Good afternoon. Thank you for allowing me to share some comments with you today. By way of introduction, I am the Vice President of Training at Kennedy Krieger Institute in Baltimore, Maryland. I am also the director of the LEND Program, Leadership Education and Neurodevelopmental and Related Disabilities at the Institute. I am a professor of neurology and pediatrics at Johns Hopkins School of Medicine. I did a full pediatrics residency and then trained in child neurology. My specialty is in neurodevelopmental disabilities, and I am the program director for the Neurodevelopmental Disabilities Residency Training Program at Kennedy Krieger. As Dr. Dawson mentioned, the removal of the requirement to have a developmental behavioral pediatrician as part of the training faculty in pediatric residency programs is really perhaps a reflection of the shifting needs of pediatricians to be able to address more psychiatric issues than ever before and also due to the shortages of developmental behavioral pediatrics faculty on the national level. The essence of pediatrics residency training is to understand and treat the emotional, physical, and developmental needs of children from birth to the transition to adult care. Without understanding what the template is of what is within the wide range of what is typical, there will be a fundamental shift in what pediatricians know about child development and may consequently impact, I think the developmental health of generations of future children if this change were to go forward. As was mentioned earlier, pediatricians play a crucial role of being the medical home, but also the gatekeepers. Without being trained what to look for in terms of signs for potential autism, intellectual disability, or other disorders within the context of pediatric outpatient settings, pediatricians will continue to feel uncomfortable about developmental issues. This is already a problem across pediatric practices as well as pediatric specialists. By diminishing the central focus of the pediatrics residency training, they typically get a month of developmental training. Shifting the burden of this training to other professionals, this may unintentionally create a generation of pediatricians who are unprepared for their future role in developmental supervision. Without requiring developmental behavioral pediatricians to be role models as teachers, the positions for these fellowships, as it is a fellowship trained position, will continue to be in jeopardy. They're often unfilled, and this will impact the future teaching workforce. When physicians are uncomfortable with what is being asked of them, they will refer to other specialists. Currently, when a pediatrician is concerned when a child is delayed or may have a disorder such as autism, they will often refer to a developmental pediatrician or to a physician such as myself, another neurodevelopmental specialist. But if they don't understand what developmental pediatricians do, or if there's no workforce available, the referral pattern will shift to other professions who may be very unprepared for this change. By shifting this role to others, this will already add to the very long wait times and may increase the age of diagnosis of ASD and delay the start of services. Now, it's important to note in the language that the ACGME is mentioning in their proposed documents, that they are mentioning some alternate professions who are not trained in typical development, and they may have a poor awareness of the complexities of the various pediatric diseases, which may alter developmental trajectories. Children with medical complexities and their families need the combined expertise of pediatric physicians and a developmental specialist such as a DBP or NDD specialists. Comprehensive programs such as Down Syndrome Centers are often led by these types of professionals. They provide a medical home, provide care supervision, and management. These centers play an important role in forging pathways and standards of care for transition to adult systems, which remain a significant need for many young adults with complex needs and disabilities. The workforce available to address parents' concerns around development is already at a crisis point. If pediatricians don't receive adequate training and understanding the complex needs of childhood disabilities, it is possible that the limited services and supports children currently receive may be under further peril due to the limited understanding of the chronicity and the extent of services children with disabilities need in both medical and community settings. In conclusion, I urge the Interagency Autism Coordinating Committee to express concerns about this change in pediatric training and consider advocacy for additional mechanisms, such as federal and state funding, to support existing clinics to identify and treat children who are at risk for developmental disorders. Developmental clinics do not fare well in terms of hospital-based economic metrics. Consideration of joint funding resources should be considered as a potential mechanism to support developmentally focused care. Thank you all for your attention.

DR. DANIELS: Thank you so much, Dr. Asato. Our next commenter is Anthony Tucci.

MR. ANTHONY TUCCI: Thank you for the

opportunity to submit comments today. I'm a parent of a 19-year-old son who has autism and is a non-speaker. I'm an advocate for the rights of all people with ASD, and I'm strongly committed to learning about autism research and evidence-based interventions. I'm offering comments around two main themes this afternoon. Theme Number 1, we need more research that promotes effective interventions led by independent and qualified themes of multidisciplinary and intradisciplinary researchers. The lack of sufficient quality research delays effective interventions and possible confirmation that prior findings were inaccurate. It is my strong belief that multidisciplinary and interdisciplinary approach to research offers the best opportunities to effectively understand the communication challenges of individuals with ASD. The NCCIH has offered amazing insight on the value of using a cross-disciplinary approach to draw a bridge between the deep-rooted silos in the field of medicine and health. IACC’s 2023 strategic plan masterfully calls for researchers to develop new approaches and technologies to help individuals with communication challenges and to deliver innovative scientific research while fostering collaboration. The strategic plan is perfectly calibrated to effectively-

[Inaudible Comment]

DR. DANIELS: Seems we had a technical difficulty for our speaker. Give him a minute and see if he can log back on. I'm not seeing him. Maybe we will go to the next speaker and come back to Mr. Tucci when he is able to log back on. He seemed like he had a bad connection. We will next have Chris Banks from the Autism Society.

MR. CHRISTOPHER BANKS: Yes, thank you for allowing me to speak before the IACC today. My name is Christopher Banks. I'm the President and CEO of the Autism Society of America. This April, the Autism Society of America is proud to continue its Fifth Annual to celebrate differences campaign in honor of Autism Acceptance Month. Every day, we work to create the connections. Empowering people in the autism community to live fully. We believe that acceptance is creating a world where everyone in the autism community is connected to the support they need when they need it. By everyone we mean every unique individual, implacable, immutable, and irreplaceable, you. Today, I would like to share with you an overview of our health equity work and highlight our programmatic impact around accessible vaccinations. Health equity is the foundation for a healthy life. The autism community faces unique barriers to accessing care. Resulting in healthcare inequities, which are exacerbated by social and economic factors. These inequities can result in differences in length and quality of life, disease rates, access to treatment, disability, and death. Too often these barriers to care are viewed as patient barriers, when in fact they're environmental, resources, training, and systems barriers, all which contribute to trust barriers. To realize health equity, we must work together to reduce these barriers and create accessible solutions. In 2021, the Autism Society received funding from the CDC through a subgrant of the AUCD to address vaccine hesitancy, a longstanding issue within the autism community that has perpetuated by access and trust barriers. The Autism Society developed its Vaccine and Education Initiative, or VEI, to advance health equity through a focus on education, confidence, and accessibility. The VEI is a tailored public health model that reduces barriers to vaccination faced by the autism community by supporting autistic individuals, their families and caregivers, and the healthcare providers and systems. We piloted the VEI with 12 of our affiliates, which allowed us to learn from our community, identify best practices, train professionals, support individuals, and families, for an improved vaccine experience. Through this work, we have an opportunity to impact lasting change by promoting vaccine education within the autism and disability community so that individuals, families, and caregivers are empowered with the knowledge they need to make informed decisions. Equipping healthcare providers with the training and resources they need to meet the unique and diverse healthcare needs and autism community, which supports universal accessibility. Creating community connections that lead to improved patient provider confidence, communication, interaction, and outcomes. We are happy to report that earlier this year we received additional funding through the Administration for Community Living, working with US Aging that will allow us to expand the VEI program within our network of approximately 70 affiliates in 34 states. In the greatest scope of our healthcare equity focus, our public policy work is currently spotlighting the crisis of underpaid and understaffed direct support professionals, inequitable access to home and community-based services and systematic employment barriers, among many other public policy priorities that impact the Autistic American. As you recall, Joe Joyce previously provided remarks at a previous meeting with this group on the crisis in our service centers. We'll continue through our public policy efforts and our national programs to address the needs of people in the autism community. Other areas of health equity in which the Autism Societies work include mental health, suicide prevention, law enforcement training, and first responder training. Lastly, I want to briefly echo the concerns that have been previously provided today regarding the issue of training for medical professionals to work with people with autism. Improved training for healthcare professionals is a core need that has emerged out of our health equity work. As others have mentioned, the recent changes in the pediatric residency education proposed by the Accreditation Council for Graduate Medical Education, will result in even fewer developmental pediatricians with the ability to screen, to diagnose, and support individuals with autism and other disabilities to achieve their full health potential. The Autism Society of America, will be providing comments to oppose these changes. Stakeholders have until April 5th to provide feedback on the proposals and hopefully bring about course correction. During Autism Acceptance Month, the Autism Society of America will be highlighting its work to impact and ensure accessible experiences in healthcare and other social determinants of health. I thank you all for allowing me to cover these important topics today.

DR. DANIELS: Thank you so much for those comments, Mr. Banks. Next, I'd like to welcome back Idil Abdull as a former member of the IACC to provide us with public comments today. Welcome, Idil.

MS. IDIL ABDULL: Hi. Good afternoon, everyone. Dear, Mr. Chair, members, many thanks for the opportunity to be able to speak today. My name is Idil Abdull. I am a Somali autism mom and a tiring advocate. First, I want to thank Dr. Daniels for her support and guidance in the Somalia autism community in Minnesota, as well as all autism families across the nation. I was lucky enough, as Dr. Daniel said, to be part of IACC almost a decade ago now. My goodness. We've made a lot of progress back then, and you all now on the current committee have made even more progress. However, there are two areas that I believe we still need more work and support. Let me start with adult services. My son now is 20 years old. He'll be 21 in July of this year. There are almost no services for adults with autism in Minnesota and nationwide. Our children grow and become adults, but we as a nation are not ready for them. The system is simply not set up for adults with autism from employment, to housing, to safety, and in between. One of my biggest worries in life is who will care for my son when I'm no longer here? I want to ask IACC members, particularly the federal agencies that oversee adult services to concentrate more not just research, but on services and support for adults with autism. They will need housing that is person-centered and culturally responsive and employment that is fulfilling and rewarding. They will also need to be safe in their communities, including with law enforcement. We must make sure adults with autism are able to live and work safely in their communities with dignity and respect. My second request is about the ability to communicate. As you may have heard, Somalis are an oral society. Sadly, most of our children, including my son, have non-verbal autism. In other words, autism is silencing a nation of poets who are known for their oral communication. I thank Dr. Kasari out of UCLA and Dr. Helen in Boston University, but we need more research into this area, particularly teaching our kids the ability to communicate from their hearts, their minds via spelling. I think PECS is fine, but those are pictures and do not give our kids the ability to communicate their true needs and wants. It's a limited system. I ask IACC to raise awareness of the spell to communicate method to have insurance companies and Medicaid via CMS coverage, and to ensure we're giving every individual with autism the opportunity to be able to tell, to say what they want, what they need, what they're thinking, and tell us their dreams. I would give every organ in my body for my son to be able to speak orally. It is my hope that one day God willing, he'll tell me his thoughts, wants, and needs. I would love to ask my kid and have him answer me why he likes to listen to that '70s song --

[Singing]

-- while we're in the car or Bette Midler when we're traveling out of state. You see Mr. Chair and members, individuals who were not verbal autism are smart, funny, thoughtful, and want to live a happy, healthy, and safe life just like all of us do. I respectfully ask IACC to tackle these incredibly important issues. Thank you so much for your time.

DR. DANIELS: Thank you so much, Ms. Abdull for being here with us today. Next, we will go back to Anthony Tucci and allow him to finish his public comment. He was able to log back on.

MR. ANTHONY TUCCI: Great. Yes. I'll begin again. I apologize. I'm not sure where I cut off, so I have no alternative, but to be duplicative. I'll start right from the beginning. I appreciate the opportunity to present my comments this afternoon. I'm a parent of a 19-year-old son who has autism and is a non-speaker. I am an advocate for the rights of all people with ASD, and I am strongly committed to learning about autism research and evidence-based interventions. My comments will revolve around two main themes.

Theme Number 1, we need more research that promotes effective interventions led by independent and qualified teams of multidisciplinary and interdisciplinary researchers. The lack of sufficient quality research delays effective interventions and possible confirmations that prior findings were inaccurate. It is my strong belief that a multidisciplinary and an interdisciplinary approach to research offers the best opportunities to effectively understand the communication challenges of individuals with ASD. The NCCIH has offered amazing insight on the value of using a cross-disciplinary approach to draw a bridge between the deep-rooted silos in the field of medicine and health. IACC's 2023 strategic plan masterfully calls for researchers to develop new approaches and technologies to help individuals with communication challenges and deliver innovative scientific research while fostering collaboration. The strategic plan is perfectly calibrated to effectively resolve research gaps involving techniques like spell to communicate used by some non-speakers. Now, it is up to the scientific community to collaborate and to engage in cross-disciplinary research so that they can replace research gaps often filled with one-sided bias and speculation with independence and genuine wisdom. Theme Number 2, human rights and equitable rights must always lead an evidence-based practice model. Research gaps or disagreements between professionals should never serve to condone unprofessional turf wars. Similarly, non-speakers should never be condemned for selecting a mode of communication that has proven to be effective for them. This misguided advocacy violates the communication rights and ethical rights of non-speakers, and represents a violation of the evidence-based practice model. To help prevent these types of challenges, we are asking that IACC form a committee that can help guide the scientific community to develop appropriate due process methods before professional trade association's issue position statements that may have the effect of denying communication rights. This process will help to ensure that research which informs position papers will be guided by independence, fairness, and a deep-rooted form of best practice science. Experts on both sides of the aisle will be given a fair opportunity to present their best scientific evidence in an unbiased independent process. I hope it worked this time. Thank you very much.

DR. DANIELS: Yes, thank you so much Mr. Tucci, for your comments, and that worked well this time around. Thank you for your patience.

MR. ANTHONY TUCCI: Thank you.

DR. DANIELS: Our final oral commenter today will be Ms. Mariam Egal.

MS. MARIAM EGAL: Yeah. Good afternoon, everybody. Thank you so much for letting me come here. Thank you, Idil for inviting me to this meeting. I'm here today. I'm a mom with a 25-year-old with an undiagnosed behavioral condition. I'm also Somali, and I'm here to bring to you guys the recommendations that those families have made and the problems that they are going with. Also, I have referenced studies that have been done that can show you what those things are. On top of the list, parents said that they were very much suffering of racism in getting services. Poverty, large household families, lack of knowledge of existing services, single parent household, lack of funding for grassroots organizations that can provide cultural responsive services. Like my colleague just mentioned, lack of services for autistic young adults that are out there and neither post-secondary nor - no services. Undiagnosed young autistics with no services running around and no safety net. Housing also poses a great problem for these families since they are families of large household and they're being evicted all around. Undiagnosed mental health issues that goes around untreated.

Parents and siblings tend to manifest signs of depression, anxiety, chronic diseases, and other relating issues. It's not only affecting the individual with this autism, but it's also affecting the whole families. For recommendations, resources, and funding, targeting community-based grassroots organizations of parents with individuals with autism. These organizations strive without funds that are doing astronomically community engagement activities in a culturally and linguistically appropriate manner. Change our communicating strategies. It's not one-size-fits-all. Be mindful of all culturally and linguistically appropriate communication strategies. Oral versus written, English versus other languages, and through other channels. Diversify our workforce. Be inclusive of minority communities. Those with cultural and linguistic barriers, in particular. Incentivizing scholarships to increase the workforce in the area of mental health and behavioral health for minorities. Research in causation. Addressing, that's the main thing the parents have vocalized research in causation. Why the higher prevalence in this community? They die and we all die and we need research to find out what the cause is so we can have preventive measures to address what the issues are and nothing is happening. Thank you so much for having me testify.

DR. DANIELS: Thank you so much Ms. Egal for being here and sharing those comments. I'd like to remind everyone that you can access the written statements that go with the oral comments on our website. If you go to the meeting page and you scroll down to the meeting materials, you'll find it there as well as all of our written oral comments that came in the public comment packet. Feel free to access those.

Now, we will be moving to the written comments if I can have the slides. Wonderful. If I can have control of the slides as well. First, we're going to be starting on this page. We have 38 written public comments total that were submitted, and we have 28 comments that were on the topic of research and service needs, resources, and policy implications. The names of all the commenters are listed here. We also received four comments on the topic of research, services, and supports for adults on the autism spectrum, and two comments on mental health research, services, and treatment. In addition, we had one comment on the role of IACC in the federal government, one comment on employment, one comment on the inclusion of autistic perspectives in research, and one comment about concern about medical practices. I believe that is the full list. Yes, that's the full list of written public comments, and those are in your packet. Now, we have some time for committee discussion.

DR. GORDON: I'd like to invite members of the IACC to go ahead and raise your hands and I can call on you. The first up that I see is Paul Wang. Paul.

DR. WANG: Thanks, Dr. Gordon. Thanks, Dr. Daniels as well. I wanted to follow up on the oral comments that we heard from Dr. Asato and Dr. Dawson, and that Mr. Banks touched on as well regarding the proposed changes in the requirements for pediatric training. To be brief and I will be brief, I share their very deep concerns here that these proposed changes are terribly ill advised on multiple fronts. I'm just going to go through three points in the proposed changes that they've touched on already. First of all, it is proposed to eliminate the requirement for, "ensuring exposure to the spectrum of normal development at all ages." I simply cannot fathom why this requirement would be eliminated. In short, to use just slightly different words, the suggestion is that pediatricians in training would not have to have adequate understanding of the spectrum of neurodiversity. That flies in the face of what we understand now to be so very, very important, pediatricians really lead the evaluation of children. They're the ones who are called upon to help parents understand when a child might need additional supports, when the behaviors that they are showing are within the spectrum of typical development. Understanding strengths and weaknesses, pediatricians must get this kind of training, and it just makes no sense to eliminate the requirement for adequate exposure to the spectrum of normal development. Secondly, it is proposed that they would eliminate the requirement of exposure to longitudinal management of children with special healthcare needs and chronic conditions. Again, it is simply impossible for me to fathom the motivation behind this. As others have spoken to and as we see very broadly in the medical community, now there's a strong movement that we must provide a medical home for every child. This applies beyond pediatrics, of course, but we need to have somebody who's at the center coordinating medical care for individuals, for children, and especially those with special healthcare needs. It again, just makes no sense to eliminate the requirement that pediatricians in training get exposure to longitudinal management of these kinds of issues. Finally, there's the proposal to eliminate the requirement of having a faculty member on the training faculty who's certified in developmental behavioral pediatrics. I'm biased here because I am a developmental behavioral pediatrician, although I'm not deeply involved. I certainly receive no salary support for training of pediatric residents or med students, anything like that. But as others have pointed out, these are core faculty. These are the people who within the pediatric specialty have known certified indeed expertise in the care of children with autism and related conditions. There are certainly child neurologists like Dr. Asato, child psychiatrists like my colleagues on the IACC, Dr. Siegel, Dr. Piven, who could provide this kind of training to pediatricians. But in fact, the proposed changes do not mandate that you could have a child psychiatrist or a child neurologist with similar expertise. They simply drop the requirement for any particular certified expertise, and that is simply unacceptable. As John Robison, and again my IACC colleague, Dena Gassner have made the point recently in print, there is in fact an epidemic of need. This is a terrible time to be weakening the training of future pediatricians. The IACC has sponsored workshops on co-occurring conditions in autism, highlighting the lack of medical training related to autism. What we need to do now, what ACGME needs to do, is to help bolster the training of the medical workforce on the needs of the autism community, not compromise it.

DR. GORDON: Thank you, Paul for those comments. Dena.

MS. GASSNER: I just want to again reinforce what all the doctors before me have said. I think if it's possible, maybe we could discuss a statement from the IACC about these potential changes. I don't know if that's possible, but I wanted to focus on the comments related to adults.

DR. GORDON: Dena, may I make a suggestion? Let's come back to your comments on the adults, but I promise we'll come back to you. Put your hand back up just so I don't forget that. But if you don't mind, you've made a thought that the proposition that we as IACC could provide some form of recommendation. I'm going to ask everyone who would like to comment on that particular thing to go ahead and raise your hands and hold off on raising your hand for other comments for the moment. Let me just say that we are advisory - go ahead, Dena. Yeah.

DR. GASSNER: On that topic, I just want to say this is the opposite of what the American Dental Association has done. They are mandating training with people with developmental disability in their protocols.

This is really opposite of what other medical fields have seen as valuable and necessary. Then I'll hold my other comment. Thanks.

DR. GORDON: Great, and we'll come back to you for that. In the meantime, I'm going to go to other folks. Before I go to your other folks, I just want to clarify something. Susan, please jump in if I get this wrong. We are an advisory body to the secretary for Health and Human Services, HHS. We as a committee, again Susan, jump in if you think I'm wrong, can express our concern as a committee to the secretary and ask the secretary take whatever action. In this case, we have a male, that he, deems appropriate given our concerns. We can't as a committee provide a recommendation to the American Academy of Pediatrics. Sorry, it's not the American Academy of Pediatrics, but ACGME folks. As individuals or as organizations who are on the committee, you can provide that input. But as a committee, our input should go to the secretary, Susan, just confirm that

I'm right or not.

DR. DANIELS: The committee is permitted to make a statement. We have made statements before on our website, and I believe we could send a letter, but we would want to copy the secretary. I could look into whether we could send a letter to the actual committee, but we can certainly make a statement on our website and make sure it gets to the committee that needs to see it.

DR. GORDON: Good. I take that back so we can, if we wish then, make a statement. Before we formulate what that statement would look like, what I'm going to ask is there's a bunch of people who've raised their hands. We can keep this brief unless there is disagreement. So far I've heard expressions from two members of the committee that they would like to make a statement as a committee against this move. If you raise your hand because you want to agree with the previous speakers, please just say, I agree. Or if there's a pertinent point that others haven't raised, say that, but briefly. If you are against saying something as a committee, do express the reasons why you might be against that move. You do not have to at this point say anything if you agree. If you just want to say I agree, we're going to take a vote later on this to make sure that we're getting everything right. But if you want to express verbally something about it, raise your hand now, either pro or against. But if the pro prize, please try to keep it brief and only say something that hasn't already been said before. I'm going to start with Yetta Myrick. Yetta.

MS. MYRICK: Thank you, Dr. Gordon. Yes, I agree. That's all I need to say.

DR. GORDON: Thank you very much. Dr. Tager-Flusberg.

DR. TAGER-FLUSBERG: I agree. Definitely an important issue for us to comment on.

DR. GORDON: JaLynn Prince.

DR. PRINCE: I commented this a little bit differently. I'm very much in favor of us making a statement. Over the last 30 years with my husband's research with RSV, we have been around numerous, numerous pediatricians in many different levels. One of the major things that I see is that pediatricians are educators. They educate the families, they educate people to know what can be expected, what developmental milestones there are. If you don't know what those are, you cannot educate families and individuals as well as lookout for the patient. With the numerous people that we've had the opportunity of being with and around, across the country with pediatricians, I would say let's give them as much training as we possibly can, and in fact, even increase it if possible in medical schools. Thank you.

DR. GORDON: Thank you, JaLynn. Lauren. Lauren Ramos.

MS. RAMOS: Thanks, Dr. Gordon. Just wondering if there's an opportunity for the committee to interact with ACGME directly to learn more about why the change that might help us understand the perspective and maybe offer some suggestions in addition to what might be a letter.

DR. GORDON: It's an excellent point, and we can figure out how to incorporate that into any statement that we want to make. Morenike.

MR. ISAACSON: Good afternoon. Just wanted to say that Morenike sent in some comments. They called the proposal horrifying, and she says, "Please raise your voices and oppose this." Directs people to Dr. Dawson's comment on the IACC webpage, and also a link to the Society for Developmental Behavioral Pediatrics.

DR. GORDON: Thank you for that. Just to reinforce Morenike has said and what I said earlier, as individuals, any member of this committee and anyone watching can express their opinion. If you want to know how to express that opinion to the organization directly, do visit the website mentioned in the public comments, which are posted on the

IACC website already. Scott, did you want to add something else?

DR. ROBERTSON: Thanks, Dr. Gordon. I just want to say I agree, and I was a public member previously on the IACC before joining the federal government years ago. I remember when we did a statement years ago. I think it was about gun violence and how autistic people were more likely to have victimization than to be perpetrators. The committee has had some experience in this area, so I'd be happy to contribute to that. If folks are in concurring about doing a statement, I think it would definitely be beneficial, especially since a lot of folks feel strongly about this. Thank you.

DR. GORDON: What I'm hearing is enthusiasm for making a statement as a committee objecting to the change, and also I think Lauren suggested inviting ACGME to come meet with us to discuss the change at our next meeting. I see a couple of thumbs up coming through.

MS. GASSNER: Sorry for the timing, Dr. Gordon. We have limited time to respond. They may not be able to do that with us.

DR. GORDON: Absolutely. Obviously since tomorrow is the day that they have limited for public comment, but I don't know if that means that they're going to make the change prior to that. But regardless, we can certainly formulate that simplest statement and send it to that group as well as posted on our website and send it to the secretary as well. Sorry. Was there another comment sent in via text that we need to read?

MR. ISAACSON: Kamila Mistry had a question. They asked, do we have any idea on the AAP, the Association of American Pediatrics position on the proposed changes?

DR. GORDON: I do not know that. Does anyone know that?

DR. WANG: This is Paul Wang. I can report that, yes. One of the AAP's senior vice presidents has expressed their objections to the ACGME proposal.

DR. GORDON: Morenike is raising a hand again. Morenike, do you have additional statement to make?

MR. ISAACSON: Morenike wanted me to read a link that they sent over the chat. They sent the Society for Developmental Behavioral Pediatrics link, sdbp.org/acgme-information.

DR. GORDON: Thank you very much. I think what I'd like to do at this point is suggest that Susan and our staff can write the relatively straightforward statement that given the importance of educating pediatricians about autism and individuals in the autism spectrum and the importance of pediatricians learning appropriately to care, for such individuals we object to these changes, and that we invite members of the ACGME group, contemplating these changes to meet with us at our next meeting. Susan, you think you can handle drafting, something like that?

DR. DANIELS: Yes, I think I can, and I will reach out to members that may be able to help with that. Then once we have a draft, we can circulate it and we can either vote on it via email and just tabulate it, or we could have extra meeting.

DR. GORDON: I would say, let's vote right now for the gist of the statement with the understanding that you'll all receive a draft of the statement. We need to do this fast. Susan, tell us what's a good time that they can expect the email of the statement by? Because we want to get it done tomorrow.

DR. DANIELS: Well, you mean to submit for public comment tomorrow?

DR. GORDON: Yes, yes. That's what I mean.

DR. DANIELS: I'm not sure if we would make the deadline for that. We can try to.

DR. GORDON: What time is the deadline?

DR. DANIELS: Well, it's tomorrow.

DR. GORDON: Let's agree on wording right now. I'm going to go ahead and try to type something into the text if I'm going to have to send a comment line. I'll just say it loud as I type it. Interagency Autism Coordinating Committee objects to the proposed changes in ACGME requirements -- -- for the inclusion of an expert. Sorry. Paul, what is the exact nature of the requirement that's being dropped, the inclusion of an expert?

DR. WANG: They are dropping the requirement for a board-certified developmental behavioral pediatrician on the residency faculty.

DR. GORDON: Hold on. Of a board-certified developmental behavioral, is that right?

DR. WANG: Yes.

DR. GORDON: Behavioral pediatrician

DR. WANG: On the residency faculty.

DR. GORDON: On the residency faculty for pediatric residencies.

DR. WANG: Yes.

DR. GORDON: The Interagency Autism Coordinating Committee, I'm going to say strongly, objects to the proposed changes in ACGME requirements for the inclusion of a board-certified developmental behavioral pediatrician on the residency faculty for pediatric residencies. We urge the ACGME not to adopt this change. We invite representatives of the ACGME to meet with the IACC at a future meeting. Very, very simple.

DR. WANG: If I may, Dr. Gordon, there is a second change, which I mentioned in my comments. They're dropping the requirement for exposure to the spectrum of normal development and the longitudinal management of children with special healthcare needs.

DR. GORDON: We further object to dropping the requirement. Yeah, go ahead.

DR. WANG: For exposure to the spectrum of normal development at all age levels and the longitudinal management of children with special healthcare needs.

DR. GORDON: Longitudinal -- -- of children with, sorry. Say it again.

DR. WANG: With special healthcare needs.

DR. GORDON: Alice, did you want to say something?

DR. CARTER: Yes, thank you. First, I just want to say that I really appreciate your being this nimble to make this statement about such an important issue. Then I just wanted to say, I think we should flip them because I think the issue is training and short-term getting rid of Developmental Behavioral Pediatricians, is going to decimate this kind of training. But for me personally, if there are other people who can do this, I don't have a problem with that. But for right now, it's a terrible idea.

DR. GORDON: What you're suggesting is that we just swap the two. We now would say the Interagency Autism Coordinating Committee strongly objects to the dropping the requirement for exposure to the spectrum of normal development at all ages and the longitudinal management of children with special healthcare needs. We further object to dropping the requirements for the inclusion of a board-certified developmental behavioral pediatrician on the residency of faculty for pediatric residencies. We urge the ACGME not to adopt these changes. We invite representatives of the ACGME to meet with the IACC at a future meeting. Now, I apologize in advance to members. We're doing this very, very quickly, and so there are members of this committee who may not be able to process this information quickly enough. Assuming that we have an overwhelmingly positive vote, we will move forward with this. If the vote is close, then we may need to take a pause and make sure that we email the language out to everyone so that everyone gets to consider it. But due to the urgency of getting this into the hands of the AGCME before the close of the public comment period, I'd like to vote on this today, regardless of the fact that I know some of you will not have the opportunity to fully process the language that we're about to give.

DR. RIVERA: Josh, I'm so sorry. It's Susan Rivera. I just want to make really one quick suggestion, and goes to your last comment. Could you in the chat just copy and paste what we are voting on so we can take a quick look and then do the vote?

DR. GORDON: I'm going to try to do that. We're not really supposed to be using the chat for that function, so I don't know if we're going to be able to send that.

DR. RIVERA: You share a screen then and show us then.

DR. GORDON: Oh, that's a great idea.

DR. RIVERA: Great. Thank you.

DR. GORDON: I think I can do that.

MS. MYRICK: I agree with Susan. Thank you.

DR. RIVERA: You bet.

DR. GORDON: That's a great idea. I'm just going to copy and paste this stuff into Word and then I will share the screen. I'll make sure we get the language right. I want make sure as many people are on board as possible. I think that's a great suggestion. Give me a moment. While I do this, why don't we move on to the next comment Dena was going to make? I'm going to focus on getting the language right. We'll come back to it after Dena's comment. Is that okay with you, Susan?

DR. RIVERA: Yeah, that sounds great. Thank you.

MS. GASSNER: Dr. Gordon, thank you so much for your quick action on this. I'm actually a little emotional that we're taking such a firm stand. I just want to go back to some of the talk today about adult issues. When I was working with John to draft our commentary response to the new rates, I was taking a really hard look at research globally in terms of adult outcomes. I just want to make a statement that we have failed. We have failed our community. Our focus on employment as the end-all-be-all, our suggestion that Social Security provides people a high quality of life, our suggestions that people diagnosed late are non-disabled, it's not in the literature. The reality of it is if you warrant a diagnosis of autism wherever you land on the spectrum, this includes inherent functional limitations. Why we tend to approach challenges in the workplace, we're failing to recognize that there's no mechanism to unpack years and years of trauma that ensued from a lack of diagnosis. There's no mechanism in our therapeutic models to help people with functional, daily independent living skills that were never taught because they were on a diploma track as if their intellect could suddenly override this other impaired part of their neurology. I would really like to see if we can set aside a time or a space to have an in-depth conversation on shifting our trajectories to focus on these very impairing aspects of autism that we've almost been shamed talking about. Because if we have higher IQs, we're supposed to be able to use that to overcome the parts of our brains that don't initiate or sustain tasks. We're supposed to be able to juggle a work-life balance with no in-home support. Many states don't provide any services whatsoever other than employment services for people whose diagnosis doesn't manifest before the age of 21 or 25. That means that people are left indigent, unhoused, or with inconsistent housing. They're left without mental health services that are appropriate to this population. Given the public comments that continue to flow in about the gaps in adult services, I would really love for us to look at the service delivery models and to look at the research on these outcomes as a cumulative, informing set of evidence for us to maybe reframe some of the outcomes and our priorities.

DR. GORDON: Thank you for that, Dena. We'll look into the opportunities, so we might have to be able to do that. That's an excellent suggestion.

MS. GASSNER: Thank you.

DR. GORDON: Morenike, you have your hand raised. Do we have another comment from Morenike?

MR. ISAACSON: Yeah, they just sent me a comment. They also let me know that they emailed ACGME to ask for an extended deadline as an accommodation. The comment they shared here says there's a written comment related to subminimum wage that they want to address. As the mom of a child with an intellectual disability, they want to empathize with what the parent shared about how there's more benefit working than income. The sense of responsibility, joy, and self-actualization is relevant as well. They say, but we don't reward a broken system to do this. Subminimum wage employment is unacceptable. If it isn't about the money, then we should develop more innovative service delivery models of internships, apprenticeships, and preceptorships, et cetera.

DR. GORDON: Thank you, Morenike. I'm going to have one last comment from Ivanova, and then we will return to the earlier issue, and I'll share screen for the statement. Ivanova.

MS. SMITH: Hello. This is Ivanova Smith. Thank you for all those who have commented. I wanted to comment around the doctors for training. I think it's very important in that training that the doctors are educated on the harms of mental age theory. People with intellectual disabilities grow up just like anyone else, and we have the right to have a support in our transition to adulthood and not be restricted in our adult rights. I really encourage our doctors to not use mental age theory to describe a person with intellectual disabilities, because policy-wise, it causes a lot of harm. For people with IDD, it teaches us that we're not allowed to grow up. Then we're not allowed to live a full adult life and everybody should be able to live a full adult life. That's what I wanted to say. Thank you to everyone who's commented.

DR. GORDON: Thank you. Scott, can you make your comment brief?

DR. ROBERTSON: Yeah. Can we come back to talking about the other public comments after you go through this statement or are we going to run out of time for that?

DR. GORDON: We're already actually over time. Go ahead and make your comment.

DR. ROBERTSON: I'll stay brief then. I'll be brief. I just wanted to say that I appreciate the emphasis in the oral and written comments on augmented alternative communication access for folks. I think we should be focusing more on that. Then also on the employment end, there was a lot of great emphasis on employment in the public comments. But I especially wanted to highlight one of them that mentioned specifically that a large percentage of autistic adults are either unemployed or chronically in a state of burnout and fight or flight. That's due to a lack of accommodations, lack of understanding, and largely living in a neurotypically based world. I think that's really important for us as we think about how to enhance access to employment supports, community-based supports for supporting better quality of life. We take this to heart, and I appreciate when autistic people, family members, and others have been sharing the comments like this. It's really valuable for us as far as the input. Thanks.

DR. GORDON: Thank you very much. We're going to close now our discussion on the public comments. We're going to return, however, to suggestion that we provide a statement to the ACGME. I would say we would also supply the statement to the secretary and post on the website. This is a statement that I drafted and incorporated your comments. I'm going to read it to you as well. It should be visible on your screens. Let me try to increase the font a little bit just to make sure that everyone has the best chance of reading it. Did that work? I'm not sure it did. Oops. No, because I didn't select the font first. That should still fit on everyone's screen. The Interagency Autism

Coordinating Committee strongly objects to the proposed changes in ACGME requirements. Let me delete this. In the ACGME requirement, for exposure to the spectrum of normal development at all ages and the longitudinal management of children with special healthcare needs, we further object to dropping the requirement for the inclusion of a board-certified developmental behavioral pediatrician on the residency faculty for pediatric residencies. We urge the ACGME not to adopt these changes. We invite representatives of the ACGME to meet with the IACC at a future meeting to discuss this important matter. I realize I need to make one more change and I'll apologize. I will read it all again. I'm going to just move this for pediatric residencies up. I'm going to read it again. Then just so you know, I will take comments on this if there are any other minor suggested changes. We don't have a lot of time to completely rewrite it. The Interagency Autism Coordinating Committee, IACC strongly objects to the proposed changes in the ACGME requirement for exposure to the spectrum of normal development at all ages and the longitudinal management of children with special healthcare needs for pediatric residencies. We further object to the dropping the requirement for inclusion of a board-certified developmental behavioral pediatrician on the residency faculty. We urge the ACGME not to adopt these changes. We invite representatives at the ACGME to meet with the IACC at a future meeting to discuss this important matter. Dena, did you have a suggestion?

MS. GASSNER: A small one. I apologize, my Hollywood squares don't work for me, but the comment that was made earlier about the role of these pediatricians in the lives of the families, any element of that in terms of like the justification, the so what question might be helpful.

DR. GORDON: You're right. These changes would make it more difficult. Actually, I'm going to hold off on saying it. Let me take Joseph's comment first. Perhaps, Joe has a suggestion for language or some other suggestion.

DR. PIVEN: Just a very, very minor. I guess we're assuming they'll know what the Interagency Autism Coordinating Committee is, but maybe an introductory sentence that it's a federal panel or advisory panel. Just something to orient it.

DR. GORDON: Thank you.

DR. DANIELS: I have something on that that can be added.

DR. PIVEN: All right.

DR. GORDON: Yeah. I'll put an asterisk here and we'll add it as a footnote below. Does that sound good?

DR. DANIELS: We could introduce it with the explaining what the committee is before we make the recommendation.

DR. GORDON: Morenike. Do we have another comment from Morenike?

MS. PRINCE: There is one other comment

if I may make it. Very often we find that the adults we work with have remained with pediatricians until they're in their mid-20s. This goes for a very long time because there aren't people on the other side that are qualified and ready to handle many of the issues that have been identified earlier, if that plays.

DR. GORDON: Thank you, JaLynn. Thank you. Was there a comment that needed to be read from Morenike?

MR. ISAACSON: Yeah. Morenike says that there's many templates to go from on the sdbp.org website for organizations, parents, and pediatricians. Dr. Scott Robertson also mentioned, board-certified needs a hyphen between board and certified, and he was wondering if we can also mention how the IACC helps support the Autism CARES Act.

DR. GORDON: Will that kind of language be in your explication, Susan, that we support the Autism CARES Act?

DR. DANIELS: We have some standard

language about what the committee is, and so that'll be explained.

DR. GORDON: Thank you. I'm now going to add a question of justification. Please jump in if someone has a better way of expressing it.

DR. GORDON: Dramatically and adversely affect the ability of pediatricians to care for individuals on the autism spectrum and to educate patients and families affected by autism. Any other suggestions for that sentence?

MS. MYRICK: This is Yetta. Can we say equitably care for?

DR. GORDON: Sure. Add dramatically adversely affect the ability of pediatricians to equitably.

MS. MYRICK: Thank you.

DR. GORDON: I want to add it's not only equitably, right? So, and effectively.

MS. MYRICK: Yes, thank you.

DR. GORDON: Does that sound good?

MS. MYRICK: Amazing. I'm so happy you're doing this.

DR. GORDON: Okay. Sorry, now it doesn't fit on one page. I'm going to shrink it again. Yes, is there another comment?

DR. WANG: Typo. You typed education instead of educate.

DR. GORDON: Thank you.

DR. WEXLER: Josh are you --

DR. GORDON: What happens? Please go ahead.

DR. WEXLER: Yeah, it's Larry Wexler. Given that the IACC is supposed to be driven by research, what we're saying, I think has common sense to it, but I would ask the question of people who know much more about the training of pediatricians than I do. Is there any research, even at the descriptive level that demonstrates that having a board certified developmental behavioral pediatrician on faculty has a positive effect? Because I'm hoping that there is something out there because stating that based on research we know this, I think would make the overall statement much more powerful. I have no objection to the statement. Like I said, common sense is not too--

DR. GORDON: Right. You're asking a legitimate question, which is, can we honestly argue for that second sentence that this was an evidence-based approach? I do not know of any research in that area. Does anyone on the committee know of any specific research to support that statement?

DR. WANG: There cannot be any controlled research on that because before there were developmental behavioral pediatricians, it was not required that they'd be on the faculty and then at some point ACGME added it, so any comparison would be confounded just by the change in year, if you will.

DR. WEXLER: Paul, I'm sure you're right. I was just looking at, is there even anecdotal research?

DR. GORDON: Yeah, I wouldn't be comfortable adding a research support statement without something a little bit more than anecdotal in any case.

MS. PRINCE: There might be something. My husband's partner in doing the research on RSV happened to have been the chief pediatrician of the Air Force and also the head of the Uniform Services.

DR. GORDON: JaLynn, sorry. I'm going to go ahead and interrupt and I apologize. I'm going to take the chair's prerogative because we are running quite late now. I want to make sure that --

MS. PRINCE: Would a statement from him be helpful?

DR. GORDON: At this point, I don't think we can add anything to this given that we want to get it out tomorrow. If the committee wanted to investigate providing a more formal --

MS. PRINCE: I can get him on the phone right now.

DR. GORDON: I don't think that would be helpful at this point because he is not a member of the committee, but I appreciate that thought. What I'd like to do now is ask if someone might move that we send this statement that we have drafted to the ACGME and copy the secretary. Do I have a motion?

MS. GASSNER: I move.

DR. GORDON: Thank you. Do I have a second?

MS. MYRICK: I'll second.

DR. GORDON: Okay. Let me ask everyone who is in favor to raise their hands on the Zoom call using the Zoom. If you are unable to raise your hand, please email. Sorry, text the send comments in the chat or otherwise unmute and say that you're pro, but it looks like everyone's able to raise their hands. Susan, do we have a full count yet?

DR. DANIELS: We have 25 participants that have raised their hand according to what I was able to see.

DR. GORDON: Thank you. Would everyone please now lower their hands.

MS. SMITH: Sorry, I was too slow in

raising my hand.

DR. GORDON: We'll make it 26. Thank you Ivanova. Alice, can you lower your hand? Now everyone who is against sending this statement as written, please raise your hand or so state verbally. I see no hands raised and no one is verbally stating they're against. Would anyone like to abstain from this vote? Anyone who wants to abstain from voting on sending this statement, please raise your hand or so indicate verbally. We have one abstention. Two abstentions. Three abstentions. Any others? Okay. You may lower your hands. It's 25-4, no against, three Abstentions. It looks like, maybe four abstentions. I think one came in late. Was that your intent, Jodi?

MS. SUMERACKI: Yes.

DR. GORDON: Okay, thank you. Four abstentions. All right, so the motion passes. We will include an explication of what the IACC is in this and submit it to the ACGME for comment as well as send a copy of this from the IACC to the secretary and post this statement on our website. Thank you very much everyone. I think that was really wonderful to see us figure out a way to respond appropriately to the public comments in this way. With that, I'm going to again turn the meeting over to Susan. I apologize again, but I have to resume taking care of the family emergency and wish you all a very informative and enjoyable rest of the meeting. Bye-bye.

DR. DANIELS: Thank you. We were scheduled to take a break. We were scheduled to take a break, but we are behind time, so I'm going to propose that we just start the next panel and if anyone needs to take a quick break, you will have your cameras off and just take that quick break and then we will return. I will hand it over to Shelli to provide the welcome for this panel. I'm also really excited about this panel and I'm looking forward to hearing all these presentations.

DR. AVENEVOLI: Great. Thanks so much

Susan, and thanks everyone for your active participation in the last session. Okay, so moving right along, I want to introduce our next set of presentations and presenters. This set of presentations will focus on the topic of racial disparities and racial equity in autism outcomes. The federal government is committed to actions that will reduce disparities and increase equity and the IACC has already identified this area in the upcoming IACC strategic plan as an important priority for future activities. We will have two research presentations and then we will hear from perspectives from the community about their own lived experience. After all of the panelists have presented, we will have time for questions and discussions from the IACC members. Our first presenters will be Dr. Brian Boyd. Apologies for losing my place. Dr. Brian Boyd, the William C. Friday Professor in education, and the interim director of the Frank Porter Graham Child Development Institute at the University of

North Carolina at Chapel Hill, as well as Dr. Jill Locke, an Associate Professor of Psychiatry and Behavioral Sciences at the University of Washington. Thank you for being here and welcome to both of you.

DR. BRIAN BOYD: Thank you. Hello everyone. Jill and I are happy to virtually engage you in this conversation today about understanding the impact of racism and discrimination in autism research. We're going to tag team a bit, but I'm going to start us off today. I want to thank Susan Daniels and other members of the IACC for organizing this discussion. It's important to acknowledge that autistic people have multiple cultural identities that they're navigating. These identities, such as being Black and autistic, can affect outcomes because of larger societal issues such as racism and ableism. We also know that racism has public health consequences. I want to read a statement to you from the CDC website. It reads, the data show that racial and ethnic minority groups throughout the United States experience higher rates of illness and death across a wide range of health conditions, including diabetes, hypertension, obesity, asthma, and heart disease when compared to their White counterparts. The statement goes on to say, to build a healthier America for all, we must confront the systems and policies that have resulted in the generational injustice that has given rise to racial and ethnic health inequities. This is also something we must do within autism research to ensure autistic people of color and their families can thrive and enjoy a good quality of life. Next slide, please. So really this presentation today is organized into four parts or sections. The first part I'm going to take is really to provide some context for today's presentation. I'm going to start off by simply discussing some relevant terms and how racism operates in US society and then Jill is going to walk us through some examples of racism's impact on autistic people of color and what we are learning from some of the research that is happening in the space right now in the field and then we're going to discuss some community partner solutions. There are community groups, some of whom you'll hear from today, that are doing wonderful things of finding ways to advocate on behalf of marginalized groups and so we're going to talk about some of those solutions and then we're going to discuss next steps and future directions. Next slide, please. So many people have likely seen some version of this graphic. The two center figures contrast the difference between equality and inequity. Equality being that everyone gets access to the same goods, services, and resources. Equity being that people get access to what they need, which acknowledges that not everyone needs the same thing, so equity brings in the concept of fairness. The image on the left reminds us that in reality, some people start off unlike everyone start off with way less, so we're not starting at a place of equality. Opportunity gaps already exist in society, in particular along racial and ethnic lines. The image on the far right asks us to consider how do we free all groups from oppression and marginalization? And in many ways, it employs us to ask the question, why did someone erect the fence in the first place? Next slide, please. I'll start off today by defining some terms, and I'm borrowing heavily from the work of Dr. Kamara Jones who is pictured on the screen there. We can start with the outermost layer and this is really just to make sure we're all on the same page on how we think about some of these terms. If we think about institutionalized racism, it's really defined as the structures, policies, practices, and norms that result in differential access to good, services, and experiences in society because of race. We know that institutional and structural racism is really embedded in the larger social, political and economic systems that people of color are having to navigate. I'll give you some examples of institutionalized or structural racism on the next few slides. Cultural racism is ideology grounded in superiority of one group over another, so in this case, usually, the superiority of White people and the inferiority of those who are non-White. It's often deeply embedded in the language, symbols, media and just general assumptions about people of color we make in society. Inter-personal racism is really those racialized and discriminatory experiences that ethnic minorities face in their everyday social interactions such as racial microaggressions. These forms of racism can contribute to what is called internalized racism. For example, we know from research that Black people's acceptance of White superiority and their own inferiority is associated with lower self-esteem and psychological wellbeing and higher levels of depressive symptoms and obesity. Next slide, please. So a good friend of mine here at the University of North Carolina Chapel Hill, who is a social psychologist, Keith Payne, published a paper in 2019 in the proceeding of the National Academy of Sciences. In that paper, he was looking at the relationship between the number of slaves in states in 1860 and he started with 1860 because that was the first year the US census started to document the number of slaves in slave holding states and looking at the association between number of slaves and present day levels of implicit racial biases. You can already see a little bit from that graphic that the slave holding states in the south, the darker colors mean more slaves, that there's already some overlap with the darker colors on the map of the United States at the bottom there, where darker colors mean higher levels of implicit racial biases in those same states. Next slide, please. What Keith found was indeed a relationship between the number of slaves in 1860 and present day levels of implicit racial bias. But what he also found in his group is that though that association was mediated by what we think of as forms of systemic racism, so those states also tended to have higher levels of residential segregation, more disparity in poverty, in particular, the number of Black people in concentrated poverty, and more disparity in upward mobility, so the ability of people in poverty to climb out of poverty. We can think about those things right as the remnants often of slavery, but also subsequent laws such as Jim Crow laws or laws like Redlining that affected the ability of people to get bank loans to buy homes, that all of those products of systemic racism contribute to modern day levels of implicit racial bias. We can see how the socio-historical context is contributing to current forms of discrimination and implicit racial biases that are operating in today's society. Next slide, please. This is just one example. I know there is a lot on this screen, but that was published around how structural racism could be operating in pediatric healthcare. I'm not going to walk you through the whole thing, but you can see they document some forms of structural racism, some I just talked about, such as residential segregation or school segregation and how those then contribute or affect the environments in which people live. It affects the safety of their neighborhoods, the kind of educational access and opportunities they're able to have access to, then those things contribute to many forms of interpersonal racism, both implicit as well as explicit and all of these things really then begin to impact outcomes, the quality of relationships that are happening and that one may have with their healthcare provider or with their teacher in schools and that these further contribute to all kinds of disparities that we see on the right in terms of outcomes for people and that there's often intergenerational transmission of these issues. As I said, the ability of people to climb out of poverty is then impacted by some of the structural remnants of racism that are operating in our society. Next slide, please. Just as a basic example and this is actually pre-pandemic data, and we know the pandemic exacerbated disparities in many ways, but one of the things we know within the US society is that there is interaction between race and class. In particular, people of color who are Black, Latinx, or indigenous are more likely to live in low income households. One of the ways we talk about this is as concentrated or compounded disadvantage. If you are a poor racial ethnic minority, you're also then more likely to live in segregated housing and you're then more likely to attend lower quality schools because of how schools are funded within US society, a large part based on property taxpayers and so all of those things compound disadvantage. It affects the resources available to one in that particular neighborhood. We often think about these things as concentrated or compounded disadvantage that groups are facing that really, again, are the remnants of a polarized, racialized society that we're living in. Next slide, please. The question we're beginning to ask and maybe should have been asking much longer than this, is how does racism and discrimination impact autistic people of color? Next slide, please. I think an earlier discussion was about the new prevalence data that was released by the CDC that was saying prevalence of ASD was lower among White children than among other racial and ethnic groups and so it's a good thing that we're beginning to identify more racial and ethnic minority children, but what that should lead us to do is to ask more questions to help us better understand the experiences of racial and ethnic autistic children and their families. This should really lead us to ask questions of how racism and discrimination are impacting these communities and their outcomes. We shouldn't just stop with identification. The next thing is to understand what their lives are like to really begin to think about these questions. We also still see in the CDC data that racial and ethnic disparities exist, such as Black children with ASD were more likely than White children with ASD to have a co-occurring intellectual disability. This is pulled from the CDC website. Again, I think the new numbers should really push us forward with asking some important questions. Next slide, please. This is just a brief video that I've shown before. It's a Black mother of an autistic son talking about really from her experience why we should be asking some of these questions around racism and discrimination, so if you could play the video. "I could start with what does it mean to be a Black mother, period. For us as parents, there is always an anxiety. I like to say that the feelings, the memory, and the spirit of historical trauma and the story of Emmett Till just lies within our womb, within our soul in the Black community, the fear of a Black mother. I always say Black folks are not allowed to be unapologetically themselves. They are not permitted to be neurodiverse and we know this on a lot of levels, so my biggest fear is if an officer approaches my child and my child begins to stim, have to put his hands in his pocket to take out one of the little things he likes to hold onto to help him with his anxiety, he has got one of his little trinkets or things that he holds onto and reaches into that pocket to pull it out to calm himself, what is going to happen to my son?”

DR. BOYD: I think those are the kinds of questions we need to be asking and answering. What's going to happen to her son in that situation because he is a Black autistic man, right? Next slide, please.

DR. JILL LOCKE: Thanks, Brian. Today, I get the opportunity to talk a little bit about the racial and ethnic disparities that are apparent in various aspects of autism research. Holly, if you can just click the button, there's going to be some animation that happens. We're going to present several examples today that touch on different domains across the lifespan, but this is not an exhaustive list by any means. I want to start with the documented disparities and diagnosis and I want to thank Wendy Stone for sharing this slide with us. What she typically explains in a lot of her diagnostic work is that parents typically express concerns in development about their children around 18 months. Perhaps this is when their child is not consistently responding to their name or infrequently makes eye contact, which we know also has some cultural undertones or isn't communicating in the way that parents expect, so they begin to suspect that something may be different about their child's development and they go to the pediatrician's office and the pediatrician tells the parents to let's wait and see what happens. On average, most children don't receive an autism diagnosis until about ages three or four and some of the recent research is suggesting it's closer to age four. However, on average, children from racial ethnic minority backgrounds don't receive a diagnosis until about ages five or six and in some research we've seen that age even older, so closer to eight. While there is a gap in parents expressing concerns and receipt of an autism diagnosis for everyone, that gap is much wider from children from racial and ethnic minority backgrounds. We know there is a long waiting period for diagnostics across the board, but if you think about it, on average, a child has to wait most of their life to get an autism classification or diagnosis and that's really unacceptable if you think about what services get layered on top of that. Early intervention services are offered between zero to three years of life typically and in some states it goes up to five, which is a critically important time for brain plasticity and growth. But children who are getting that diagnosis later, they're missing that entire window for early intervention services and that's a critical period that we know can help improve outcome. Next slide. Once children get an autism diagnosis and they enter school, we also see some racial and ethnic disparities in the school system in terms of classroom placement. What this slide is showing us is that Black students, regardless of diagnosis, has a significantly higher risk of being placed in a self-contained setting or a special day class, and more specifically Black autistic students had a significantly higher risk of being placed in a self-contained setting or a special day class, regardless of their free and reduced price lunch status, so this is on top. Again, adding on, noticing that there are some disparities in where students are accessing their education. Next slide. When you think a little bit further about some of the social relationships that exist in school settings, we also see some of those racial and ethnic disparities. In lower elementary school grades, so K to 2 we see that neurotypical Black children receive the highest number of friendship nominations, and Holly if you want to click there is some circular animations that will pop up. Thank you. The K to 2 Black kids typically have the highest number of friendship nominations, but that number of friendship nominations tends to go down in Black autistic children in upper elementary grades. It actually declines quite dramatically, even though that's the racial ethnic group that has the most nominations in the younger grades. If you click it one more time, Holly, I'm sorry, I should have taken off all of these animations. But of interest, we also see that neurotypical Latin children were the only group in which friendship nominations increased from lower to upper elementary school grades. But Latin autistic children experienced the greatest decline in the number of friendship nominations from younger to older grades. I should say these are all peer nominations that did not come from the research team. It came from the children themselves. The bottom graph shows us that all autistic children, with the exception of Asian autistic children in grades K to 2 were significantly less integrated in their classroom social network than neurotypical White children in grades K to 2, so we're seeing some of those disparities play out in social relationships as well. Next slide. These are demographic data across 20 years of school-based research with over 400 autistic youth, 349 teachers, and 266 para-educators across four states. We ran some preliminary analyses recently to understand who participates in school-based research and you can see that that sample is predominantly White. If you think about it, school-based research is intended to reach more autistic youth in their natural service settings and the numbers look slightly better than we see in university-based or clinic settings, but we still see more White autistic youth participating and accessing research-based services in schools. What is even more striking is the percentage of White teachers far outnumbers all other racial and ethnic categories. This is really important because we are asking teachers oftentimes to be the intervention providers or support providers in a lot of these studies and we know there is a greater likelihood of intervention success and outcome when there is concordance between the providers and their clients. To say that differently, there may be greater success if the race and ethnicity of the teacher matches that of the autistic child, but we're seeing a predominantly overwhelmingly White sample of teachers. Next slide. On a broader policy scale, when we look at federal dollars spent or appropriated to fund special education, we see that the states with larger shares of children eligible for special education receive on average fewer dollars per child than other states with less need. In addition, large states and states with more children experiencing poverty also receive fewer IDEA dollars, that's Individuals with Disabilities Education Act dollars per child. Put differently, states that likely need at least as much and perhaps even more funding to meet higher levels of student need than other states on average get fewer federal special education dollars for each child who receives special education services. I want to be sure I thank David Mandell for this slide. He wasn't able to be here with us today. The next slide, please. When we look at autistic adults, I know this graph is very busy, we also see racial ethnic disparities. I'll walk us through what this graph is showing, but essentially, autistic adults may have several co-occurring physical and mental health conditions, which could differ by race and ethnic group. Whitney Shott and her colleagues found that compared to the general Medicaid population, autistic adult Medicaid beneficiaries have elevated odds of some health conditions like epilepsy and nutrition conditions, as well as some psychiatric conditions such as anxiety and attention disorders. They also found that many of the same health disparities, by racial and ethnic group in the general population persist among the autistic adult Medicaid population as well. For example, Black, Hispanic and Asian Medicaid autistic beneficiaries have higher odds of diabetes, and Black and Hispanic autistic beneficiaries have higher odds of obesity and nutrition conditions than the White autistic beneficiaries. We're seeing this across age groups, we're seeing this across populations, we're seeing this across racial and ethnic groups as well. Next slide. In our final example, again, this is just a spattering of the recent literature that is out there looking at racial and ethnic disparities in autism research. This paper is by Amber Davis and colleagues, and they surveyed autistic and non-autistic Black young adults to understand how that intersectionality between identities of race and disability look like. They found that autistic Black participants reported fewer everyday discriminatory experiences than non-autistic Black participants, but stress or perceived stress was not different. Both groups were experiencing high levels of stress. Most of the non-autistic Black participants listed race as their primary source of discrimination experiences, whereas autistic Black participants are citing both being autistic as a major contributor as well as their race. It's really important for us to understand the intersectionality between race and ethnicity as well as disability and identity. Next slide. While we only provided a snapshot of the research highlighting racial and ethnic disparities in autism research, the take home message is this, racial and ethnic disparities permeate all levels. We see these disparities in autistic children, in autistic adults, in different settings like clinics, hospitals, and schools, and even in federal law and policy and so we can and we need to do better. Next slide.

DR. BRIAN BOYD: If we sum up a little bit, what we know is that structural inequities lead to differences in basically three areas. Differences in access to goods, services, and resources, differential outcomes by race and ethnicity and differential experiences that are often inferior in quality. If you take that one study that Jill looked at, that Black autistic students in that particular school district were more likely to be placed in segregated classroom settings, we can think about this access to the same school, but different schooling experiences that are happening for them. All right, next slide, please. Just as one example here, Sarah Dababnah and her colleagues actually taking from Dr. Sandy Magana work with Latinx families adapted the parent taking action for manualized programs for Black parents of autistic children, and really they applied what is called the SHARP framework to adapt this intervention and it's really a parent advocacy intervention. That SHARP framework really had them think about the structural oppression that this group has been facing, the historical context of this community, so why that Black parents of autistic children may come to research with mistrust because of historical issues that have happened to the Black community and their participation in research. It really has the researcher take into account the provider's role, so is the provider there to maintain or to help disrupt the status quo? Also, thinking about reciprocity in the relationship between the provider and the client and also not just understanding power dynamics of the relationship between the provider and the client, but more so working to support the client's power and ability to engage in advocacy and to work to change their current circumstances, so just as one model of how to take some of these issues that we're talking about and apply it to advocacy and parent support compare training as an example. Next slide, please. I'm just going to define two terms for you because I think if we're going to think about action and next steps, we should be on the same page with some things. One, health equity is defined as the state in which everyone has the opportunity to attain full potential and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstance. Next slide. Racial equity is defined as a process of eliminating racial disparities and improving outcomes for everyone. It is the intentional and continual practice of changing policies, practices, systems, and structures by prioritizing measurable change in the lives of people of color. I think it's important to remember that health equity and racial equity are not synonymous. They're not interchangeable terms, they're two different things, so if we're going to think about outcomes and moving forward, what are we talking about? It's also good to have some working definitions because really this is what we're hoping to achieve both health equity for all and racial equity as well for autistic people of color. All right, next slide, please.

DR. LOCKE: One potential pathway for us to address these disparities is to think about and develop programs from the ground up as opposed to traditional methods of research testing interventions, first through rigorous clinical trials, which may end up or not implemented in underserved communities. It's important for us researchers to think and support communities in the development of inherently culturally grounded interventions. One way we can do that is to study practice-based interventions as they might be more feasibly and meaningfully implemented in everyday practice. What are practice-based interventions? These are interventions that emerge from practice that may have an advantage compared to these university developed interventions or clinic-based interventions in that much of the work of fitting the treatment or support or intervention to the setting has already been done, so the intervention is more appropriate and relevant to the community and the people that ultimately will be reached by that service or that support or that intervention. Culturally grounded interventions that are developed for and by Black communities may ultimately have a better chance of being used and sustained than those developed in other settings like universities or clinics. Practice-based research increases the likelihood that resulting interventions will be more culturally relevant, tailored, and actionable than if they were developed in a laboratory or university-based setting. There is a lot of utility and a lot of value in learning from what happens in practice and that's something that is often understudied in research. Next slide. We've thought a lot about some potential next steps in terms of where autism research can go. First, we must disentangle and unpack the impact of race and ethnicity in research trials. Many published research trials don't look at this outcome, and it's an important one we cannot ignore or forget. We also need to involve autistic self-advocates in our research. We've been doing a little bit better at that in recent research, but more work needs to be done especially to include self-advocates of color and getting them a seat at the table and really to think about how we can better understand that intersectionality of race and autism. We also need to develop and evaluate culturally responsive interventions and anti-racist programs for racially minoritized autistic individuals and their families and we need to increase our workforce diversity, both among our research teams and between provider and client or school educator and students, and that includes not just race and ethnicity, but also neurodiversity. We also need to fund existing systems and change policies that contribute to inequities, so thinking about, again, those special education dollars that are appropriated. We need funding mechanisms and mechanisms beyond single investigator R01s to really think about and address both health and racial equity in autism. Like Brian mentioned, those are two distinct constructs. Next slide. In ending, we want to thank our colleagues, Beza Ayalew, Wendy Stone, and David Mandell for their contributions to this project. Thank you so much for having us today and for your time.

DR. AVENEVOLI: Thank you so much, Drs. Boyd and Locke. It was a pleasure to hear your perspectives. I'm going to now highlight our next speaker, which is Dr. Sandy Magana, a professor of autism and neurodevelopmental disabilities at the University of Texas at Austin. Welcome and thank you Dr. Magana.

DR. SANDY MAGANA: Great. Thank you very

much for having me. I really enjoyed the previous presentation and hopefully my presentation can map on a little bit to that because I totally [inaudible] the really understanding the structural inequalities and racism that goes on and how it contributes to the lives of people with autism and their families. I'm going to talk a little bit -- oh, next slide. I keep thinking I'm the one that has to move the slide, but, yeah. I'm going to talk about kind of extending, looking at racial and ethnic disparities in actual health outcomes and talk a little bit about some work that we've done in relationship to that. Then I want to build on the idea that was mentioned earlier about culturally tailored interventions and why we need more funding for that in autism and give an example of an intervention we're currently developing from a study called PODER. Next slide. Next slide. We heard a lot of overview of research that's going on disparities in autism, racial, and ethnic disparities, and I think that was really good. I want to get a hold of those slides so I can look into the many of the studies that were highlighted there. We've talked about disparities in differences in diagnosis and disparities in age of diagnosis and all of that sort of thing. Disparities in specialty services has been done in education. A lot of what was highlighted previously had to do with education and I've done some work on disparities in healthcare access and quality and, of course, we need more research on all of those things right now. I think we also need to focus on health outcomes among autistic adults and children. As Brian said, I think it's important to understand that you have to identify those disparities in order to create equity, right? In order to lead to equity or develop interventions towards equity, it's important to identify where the issues are and so we need to understand actual physical health outcomes for adults and children, autistic adults and children and then also what contributes to them and how we can address them. Next slide. I'm going to tell you a little bit about some analysis that we did with the Healthy Weight Research Network, which is funded by HRSA, one of the member organizations here. We were looking at racial ethnic disparities and obesity and overweight status among boys with autism. Next slide. We actually looked at the ABCD study, which is an NIH funded study, the Adolescent Brain Cognitive Development Study. What's really nice about this study is, it is a very large sample that has multi stage probability. They sample children between ages of nine and 10, and they do have a lot of social determinants of health as variables in this data set, which I think is nice and I'll just briefly about that when I get to talking about results. In this analysis, we selected only boys because the sample of girls is super small. First of all, the sample of people with autism in this huge study is very small and then when you narrow it down by gender it's very small, so we're looking specifically at boys between nine and 10. Next slide. We did some mean comparisons on body mass index and the Z score of the body mass index and you can see a similar pattern there. You see that the non-Latino Whites, which are in the middle have the lowest BMI score and it's significantly lower. Yeah, next slide. Next slide shows when you divide it up into overweight obesity status, so combining overweight and obesity using the BMI score. You can see that pattern here a little more starkly, very significant findings where White children have the lowest rate of obesity, overweight, or obesity status, then Latino and then Black, so quite significant. What I want to say about this, we have done some further analysis just looking at some of those social determinant issues that Brian highlighted, things like neighborhood environment where people live their socioeconomic position, all of those variables are very different between White, Latino and Black, where Black and Latino compared to White is quite different. We're trying to determine to what extent they contribute to these differences, but in a small sample, it's really hard to get to that point. Next slide. Yeah. I just want to say that looking at obesity is super important and other health outcomes, right? But it was mentioned previously diabetes and other things might be different for racial and ethnic groups and the other thing is we do know that Latinos, for example, or Black children compared to White children in general and the general population, there are disparities there and we know that there are disparities between autistic children and typically developing children in obesity as well, so really important to look at those intersections. This is a study that we're doing that's also funded by our partner agency Administration on Community Living, NIDILRR and we're looking at promoting obesity prevention or promoting positive health outcomes. Next slide. In this study we interviewed 100 Latino parent child dyads in Texas and Illinois, so our partners in Illinois are helping with this led by Yolanda Suarez-Balcazar, and we are finding in our sample, the blue, there is the highest rate of obesity there compared to general sample of Mexican-American children, which is also very high, but ours is slightly higher and then a sample of autistic children so significantly higher than those groups, so you can see how that intersection plays out within this sample, so we're doing further research on that. Next slide. Currently we're working on understanding a little bit about what contributes to BMI percentile among these children and one of the things we examined was parenting diet strategies and what is interesting is that in the general literature for children and diet strategies, as well as exercise strategies related to BMI is that usually they say it's better to monitor your child, but not to be controlling in a diet strategy. Controlling strategies would be like telling your child they need to eat everything on their plate. My parents told me that, I don't know how many of your parents told you that. Monitoring might be just maybe making suggestions and setting example and keeping track of what the children are eating, right, and similarly with physical activity. But what we found is interesting. We found that actually parents who use controlling strategies, their children had lower BMI. This is in a sample of Latino children and the children had either autism intellectual disability or down syndrome, but I would say the majority had autism, and then also similar finding with physical activity. Those findings could be related to Latino culture, but they could just be related to being children with autism and intellectual disabilities because we do find that many of the kids with autism, they have sensory issues which may relate to eating certain foods, right, that may not be healthy. It may be that parents who tell their children eat everything on your plate and make sure they do that might be good for them because maybe they are getting a more healthy variety. But more research needs to be done on that topic. We did recruit a small sample of White children in this study and there was a similar pattern that wasn't different from the Latino kids in this finding, so it might be children with autism and IDD that you really need different strategies. Next slide. Now I want to move into talking about culturally tailoring because we can gather data on what issues and challenges are, where the disparities are, but how do we address them? Next slide. People are probably familiar with the study led by Steinbrenner and colleagues. They did a meta-analysis to find out to what extent autism intervention research includes people of color or people from low socioeconomic status. They found out of 1,013 articles, only 25% reported any data on race and ethnicity. To me that says that there probably isn't a lot of diversity in their sample. They found over time that it slightly increased, but not a lot and then the ones that did report, those 25% that did report 64%, 65% were White, 9.4% were Latinos, 7.7% were Black, and 6.5% were Asians. It doesn't quite match like a census of the US population even though it was 25%, so we know that people of color are not being included in intervention research for autism. Well, next slide. You could think about the reasons why people are underrepresented in autism research. There could be some mistrust of healthcare providers in research. The research may be conducted in unfamiliar settings like clinics on the university campus, for example. The sites may be far away from BIPOC communities. The families may not be able to take time off work to do these studies, they may have multiple caregiving responsibilities. If it's an internet based study, maybe they don't have fast and reliable internet. Often non-English speakers are excluded and another issue that was brought to me by a group of autistic adults is that a lot of these studies only include people with a solid diagnosis of autism if they're looking at that and even as adults, right, but if they're not diagnosed and we know that the BIPOC populations are diagnosed later, so they may be excluded for that reason too. Next slide. I want to point out that doing cultural adaptations is much more widely done in the mental health field, so looking at mental health interventions with children and adults, there's a lot more research on that to the extent that they can even do several meta-analysis on cultural adaptations. In those meta-analyses they actually found great effects, important evidence that shows that cultural adaptations make a difference. They found moderate to large effects for culturally adapted interventions. They found that those conducted in native language were twice as effective as those in English. For example, many people who might be immigrant and speak some English, they might get included in an English speaking intervention when they would've been more comfortable in their language of origin. Interventions tailored for specific groups were four times more likely than those provided to all groups and that's one of the reasons that we worked with Sarah Dababnah and others to adapt Parents Taking Action to Black families specifically, but then also we did a separate adaptation for Chinese immigrant families, another one for Navajo families, and just really using the stakeholders to make the adaptations that are important for those interventions. Next slide. One of the things that is important is to understand the process of cultural adaptation. It is iterative. It's not a one and done thing and updating the intervention is continual based on feedback. We're still changing Parents Taking Action right now for different groups, but also feedback that we've gotten. It's important to involve stakeholders and those stakeholders include families and autistic self-advocates or autistic adults and then making an appropriate selection of the intervention, whether it's an existing one or you're creating a new one for that community, making those changes or making that intervention based on stakeholder input, doing a pilot implementation of that, and then evaluating the pilot study and making tweaks to it, right? And updating the intervention, implementing again, so it's a continual cycle. Next slide. These are some of the best practices that we've found in terms of the research, but also our own experience when you're culturally developing or adapting an intervention. Involving stakeholders is super, super important every single time. Also I think using peer-based methods, so whether it's using peers to help deliver the intervention or help doing recruitment or help different aspects of the research, super important. Creating and adapting translating materials for that group, ensuring the content is relevant to that group, so if you're adapting something, you have to make sure that you're not talking about something that they're not even using or doing or wouldn't be able to relate to, ensuring accessibility and reducing efforts so making sure you're in those neighborhoods so it doesn't become challenging to get to another neighborhood or area. We use the ecological validity framework, which I'm not going to talk a lot about, but it does focus you on different dimensions that you want to think about, whether it's language, persons. I'll just give you an example of a project PODER Familiar. We had the PODER Study where we interviewed Latino parent and child dyads and then from that we're leading into a pilot intervention that will develop even further along, so I'll tell you a little bit about how that's going. Next slide. PODER Familiar, the goal is to promote health and wellbeing of not only the children with intellectual and developmental disabilities, but also their mothers and family members, right? We do know that mothers are often the primary caregiver, or it could be a grandmother or other member of the family that's the primary caregiver and often they're not focusing on their own health, so it's important to also pay attention to them. We created a 10 week curriculum and so we have 10 individual remote sessions and then we have a multi-family gathering that will take place when we have a group of families who've been starting the program where they can all share experiences, but also do demonstration projects and physical activity projects with the whole family. The multi-family group gatherings will be not just the child and the mother, but dads, siblings, whoever else wants to come. Next slide. Yeah, so as I mentioned, we use the cross-sectional data and also other feedback to develop the intervention. We're doing pre and post-tests conducted by grad students. Well, I do want to say the people delivering the intervention, as I mentioned before, it's important to use peers, so they are parents of children with developmental disabilities and they're doing the remote sessions with the participants. We will be doing a randomized controlled trial once we get back the results and analyze and tweak the intervention and doing a larger study, so going through those different iterations I talked about. Next slide. That's all I have, but I did want to add one thing that I didn't make a slide for, but I want to talk about a little bit briefly about the workforce. I know that was mentioned earlier, the importance of having a diverse workforce, and I think that's true with research, right? We need to have researchers who come from different racial and ethnic backgrounds who can bring in different research questions. Also, researchers who are autistic and researchers who have different levels of disability, different disabilities, it's important to have those voices as part of the research team. One of the things I noticed between agencies is that NIDILRR which is under ACL does require you in your proposal to say who is in your research team and what diversity they bring in whereas NIH doesn't and so I want to suggest NIH take a look at that because I am on the study section and I do read a lot of grant proposals and I see that often there might be a group that's proposing to do a study with racial ethnic minority groups, but their team itself has no experience doing that and there's no racial ethnic diversity on the team. Think about ways to bring in to ensure that people writing proposals are thinking about that and bringing in racial minority researchers will help with that workforce issue. That's all I want to say.

DR. AVENEVOLI: Thank you so much, Dr. Magana. That issue has been brought up to NIH before, and I want you to know that we've been talking about it at the larger NIH level as well. Okay, so now we're going to hear from four individuals who are going to share with us community perspectives from their own lived experience and their advocacy work on behalf of underserved communities. First, Mr. Gyasi Burks-Abbott is a self-advocate and LEND fellow at Boston Children's Hospital and a UCEDD fellow at the UMass Boston's Institute for Community Inclusion. Next is Lydia Brown, they are a self-advocate disability rights attorney, and the founder and director of the Autistic People of Color Fund. We also have Ms. Camille Proctor, she is the founder and executive director of the Color of Autism Foundation and mother of a child on the autism spectrum. Finally, Dr. Crystal Hernandez is the executive director of the Tulsa Center for Behavioral Health and mother of a child on the autism spectrum. Welcome and thank you all very much for being here.

MR. GYASI BURKS-ABBOTT: Okay, like it's

been said my name is Gyasi Burks-Abbott. LEND stands for Leadership Education and Neurodevelopmental Disabilities, and I'm a self-advocate faculty member. I want to thank the IACC for hosting this panel about racial equity and racial diversity because actually a lot of the challenges that people on the autism spectrum and the disability community have are related to disinvestment in government services, which has a legacy of systemic racism. For instance, if we think about some of the problems that we have like with the SSI asset limits that haven't been updated since 1989, so it's like $2,000 you can have in your account, which I've personally have suffered from. I've always been in the position of not being able to make enough money to be self-supporting, but making just enough to jeopardize my benefits or the workforce crisis, which was exacerbated by the pandemic, but which is also driven by the low wages that DPS professionals get. Of course, even some 20 years after the Supreme Court Olmstead decision, you still have a long waitlist for home and community based services and a lot of this is because of government. In fact, the National Council on Disability recently issued a report saying that basically the reason for the wait list is because of the disinvestment in government services and the HBCS system. A lot of this can actually be traced back to the legacy of institutionalized racism. For instance, one reason why we don't have universal healthcare is because actually back in the '40s, President Harry Truman proposed a universal healthcare plan, but he got pushback. It was a scuttled because senators from Southern states worried about that universal healthcare would lead to integration of hospitals, so that was not done. Then more recently, the economist, Heather McGhee talks about what happened in response to the civil rights movement in the South, where public swimming pools, instead of integrating them, they were shut down and drained so that no one had that public benefit. McGhee talks about how a similar process happened on the federal level, where it was no longer a feasible to talk overt racism because of the civil rights movement. The language became things like state rights, lowering taxes, so as people of color got more access to government services and benefits, they were in essence drained and shrank. But even when race is not specifically involved, the simple question of how much will this cost is always complicated by assumptions or judgments about who is worthy and not worthy. Like when President Biden wanted to do his American jobs plan and he wanted infrastructure to not just include roads and bridges, but also the human infrastructure. Direct service professionals, paid medical leave, he got a lot of push back from Republicans and some Democrats saying that's a waste of money and he should just stick with roads and bridges and don't worry about the people who are going to use those roads and bridges. It's always interesting how social services are often seen as a waste of money, but for instance, not defense or tax cuts for the rich. I think that moving forward, I think we need to move away from trickledown economics to an economics of a lifting up or as Heather McGhee talks about it, we need to move away from what she calls zero sum thinking that giving to one group automatically takes away from another group and we need to think in terms of solidarity dividends, where in essence we all benefit when we all contribute to each other's welfare. Thanks for listening.

MS. CAMILLE PROCTOR: I guess I'll go next. Hi. I'm Camille Proctor and I'm the executive director of the Color of Autism Foundation. I guess I would have to dovetail off of what Dr. Locke and Dr. Boyd spoke about. There is a disparity still. More children are being diagnosed and that's a good thing, but the disparity still exists.

Perhaps more African-Americans or Black people know about autism, but are they taking action? When we look at certain areas of this country, or should I say, or do they have access. When we look at certain areas of this country like in Atlanta, there is a black community called Cascades and it's primarily an upper middle class Black community. In that particular community, there are no service providers and so those families have to drive between 30 to even up to two hours to get the services that they need. I think that we do need to take action in regards to creating equitable outcomes for all. Whether it be early intervention, whether it be jobs, there just needs to be some equity given into these communities of color. I don't have an awful lot to say today because I think Dr. Boyd and Dr. Locke covered a lot of what I was thinking, so I will let someone else speak now.

MX. LYDIA X.Z. BROWN: This is Lydia X.Z. Brown, pronouns are they/them. I am a youngish East Asian person with short black hair and glasses. I'm wearing a blue collared shirt, a jade pendant and a light tan suit jacket. My lapel pin says there is no wrong way to have a body. Behind me is a fake background that shows a wall from floor to ceiling of books and bookshelves and it's a dreamy wall that I wish I actually had and if any of you have such a wall, I would be incredibly envious. Thank you all for the opportunity to join you here and to speak to some of the issues that autistic people of color experience individually as well as the result of systematic racism and ableism impacting our lives. As the founding executive director of the Autistic People of Color Fund, I have experienced countless stories from hundreds if not thousands of autistic people of color from many different backgrounds, many different specific communities who experience the impact of lifelong economic, racial, and disability based disparities. We know that according to the Bureau of Labor Statistics and other statistics collected on employment outcomes for disabled people, that autistic people along with the broader disability community face higher rates of unemployment as well as higher rates of poverty compared to the population in general. We also know that autistic people of color, like disabled people of color, more generally face sharper disparities. We know that the earnings threshold for people with disabilities is already expected to be lower in terms of actual wages and lifetime earnings compared to people without disabilities and for autistic people of color, those disparities are further exacerbated. In real terms, this means that we encounter stories from countless autistic people of color who are facing an inability to meet the most basic rent payment obligations as well as to make utilities payments and as a result are scrambling from month to month, desperately attempting to grab together different resources to attempt to pool enough money to be able to stave off a potential eviction and homelessness. There are many autistic people of color who receive grants from the autistic people of color fund who have faced chronic homelessness, who have faced multiple evictions and who live in a state of chronic housing instability and economic insecurity. The reasons are vast and they include employment discrimination on the job and in the recruitment and hiring process, as well as in determinations of pay, compensation, raises, and promotions. They also include experiences of discrimination in regard to accessing programs that are meant to provide some form of social safety net for people with disabilities and others who are low and moderate income. We know that many autistic people of color are placed in a situation where through no fault of their own, they are unable to adequately maintain access to the long-term supports and services that they actually need in order to maintain independence and connection to the community, as well as to be able to access the support economically necessary to live a minimally decent quality of life. This is before reaching disparities in diagnosis, assessment, and access to autism specific therapies and services that many autistic people of color remain disproportionately shut out of. It is not lost on me that those of us who have created and who lead the autistic people of color funds are among the more privileged in the community, if only relatively and precariously so because we have access to community support, because we currently have access to employment and because we currently have access to housing, that is not true for a significant proportion of the autistic people of color who receive micro grant support from the organization. For a range of reasons, autistic people of color who come from minoritized religious communities, minoritized ethnic communities, and who are multiracial and multiethnic themselves face a multitude of forms of systematic discrimination that lead to poorer outcomes, both in the short term and the long term. Autistic people of color, whether from Black, Brown, Latinx, Native, or Asian communities, whether from those who currently hold citizenship and or may be from immigrant or refugee communities regardless of current documentation status, face higher rates of school pushout, on the job discrimination, housing discrimination, discrimination in credit and lending decisions, and ability to maintain access to community integration as well as to live a life free of criminalization and profiling. I think about the experiences that many of us have shared in our own community conversations, how it is unfortunately a common experience for many of us to have experienced profiling and accusations of being inherently suspicious, potentially violent, sexual predators, or even would-be mass shooters simply for the experience of living as negatively racialized and living as autistic at the same time. I think about the experiences of autistic people of color who belong to the LGBTQ community as well, and how our rights and ability to exercise bodily autonomy are now under direct attack in dozens of states across the US and without the ability to reliably access not only gender confirming care, but even culturally responsive support within disability services providers leaves many autistic people of color, queer and trans in particular in a particularly hard place where we have to choose between losing access to necessary services to live, to survive, and to participate in our communities or to being basically respected and treated with care and support. This should not be a choice that we ever have to make, and yet these are the stories that we hear over and over and over again. It should not be the case that those of us who have the most, again, however conditional privilege, are still concerned about the impact of discrimination in the short term and in the long term. It should not be the case that we are worried about the long-term mental and physical health impacts of systematic and continuous discrimination and trauma. It should not be the case that we are worried about the ability to access dignity and end of life care and after death and it should not be the case that we are worried about having a lifespan cut tragically short because of interpersonal violence, because of state violence and because of the accumulated impact of stress physiologically and psychologically. I only have a few minutes to share with you what some of these experiences have been for autistic people of color in the community, but I will leave with further emphasis on one area that we know remains under-addressed and not sufficiently funded, resourced or supported in terms of research, advocacy or policymaking, and that is the financial impact on autistic people of color and other disabled people of color in general, who also serve as family caregivers within our own families. I am myself a family caregiver who is both autistic and responsible for providing care and support to other family members who have disabilities and this is not an unusual situation. Whether as parents, siblings, spouses, or other familial caregivers, those of us in communities of color who are also autistic or otherwise disabled, will experience significantly diminished capacity from our earnings and ability to build income and assets and maintain access to those assets. Because of our care work and because of the responsibilities that we have within our families, we face additional stressors in our lives, we face lack of support and understanding, and we face discrimination in the child and family regulatory systems, in court, and in foster services and in parental support agencies, as well as in programs that are intended to support families in which one or more people are autistic. We've simultaneously faced consistent erasure and removal from public discourse and conversation when considering what types of support autistic people need and the fact that many of us are direct caregivers and direct support workers while also needing support ourselves in our own lives. I'll just leave you with this, again, reminder of the issues that disproportionately impact autistic people of color and other disabled people of color. We refer to this in many such marginalized communities as an additional tax levied on our earnings capacity, again in the short-term in terms of wages and salaries, as well as the long-term impact over lifetime earnings and that the earnings potential of a person who does not have any disabilities and is not a caretaker are going to be significantly higher than the earnings capacity of a person who is disabled, let alone disabled, and also a caregiver at the same time. Thank you very much for your time and I believe that all three of us are available to respond to questions and further comments from the committee members.

DR. DANIELS: So our last speaker on this panel will be Crystal Hernandez.

DR. CRYSTAL HERNANDEZ: My name is Dr. Crystal Hernandez. I am first and foremost a mother with my youngest being autistic. We started our autism journey nearly six years ago with terrible experiences and limited supports. Since that time, I've made it my mission to help others share their voice and stories to push for positive change focused on quality, inclusion, dignity, and equity. My family walks two cultures. We are Native American Cherokee Nation citizens as well as Latinos. This blend has given me so many unique experiences and perspectives, but also a look into the intersectionality of both, specifically as it relates to the autism journey. Everyday I'm contacted by dozens of people all over the United States. I hear stories from parents, individuals, grandparents, aunties and uncles, communities. We have to build systems of equity and safety for these individuals. There continues to be a need for more specific research, funding, data, supports and services truly built by and for Native Americans and Latinos in autism. When we talk about tribal nations, we also need to recognize and honor sovereignty, giving them the same abilities to manage funding and services and programs just like states do. We have segmented and one-off projects, catchy marketing campaigns, service deserts, lack of representation and providers, and an absolute disconnect with culture. We need more and deserve more. We need to be in the spaces where decisions are made, lending our own knowledge and experiences to the items of consideration for funding, policy and practice. We must continue to challenge stagnant, oppressive, and disrespectful ways of business and communication. We need culturally rooted policy and services, which is much more than a class or marketing. It is about honoring and giving space, not as an aside and our accompaniment, but as the backbone in service and support. Our culture is beautiful and vital. It is our identity. When we tell the person that they are not welcomed, all of them, they're whole person into spaces where safety and wellness are supposed to be paramount, what are we saying? How does this contribute to biases, trauma and barriers to care? With respect to time, I wanted to share a few items with you. Roughly seven months ago, in partnership with the state of the states in intellectual and developmental disabilities, we launched Black Feathers Podcast and you can see the flyer there on your screen, which focuses on Native American experiences and journeys with intellectual and developmental disabilities. We have had amazing guests join us so far and much more to come. We get to hear their struggles, their triumphs, beliefs and customs and their call to action. It is their words that hold such critical perspective and power. On a recent episode, we were able to hear how the lack of accommodations impact someone's ability to participate in their traditional ceremony and practices. For example, a powwow. This lack of accommodation robs one of knowing and learning within their culture from belonging. Our culture is a protective factor and we need to accommodate for this, for our autistic citizens to anchor them in our circle. We have also had tribal nations come on and discuss their unique projects related to service and supports for this population. Specifically, this month's episode, which is coming out Monday, is the Chickasaw Nation outlining how they are funding massive developmental disabilities programs and creating a shift to be more responsive for their autistic citizens and their families. They have really stepped up to the call and are challenging other tribal nations to do the same. We also have had guests discuss their personal journeys with advocacy and allyship, critical social issues and the intersectionality with mental health. The National Indian Council on Aging recently published a new toolkit. It was a two year project titled Understanding Disabilities in American Indian and Alaska Native Communities. I was extremely fortunate to have worked on this meaningful and much needed project. Please share this, it was featured in your newsletter. This is geared towards tribal nations and stakeholders, families and individuals. It's a plethora of resources and information. One additional point I would like to make, Latinos are often utilizers of clinic systems, and I hear this from parents all the time and grandparents, which have rotating doctors and providers, removing consistency in developmental monitoring and reducing detection opportunities. Also, language barriers pose significant obstacles to discuss development, advocate for screening or acquire diagnostic evaluations. Trust in citizenship status plays a significant role in acquiring and accepting interventions. You don't know what you don't know and you don't know how to get what you don't know you need. Representation matters. Our voices and experiences matter, and most significantly, we matter. To end, I would like to quote a powerful historical Cherokee principle, Chief Wilma Mankiller. The secret of our success is that we never, never give up. We are resilient people, yes, who never give up, but at some point our society needs to make it less of a fight for equity and access. We need to have our journeys inform true change. I'm available to connect and together we are stronger and I'm so extremely thankful for IACC for this critical focus on equity and inclusion.

DR. DANIELS: Thank you so much to all of our panelists today and all of our speakers for this wonderful session. We all learned a lot and heard some really incredibly powerful perspectives on this issue. Looking forward to questions and answers with the committee and we have some time for questions, so I see Yetta Myrick.

MS. MYRICK: Hello everyone. I've transitioned to the car, so bear with me. So very, very happy to the IACC team for bringing this panel together. Many of you on this panel I have either worked with or collaborate with you or have known you for many years either in passing and just so thankful for you all to come on and share your experience and your thoughts. The research that you all are doing is amazing and it gives me hope really for the future of autism research specifically for people of color. This work is vital and I just wanted to say thank you to you all for what you shared today. That's all I had to say. Good to see you all. Thank you.

MR. BURKS-ABBOTT: Thank you. Nice seeing you too.

DR. DANIELS: Thank you, Yetta. Jenny Mai Phan?

DR. JENNY MAI PHAN: Hi. I'll also echo

Yetta's comment. Thank you so much for coming here to the IACC and sharing your work. I have two statements to share and one to hopefully give you some food for thought to bring back to your work, your respective works. The first is about how autism stigma is being addressed among community partners of racial ethnic minoritized groups. There are communities where there is low autism awareness and not accepted that still exist within the United States and there are small grassroots advocacy groups who provide education to these communities that are underfunded and lack resources to fight the stigma in their racial ethnic communities. In talking with some of these advocacy groups myself they learn that autistic children who are exposed to stigmatizing perspectives about autism that negatively affect their mental health and that some of these children are physically abused, maltreated and neglected, it's such a critical and beneficial opportunity for researchers to engage with these communities in a responsive way and researchers can partner with these grassroots advocacy groups for help if they don't know where to start. That's the question I always hear a lot. And the second statement I'd like to add for you to think about in your work, which I'm sure you already are is about non-English communicators or minimally English communicators who are referred to English as a second language or ESL classes in schools who would meet the criteria for an autism diagnosis if they were appropriately referred. Some of these kids are met with a double stigma in which schools and caregivers believe that the solution to their education underperformance is to teach them English and then ignore that there are other developmental factors that would explain their underperformance. I spoke with an ESL teacher who lacks administrative support to make a referral for her students whom she suspect has a developmental disability and then she and her colleagues experience exact same problem in their schools, and then when talking with caregivers, the stigma is so ingrained in the home that they refuse to seek a diagnosis for their child. There are many who are left behind in our country who either do not speak English fluently or not fluent enough. With the talks that you have given today, I so appreciate the work that you do. Please keep doing it, please spread it to all of our communities in our country and remember those who are still left behind. Thank you.

MR. BURKS-ABBOTT: Thanks for your comments. I would just respond to that by saying that actually in the LEND program, one of the things we have the fellows do is work with community-based organizations and a lot of the community-based organizations are actually dealing with underserved communities. There's an organization called SAB, which is they talk about autism with the Somali community and there's another community that deals with people or immigrants from Latin speaking countries. We are probably not doing enough, but we are doing something. I'm glad for your comment.

MS. PROCTOR: I would just like to say this. I know that Dr. Boyd and I and Jill Locke, we've worked on a project together, but my organization, the Color of Autism Foundation, we take a holistic approach. We work with the parents. We train the parents on how to support their children to have better outcomes and we encourage the parents to embrace their child's identity. We work with them so they can understand who their child really is, who they truly are, so their children have a sense of worth because that's the biggest problem is that a lot of these parents don't have the tools they need to support themselves, let alone their child. I word it like this, if you continue to act as if your child is the catalyst of your sorrow, you're burdening them with guilt and a lack of self-worth. We are totally against that and we do everything we can to support the parent as well as the child that will be an adult.

DR. DANIELS: Thank you. Any other comments?

MR. GYASI BURKS -ABBOTT: Actually, I wanted to piggy back off my own identity. One of the ways that I learned how to read actually was, my mom was an academic and her specialty was African-American literature and film and I went to an all-White school. I went to all-White schools, and one of the things she would do is have me read books by and about African-Americans. In essence, while I was getting into the reading as I wasn't doing, but I was also learning about my own culture, my own identity, and having a sense of pride, so that's certainly important. I'll definitely endorse that.

MX. BROWN: This is Lydia. Thank you all for your comments and I appreciate that our information as a group has been useful to you all. I think that it's also important for all of us to be very clear about our positionality. I spoke about the experience of conditional or precarious privilege that we may hold by virtue of participating in this forum and being in this type of space, even though there are those of us here, including the four on this panel, who experience multiple forms of marginalization at the same time and so one thing that is really important for us to be specifically concerned with, and I spoke in generalities because our organization does national and global work, and I only had a few minutes to speak with you, but to name what communities we are working with, what communities are being funded and researched, what communities people represent and come from and where it is we are doing our work. I am joining you today from the unceded traditional lands of the Ho-Chunk Nation, which were deliberately stolen from the Ho-Chunk Nation's people in which the lands that Ho-Chunk people today live on had to be purchased back from the territorial government as opposed to repatriated and returned and furthering economic injustice and insult. These realities of historical and ongoing trauma and colonialization actually continue to impact disabled people of color and the ways in which we can be assessed and receive services and be understood within and outside of our community. We need to be very deliberate in naming where we are and who we are working with and where it is that we are doing that work.

DR. DANIELS: Anyone else? We will move on to the next session. Thank you for those comments. Dena Gassner.

MS. GASSNER: I'm going to take a pause and let Morenike go before me, please.

DR. DANIELS: All right, go ahead, Morenike.

MR. ISAACSON: Hi there. Morenike sent their question over chat, or it's more of a comment. They say, "I don't have too much to say because I'm too emotional to gather my thoughts. People often say, why do you have to keep bringing up race? We're talking about autism. They say race has nothing to do with it. It is frightening that even now people don't understand how these factors are so deeply intertwined. For people of the global majority, we don't have the luxury of ignoring cultural aspects. They want to thank Brian, Jill, Gyasi, Camille, Lydia, and Crystal for making myself and my children visible. Yetta also sent a comment through saying, Lydia, you're 100% correct. We need to think about the fact that we're privileged to have a seat at the table, and it's our duty, they believe to support our communities.

DR. DANIELS: Thank you for those comments.

DR. BRIAN BOYD: Can I just quickly say one thing? Morenike, thank you for the comment. I just want to respond a little bit and it was actually brought up with the issue of stigma to talk about how these issues of race and disability are intertwined and should be thought of together. I really want to credit Dr. Elizabeth Morgan for this because this issue of stigma was brought up in another meeting that Yetta hosted for her group. Dr. Morgan reminded us that issues of stigma often, in particular for the Black community, are rooted in historical issues that blackness itself was thought of as a disability. How people measured the skull sizes of Black people to suggest that they were lower in intelligence. The resulting stigma that we sometimes see from racialized and minoritized communities are often historically rooted in other issues, and so this issue of how identity and disability and race all intersect, it really is intertwined and it can't be divorced because those identities are affecting the experiences we're having and the outcomes that people are able to realize or not realize. That's just an example of how these issues really are rooted in the larger context of our society.

Thank you for that comment, Morenike.

DR. HERNANDEZ: If I may piggyback off of Dr. Boyd, we talked about this on podcast. We had four individuals two of which were Ho-Chunk Nation citizens talking about their journeys and some of the stigmas and things like that. Native Americans, we also have that historical trauma lens and we talked about it as an ongoing trauma because of the fact that people don't recognize that it's still an issue, that it's still ongoing, that it's still matters and so it's ongoing.

MX. LYDIA BROWN: This is Lydia. This is true across all negatively racialized communities for both culturally and historically specific reasons and because of the ways in which, as I teach my own students in my courses on disability and race and the histories of disability and race in this country. Our conceptualizations of whiteness and ableness and health are deeply intertwined and always have been. Whether that is in East Asian immigrant families feeling a drive to pursue so-called excellence in order to be seen as sufficiently well behaved and compliant and participatory in White settler structures or whether that is the resistance that Dr. Boyd spoke about in Black communities to speaking about disability openly or as Dr. Hernandez was discussing in native communities across different tribal nations and communities, that we experience this expectation and pressure to disavow disability and to dissociate and distance ourselves from disability in communities of color because of the ways in which ableness and whiteness are so closely intertwined. We may often internalize the belief that if we accept categorization as disabled and recognize disabilities in our communities that that would be internalizing a White and colonizer's lens or framework for our people and for our communities. In reality, it is disabled people of color who are resisting this type of racialized and deeply ableist prejudice and the impact that it has intergenerationally in our communities as well as our ability to seek redress and to seek justice.

MR. BURKS-ABBOTT: I guess I would add that it is interesting the way that people of color and people with disabilities often have to go above and beyond to prove their basic humanity. Even going back to slavery where in order to prove that they were human, slaves wrote slave narratives. They had to write, literally write themselves into humanity. But also in terms of disability and race, it's also that because of historic systemic racism and things like redlining that put people of color in certain neighborhoods that decreases their access to healthy food, makes it more likely to be exposed to pollutants. They're actually more likely to maybe be disabled or to have their disabilities exacerbated because of racism and the natural and the physical built environment. That's another connection there.

DR. DANIELS: Any other comments on that topic? Thank you for the great comments. Dena Gassner, you have your hand up.

MS. GASSNER: Thank you. I just wanted to thank everybody. Your input is helping me to continue in my journey to grow and to be more sensitized and to be more effective as a researcher. I do want to highlight one thing that has been missed twice today. We didn't discuss it this morning and we need to discuss it now and that is that the prevalence rates of identification of girls on the autism spectrum is the most marginalized subset of autistic people and then when you add multiple marginalizations that include race or ethnic differences on top of that. This is in due respect when we're not intentionally recruiting girls when we have a low sample size, it does a disservice to the entirety of our community and it suggests that autistic girls and women, and in some of these studies we looked at today, women of color, don't exist. It's an erasure and doesn't consider the tiers of marginalized identities that are packed on the back of these autistic women. I just want to say that these numbers are really doing a disservice to the idea that we can intentionally recruit and find autistic women to study. We have gatekeepers who have access to our community. All the top people are right here on the screen and so if we need to find people who meet that criteria as a marginalized woman, we have access through these networks and we need to teach researchers how to capitalize on them. Then I just wanted to emphasize, if you will, the role of administrative burden that is layered on top of accessing services for the entirety of the community, but again, is more complicated when English is not your first language. Systems that are almost prenabracans of disbelief that people are conning them out of money, like it's their own personal money instead of giving people access to the amount of money and the amount of resources they need to live. People who live in poverty have a 20 year shorter life expectancy. Many autistic people, as Lydia pointed out, are living at the brink or below the federal poverty line at all times, so we've just got to do better. I'm preaching to the choir here, but I was just distressed that we didn't talk about the rates on females. Thank you.

DR. DANIELS: Thank you. Any responses or comments on that?

MX. BROWN: This is Lydia. I'd be happy to share further resources and information on gender and racial disparities impacting autistic people as well. Thank you for raising that, Dena.

DR. HERNANDEZ: I'll say if I can, I run psychiatric hospitals, that's what I do in my day job and I will tell you the number of females that I get through the door that do not have a formal diagnosis and have everything but the kitchen sink on their packet is just alarming. We definitely need to do a whole tremendous amount of work on that particular issue.

MS. GASSNER: Thank you. I do want to say I'm a social worker by training and in my day job, one of the things I do is run an adult support group for autistic women. Last month we had 35 women attend, one diagnosed before the age of three, one diagnosed before the age of 30, everybody else was in their late 30s or their 40s or their 50s or their 60s. I realized there was no diagnosis available to that segment of the population, but were doing the same injustice to the new and younger people that are coming aboard. Thanks for affirming, Dr. Hernandez, that in the community we know that number can't be accurate.

DR. BOYD: Really just to underscore Dena's point a little bit, and this is more anecdotal, but I had a Black mother of an autistic girl reach out to me and ask me to send her research on Black women and girls who were autistic. I couldn't really point to any. I think there've been one or two small scale studies that have done, but not a lot, so just to underscore your point, Dena, so thanks for bringing that up.

MR. BURKS-ABBOTT: In a way there is really no excuse for a disparity because some of the early research on autism, some of the most famous books written were written about and by women. If you think about Jesse Clayborne, her mother, Clara Claiborne writing two books about her raising her daughter with autism, or there's Temple Grandin, or there's Donna Williams. In essence, it's almost like it's such as willful blindness to not see that women can obviously have autism.

MS. PROCTOR: I can speak from a cultural standpoint as in the Black community. I think that it's difficult for families to come to terms with their daughters possibly being different because in the Black community, the Black woman is the roots to the tree. She is supposed to be able to do everything and anything. From the time we're born, we're groomed to do everything and anything. I think that it's just a cultural thing at least for Black families and I think that's the problem is that we don't talk about it enough and that's why my organization strives to get families to embrace who their children are. I think that if we keep doing what we do, you will get those unicorns. But it has to be a community effort in regards to making these communities of color feel comfortable enough in saying who their children are. One of the things that we do in our training is that we bring in people of color, we bring in Black facilitators so that our parents aren't closed off. They become relaxed with them and they ask the right questions and from that, they gain a sense of empowerment. A, they see that there's providers that can service them that look like them that are out there somewhere and they also have a community in these classes that we have and facilitate on Saturdays. They have a community of people so they know that they're not alone. We also bring in self-advocates and most of the time it's a female self-advocate who is talking about her experience. We do that purposefully because lately we have a lot of parents in our groups who have young women. I just wanted to bring this up because we are addressing that particular issue, but you have to understand everything takes time and you have to get the community comfortable first with who they are and who their child is before you can really make any significant changes for the future or you'll continue to have that older self-advocate that's 20 and up.

DR. MAGANA: If I could add to just build on that a little bit. In the Latino community, we do a lot of research with a large number of Latino families and we do see families who have girls with autism, but often we do see that same proportion that's in the general in the White or whatever population research. I think it goes even deeper than culture. It goes to the culture of our society, right? Because I think girls are taught to internalize their problems. I have two kids with ADHD, one is a girl and one is a boy and the girl her ADHD wasn't recognized till later because it doesn't exhibit as behavioral challenges that maybe it did in my son, right? I think you have a similar pattern in our society where girls are taught to internalize things and maybe if they do have some meltdown related to sensory issues or whatever, it might get interpreted differently, right, in our society. I think it's a societal problem that replicates itself in different communities as well.

DR. HERNANDEZ: I would like to also just highlight something that's been said a couple times throughout the day is who is in the room when we're creating these instruments? Who is in the room when we're creating these research projects? Who is in the room? Oftentimes, it's not people that look like those of us on this panel.

MR. BURKS-ABBOTT: I often wonder who the onus is being put on for being diagnosed and recognized? Even the idea that girls aren't diagnosed because they're somehow hiding, it's like, isn't the doctor's job to ascertain that? It's not the patient's job to say this is what's wrong with me. It's a doctor's job to. It's like blaming the patient. I sometimes feel it's like, wait a second, whose responsibility is it to see that, okay, this person has autism even if they don't fit whatever profile I have in my head? Isn't that the doctor's job? Always I'm interested in that who we're blaming and who has the responsibility. I always find that curious.

MS. PROCTOR: I'm not necessarily blaming anybody, but I do know that culturally it’s difficult. I know that I've talked to parents who have fought tooth and nail against a diagnosis for their daughter. Just tooth and nail for a diagnosis for their child, period. I don't know what an autistic adult goes through, but what I do know that these autistic children are being pushed to the side because of their parents' views. We try to educate parents so they better understand why it's important to be identified, why it's important to get a diagnosis, and why it's important to support their children the right way. When I say this, it's not to blame the victim because there's been victimization through systemic racism and so that is what has conditioned Black people, and I'm only speaking for my culture, to not embrace mental health issues, autism, whatever the case may be. Sometimes even diabetes, they'll just keep eating candy. So the point is, it's just a thing. We are here today to, number one, get more resources for our communities, our respective communities, and number two, end the stigmatization of autism.

MR. BURKS-ABBOTT: Yeah, I wasn't referring to you. I'm not saying you're blaming the victim.

DR. PROCTOR: No, no, no, I know you're

not, but I just wanted to make that point. I totally get what you're saying and you made some wonderful points. I get it. I get it. But there's others out there who are watching this and I want to just be clear on the hurdles that these communities of color have to clear. I know that Dr. Hernandez can say pretty much just what I said, they have to clear these hurdles because you're telling them, oh, he or she is doing something that is presenting as autistic and that parent will tell you, no, they aren't. To be honest with you, a doctor can't make a parent accept a diagnosis that's the only thing I wanted to and Dr. Hernandez might be able to speak on that a little bit more.

DR. HERNANDEZ: Absolutely. I can definitely chime in. I think it's a couple things. One, it's like a perfect storm of the instruments and all the other stuff that we just talked about, but it's also, I'll just use my own personal journey, it's also accepting that and going through that process. I wake up every day knowing who I am in terms of what color I am, where my position is based off that in life and my son, I already think about, oh gosh, he is already going to struggle, they're already going to judge him, oh my gosh, oh my gosh and it's an everyday thing. It's really hard when I talk to other parents about this journey and it's a lot of mixed emotions for them. Some accept it, some don't want to talk about it. Some are very angry. Some are crying and grieving. I think it's so different for so many different people, but knowing what I know and knowing the folks that I've talked to, it's really hard to sometimes want that spotlight on you when you already feel that spotlight of judgment. It's not something to be judged and I'm not saying that, but what I'm saying is that's how I have felt, especially early on, is my son is already going to face a world of challenges because of who he is in terms of his color and where he comes from. Now he is going to face an additional layer if I acknowledge and accept this and this is his path forward. It took a lot of emotional work to get through all of that and get over my own mind and to really fight, but there is never a day that goes by where somebody somewhere isn't judging.

MX. BROWN: This is Lydia. I had this conversation with some of my students last night because this is also an experience that many disabled adults go through as well of realizing that if you have not had another disability correctly identified and diagnosed earlier, or you are acquiring a new condition, for example, the onset of an autoimmune disease that occurs later in life, that many people struggle with the internalized ableism because that's what that boils down to. It's ableism and it's fear of the impact of ableism of realizing that there is another experience you have that will result in societal discrimination, and that that could translate into poorer health outcomes, poorer economic outcomes, very real material consequences and so for those of us in marginalized communities, that ableism most often takes the form of, again, if I can shield myself from having to accept or name or claim disability as part of an experience, then perhaps that will decrease the amount of prejudice and discrimination that I or my family member will experience and so when disavowing disability, we believe falsely that, that will free us from or protect us from discrimination when that's not actually true, so it boils down to both internalized ableism as well as the fear of the consequences of ableism. But whether somebody accepts a diagnosis or not, the disability is there, the ableism will be there, the discrimination will be there and so our charge has to be how we can transform our systems to reduce the harm of ableism from our policies and our practices. I know that there have been several members of IACC who've been waiting to comment or ask questions.

DR. DANIELS: This is a great discussion among the panelists here, but we'll take a question from Scott Robertson.

DR. ROBERTSON: Yeah, thanks Susan and thank you everybody. I just find it very valuable in terms of the discussions and the presentation and the social justice related issues and intersectionality on race and ethnicity. It really aligns with the priorities we have for diversity, equity, inclusion, accessibility here in the federal government, what agencies have been doing right now and it's very helpful to hear more insight from research practice and advocacy in this space. We've made a big priority, for instance, here at the Department of Labor on our employment for autism and REYAAS project: Research support services for Employment of Young Adults in Autism Spectrum to make sure there is a priority on intersectionality of race, ethnicity, gender, gender identity, sexual orientation, socioeconomic status, access and support, needs, et cetera, in terms of diversity there. What I'm wondering is on the workforce end of things. I know that in the presentations it mentioned lack of educator diversity, lack of diversity in the workforce in terms of for supports and services for empowering greater access and support needs and services access for autistic children, adolescents and adults. Do you all have any other specific suggestions about what we could be doing on the workforce and community living end here in the government and in our partnerships and collaborations? I know that's a big ask out there, but I saw that highlighted there on the workforce diversity and I just wondered if there's something else that we could be doing maybe that we're not already doing or maybe say, amplify something that we're already doing. Thanks.

MX. BROWN: This is Lydia. Thank you for that question, Scott and that issue is one that I raised consistently, right? Is that we do not have that many openly disabled, let alone, specifically openly autistic people who are conducting research, specifically as PIs or co-PIs of studies about issues that directly affect us. We do not have enough disabled people who are open about being disabled, who are in positions making decisions in direct services, whether that is community-based services or not. We don't have enough people who are openly disabled who are the ones in educational leadership or who are running workforce development programs even. There are vanishingly few of us and like fully 10% of them are in the Zoom right now and that's a problem. I think your question raises, again, the same kinds of systemic issues and pipeline issues that come up around all conversations on training, apprenticeships, pre-doctoral, post-doctoral training, support in academia and mentorship and support in not just hiring, but in retention and promotion and professional development across a wide range of fields for people from all marginalized communities. I practiced special education law for a time and I know that I was one of very few openly autistic attorneys who was practicing special education law and working with students with disabilities and their families and that mattered to the clients that I worked with and to their families and yet, that's not the norm, right? I think about what I've often referred to as a plexiglass ceiling that happens in the workforce development world and this mirrors conversations around general services for people with intellectual developmental disabilities, not just for autistic people, but all people with IDD that many people who are explicitly categorized as developmentally disabled are shunted into the 4F's for jobs, which is food, flowers, filth and I always forget what the fourth one is. If someone knows, please tell me, I never remember correctly.

MR. BURKS-ABBOTT: Filing.

MX. BROWN: What is it?

MR. BURKS-ABBOTT: Filing.

MX. BROWN: Filing. That's it. Thank you. So, food, flowers, filth, and filing, right? These are referring to types of jobs that are extremely low paid and that's even for those that are not subject to 14C sub minimum wage or commensurate wage certificate holders, they're usually paid minimum or sub-minimum wage, right, and they're considered to be dead end jobs. The specific jobs that people with developmental disabilities are considered hirable for, even for some workforce development programs that are allegedly promoting supported employment or even competitive integrated employment are still shunting disabled people either to the 4Fs or if in other fields or sectors into nonetheless entry level positions of no expectation for promotion. For example, I spoke to somebody in the last few years who is an employee with developmental disabilities working for the federal government who is still being paid at one of the lowest scales. I think it was a GS7 and this person was at a GS7 pay rate for 30 years. That's a pay rate that's intended for a temporary seasonal worker or for a student trainee, again, in a temporary position, rather than to be a career position and to be paid at that same grade scale level for 30 years indicates that absolutely nobody in the agency for whom this person was hired, likely as a Schedule A special appointment authority, believe that this person was capable or deserving of any support for any promotional advancement. For those of us who do have, again, the conditional privilege of pursuing an advanced degree or any college degree at all, and pursuing a professional career path, that plexiglass ceiling still remains. Autistic journalist, Sara Luterman once commented that autistic people in DC working in policy are often not able to be advanced out of junior level positions. It is incredibly and vanishingly rare for autistic and presumably other developmentally disabled people to be considered for promotional opportunity out of junior level positions, except in self-advocacy organizations, which are led entirely by people with disabilities by definition. These disparities persist and, of course, are further exacerbated for disabled people, autistic and otherwise, who belong to other marginalized communities, especially those of us who are here speaking about the intersection of race and disability. I think about how and why autistic people are more than ever making it to doctoral training, but not to post-doctoral fellowships. We're making it to college, but not to programs that are supporting us for promotional potential. We're making it into jobs for those of us that are able to be employed and one statistic that I've encountered is that only 30% of autistic adults are actually employed full-time. So those that make it to employment, which is still more than perhaps was the case 20 years ago, are not making it to middle management let alone senior management positions. We are not considered leadership material. That is even feedback that I received at one point when pursuing a job opportunity for a senior level position was that those who were in a position to make the decision did not envision me as an organizational leader, even though I have 15 years of leadership experience and that is not a comment that likely would've been made about a peer who is non-autistic, White or male. All this to say, there are many systematic disparities at every single stage of education, training, workforce development that result in a lack of autistic and other disabled people making it through educational and training programs or staying in professional fields where they would have the opportunity to make decisions, run research, provide services that directly affect autistic people's quality of life and ability to participate in the community. I'll just end my, I'm sorry, long comment with acknowledging that, for example, even our WIOA funded programs are not primarily targeting or providing services to autistic people and people with disabilities with a view that we could be legitimate, qualified, credible candidates for positions other than junior entry level jobs.

DR. LOCKE: I'm just going to piggyback on Lydia's brilliant comments and hold up the other side of the workforce in terms of, again, once autistic people actually make it into the jobs, their jobs or their workplace, there aren't supports in place to help them succeed and so they quickly get written up, excluded from social groups. Some of those soft skills that happen on the job often really are hard to navigate and so employers, managers, support systems, how the workplace is even structured oftentimes isn't set up to support autistic people and so they get forced out or they quit because of all that mental strain, all of that burden that they have to carry. I think a lot of the things that we're naming in terms of that workforce pipeline, the onus is put on that autistic individual and that's not okay. It should be collective. It should be about supporting that person through the process that historically these things that we make them go through in terms of the interview, the resume, the cover letter, those are grounded in a lot of ableist culture, right, and so teaching them how to do those things, we can do that, but it's again, putting that onus on that autistic individual and I think that onus should be shifted a little bit or a lot to the workplaces that support those individuals and creating cultures that are really truly inclusive.

MR. BURKS-ABBOTT: Also, there's the resistance to accommodations even when they’re reasonable. There are some employers who just will resist accommodations just because they don't like the idea of doing something differently. It's interesting that during the pandemic something that disabled people have been fighting for years is the ability to work from home and work remotely became actually standard operating procedure because of the pandemic. It obviously could be done, and it's something that's very useful. It's just thinking outside the box or not having an attitudinal barrier to making an accommodation for someone.

DR. LOCKE: Even knowing what to ask for in terms of what you need to succeed at work, right? A lot of people are just so grateful for this job. They don't want to ask for all the other things that they might need to continue to thrive and climb that ladder to get promoted or even be retained.

MX. BROWN: Another issue that comes up in targeted hiring programs for autistic and other disabled people that I've witnessed time and time again is that when companies or organizations are making the so-called business case for hiring workers with disabilities, whether autistic workers or otherwise, one reason that they state that we should be hired is because we have the lowest absenteeism rates. We are most likely to show up on time, to stay loyal to a company, and to come to work. I actually find that reflective of patterns of exploitation and trauma, especially for multiply marginalized, disabled people. Why are we perhaps less likely to engage in absenteeism or to be loyal to a company? Because we're afraid we'll be discriminated against should we leave that job, because we're afraid of retaliatory discrimination on the job if we are not seen as the most reliable worker out of everybody else who is there. We shouldn't have to be subjected to exploitative and thinly veiled charity pity-based reasons to hire us in order to be able to participate in the workforce and to gain economic security.

MR. BURKS-ABBOTT: Then to not get credit for what we do, in other words, you're making me think of an experience I had when I worked at a bookstore in which because I was reliable, my supervisor always gave me the

Friday evening and Saturday shift because she knew I would be there. But on my evaluation, she gave me all average, right? Even when I said that you say, I'm great at customer service, she said, "Yeah, but you're supposed to be great at customer service. That's still average." But, anyway, you don't get credit for the work you do because, like you're saying Lydia, you get exploited. It's almost like you're expected of you.

DR. DANIELS: Thank you for those comments. If you don't mind, I'm going to skip to Hari Srinivasan because he hasn't had a lot of comments today and I saw his hand up.

MR. ISAACSON: Yes. good afternoon. Hari sent me a comment through the chat. Hari said: "This was a very meaningful and informative discussion. Thank you so much. The data and discussion helps support and pinpoint what we knew or guessed around race/female disparities in autism space. What we need now is to see real translatable action on the ground.

DR. DANIELS: Thank you for that comment.

DR. HERNANDEZ: I could not agree more and if I may, I think we're all and I'll speak for myself, but we're all tired of consultant puppet theater. They invite you, they want you to hear about it and then basically they've checked the box and onto the next.

MX. BROWN: They never follow up.

DR. HERNANDEZ: Correct.

MX. BROWN: There's no follow up.

DR. HERNANDEZ: I think we're ready for some action.

DR. DANIELS: All right, thank you. Ivanova Smith, you're next.

MS. SMITH: Hello. I'm Ivanova Smith. Thank you so much all the panelists for this wonderful discussion and for all the wonderful things you said. I'm so sorry that this is very hard to say and they all are true. One question I had was, what work is there in preventing reinstitutionalization?

There is a lot of talk about bringing back institutions and I worry that will impact the most marginalized communities first. What things are you all working on to try to prevent that? Thank you so much.

MX. BROWN: This is Lydia. Thank you for that question and for raising the urgent issue of policymakers and unfortunately political pundits pushing to bring back institutions and to put more people with disabilities into institutions. At the Autistic People of Color Fund, one of the reasons why the micro grant program, which is the core and foundation of our work is so important is because so many autistic people of color are facing potential eviction, homelessness, housing instability, and otherwise, which are all risk factors for being deemed institutionalizable and facing the risk of other people in positions of power, especially people who are not disabled, deciding that people in our community would be better served under the control of other people in an institution or institutional-like setting. Unfortunately, we are a front lines organization and we are not enough. We are not a systemic solution. The Autistic People of Color Fund micro grant program does not solve centuries, literal centuries of ableism and policies that support the belief that disabled people do not belong in public life, do not belong in the community, and do not deserve to live in the community and we are not a solution to policy proposals that seek to restrict the ability to be integrated into the community. But that type of work is so essential and remains incredibly underfunded, especially for those who are at the most risk of being targeted by abusive service providers and family members for placement in an institution and for losing legal ability to exercise autonomy and control over their own choices. Thank you for raising that.

MR. BURKS-ABBOTT: Yeah, thank you. I would say that there are things that are being done slowly. Like for instance, there is a move, like for instance in Massachusetts to pass what's called supported decision making as an alternative to guardianship to give people with disabilities more autonomy and also moving away from the traditional model of the group home there is a self-direction so that you can actually choose what agency you want to go with or you can choose what services you want. On the federal level, there are bills for instance like Bob Casey of Pennsylvania has recently introduced a bill to provide more funding for home and community based services and Sharrod Brown of Ohio reintroduced the SSI Restoration Act to actually increase the asset limit. There are things that are happening, but we need to push them forward. It's like there is a slight paradigm shift, but we need to push them forward and we need to stay active.

DR. DANIELS: I will take a question from Morenike.

MR. ISAACSON: Morenike sent me a comment through the chat. They say “there is a great deal of racism and ableism in these "communities." Misogyny is real in autism and autistic individuals need to own the fact that they have projected a lot of their experiences and their privilege into the concept of neurodiversity. Families of color have bigger concerns than person first versus identity first language and puzzle pieces. It isn't hashtag actually autistics people's place to chastise, non-autistic parents of autistic children of color. You might have good intentions, but you're actually doing more harm than good. There is a lot of learning, unlearning and humility that needs to occur among many of these individuals.” They say “additionally, why do we only exist theoretically? Where are the Black and Brown autistic people, Black and Brown autistic executive directors? Why are other organizations given grant money in six or seven figure multi-year amounts and then they subcontract with marginalized individuals for pennies? We get perpetually Jim Crowed into lifelong "advisory roles" and never given an opportunity to show what we can even do.”

MR. BURKS-ABBOTT: I definitely hear you there. I've been involved with autism organizations that will actually talk about autism or Asperger's Syndrome as a gift and even have on their website all the historical figures that may or may not have had autism, but they themselves are not going to hire an autistic person. They'll be asking corporate America to do it, but they won't do it themselves. Totally insane. That's why I'm actually impressed when I do see some organizations that actually do put their money where their mouth is and at least hire disabled people like the Institute for Community Inclusion at UMass Boston. I think the Autism Society of America has some autistics they've hired. I've found that really frustrating, almost maddening, because they won't hire an autistic person. They just won't.

MX. BROWN: This is Lydia. It is simultaneously true that the organizations that purport to be working on advocacy and breaking down barriers for our community are often not model employers, but we also should not be siloed into only working in autism and disability related advocacy. There are many of us who are passionate about working in this field. I am clearly one of them. I am here, many of my colleagues here are as well, but our only career path -- this should not be our only available career path to escape the 4Fs.

MR. BURKS-ABBOTT: Yeah. Even the parts of the economy that are interested in hiring us that are like in the private sector, they shouldn't always be tech or finance. Why aren't newspapers interested or publishing companies or basically the whole economy? Everyone should be interested in hiring us because we have all different types of skills and abilities. We're not all the same.

DR. DANIELS: Thank you. We'll take a

question from Dena Gassner.

MS. GASSNER: I just wanted to thank Jill for her statement when she says that people don't even know what to ask for. This goes back to what Dr. Hernandez and I have been talking about in regard to intensive intervention support at the time of diagnosis, right? We as autistic adults are so busy trying to conform that no one has ever sat us down and helped us explore how we experience autism and in turn what accommodations could be helpful. All of that responsibility falls on the autistic individual for change and what we really need to do is transform our workplace environments and spend much more time making these environments more neurodiversity-friendly, neurodiversity savvy, and supportive from everything from the environment to the hiring procedures. I did want to say too that Lydia brought up Schedule A hiring. That system itself is inaccessible like many of these systems that it's still fraught with administrative burden, a lot of passwords and a lot of presumed cognitive capacities, so we really need to break down these barriers. Lastly to Camille, you're totally right. We are not always culturally savvy about why things aren't working in your community. I want to know what we can do as a research community to make sure we're researching the phenomenon that you're describing, Camille or other phenomenon that come from within the community that we need to help close that gap, and it starts with leadership like yours.

DR. LOCKE: Thanks Dena for sharing those comments. I just wanted to add one more thing that I did not say and I think we alluded to earlier today or I heard on the meeting earlier, but this issue of masking, which happens a lot among autistic women and just an anecdote that popped in my head from an experience I had a few weeks ago with a young Black autistic woman. She was reflecting on her high school experiences. She is now a young adult looking for employment, but sometimes when we ask about what do you need to be successful in the moment, the autistic person can't answer that. They need some time to process and think. What she was sharing with me is that they asked her that in high school when she had her 504 plan meeting and there were like six pairs of eyes on her just waiting for her to speak and then she just couldn't articulate in the moment those necessary accommodations and supports that she needed and she fell silent for three years because she just said one out of her six teachers even looked at her 504 plan to do something and help her with her supports, but the other five teachers didn't and she felt so much pressure to name the thing that she needed because she couldn't figure out in that moment what she needed. I think that's something that happens a lot in terms of like, we thought to ask, you didn't say anything, we're not going to provide those supports and so that happens not just in schools, but also in the workplace as well. Thanks Dena for that comment.

DR. DANIELS: Great. I have a comment from Morenike. She just wanted to make a couple of corrections in what was in her comment that came in through Steven, Send Comments Here. “It was meant to be Black and Brown principal investigators, and not people. And misogynoir not misogyny.” So a combination of misogyny and people of color. “Also it is not non-people of color, hashtag actually autistic people's place to chastise.” Just they wanted the comments made here in the room. I would like to have the privilege of just asking you a final comment. What would you like to tell members of our committee, whether in federal agencies or in private organizations that are sitting around our table that you would like to see happen and things that they might be able to actually take action on, either individually in their own agencies or at their organization, or collectively as a committee?

MX. LYDIA BROWN: This is Lydia. I know that I've taken up a fair amount of airtime today, so I'm going to try to keep this very brief, but the caveat being that as an autistic person with ADD, brevity is not my strong point. I apologize for that. I do believe that we need much more sustained funding to support the leadership and leadership development of autistic people who come from specific marginalized communities or have had specific marginalized experiences that continue to be sidelined and to be removed even from conversations like the one that we've had today. Specifically, I'm thinking about the many people connected to the Autistic People of Color Fund who have been incarcerated in jails or prisons. The many autistic people who are struggling with addiction to alcohol and other substances. The many autistic people of color who have experienced or are currently homeless either because of short term homelessness or who are chronically homeless. The autistic people of color who are deeply committed to advocacy work, but who are not affiliated with an organization and do not have the resources or the institutional support to form a project that may be covered in the news or invited to participate in a meeting like this one. The autistic people of color who do not speak English at all, either in writing or out loud. Autistic people of color in deaf and deaf-blind communities who communicate through home sign or highly localized sign dialects. The autistic people of color from immigrant and refugee communities that do not speak languages that are commonly recognized within the United States. The autistic people in native and indigenous communities who are not speakers of English, who are living on tribal land, whether recognized or not by the federal government, which has continued to fail all of its treaty obligations to native and indigenous peoples that have been made over the last couple of centuries. The autistic people of color who, in other words, continue to be shut out of and not elevated even in conversations that are ostensibly about bringing in people from the margins. I say this very keenly aware, again, of all of our own conditional privilege of being able to participate in this conversation today, of being able to communicate in writing or verbally with each of you today and we do not speak for every single person in all of our communities, but it is our responsibility and a serious responsibility at that, to call forward, to bear witness and to lift up the work, the lives, the experiences, and the wisdom of all of the autistic people who are not able to be present today, who are not part of this conversation currently, but who should be in the future. This goes for programmatic goals and outcomes across all of the agencies that are represented. In our workforce development programs, where are the workforce development programs that are supporting autistic people who are returning to the community from jail or prison? When we're thinking about education in primary, secondary, or post-secondary education, how are we supporting autistic people that are returning to complete an apprenticeship, a technical degree, or a research-based degree who were not supported, who received a certificate instead of a high school diploma, who received a GED, who were forced out of numerous community college or four-year university programs before being able to pursue their degree. When we're thinking about healthcare and delivery of health services, how are we specifically supporting the larger proportion of autistic people within the transgender community who are continually deprived of access to culturally responsive and gender supportive and affirming care? When we're thinking about ways to ensure that autistic people are able to attain economic security, are we considering the impact of asset and income limits on autistic people who are also family caregivers who are working multiple jobs and who are trapped between the rock and a hard place of not making enough income to be able to pay for their own services, but making too much income or having the capacity to earn too much income to qualify for federally funded or subsidized services? This is just a tip of the iceberg. I could literally keep talking about this for hours, I will not do that. But thank you for that question, Susan.

DR. DANIELS: Thank you. Yes, and I'd like to just hear from each person on the panel.

MR. BURKS-ABBOTT: I guess if I had anything specific, one is that I would say that you guys can be the leader either as individual organizations or as a committee because in essence, you're so close to this work. In essence, you have the expertise. You could actually show the rest of the world, the rest of the country, the rest of society how it should be done, the best practices. If you realize there is something that needs to be done, do hire some people with on the autism spectrum or people of color, do institute the programs that Lydia was suggesting. Do that, show best practices. I would also suggest that, and I saw this actually this morning when you were coming up with the public comment, to submit to the medical school, graduation board. In other words, do that, be more actively engaged in public policy and legislation like some of the bills that I mentioned that are on Capitol Hill. Advocate for those bills, join with other organizations like the ARC of the United States or the Autism Society that are also going to be advocating for those bills or the AUCD, the Association of University Centers on Disability to actually put your weight behind legislation and public policy that could actually move us forward. I guess that'll be my advice.

DR. HERNANDEZ: I'll go next. I would say not be afraid of change, not be afraid to challenge yourselves, your systems, the status quo, the way that we've always done things, also be more accessible. It shouldn't take special invites, special meetings, special pathways to be accessible to people, to hear their stories, hear their situations. I think also to get out of the silo mentality and territorial and a mentality that has always loomed around a lot of these systems. I think we are definitely headed in the right direction and making active strides to really have people with these types of lived experience with these hearts and minds on committees on projects in research. I think we've also come to realize that the way that the systems have been structured have been doing more harm than good and so I would just say be accessible, be open and get out of your own way.

MS. PROCTOR: I would just say be more considerate.

DR. JILL LOCKE: I think for me from the research perspective, I think as funders on the call, you should really think about how to include that race and ethnicity question and require it even among the people that you fund or the research that you do fund because, again, oftentimes that variable is ignored and not published on. I also think, again, there's been some movement of including self-advocates in research, but I think a lot of times some of the research that's out there, and forgive me for saying this, it's for show and that those voices often aren't included or incorporated into the research and really valued as part, again, given a seat at the table in terms of their input. I also think a lot about how we rethink some of our partnerships and so focusing a lot on more community partnered research, so thinking about how we might partner with organizations like Camille's or Lydia's in research so we can support the funding of their organizations, but also elevate their work. Because the sad truth from an academics perspective, it's the grant dollars and the publications that you get scored on or evaluated on and so if we can elevate the voices of the people that are actually doing this work and partner with them. I was thinking a lot about what Lydia was saying when they were talking and they clearly articulated so many really awesome research questions that really would make an impact in terms of the service access and delivery in the system. I think more partnerships in the research world, and, again, if you're writing a funding mechanism or PAR or something, including that as a requirement would be awesome. Going back to something someone else had said earlier about having more BIPOC researchers, that's also something that I think some of the funding mechanisms can call out. If you are elevating a junior scientist or a researcher of color or trainees of color, that's all really important to build that workforce for the research side. That's the only side that I think I can speak of. Sorry, I'm still recovering from a lingering cold from all these young children.

DR. MAGANA: Again, just to build on some of the things that Jill talked about in terms of funders of research. First of all, we do have to fund more lifespan research in general, right? The majority of dollars still go into biological research, so being able to understand not only children, but adults and people who are going through aging process that are autistic and have IDDs, but then making sure that you're narrowing in on different BIPOC communities within that research. I do strongly think it's important to do studies with particular populations, whether it's cultural adaptation projects, they've done a better job at that in the mental health field than they have in our field, so really focusing on these communities and what they need and what they want and then of course what Jill said about the workforce. I think there are some agencies that are doing a better job than others at identifying who is in the workforce. I talked about NIDILRR how they not only require you in your proposal to indicate who is your team and what their identities are and including people with disabilities, making sure that people with disabilities are researchers in addition to racial ethnic minorities and then they want you to identify how are you going to recruit them for positions that you haven't hired yet, how are you going to recruit diverse folks for those? So there are ways that different agencies can borrow from each other maybe in some of those practices.

DR. BOYD: I'll just say, and I think first, some of these issues like structural racism, racial equity, health equity can feel like big issues that can prevent people from taking action, but these issues are big issues that require some big funding. We have to think about mechanisms a little bit differently to address structural racism, right? That is a different landscape of research and if we really want to change things, it makes us have to think about and envision research and how it gets funded a little bit differently and all the researchers are in agreement a little bit. Community partner research is really important, but if we really want to meaningfully include our community partners, we have to have mechanisms in place to really support and fund them. Current grants where we're trying to fund the research team, but also a community partner, it feels more tokenistic simply because we don't have the funds to really support the work that they're doing. Camille and I have been trying to do community partner research, but I think of Camille as a true partner and I want to think about how we can support the work her organization is doing. Thinking about it differently if we're going to move down this pathway of community partnered research, how are we putting mechanisms in place to really treat them, to be able to treat them as partners in that process. I think that's the other thing. It's not just the amount of funding though, it's the kinds of research questions that are being asked. With all of our identities, there are things that lead to risk, but there are also lots of things that lead to resilience and so also understanding the cultural assets and cultural wealth of marginalized communities so that we are thinking about protective mechanisms that are in place like Gyasi brought up something that his mother had him read about being Black and what that meant. While we know from research that cultural and racial socialization practices are a protective mechanism, we don't know about that enough in autism. The kinds of questions we should be asking to really advance research on racial and ethnic communities and so it's not just the amount of money, but it's the questions that are being asked and who is asking them and so that does relate to the broader issue of creating a workforce of researchers and others who are more diverse in all kinds of ways. Neurodiverse, racial and ethnically diverse, gender diverse. I think really that will help lead to asking some of these important questions, but also help us think about how we are addressing some of these more complex issues around equity and structural racism.

MR. BURKS-ABBOTT: I guess I wanted to address the funding piece because one thing, the funding piece is actually part of the problem of the racism. In other words, one reason why there is so little funding is because for the last 40 years or so, there has been a disinvestment in the government, so we need to fight against that too.

DR. DANIELS: Thank you all for those wonderful comments and this really robust and interactive discussion. We really enjoyed hearing from all of you and you had some incredible points to share with us. We really appreciate your presence with us and I appreciate this last bit where you also shared some of your take home messages for people on our committee. Thank you so much.

Shelli, I don't know if you'd like to comment as well.

DR. AVENEVOLI: Thanks so much, Susan. I just want to once again thank all of the speakers, all of the panelists, everyone who had an opportunity to present today, we really appreciate that. I also want to thank the whole committee for your engagement, your good questions, your good thoughts, your recommendations throughout the day to make the committee more proactive and impactful in the bigger sense of the word. I want to thank Susan and her office for organizing the meeting and doing such a great job at organizing and moderating. Again, thank you. It's been my pleasure to be part of this today.

DR. DANIELS: Thank you.

MR. BURKS-ABBOTT: Thank you.

DR. DANIELS: Well, thanks to everyone who participated in this session, and we just have a few minutes to wrap up the meeting and we're going to go to a round robin session.

You'll see that in your packets, you have a round robin packet where members of our committee shared updates from around the federal agencies and private organizations and individuals as well. We have a few minutes if anyone wants to speak about their updates or even if you didn't contribute to the packet, and if you have an update, we can hear your updates at this time. Is there anyone that would like to verbally share an update in the comments? I see that Morenike has one but needs a moment.

DR. AVENEVOLI: You have two hands. Alison is first, Susan.

DR. DANIELS: Oh, thank you. All right, thank you. Alison?

DR. MARVIN: Yeah. Hi. This is Alison from Social Security. We don't got much time, but I just wanted to draw attention to the ARDRAW grant administrative opening. We're posting the solicitation for the new grant administrator for the ARDRAW: Analyzing Relationships between Disability

Rehabilitation And Work small grant program. It's due to come out this month or May, so please look in the packet. If you are an organization that does grant administration, your university UCEDD either please take a look and apply. Thank you.

DR. DANIELS: Thank you, Alison. Judith Cooper.

DR. COOPER: Hi, good afternoon. I represent NIDCD along with Dr. Tucci. I did just want to mention that in January NIDCD sponsored a webinar, minimally verbal non-speaking individuals with autism research directions for interventions to promote language and communication and one of our own IACC members Dr. Helen Tager-Flusberg was one of the co-chairs. Anyway, we now have on our NIDCD website, a summary of the meeting, the agenda, a list of the participants, and some of the participants suggested publications and you can get it right on the nidcd.nih.gov website. I want to mention that we are continuing to address the research needs of minimally verbal, non-speaking individuals. In fact, yesterday in record speed, NIDCD notice of significant interest, a NOSI, was actually published in the NIH guide and it focuses on many of the areas that were highlighted at the webinar. I also want to point out that since the webinar, NIDCD has met with minimally verbal non-speaking individuals as well as agencies that serve them, and we're going to continue to do so. Finally, we will keep everybody informed about any future funding opportunities that are focused on this population. Thank you, Susan.

DR. DANIELS: Thank you, Judith. The video is available for people to watch the meeting as well, right?

DR. COOPER: Absolutely, both days.

DR. DANIELS: Wonderful. It's in the round robin packet. It's also in the events section on our website if you're looking for it. Thank you. Amanda Reichard.

DR. REICHARD: Hi. I just wanted to point out that, and you may have gotten it in your email today, but maybe not, NIDILRR is mandated by Congress to come up with a long range plan and our long range plan spans five years. For the past year, NIDILRR initiated the development of the new long range plan for 2024 to 2028 and our director was great about going out and making sure she got input from the field and from all sorts of stakeholders. Now based on that feedback NIDILRR has finalized the direction for the new long range plan, so they will be holding a webinar on, let me get the date right. I'm not seeing the date right now. That's silly. I can send the information. I believe it's on April 16th, but you do need to register for the webinar if you want to attend, but they will be presenting the key themes and priorities for the new long range plan and these impact and steer where the money is offered for disability related research. Thank you.

DR. DANIELS: Thank you. If you have an

updated link or something to send us, we can add it into the round robin packet after this.

DR. REICHARD: Oh, great. Thank you.

DR. DANIELS: Next I will go to Scott Robertson.

DR. ROBERTSON: Yeah, thanks Susan. I know we have a few updates for Office of Disability Employment Policy at DOL in the updates. I just wanted to spotlight just a couple in here. One is the Job Accommodation Network. Many folks are familiar with JAN as jan.org has like a webinar training session that's coming up on April 13th. That's a week from this coming Thursday at two o'clock. There's a registration link in that update’s listing in terms of the bullet points we have in there, in terms of updates. It's free, again, at two o'clock on April 13th. On the neurodiversity also and the apprenticeship has come up by happenstance a number of times so I think some folks know that we have a project on inclusive apprenticeship called the Partnership on Inclusive Apprenticeship, inclusiveapprenticeship.org. Maybe to shameless self plug a little bit that the latest podcast episode on neurodiversity features myself actually discussing the intersection on neurodiversity, including autism and access to apprenticeships with support systems and services for success to support career pathways for folks, fields, and job areas that fit skills counts and strength areas. You can find the link there in the packet, but it's inclusiveapprenticeship.org is the main website for that project. Again, happy national autism month. I just think it was really exciting today in terms of discussions we had, so thank you Susan and everybody else in terms of who orchestrates these sessions and keeps us all in order and also for that statement in terms of the drafting for that, like that was especially great and I appreciate that. This was a very, very valuable discussion we had today. Thanks.

DR. DANIELS: Thank you so much. I'm going to read a comment from Morenike. This is an announcement about a partnership between University of Pittsburgh ACE Center, Howard University, Foundations for Divergent Minds, Color of Autism, and Autistic Women and Non-binary Network and they're hosting a free online event, suffering in silence, suicidality in neurodiverse communities of color on Friday, April 28th from 12:00 to 01:30 PM Eastern. It's going to be a webinar coordinated by researchers, self-advocates, parents and clinical experts in autism crisis support and suicide. We can add this event into the round robin document and also put it up on our website so that people can access it and you're welcome to attend that. Thank you Morenike. Next, JaLynn.

MS. PRINCE: Thank you. This has been an excellent meeting today, an extremely informative. Kudos to all of you for putting this together and for the excellent presentations. I wanted to mention that April

21st has been declared in Congress as Autism After 21 Day. Madison House Autism Foundation has been instrumental in working on that for the last 20 years, trying to promote information within communities about adult autism. We will be having our annual breakfast. We are fortunate to have Dr. Daniels who will be with us and will be sharing her interviews with some of the artists that she has been working with this month. Our breakfasts are for thought leaders because we have figured that we need to educate, especially our newly elected officials so they understand that they have constituencies that are in need of their understanding and their efforts in putting people into policy and into all of the thinking that they make in the community. We have seen a lot of movement forward. We're very community based in trying to see what we can do in communities and we are working on a pilot program across the country, on the other side of the country, with numerous communities and organizations in doing such. We will have a new documentary and we do many documentaries, so people who may not feel comfortable in being in crowds can also have their voice heard and that people can see who they are and understand their stories. We also continue to work in the national program on mental health, but remember Autism After 21 Day on Friday this year and think about the adults in your life that are on the spectrum. Thank you.

DR. DANIELS: Thank you, JaLynn. Your event is also in our round robin packet. I will also just throw in a plug again for our event that's going to be on April 14th. Everyone is welcome. I don't think I put in a slide here at the end for that, but check it out on our website. It's on the carousel that rotates on our website if you go there, and it's sure to be a really exciting event. In terms of our action items, my slides are here and I just need the control. There we go. Our next full committee meeting of the IACC is in

October, 2023, and we are hoping that we will be hybrid, but we also have the possibility being virtual if we don't have the room available. We'll keep you posted on that. Check the IACC website for meeting information and updates and, of course, I will be emailing you about that as well. I guess the other piece is that in terms of action items going out, we'll be communicating with you about the summary of advances and the co-occurring conditions document in the interim between now and the next meeting. We don't have a lot of items since you've finished the strategic plan successfully and we'll share with you any updates on published materials. Shelli, do you have any final words for the group today?

DR. AVENEVOLI: Thanks, Susan. I'll just say again I'm echoing my earlier comments, thank you all so much for your participation. It was a very informative set of discussions today. I think we all benefit from hearing the perspectives and trying to think forward about how we can make change. Thank you again for your participation and thanks again to Susan and her office as she is showing on this last slide. It's really quite a feat to pull these meetings off particularly online and I think they always do a fantastic job.

DR. DANIELS: Thank you. Yes, thank you to the team that supported us today, the Office of Autism Research Coordination, as well as Rose Li and Associates and the Center for Information Technology at NIH that supports NIH Videocast. We really appreciate your support and a wonderful way for us to recognize this special month. We hope that you all have a wonderful rest of your day, and we look forward to being in touch. Take care. Thank you and bye-bye.

(Whereupon, at 4:58 p.m., the Subcommittee adjourned.)