INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JANUARY 18, 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, 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

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

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

NAKELA COOK, M.D., M.P.H., Patient-Centered Outcomes Research Institute (PCORI)

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

PRESENT: (continued)

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

AISHA DICKERSON, Ph.D., Johns Hopkins University

REBECCA DZUBOW, M.P.H., U.S. Environmental Protection Agency (EPA)

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

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

DAYANA J. GARCIA, M.Ed., Administration for Children and Families (ACF)

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

KRISTINA HARDY, Ph.D.,National Institute of Neurological Disorders and Stroke

CRAIG JOHNSON, Champions Foundation

JENNIFER JOHNSON, Ed.D., Administration Community Living (ACL)

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)

PRESENT: (continued)

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

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, M.A., 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., University of Wisconsin-Madison

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

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

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

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

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

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

IVANOVA SMITH, B.A., University of Washington

MARTINE SOLAGES, M.D., U.S. Food and Drug Administration (FDA)

MATTHEW SIEGEL, M.D., Tufts University

PRESENT: (continued)

HARI SRINIVASAN, University of California, Berkeley)

JODIE SUMERACKI, B.A., Centers for Medicare and Medicaid Services (CMS

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

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

ANNA TSCHIFFELY, Ph.D., U.S. Department of Defense (DoD)

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

MEGHAN WARREN, Ph.D., M.P.H., PT, PCORI

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

STEPHEN WHITLOW, J.D., Merakey

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

TARYN MACKENZIE WILLIAMS, M.A., U.S. Department of Labor

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome, everybody, to this meeting of the Interagency Autism Coordinating Committee. I'm JOSHUA GORDON and the Director of the U.S. National Institute of Mental Health and Chair of the IACC. And I'm joined, of course, by Dr. Susan Daniels as Director of the Office of Autism Research Coordination, Acting National Autism Coordinator and, the purpose of this meeting, the Executive Secretary of the IACC.

I want to welcome all our Committee members who are joining us today and ask them please to turn on their videos and make sure that they are viewable for the public that is joining us today on the videocast of this meeting. We have a busy day today and I want to remind you of our virtual meeting etiquette before we get started. Please keep your microphones off unless you are speaking. Please do keep your cameras on when we're meeting as a whole, but you may leave them off if for some reason you need to. But, if you can, please leave them on. During presentations, we do encourage you to leave them off so that people can see the presenting speaker. But during our discussions it would be great if we can be as if we are in the same room together. During discussion, because there are so many of us, we please ask you to keep your comments brief, and I'm going to apologize in advance if I cut you off to try to make sure that other members of the Committee have an opportunity to speak. Do try to keep those brief so that I don't have to do that. For Committee members that would like to make a comment and have it read aloud, please send the text of your comment via the Zoom chat function to the staff member listed under the category of “Send Comments Here”. I'm looking for it now in the chat and I'm not sure someone's got that name. I don't see it popping up. Yeah, there it is. “Send Comments Here” is listed as a co-host. That's where you can send your comments if you prefer to type it in. When it's your turn to be recognized, the OARC staff member will read your comment to the group. Mr. Steven Isaacson from the OARC team will be reading those member comments sent through the Zoom chat. As usual, if you do want to speak, please raise your hand using the “Raise Hand” function under the Reactions button on Zoom. If for whatever reason that fails, just send a chat -- again to that “Send Comments Here” -- indicating that you'd like to make a comment but you're having trouble raising your hand. Finally, for those of you who are on videocast or on Zoom and would like it, there is closed captioning that is available for the Zoom. I think you do it under the “Live Transcript” -- Yes, you do it under the “Live Transcript” function at the bottom of your window, and on videocast just look for the way to enable closed captioning.

With those virtual meeting etiquette points brought up, I'm going to go ahead and start the meeting with some Committee member updates. We'd like to welcome Dr. Karyl

Rattay. I hope I'm getting that right. Karyl, can you speak up if I'm getting that wrong or maybe just speak up anyway so we get to see your face.

DR. KARYL RATTAY: Good morning everyone and thank you so much. Dr. Karyl Rattay is my name and I'm really thrilled to be a part of this Committee.

DR. GORDON: Well, thank you for joining us. You're our new representative from the Centers for Disease Control. Dr. Rattay is the Director of the Division of Human Development and Disability in the National Center on Birth Defects and Developmental Disabilities. She's replacing Dr. Georgina Peacock who served on the IACC for about a year before being assigned to new duties at the CDC. Dr. Stuart Shapira, who has long been an active member of this group, will continue to serve as the alternate for CDC. I want to thank you all for your service to the IACC. Do you want to say anything else to introduce yourself at this point, Dr. Rattay?

DR. RATTAY: Just a little bit of background. I am a pediatrician by background, but I've been working in public health for about 23 years now in a combination of federal governments and then for a children's health system. The last 13 years I've been Delaware's state health official and am really thrilled to be at the CDC and really focusing in on some work that I'm very passionate about. Excited to learn from you all and hopefully contribute as well. Thank you.

DR. GORDON: Great. Well, thank you and welcome. I also want to welcome back to this group Dr. Walter Koroshetz as the representative from the National Institute on Neurologic Disease and Stroke, or NINDS, one of NIMH’s closest partners at the National Institutes of Health. Dr. Koroshetz is the NINDS Director and has served for many years as an IACC member in his previous incarnation. He is most recently serving as the alternate to Dr. Nina Shore, the Deputy

Director of NINDS, but Dr. Shore’s is a new position at NIH and so Dr. Koroshetz will be the official IACC member. I believe – there he is --

DR. WALTER KOROSHETZ: Very happy to be here. Yes. It's been a fantastic Committee for many years and happy to help in any way.

DR. GORDON: We're glad to have you and we do have an alternate as well for NINDS, Dr. Kristi Hardy, who will be filling in when and if Dr. Koroshetz is unable to join us. Well, thank you, both of our new members.

With that, I want to just make a few remarks about today's meeting. We're looking forward to some very exciting presentations and discussion. We're going to start the morning off with some welcoming remarks from Dr. Daniels and then a report from her in her capacities as the Acting National Autism Coordinator. Then we're going to be conducting IACC Committee business with two important items to cover today -- hopefully, finalization of the IACC strategic plan as well as the discussion of the IACC Summary of Advances for 2022, in which, as you'll remember, we highlight articles, papers, reports of note for inclusion in a report to Congress. Then, in the afternoon after our lunch break, we're going to hear public comments and have a discussion about supportive services for autistic individuals. Finally, we'll hear a presentation -- I'm very excited about this -- from Dr. Nakela Cook and Dr. Meghan Warren from the Patient-Centered Outcomes Research Institute on their intellectual and developmental disability research programs and projects. I'm particularly excited about that because PCORI -- the Patient Centered Outcomes Research Institute, PCORI -- is tasked with doing comparative efficacy and other kinds of trials that many in the IACC would like to see expanded and has recently become more engaged and interested in expanding their own efforts in the developmental disability and autism arena. That's the agenda for today.

With that, I'm going to turn it over to SUSAN for some welcoming remarks and other announcements. SUSAN.

DR. SUSAN DANIELS: Wonderful. Thank you, Dr. Gordon. Welcome to everyone to our first meeting of 2023 and welcome to our new members and returning member, Dr. Koroshetz, to the IACC. We're looking forward to today working on the strategic plan, the Summary of Advances, and hearing some of these speakers we have, as well as the services session. At this point I will do attendance. We haven't been doing attendance regularly on Zoom because we can electronically track it, but for the benefit of our audience, so that you just know who's here, I'm going to go through this quickly. Dr. Joshua Gordon? Yes?

DR. GORDON: Here.

DR. DANIELS: Wonderful. Skye Bass from the Indian Health Service? Dr. Diana Bianchi?

MS. ALICE KAU: Alice Kau is sitting in for Dr. Bianchi. Here.

DR. DANIELS: Thank you, Alice. Dr. Anita

Everett?

MR. MITCHELL BERGER: Mitchell Berger sitting in for Dr. Everett.

DR. DANIELS: Thank you, Mitchell. Dr. Tiffany Farchione?

DR. TIFFANY FARCHIONE: Hi, Tiffany Farchione, FDA.

DR. DANIELS: Thank you. Yes. If you all can say your agency when I go through your names, that would be great and welcome to turn on your camera and say hello to everybody. Maria Fryer?

MS. MARIA FRYER: Reporting, here, Department Bureau of Justice Assistance.

DR. DANIELS: Thank you. Diana Garcia? Diana may be joining us. Oh, no, she is not able to attend today. Sorry. Elaine Hobble?

MS. REBECCA DZUBOW: Hi. This is Rebecca Dzubow filling in for Elaine from EPA.

DR. DANIELS: Thank you. Jennifer Johnson?

DR. JENNIFER JOHNSON: Here.

DR. DANIELS: Walter Koroshetz? We just

saw Walter a minute ago. He is here.

DR. WALTER KOROSHETZ: I'm here, here I am.

DR. DANIELS: Dr. Leah Lozier?

DR. LEAH LOZIER: Good morning. I'm with Housing and Urban Development.

DR. DANIELS: Thank you. Dr Alison Marvin?

DR. ALISON MARVIN: Good morning. I'm with SSA.

DR. DANIELS: Dr. Matthew Miller, or, actually, Scott Patterson?

DR. SCOTT PATTERSON: Scott Patterson sitting in for Matt Miller from Department of Veterans Affairs.

DR. DANIELS: Thank you. Kamila Mistry is not able to join us from AHRQ. I don t know if Justin Mills is here, but she had an emergency this morning and may join us later. Lauren Ramos?

MS. LAUREN RAMOS: Good morning. I'm here from the Health Resources and Services Administration.

DR. DANIELS: Thank you. Jodie Sumeracki?

MS. JODIE SUMERACKI: Morning. Here from Centers for Medicare and Medicaid Services.

DR. DANIELS: Courtney Acklin? Dr. Acklin might be joining us a little bit later. Dr. Debara Tucci?

DR. DEBARA TUCCI: Yes. Hello. I'm here for the National Institute on Deafness and Other Communication Disorders at NIH. Judith Cooper -- or the alternate, our Deputy Director -- is also here.

DR. DANIELS: Thank you. Dr Larry Wexler?

DR. LARRY WEXLER: Here. Larry Wexler, U.S. Department of Education, Office of Special Education Programs. Good morning.

DR. DANIELS: Good morning. Dr Nicole Williams?

DR. NICOLE WILLIAMS: Hi, Nicole Williams with the Autism Research Program under the Department of Defense.

DR. DANIELS: Thank you. Dr. Taryn Mackenzie Williams -- or Scott Robertson?

DR. SCOTT MICHAEL ROBERTSON: Dr. Scott

Michael Robertson here with the Office of Disability Employment Policy and the U.S. Department of Labor.

DR. DANIELS: Thank you. Dr. Cindy Lawler?

DR. CINDY LAWLER: Hi. Good morning. I'm representing the National Institute of Environmental Health Sciences.

DR. DANIELS: Thank you. Now I'll go through the public member list. Dr. Maria Mercedes Avila?

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

DR. DANIELS: Thank you. Dr. Alice Carter?

DR. ALICE CARTER: Good morning. Nice to see you all.

DR. DANIELS: Sam Crane? Sam might be joining us later.

MS. SAM CRANE: Hi, sorry. I just had to get off of -- and everything. I'm Sam Crane from Quality Trust for Individuals with Disabilities.

DR. DANIELS: Thank you. Dr. Aisha Dickerson?

DR. AISHA DICKERSON: Good morning, I'm present from the Johns Hopkins Bloomberg School of Public Health.

DR. DANIELS: Thank you. Dena Gassner?

MS. DENA GASSNER: Dena Gassner. I'm a member for the public grouping and I'm a professor at Towson University. I'm also the co-chair of the INSAR autistic researchers group. Thank you. Good morning, everyone.

DR. DANIELS: Thank you. Morénike Giwa Onaiwu? And, I have a note here. She will be joining us this afternoon. Dr. Alycia Halladay?

DR. ALYCIA HALLADAY: Hi, everybody. I'm Alycia Halladay from the Autism Science Foundation.

DR. DANIELS: Craig Johnson?

MR. CRAIG JOHNSON: I am Craig Johnson and representing Champions Foundation for Special Needs.

DR. DANIELS: Thank you. Yetta Myrick?

MS. YETTA MYRICK: Happy Wednesday, everyone, Yetta Myrick here from D.C. Autism Parents. I'm a parent and an advocate.

DR. DANIELS: Thank you. Lindsey Nebeker?

MS. LINDSEY NEBEKER: Here. Hi. Good morning, everyone. Hope you all are doing well.

DR. DANIELS: Good morning. Dr. Jenny Mai Phan?

DR. JENNY MAI PHAN: Good morning, everybody. I'm Jenny Mai Phan, a parent, self advocate and a researcher at Children's National Hospital in D.C.

DR. DANIELS: Thank you. Dr. Joseph Piven?

DR. JOSEPH PIVEN: Good morning. I’m from the University of North Carolina.

DR. DANIELS: Thank you. JaLynn Prince? JaLynn may be joining us late – she may be joining us later. Dr. Susan Rivera?

DR. SUSAN RIVERA: Good morning. Susan Rivera from the University of Maryland. I’m a researcher and Dean at UMD.

DR. DANIELS: Thank you. Dr. Matthew Siegel? And if he's not here, I believe he's joining us later. Ivanova Smith?

MS. IVANOVA SMITH: This is Ivanova Smith, a self-advocate.

DR. DANIELS: Thank you. Hari Srinivasan? And I saw Hari a minute ago.

MS. HARI SRINIVASAN: I'm a self-advocate on various autism boards and PAHD neuroscience student at Vanderbilt doing autism research.

DR. DANIELS: Thank you, Hari. Dr. Helen Tager-Flusberg?

DR. HELEN TAGER-FLUSBERG: Hi, good morning from Boston University, Center for Autism Research Excellence.

DR. DANIELS: Thank you. Dr. Julie Lounds Taylor?

DR. JULIE LOUNDS TAYLOR: Good morning, everyone. Julie Taylor from Vanderbilt University Medical Center.

DR. DANIELS: Thank you. Dr. Paul Wang?

DR. PAUL WANG: Hi. Good morning from the

Simons Foundation.

DR. DANIELS: And finally, Steven Whitlow.

MR. STEVEN WHITLOW: Good morning. I’m Steven Whitlow. I’m a parent but also have been involved in various autism projects, particularly within the transition area.

DR. DANIELS: Thank you and we really appreciate the great attendance today – the full house – and we do look forward to the day that we’ll meet in person. We hope that day is coming soon. That is our roster of people who are here today. You’ll be seeing people pop up throughout the day during our discussions.

We also would like to take a moment now to continue with the approval of the minutes from October. On our website, we posted the draft minutes from the October meeting. I wanted to ask if there’s any discussion of the minutes. Is there anything that anyone wanted to share or any corrections? If there’s no further discussion, can I get a motion on the floor to approve the minutes?

DR. RIVERA: I'll move –

MS. MYRICK: This is Yetta Myrick, I can second. Go ahead, Susan. This is Yetta, I'll second.

DR. DANIELS: Thank you, Yetta. All in favor can you please raise your hand in Zoom? Our staff will take note of the raised hands. Thank you. You can lower your hands. Anyone – oh – I'll let you lower all those hands. Great. Thank you. Is there anyone who's opposed to accepting the minutes? You can raise your hand if you are. I don't see any. Is there anyone who'd like to abstain from accepting the minutes? I believe it's unanimous in favor of accepting the minutes, so thank you so much. The motion carries to accept the minutes and we will post the finalized minutes to the website. So we really appreciate that.

Now I believe we can move on to the National Autism Coordinator Update. This is my update that I usually give to the IACC.

It’ll help you understand some of the larger events that are going on around the government and around our nation and around the world that may be impactful for our Committee and the things that we're thinking about doing as activities for the IACC.

I have a few non-federal government updates to share with you. One is that I wanted to point out to you that the International Society for Autism Research recently put out a new policy brief on the criminal justice system. I wanted to flag this for you. Those who may be interested in this topic, it’s a very nice, concise policy brief with a lot of wonderful references. When you see the slides posted on the IACC website afterwards you can access the document on the link that’s provided on the slide. Next, mentioning PCORI will be speaking with us this afternoon. I wanted to point out that they have recently made a four million dollar award to evaluate mental health interventions for autistic adults. I’m sure they’re going to be sharing something about that with us this afternoon. I wanted to share that with you and the press release is on this slide.

Also in December, it was the International Day of Persons with Disabilities. The UN Secretary General made a statement in which he talked about the role of innovation and technology in achieving an accessible and equitable world, and also stated that the cornerstone of this public-private partnership toward technology and innovation involve the active participation of people with disabilities in their full diversity and their full inclusion in all decision-making processes. We also have a link for you to the United Nations Disability Inclusion Strategy.

In addition, as a part of that same celebration, that WHO launched a global report on health equity for persons with disabilities, and we have this report available for you as well and so you may want to check that out.

Then I have a few federal updates for you, including President Biden's proclamation for the International Day of Persons with Disabilities on December 2nd. In this proclamation, he reaffirmed the administration's commitment to ensuring that people with disabilities are afforded the same opportunities, independence, and respect as everyone else in our nation, also emphasizing his administration support for equity in health care and employment, as well as disability rights and disability pride. You can read about that in the proclamation which is provided on the link.

There have been some legislative updates that are important to our work on autism. First, the newly approved Consolidated Appropriations Act of 2023 included funding for several important programs related to autism and disabilites, including CDC's Autism and Developmental Disabilities Monitoring Network, or the ADDM Network;

Department of Education’s IDEA grants for special education; DoD’s Autism Research Program; and grants under the Kevin and Avonte’s Law program; as well as Medicaid’s Money Follows the Person program that helps people move from institutions to community-based settings. In addition, the National Defense Reauthorization Act was enacted on December 23rd, and that reauthorized Kevin and Avonte’s Law, which has a program to support children with autism and developmental disabilities who wander. We included some different news articles that describe some of the specific autism interests – items from these pieces of legislation, as well as press releases.

I would also like to share with you that the Interagency Committee on Disability Research had a few new happenings. On December 2nd, they held their executive Committee meeting and heard updates from working groups. They also published a white paper on the Impact of COVID-19 on disability research, which is linked here. This was actually the updated paper. They had an initial paper and they've created an updated one, so both are linked from this slide.

With the RAISE Family Caregiving Advisory Council, as I mentioned to you last time, they were seeking public comments on the national strategy to support family caregivers and are working toward a meeting in 2023. The details will be forthcoming and we always put those up on our website. You can always look at events on our website to find those pieces of information.

The National Council on Disability recently released a report which examines the weaknesses in the HCBS ecosystem. The title of the report is Strengthening the HCBS Ecosystem, Responding to Dangers of Congregate Settings During COVID-19. You may find that to be of interest and the link is here.

With FPT, the Federal Partners in Transition, they're still working on their strategic plan and they met on December 15th.

The Interdepartmental Serious Mental Illness Coordinating Committee, or ISMICC, met on October 28th, last year, and the full agenda is provided there and we'll keep you updated on when they are meeting next.

With the Disability Advisory Committee, they also met in November and they are planning to meet this year with the new membership, and that iteration will go through 2024. We'll keep you posted on that.

The President's Committee for People with Intellectual Disabilities didn't have any new updates since their meeting on July 28th, 2022, but we will also keep you posted.

No new updates from the National Advisory Committee on Individuals with Disabilities and Disasters.

Two other things we wanted to point out to you is that the Department of Labor recently released a blog posting, COVID-19 and Employment Trends for People with Disabilities. You may want to read that blog and so the link is provided here.

Finally, the NIH has a request for information out right now. The National Institutes of Health Advancing Prevention Research for Health Equity Initiative is seeking public comment from community-based health and service providers and organizations on interventions or programs that prevent mental health problems or promote mental health wellness in populations that experience health disparities. They do welcome comments on individuals with disabilities as a group that experiences health disparities. Even though it’s not mentioned in the text, when you look at the texts, I spoke with somebody who’s one of the sponsors and they told me that they would welcome comments on people with disabilities as a health disparity population. Please respond to that if you have anything to share with the NIH.

With that, I conclude the National Autism Coordinator Update. Are there any questions from anyone?

Then, we will move on to our next section of the meeting. We have arrived at Committee business and DR. GORDON and I will walk you through this.

So first I'll share a few slides about some updates about the IACC/OARC Portfolio Analysis Report, the 2021 and 2023 IACC Strategic Plan Discussion, and then the last part of this session will be the 2022 IACC Summary of Advances Discussion.

First, to give you an update on the IACC Portfolio Analysis Report. As a reminder, this report provides comprehensive information about autism research funding across both federal agencies and private research organizations in the US. The first report came out in 2008, and we've been tracking autism research ever since then in the US. This report also tracks progress specifically towards IACC Strategic Plan objectives and provides analysis of funding trends over time. It also tracks progress toward the IACC Strategic Plan budget recommendation and tracks funding towards special topics of interest. Over the years, we've highlighted various topics, including, most recently, research on autism in women and girls and research on racial and ethnic disparities.

Right now, we are in the final stages of preparing the 2019 and '20 IACC Portfolio Analysis Report and planning to release that in the spring. We hope to bring you a report on this at the next IACC meetings, so you can see a little bit of the findings from that report.

We're also currently in the process of preparing data for the 2021 IACC Portfolio Analysis Report. We expect that to come out either late in 2023 or early 2024. That's what to expect on that.

Unless there are any questions, I'll move right into the IACC Strategic Plan Discussion just give an intro on that before we move into the discussion. Just as a reminder to everyone here, the charge of the IACC Strategic Plan is given to us in the Autism Cares Act of 2019 that requires the IACC to develop a strategic plan “for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals”.

I’ll just recap the process that we’ve been through up till now. You all have been working very hard since the time the Committee started in July of 2021. By the time of the first meeting, we were in the stages of planning for a Request for Information from the public about what people wanted to see in the IACC Strategic Plan going forward. We conducted that Request for Information from October to November of 2021 and presented the results at the January 2022 IACC meeting. In November 2021 to March 2022, OARC also issued a survey to the IACC members toward the initial development of the Strategic Plan to collect your ideas, and the survey results are presented at the April 2022 IACC meeting. From April to June 2022, OARC prepared the first draft of the Strategic Plan on behalf of the Committee and add a special working group meeting in July 2022. We had a discussion with the entire Committee about that first draft, and we collected further input at that meeting, and also issued another survey that went from July 2022 to September 2022 to collect feedback from IACC members on the Strategic Plan. From July to October of 2022, OARC prepared the second draft of the Strategic Plan. At the October IACC full Committee meeting, we discussed that second draft. Since then, we've issued one more survey to the IACC to collect feedback, and the results were posted ahead of the January 2023 meeting and anyone who's interested can find that on our website. For this particular meeting, we have posted a third draft to the IACC members for review and a few additional comments were incorporated. The draft plan will be discussed at this meeting today, and IACC members will have the opportunity to vote to approve the IACC Strategic Plan. That’s the stage of the process that we’re in. You can see that it has been a lengthy but very important process to take in all the input from the public as well as members to shape the Strategic Plan.

In summary, I just shared a few bullets, that’s basically repeating what I just told you. All comments submitted by IACC members and the general public were carefully considered, and a draft plan was developed with the goal of building consensus around the issues that you all shared and addressing the needs of people across the entire spectrum, the entire lifespan, and from diverse communities.

I want to take a moment to just say thank you so much to Committee members and members of the public for taking the time to share your thoughts and your feedback toward the development of the IACC Strategic Plan. We much appreciate the thought and consideration that went into your comments.

To share some of the major themes and topics covered in the Plan, we cover major research services and policy issues, some of which are the same as issues that we’ve had in the past in the Strategic Plan all along the way. As well, this Plan is the most comprehensive one we’ve had to date and we added a number of different new areas of research services and policy that had been more recent and updated. In addition, we provided updates on certain federal activities and initiatives and interagency coordination. Although for more intense detail, or more detail on federal activities, there’s also report to Congress that is worked on by HHS, but goes into a lot more detail about federal activities. But there’s an overview of federal activities and initiatives in the strategic plan. In addition, the IACC expressed a commitment to developing solutions to the challenges faced by individuals and families in the areas of health needs, services, access, opportunities, and community inclusion; and, as I mentioned, covering the whole spectrum and the whole lifespan, including those with high support needs and addressing the needs of people from diverse communities. In addition, the Committee expressed a commitment to inclusion, acceptance and equity and reducing stigma, disparities and discrimination. We also highlighted the need for greater inclusion and research, including community-based participatory research. Finally, there’s an update on the research portfolio and the budget recommendation in this new Strategic Plan draft.

Just to recap what the content or the structure of the Strategic Plan is. There is an introduction and then there are chapters on the seven question areas of the Strategic Plan: screening and diagnosis, biology, genetic and environmental factors, interventions, services and supports, and lifespan, as well as infrastructure and surveillance. There are two Cross-Cutting topics: sex and gender, and Cross-Cutting Topic 2, promoting equity and reducing disparities. A section on the COVID-19 pandemic and what we've learned from that, along with the conclusion. This is, right now, the draft that you have is approximately 200 pages, but that includes a lot of references.

It Is a comprehensive document, and some content that was emphasized in the current draft based on feedback that we received from you all includes individuals with intellectual disability; individuals with high support needs; the concerns regarding self-injurious, aggressive, and other challenging behaviors; minimally-speaking individuals and communication supports that are needed; mental health services and supports, which we discussed last time; co-occurring conditions, which is the perennial theme; autism in older adulthood, which is a new section of the Strategic Plan; sex and gender issues; equity and racial/ethnic and other disparities; and financial need and financial planning considerations.

We have some time now to hear from the Committee about the Strategic Plan, what your thoughts are on this draft that you've received. We welcome your comments and discussion. Today you will have an opportunity to vote to approve the new Strategic Plan. Also, if there are comments that are shared within this discussion that we are able to capture and incorporate, you can vote to approve the plan with agreed upon changes, if needed. With that, DR. GORDON, if you'd also like to join me, we would like to open this up to Committee discussion and hear comments from the Committee about the Strategic Plan.

DR. GORDON: I would like to make a few comments, but I don't want to color the

Committee discussion. I'll let others have first crack. Please, feel free, and I see people already raising hands. SUSAN, I'll leave it to you to run, and then I'll raise my hand when I want to add my comments.

DR. DANIELS: Wonderful. Thank you. Dena Gassner?

MS. GASSNER: I just want to say what a phenomenal job I think we've done as a Committee. I think we've covered many topics that we've never addressed in the past. I think some topics became more nuanced and more understandable. In terms of approving it with the recommended changes, I would say is to try to get closer to-- and I realized this isn't a plainer-language version. I think some of the paragraphs are hard to get through because they're long. Alternatively, we could create a bullet-point, edited version of this in plain language. It might make it more accessible to our constituents. That's my only feedback. Thank you.

DR. DANIELS: Thank you. Yes, we do plan

to release an easy-read version of the plan. Our team will be working on that. We need to first approve the regular content and then we can work on an easy-read version that would be even more accessible. We also will look through the draft for accessibility because, as you know, the Word document is not what gets printed. Finally, we usually have it professionally laid out. We'll have a chance to look at paragraph structure and so forth as we work toward a final publication, but thank you for those suggestions.

MS. GASSNER: Thank you for your work and your team.

DR. DANIELS: Thank you. Yes, the team worked hard as well. I want to acknowledge them for their role in getting all of these thoughts and ideas together that you all shared. Are there some other comments? Paul Wang?

DR. WANG: Susan, Thank you. I'll just jump on board with Dena's thanks to the staff for all the hard work they've done here and, obviously, to all the members of the Committee for the input that they've provided, and the public input, as well. I have a rather constrained comment about one small point-- although I think it's of potential importance for research-- and that is regarding what we used to call NDAR, now the NIMH Data Archive. We've talked about this a little bit in some of the previous discussions about the Strategic Plan. I think it has enormous potential importance. We're in the era of big data. This is an effort to make sure that all the data that are being generated by NIH and other funded researchers are available for sharing for additional analyses, for pooling with data that are collected by other investigators so that we have just, really, a substantial base of data as possible to develop our understanding of autism, to develop insights for autism. It's actually a shame, I think, that this data archive has not been more widely used. I think it really behooves us, it behooves the federal government, to ensure that this data archive is used more extensively. If there are issues about its usability, those should be addressed, but I think it's something that is of potentially much greater value than it has been realized to date. I promote its use and usability.

DR. DANIELS: Thank you. We certainly can check in with the NDAR team to see if there's anything we need to add. Dr. Gordon, do you have any comments about it?

DR. GORDON: No. I would just point out that this has mentioned, actually, several times in the Strategic Plan, as you know, Paul. I think the idea comes across very clearly that we want data in this space to be shared; that it's a resource of tremendous value to the research community and the community at large. We will continue to invest in it from the NIMH perspective, as well. I appreciate those comments and I think they are reflected in the Strategic Plan, at least from my read of it.

DR. DANIELS: Thank you. Do you have any suggestions for dissemination, any thoughts about what could be done from your perspective as a researcher?

DR. WANG: I'm not sure if you're addressing me, Susan?

DR. DANIELS: Yes, I am, sorry.

DR. WANG: I have not devoted significant thought to that. There are, of course, other data archives at the Simons Foundation. So far, we do run one that has been very well used, we're pleased to be able to say. I think there have been many contributions to the literature using those data. I think the point is here that it is important to promote the uses and usability of these archives, as Dr. Gordon says, it clearly is mentioned in the Strategic Plan, although I would suggest that we could emphasize more the promotion of its use and usability.

DR. DANIELS: Thank you. Well, if you have any comments about it offline that you want to pass to the NDAR our team, feel free to send them to us.

DR. GORDON: Right. Also, for that matter, specific edits to the plan where you think that aspect could be addressed.

DR. DANIELS: Thank you. I'll take a comment from Helen Tager-Flusberg.

DR. TAGER-FLUSBERG: Thank you. I wanted to follow up both on enormous praise for the document and I appreciate some of the substantive changes that you made in response to the last round of feedback.

I want to, though, also emphasize Paul's comments about NDAR. As someone who has been contributing, and spent an extensive amount of time and resources submitting data to NDAR, I do think it's time for there to be a kind of serious evaluation-- perhaps using the current Autism Centers of Excellence PIs-- get them together to provide the kind of feedback, both of a constructive nature. But if you look at the literature, there is literally a handful of studies that are published using NDAR data, in contrast to the other resources that Paul mentioned, as well, and I think it speaks to where people are putting an awful lot in there. We can cite the numbers, but it’s usability, both at the input end and at the output end, and at the analysis end, really just require, I think, a serious review and evaluation. Thank you, and should be in the plan.

DR. GORDON: I appreciate that. I think there's one point that I would make here, which is that it's no longer an autism resource. It's a much larger issue than just autism. I'm not sure about putting specifics like that into the Plan, other than to say that we need a nationally-sponsored database that is user friendly and easy to share. I think those points are coming across strongly, and if you could suggest specific edits in the places where the archive is mentioned, that would be helpful. Regarding the larger point, I think that's a discussion that we should have elsewhere, as Susan suggested, because NDA serves, actually, many communities, not just autism. It is interesting that you suggest the autism community is using other resources instead because it is, actually, quite widely cited in hundreds of papers a year for other resources. On the other hand, we are aware of usability issues and the database has not modernized with the times. That is changing, but the idea of setting up a user group that should include some members of the autism research community-- including, potentially, the ACE’s-- I think those are excellent suggestions and we'll relay them on to the office that handles that archive. Thank you.

DR. DANIELS: Thank you. I'll take a comment from sent comments here, Steven Isaacson.

MR. STEVEN ISAACSON: Morning, everybody. I have a few comments from Hari. He sends his appreciation to all the teams visible, and those behind the scenes, that work to get this all done. One issue he mentions is open access to the large databases for researchers and, regarding the data, he says the other issue is the data only reflects a small portion of autistics and he causes the quote, “testable autistics.”

DR. DANIELS: Thank you for sharing those points, Hari. To all the Committee members, we do have our team taking notes on this session and we'll take into account any comments that are shared here, so thank you for sharing those.

DR. GORDON: Actually, to add another point to that, Hari, I'd really appreciate you raising that issue again. That is also an issue that does come across very clearly in the Plan in some specific ways that I recall, for example, several places in the Strategic Plan. The Plan does note the need to be more inclusive in these studies on the individuals, on the higher service need, and higher communications challenges, and of the spectrum. I think that, again, comes across-- if there are other areas-- and then, of course, another area that is emphasized in several places throughout the Plan is the need to include a broader diversity of racial and ethnic communities in these data sets. Those come across clearly. If there are, again, other areas of inclusivity that you feel are not emphasized in the Plan, specific language would be appreciated. But I think we do a decent job of making those points in the Plan.

DR. DANIELS: Thank you so much. Scott Robertson, do you have a comment?

DR. ROBERTSON: Thanks, Susan, and thanks to the excellent work by you and your team for spearheading the development drafting of this with the input from the Committee. I think, in terms of the enhancement of the Plan over time, it's been great to see the content integrated in here.

I just wanted to say in relation to what was mentioned about data sharing, I think, maybe, consideration could be in addition to the Plan, having a focus on that, and maybe also, I don't know if there could be a brief mention of, for instance, the exploration of more collaboration with international partners, too, on that, as far as some folks doing groundbreaking research in Australia and in Europe. I know that you all have touched base with folks in Europe and Australia at times, but I wonder if there are ways to enhance that so we’re more on the same page and able to share resources, information, maybe share data between the States and other countries at times, to help enhance the research practice and policy engagement -- I also wondered, too -- it just occurred to me, for the fact that--I'm glad that we referenced key focuses, for instance, like homelessness, etc., and some of those, again, that's international research that we have for that--some of those areas, like homelessness, we lack research from here in the United States. Could it be possible, also, to make-- I think it's not in here as referenced to sometimes when the IACC has helped previous activities that are substantial in that area to just make a passing mention. For instance, the Committee had helped the prior workgroup on homelessness in 2019, and that created a major discussion. I think there was consideration at the time of potentially doing a brief, it just hadn't happened at the time. I don't know if that's something that could be mentioned in there that it's been of prior major interest to the Committee, in addition to the growing research body as a major impact on autistic people as far as community living.

Otherwise, I think the content in here is great. I'm glad that it's very inclusive of a lot of focuses, and I concur with the need as far as more research, that's emphasized on here for folks versus who use AAC, significant access, support needs, etc., I think that's a major priority, that as much as we can emphasize that in here would be wonderful, especially with the disparities, we see that in the research literature, so that's really great that's of key priority here.

DR. DANIELS: Thank you so much. Yes, we'll note those things, and it's a great idea to mention the Committee’s workshop that they did on housing, and also the workshop on co-occurring conditions, so we can certainly add those in, but thank you for sharing those comments.

DR. ROBERTSON: Just quickly, as the accessibility, too, as I concur, where possible, to enhance the accessibility for folks. In some cases, like on the paragraph, I think they're just minor adjustments. I think, in some cases, that could help enhance the access for folks.

DR. DANIELS: Yes, we appreciate your comments on that that you made to us earlier, and we'll certainly review the readability aspect and the policies that we have here at NIH and HHS to ensure that we make it as accessible as we can, while also keeping the content understandable. Thank you. Yetta

Myrick?

MS. MYRICK: Thanks, Susan, and thanks to everyone for all your hard work and getting the Strategic Plan to this point. No doubt about it, it's a heavy lift, and I really appreciate the effort that was taken to ensure that the document was reflective of the diverse and unique perspectives of those on the Committee. And I really appreciate the thoughtfulness and caretaking taken to actually craft the wording in the document, which I know can not be easy, again, with how diverse our group is. I specifically want to note the language around ABA, that can be a point of contention in the community and really just want to highlight that. Thinking about that language specifically, I'm now moved to be thinking about the dissemination to the larger autism community and I think that the easy-read document is only the beginning. This is literally off the top of my head, some of the things I'm thinking about are like, are there infographics? Could there be some type of learning session or a slide deck that can be made available to members that can possibly share out in our communities? I think that could be something that we can talk about. I don't know if there's been any thought in terms of creating a working group that can focus on dissemination. That would be something that I would love to be a part of because I think one of the things we really need to think about is, Okay, we have this document, I can share it out, but how does this translate out in the community? Researches are more than likely going to read it, but how are families, how are self advocates, really going to take this information and digest it? I'm just really thinking about, in order to do this work and to really push it forward, it's going to take everyone, and so my mind is on that, and I hope others’ minds are on that, and so I just wanted to open it up and throw that out into the ether. Thank you.

DR. DANIELS: Thank you so much. That is

very exciting. I don't think in my years of working with the IACC I've ever had anyone say they wanted to help with disseminating the Strategic Plan, which is wonderful. We would certainly welcome your feedback on that and if anyone else is interested in that, you can also feel free to email me. But would love to hear your ideas and be able to get it out there to as many people in the community who would like to have it and use it. And also, of course, to our federal partners, which we work with on the inside to ensure all our federal partners are aware of what we've done in the Strategic Plan, so thank you so much. Are there some additional comments? I see something from Stephen.

MR. ISAACSON: Hi, there. I have comments from Hari as well as Dina. Dina says there's similar accessibility issues with agency-based data in which they often charge for information. She's talking about accessibility to databases, including the need for outcome data from agencies like BR and Social Security. Hari says there's a site that uses Open AI technology, called typeset.IO, and they give simpler, everyday language to help understand more technical or scientific research papers. He says perhaps this could be used to create easy language versions of the Strategic Plan and other reports.

DR. DANIELS: Thank you for those comments. It would be a great idea, maybe, for our team to check in with the Inter-Agency Committee on Disability Research, because many of those data sources are for all disabilities and not just autism. I believe, I know, that there's a disability statistics working group and they may have some work that they've already done on accessibility and usability of some of those datasets. So I will check in with the ICBR to see if they have something to offer. But thank you for sharing those thoughts, and I’ve heard them before, and it would be great to get an update on what's being done about that. Thank you. Susan Rivera?

DR. RIVERA: Thank you, Susan. Just a quick reminder to us all that when we are using the term “international,” that we be sure we're not only referring to Europe and Australia, and that indeed, countries outside of those continents often host the most people with autism. We really need to be very intentional about including in “international,” other continents, as well. I feel we often just default to where most of the research is coming from and are not intentional enough about making sure that we include that. So I think we need to be mindful moving forward.

DR. DANIELS: Thank you, Susan. For Committee members who may be on the Committee for the first time, our office did an international portfolio analysis report back with the 2016 dataset and we had Australia, the UK, and Canada join us on that one, and that was our inaugural one. We would, in-between other reports that we're working on, like to go back and do another international report. I've heard interest from some other countries, so it would be a matter of trying to get some more countries on board with doing that. Although, just as background to, just as a reminder for, the Autism Cares Act of 2019, the charge of the Committee is domestic. However, if the Committee is interested in outreach and connection with international governments and agencies, we certainly can bring you information about international topics. However, the charge is domestic and we are, of course, doing that with our Strategic Plan that focuses on the US but appreciate everyone's interest in international ties-- as we know, global research and the services approaches and so forth are really important. So thank you. Additional comments?

DR. GORDON: Well, since there's a lull, let me take a moment and just make a few comments. First of all, I want to thank the Committee for the tremendous hard work that went into this Plan, and the back-and-forth between Committee members and the IACC staffers, who also deserve much thanks and who tried as best they could to capture your thoughts and ideas and put them into words to take the burden off of you as much as possible in terms of actually writing the report. It's been my pleasure to mostly observe this process over the last several months and to see the report evolve tremendously.

I'll make two comments on the overall impression that I get in reading the report. First, the report really has changed tremendously from the last iteration. I think, of course, that's for two reasons. One, this is a group that's very different from the last group. As we said at the outset of this IACC incarnation, there are more diverse voices of lived experience. But that's reflected in the sections, for example, on communicative needs. It's also reflected in the sections on needs for individuals who are prone to self-injury and other aggressive acts. We've got a tremendous, greater range in this report than we have in previous reports. The second reason, of course, is because the science has advanced and we now have more options for care and more understanding of the gaps that we need to cover from a research perspective. So I appreciate this report, as well, from the content perspective.

The second thing that I would make a remark overall about is the change in tone of language, which has been much commented on in our public comments. I think that the report now reads in a way that is more not neutral because autism, as many of you have said, is not a neutral condition-- but rather reflects, to a greater extent, the needs and concerns of individuals on the spectrum to ensure that their function is maximized-- I should say, that your access to the treatment and services that will serve you are more reflected in this than in previous versions.

At the same time, we've painstakingly ensured that the report also takes into consideration those on the spectrum who either cannot communicate for themselves, or who are represented by parents or family members, or who, otherwise, have such significant high service needs that the more biological, more deficit-based models are things we need to think about from the perspective both of research and of care. So I think both of those perspectives -- or, really, the full breadth of perspectives on autism-- are reflected in this Strategic Plan. I'm very proud of this group for coming together around the language that's used to ensure that it is inclusive of the full spectrum of individuals with autism; and not just the language, but also the priorities reflected in the Plan. From the content perspective, from a process perspective, I'm very pleased and proud of the Plan.

I want to make one more comment, which is inspired by many of the comments that have already been made today. That is that in the past, this report has been seen as what it is charged to be. This is a report to Congress, essentially, that sets out the strategic priorities from the perspective of this body, which is inclusive of both public members and government members. It is meant to be a guide. It is meant to be a guide for Congress. It is meant to be a guide for the Secretary. It is meant to be guide for other members across government. There are those of you who made comments today and elsewhere that this Strategic Plan can serve not just as a guide for government, which is what we're charged to do, but also potentially as a resource for those outside of government, including self-advocates and including other organizations, including family members and community members. I'm intrigued by that possibility. So we'll consider what resources we can or can't provide towards that possibility. But I think it's important to remember, as Susan said, that the charge of this body is to produce that report for the use of government. So we’ll have to think hard about what else we can do at your behest and with your interest and, importantly, with your engagement and the resources that you can potentially bring to bear, to see if we can have a wider charge. So with that, I'll turn it back over to Susan. I think there's a couple more hands raised. Perhaps I've inspired a few more comments with mine. Or perhaps there were others who were just a little bit slower to put their comments in.

DR. DANIELS: Thank you so much, Josh. I'd like to hear from Steven Isaacson.

MR. ISAACSON: Hi, everybody. Morénike sent me their comment. Briefly, I just wanted to echo all the remarks that have been made thus far by Committee members and to applaud the team for their hard work. I want to also a hundred percent concur with everything that Yetta shared about the importance of ensuring that we are very intentional about dissemination, and would also like to volunteer to be a part of such a work group. Lastly, I fully concur with Susan's remark about when we say,“"international”" being certain to also be inclusive of input from other countries outside of Europe and Australia, particularly in the global South.

DR. DANIELS: Thank you so much, Morénike. Matthew Siegel.

DR. MATTHEW SIEGEL: Thanks, Susan. Just two pretty minor comments I thought I would add. One is on page nine of the Plan, where the funding is discussed, there is a statement that there's a slight trend downward in intervention research funding. I would ask that that be reconsidered. I don't think that's an accurate characterization. What the graph shows is a decrease over the last four years from 60 million a year, roughly, to less than 40. That is a 33 percent decrease. I would not call that a slight trend, I'd call that a dramatic drop. I don't expect you to use the word dramatic, but I would just like to ask that that sentence be reconsidered. Is there a more accurate way to describe what the data is showing? That's Point 1.

Point 2, also a minor point. But on page 72, it's very nice that the Plan notes the recent research on wearable technologies, which is very much an evolving, an early area. But it makes a statement that research thus far can be useful in predicting episodes of aggression or increased stress and anxiety. I think that statement greatly overstates the current status of that field and literature, and it's an area I've worked in. I would say we have preliminary signals that that could be possible. Just a minor point, but one I wanted to make, and otherwise agree with what others said, and I'm very excited about this document. Thank you.

DR. DANIELS: Thank you. We can note those comments and certainly can make adjustments as needed. Thank you for pointing those out.

DR. GORDON: Thanks, Matt. With regard to that last one, I think, perhaps, it has the potential, or may have the potential, would be a better way to describe it.

DR. DANIELS: Yes. Thank you. Anyone else for last words on the discussion, as it seems like the discussion is slowing down.

DR. GORDON: Susan, for edits like the ones you just described, and then of course others I asked to suggest specific language, how can people get that language to you and when do you need it by in order to be able to include it in the final report?

DR. DANIELS: If you have some specific suggestions of language, you can send them to us within the next week. I mean, our team is listening and we probably can make most of those changes ourselves. We probably don't need you to give us word-by-word. But if you want to suggest particular words, if you could get them to us by early next week, that would be great.

DR. GORDON: There may be other minor

edits that people have, as well, and so want to make sure --

DR. DANIELS: Yes. We still have a little bit of time as we go through and review everything. Again, if there are little, minor things that people need to point out, feel free to just send them to our team. You can send them to IACC team or you can send them to me and I'll share them with the team. Oh, sorry. Scott?

DR. ROBERTSON: That was going to be my question; is, so, if we vote to accept that can be inclusive of the latest feedback, including that vote could be something phrased in a manner of, feedback that is sent to you in the next week could also be incorporated into the Plan.

DR. DANIELS: Yes. As long as it's something that's not a totally new or things that would dramatically change the meaning of the Plan. If it's just minor considerations, we can make those changes. I feel that within the Committee we have enough trust. We're not going to go changing something dramatic without telling you. If it's something very significant, we may need to save it for our Strategic Plan update, because we are required to do updates on the Plan and we can start compiling things for another update if there's a brand new topic that we want to bring up.

DR. ROBERTSON: Thank you.

DR. DANIELS: Thank you. Craig Johnson?

Craig Johnson: Yes, Susan. First of all, I want to say what a great job that everybody has done. It's really impressive just to watch the work that's taking place. One thing I would like to know, and I think for many of us, it's great to disseminate what the report is. It would also be great to think about how we're going to disseminate the progress as we go along here. Because [inaudible comments] important, especially for people that are coming online and they're asking questions. They're wondering, some of the work that we're doing, what kind of progress is taking place and how we disseminate that. Maybe in the months ahead, I think that's something we really need to think about. Because [inaudible comments] in there that can really encourage people, bring hope to people, and just show the progress of some of the things, the objectives, that we're about to do. That's just a suggestion. Thank you.

DR. DANIELS: Thank you, Craig. With the Committee we have, at this point, we're going to be publishing the Strategic Plan that will cover '21 to 2023 as we've been working on this the whole time. But in 2024, which is the last year of the Committee, we have a chance to put out a progress report. The Committee, we'll be talking about what we want to put in there, but if we would like to share progress, as you said, areas where we're making some significant advances that are not verbatim the same thing that we had in the previous Strategic Plan or want to do highlights on specific topics, we can really structure that document however we want, as this Strategic Plan lays out all the research and services and policy recommendations. I think I pointed out at the last meeting in October, we're changing from objective to recommendation just to make it very clear for everybody, because under PPACA, they all count as recommendations. We don't need to necessarily make recommendations and a progress report. We can structure it in a different way, so would welcome thoughts from the Committee about how we want to do that, and it's certainly great consideration to think about highlighting progress that has been made. Wonderful. Anything else?

I think then if I can have my slides back, we can move on to the next item, then, which would be based on the tone of the discussion here, it sounds like the Committee is ready to vote on the Strategic Plan. We have a slide up for the public on NIH VideoCast to be able to see what is going to be happening. First, as a reminder to everybody who’s in the Zoom room, you may vote only if you are a public member of the IACC, a federal member of the IACC, or an IACC alternate that’s representing a federal member who is not participating in the vote. We only want one vote per agency. Please don’t click “Anonymous” with your vote, because, for our offices tabulation purposes, we will track the votes and we're just required to keep that record in case there's any questions about it in the future. That's what we will be doing and we're going to use a Zoom poll to do the voting. I know that people in NIH VideoCast can't see the poll because you're in a different program than the people in Zoom, so we we’ll share what that result is with you. When we create our final slides, we will also put in a slide that shows the results of the poll.

With that, the three questions that will be on the poll are, you will have a choice between being in favor of accepting the new 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy, with changes that have been agreed upon at the IACC meeting that took place today and/or any other minor edits that may be shared within the next few days. You also could vote to not accept the new Strategic Plan that we're discussing today or to abstain from voting on the IACC's Strategic Plan. For federal agencies who are here, you are free to vote like everyone else. You don't have to abstain from voting in this particular Committee, although I know in some other federal advisory committees that feds abstain. But you are encouraged to vote, as we would like to see the thoughts of the entire Committee. Dena, did you have a question?

MS. GASSNER: Just to clarify. If we're in favor of the plan with updating the language to make it more accessible, with the caveat that we're going to have an easy-read version, we would still click number one. Yes?

DR. DANIELS: Yes.

DR. GORDON: But actually, Dena, I want

to be very, very clear on this, that the language will not go through very heavy editing at this point. That's not in the cards. We will look at it. But essentially, the tone of the report is the tone of the report. The easy language version is something that we will do, we're promising to you we'll do, that is not in the charge of this Committee. Again, this report is, I want to emphasize this, for the use of the government, not for the use of the public, per se. That's not what we're charged for. However, we recognize that that will be of tremendous value, and we will do that. But I just want to make sure that we're clear about what we're voting on now. The report, we will look for it once again, but the report will not be an easy-read version. We will try to make small changes we can make in the language now, but it's not going to be extensively revised. I want to make sure you understand what you're voting on now and that's why I'm clarifying that.

MS. GASSNER: I understand. But when we're looking at sunshine laws and transparencies, if it's not accessible to the constituents, then I'm going to ask us to find a compromise. I realized who we're writing for, but it's also a public document. Whatever we can do to reduce the paragraph sizes. Even that, just line breaks, are a huge accessibility asset. Anyway, thank you. Thanks for clarifying. I appreciate it.

DR. DANIELS: Certainly within HHS and NIH, we have standards for 508 compliance, and so we will be checking in with our 508 leads here at NIH and HHS to ensure that we're completely compliant and then there, usually within the standards, are best practices that are suggested and we'll have to look at those and see what applies. But thank you, Dr. Gordon, for bringing up those comments regarding the use of this Plan and it does contain specific kinds of language that are useful to federal agencies. For example, we didn't make it to fifth grade reading level because that wouldn't be that useful for the agent.

MS. GASSNER: No. I'm not asking that, but it's probably not a tenth-grade level either. Thank you. Thanks for clarifying. That's all I needed.

DR. DANIELS: We will produce an easy read version. These are the options for voting today that will provide. If there aren't any further questions, if our Rose Lee team could help put the poll up. Thank you. That was quick. Those who are in NIH videocast, you can see what questions people are answering. Those were eligible to vote.

DR. GORDON: How do we vote? I'm not seeing how I do that.

DR. DANIELS: It popped up on my screen. Does everyone see it?

DR. GORDON: Yeah. Pops up, I can see, but I actually did not get an opportunity to click on anything.

DR. DANIELS: I wonder if that is because you are a co-host?

DR. GORDON: Maybe so. That's okay.

DR. DANIELS: I don't know, there might be someone from our team who could vote on your behalf, perhaps, if you send to “Send Comments Here”. Then, someone from our team will vote on your behalf or whatever your choice is.

MR. ISAACSON: Susan, because I'm a co-host.

DR. DANIELS: Oh, you're a co-host as well. Sorry. If you send to another member of our team, to Tony Celeston.

DR. GORDON: Okay.

DR. DANIELS: Is there anyone still voting? You could just unmute and let us know you’re having trouble. Still working on it.-- I'm not hearing anything. Can everyone see the poll? You can all see that we have 38 out of 39 votes in favor of accepting the new 21-2023 IACC Strategic Plan. One vote, oh, there's one more vote that came in, so now it's 39 out of 40 to accept the new IACC Strategic Plan. It is one out of 40 against.

With that, that is an overwhelming majority saying that you would like to accept the new IACC Strategic Plan. With that, I'd like to congratulate the Committee on very hard work over the past year and a half to carry out this very important charge from Congress to create a new Strategic Plan. Our team will carefully go over all the feedback that was shared and make the minor edits that were suggested. Thank you so much for your very powerful engagement in this process and to members of the public who have shared your public comments and been a part of these meetings as we've been working toward completing this new Strategic Plan, that we can all feel very proud of and I also I'm proud of the Committee for your hard work. I'd also like to acknowledge the team in OARC the many staff members who spent a lot of time putting together your ideas with such care. Thank you to all the members of our team for your hard work as well. Alice Carter, I see your hand raised.

DR. CARTER: I just wanted to thank you, Susan, for your leadership in this effort. Because, really, it's been terrific.

DR. DANIELS: Thank you so much, Alice. I appreciate that. All right. I believe we have completed this very large task, for the most part, and our team will finish up the last portion of it and we will be working toward getting a final copy of this. We’ll work toward April. However, I don't know if it'll be ready for the April 4th meeting, because it's a big plan and there's a lot to lay out. It might be ready for the International Society for Autism Research meeting. But we will certainly keep you updated on when it goes out. I will consult with those who've said that they're interested in dissemination ideas. We will be very happy to share that with you. It will be sent to Congress and the President per the law when it is completed. Thank you, everyone.

Now we will move on to our next order of business. This is just the final ideas that we've already shared. Wanted to mention this before we get to the end of this session this morning, that the next IACC Full Committee meeting is April 4, 2023. We're going to try to plan it to be hybrid. Our building that we're in, it's a beautifully renovated building that we're excited to welcome you to. The meeting room that we're using is a wonderful room with a lot of great features. However, it's not quite ready yet, and we hope that it will be ready for April 4th. We will keep you posted on that. Thank you to everyone who's already sent information regarding your travel needs, so that we can get that meeting together as a hybrid, if at all possible. I will keep you posted on that. You can also check the IACC website for updates.

Now we are ready for the IACC Summary of Advances, updates and discussion. As you remember, one of the other charges of Congress is for us to produce an annual summary of advances in autism research. The way the Committee has been doing this over the years is, they like to highlight the top 20 advances in autism research as voted on by the Committee and also highlight the nominations. There are many nominations across the entire field of autism, biomedical, and services research. The preparation of the 2021 and 2022 reports is in progress, and we're soon going to begin work on the 2023 reports.

With a 2021 report, the status is that you all nominated articles. You've discussed the nominations at Committee meetings and you voted. We have the summaries prepared and a draft publication. Next we will be sending you a preview draft that will be a fast-turnaround preview just so you can see how it looks. Then we're going to prepare for final publication in spring of 2023 with that document.

The status update on the 2022 IACC summary of advances is that you all have now nominated articles and we got 85 nominations from you all. In today's meeting, we're going to discuss those nominations. Then the rest of the steps are yet to be done to complete that document. As a reminder, we're playing catch-up because the Committee was out of session for a while, so we're trying to get caught up. Now that we're in calendar year 2023, we're going to be starting the 2023 IACC Summary of Advances. After this meeting, we will be starting to solicit from you the nominations for the 2023 Summary of Advances. We have not begun that project yet.

In terms of guidelines for today's discussion of the IACC Summary of Advances, what we'd like to do is finalize the list of nominated articles that will appear on your ballot when you vote after this meeting. The selected articles that you are going to vote on should represent significant advances or progress in understanding of autism across the seven topic areas of the IACC Strategic Plan, and also our cross-cutting areas, including COVID-19 if there are areas of autism research that touch on that topic as well that are in the nominations. During the discussion, you may talk about any nominated articles that you feel are particularly noteworthy. We have flagged three articles in the list that may not fit the guidelines that you all discussed previously, either because the study is too preliminary; small sample size; it's a review, commentary or some type of a strategic plan or work group recommendations.

This is just a count of the different articles that we had, how many we had in each category, and we did get selections across all the categories and the three items that are flagged as potentially not fitting in guidelines but are up for discussion with the Committee are Talbott et al., which is in Question 4, Kuo et al., which is Question 7 and Singer et al., Question 7. With that, we can share the nominations and open it for discussion. Dr. Gordon, would you like to open that discussion?

DR. GORDON: Let me just start by saying that the NIMH team is, like many of you have, gone through and nominated mostly in many of the different categories and enthusiastically support those nominations. I think we should probably look at the three articles that were flagged by the staff and hear opinions about whether they should be taken off the list because they don't heed what we have set out to do. But, otherwise, I'll leave it up to the group to raise any articles. Typically, what we like to have done here is if there are articles that people are particularly want to bring to our attention because the member feels that is particularly meritorious, or, if on second thought, any members of the Committee want to point out an article that they think doesn't necessarily meet the criteria to be finally in the Summary Advances and wants to argue against inclusion therein, please feel free to bring it up right now.

Let's discuss those three first. The

first one is in Question 4, and it's the Talbott et al. I’m trying to find it, the right page number, in the document, we were all sent so that I can find it and tell you all, but I'm having trouble, if anyone can find it for me?

MS. MYRICK: It’s Page 17.

DR. GORDON: Thank you very much. I appreciate that. On Page 17 of the document, you have the summary of that article. Our team has flagged that as potentially not appropriate for inclusion because it's a feasibility study as opposed to a study of efficacy or other definitive study, and appropriately for a feasibility study, but not so much for a true advance. The sample size is only 32. That would be our recommendation from the IACC staff that we not include this in the voting. If there are objections to that, or particularly, if whoever nominated wants to make the case that we should keep it, please go ahead and bring that up now. Actually, on my version, it's on

Page 28. It may be peculiar to the document that I have in front of me, but it's in Section 4, it's the last article in Section 4. Anyone wish to argue for the ability to vote for this article? Not seeing any hands raised. In the final bout, we will take this one off. It is an interesting study of the experiences of caregivers participating in telehealth evaluation. Telehealth is going to be increasingly important. But as a feasibility study, it's really not a true advance, so we'll strike that from inclusion. Sorry, go ahead, Yetta.

MS. MYRICK: Really quickly. Is there anything else, another study, that is maybe comparable to this? Because I think having something on the telehealth experience would be viable. Maybe this is not it, but I'm just wondering if anyone has any other suggestions.

DR. GORDON: I don't recall offhand whether there are outcomes associated with telehealth evaluations in this particular

Summary of Advances, although I recall some in the past. Scott has his hand up. Scott, are you answering that question from Yetta, or do you have another point to make?

DR. ROBERTSON: Another point. Sorry.

DR. GORDON: Let's just hold off. Keep your hand up. Anyone want to respond to Yetta's comment?

DR. DANIELS: I believe that there's an article. I don't know if it's in this Summary of Advances set, but that is on use of telehealth for diagnosis. Zach Lauren? I think so. Might be in this group or it might be in another group of articles.

DR. GORDON: Search for telehealth. No, I'm not coming up with any. That doesn't mean it's not there, but now there are two others. Alycia, did you want to respond to Yetta, or are you raising your hand for different reasons?

DR. HALLADAY: Yes. In this particular issue of JADD that the Talbott et al. article is on, the whole issue is dedicated to telehealth approaches and their efficacy. I think I added a couple in mind. They are not huge studies. I don't know about 32. But they look at both diagnosis and telehealth-delivered interventions. It's a whole issue. Sorry, of JADD.

DR. GORDON: Got it. Now, I see you have a number of nominations. I'm trying to think of which might be from that issue. If you might point that out, if you can remember it, perhaps.

DR. HALLADAY: The first offer was Jessica Brian. If it's not on there, I'll add it, because it actually took existing intervention that was done in person and adapted it. Joe has some suggestions, too.

DR. GORDON: Thank you. Let's go to the “Send Comments Here”. Steven?

MR. ISAACSON: Morénike just to add a comment saying that it would be beneficial to have an article on telehealth experiences for people of color.

DR. GORDON: Ok. Joe?

DR. PIVEN: Yeah. I'm not familiar with this article or whether or not we have other articles included, but these are unusual times, and I think something like this is important to communicate to families that this is legitimate. Whether it's this article or another, I would strongly encourage us to include something about this whole new wave of telehealth work and feasibility for certain kinds of questions. A sample size of 32 is certainly small. But I'm not so sure for something like this that's the case, and so I'm just trying to add some support for us, including this. I think this is a big issue for families and researchers and providers.

DR. GORDON: Let me just push you on that, Joe, are you suggesting that we continue to allow this to be voted on or you’re simply suggesting --

DR. PIVEN: I take your point that I may be a little off-topic here, but if this is the only telehealth article, I would suggest that we reconsider the criteria, particularly the issue of sample size. I don't know if it needs to be this article, but I think in this best-of series, we should include something about telehealth because I think that is high impact.

DR. GORDON: Well, I'll charge it to all of you, including my own staff, to see if we can come up with an impactful telehealth article for inclusion in the final voting. It's not too late to nominate additional ones in that context, Susan?

DR. DANIELS: If you have something specific, you can send it to us and we wouldn't have a chance to come back and talk about it, so if you are comfortable with Dr. Gordon and I looking at the nominations, if people have something on telehealth they want to nominate, perhaps the two of us can look at them and decide on one or two to add to this list for the nominations if that is an approach that would work without us having to have another meeting.

DR. GORDON: Well, I don't think we necessarily have to meet because people are going to vote over email in any case and they'll have the full descriptions that are current. But what we'll need to do that is nominations from you all, I can't necessarily guarantee that my staff will come up with one that we would like to recommend, so please do take a moment to do that. Let's move to the next one. Oh, sorry, Scott, right. I have to come back to you. Go ahead, Scott.

DR. ROBERTSON: Yes. Related point that I just wanted to mention relates to the telehealth study but could come up in other cases, too. Is we do have an issue that sometimes, in key areas across the autism research literature base, the sample sizes are often lacking. Especially, I would say in the case of support services and interventions, it comes up recurrently for us, for instance, unemployment research and other focuses. I think maybe the plan I think mentions that, but I just wanted to point that out and maybe that's one of the reasons also for this issue. For instance, here on telehealth, it's reflective of a broader challenge I think we have with the autism research literature base and the broader disability research, that sometimes just finding recruiting folks for larger sample bases is difficult at times, and there are lots of barriers to that, but we need to make progress on that thing to get studies with larger samples.

DR. GORDON: It's a good point, Scott. The scientist in me would reply, just because it's a problem doesn't mean that we should allow studies through the gauntlet that don't meet the requirements for rigor and reproducibility, which small sample size don't. But I think we've overemphasized the small sample size with this particular study. If you look at the particulars with the study, it's essentially a post-hoc, online interview with some participants in a telehealth evaluation to ask them, did they find it helpful. I'm not saying it has no value, but it's not necessarily going to an advance in terms of demonstrating that a telehealth evaluation works. That said, now I see a hand up, I believe someone from the organization that nominated it, so maybe someone who knows more about it would like to make a comment. Alice, please comment.

DR. CARTER: Hi, I didn't nominate this, but I would argue against including this for the reasons you said. I do want to say, though, I think we need to be a little careful with sample size when we’re talking abou- This isn't really a qualitative study, but when we're looking at qualitative studies, there could be a small sample size and that might be fine. I do think we could find better telehealth articles and I really agree with Joe that it is important to put the message out there that telehealth is critical right now because it's not just families and individuals who may not be pursuing needed interventions because they don't think it's going to work for them. It's also agencies are making some not-so-great decisions around requiring in-person when not everybody is comfortable doing that given changes in health conditions on the ground. I love the idea of including a telehealth something, but I personally don't think this is the one.

DR. GORDON: Great. Thanks, Alice. I see two more hands up. I'm assuming they're still on this topic, so we'll stick with them before moving on. Larry?

DR. WEXLER: Thanks, Josh. I totally agree with you that the rigor of the study doesn't rise to a level that is really too scientific. On the other hand, and I've harped on this in the past and I'll be brief, it feels like, given the limited range of studies that we have on autism and the challenges in getting subjects, and especially getting subjects that aren't so heterogeneous, that it's hard to generalize findings. I do think that we should explore, as a Committee, a lower-level compendium of promising practices. I'm sure there's a scientific term for it, but basically, things that would really interest the field. I'll say it, I'll say what I've said over the last, I don't know, Susan, has it been what, 12, 13 years that I've been on this group? From my perspective, the school bus pulls up every day and kids get out and teachers, interventionists have to address those kids' needs, and there isn't always a stringently-developed, evidence-based practice on which to base all of those interventions. I get it, that’s scientific heresy in a way, but there is a reality out there. I'm not saying that this particular study should be included, but the larger issue is practicality and usefulness. We need to support the whole field and we need to think about that. Thank you.

DR. GORDON: Thanks, Larry, and Dena.

MS. GASSNER: I'm sorry to chime in late here. I, unfortunately, was unable to contribute much to this because I had a surgery in January. But I do have a study here by Rothman et al. from April. They did a six-week online class on developing relationships, and it was co-created by autistic individuals, and of course, that would fit into the telehealth standard. The sample size was 55 autistic people between 18 and 44. I'm happy to submit that citation if we want to consider it.

DR. GORDON: Please go ahead and email it in to Susan. Like Susan mentioned, we encourage everyone to do that if we'd like to see something with telehealth in there and we'll look through what we get and correspond with you all about those nominations.

Let's move on to the next two that we suggested to take off. Actually, I don't have the timing, the agenda. Oh, we have until 12:15. We have plenty of time. Let's move on to the next one that we suggest, the IACC staff has suggested might not meet our criteria. Can we have the next slide? I hope it's on the next one.

DR. DANIELS: It's a few slides. We had 85 nominations, so all parties were all--

DR. GORDON: It's in Section 7. There are two in a row, I think.

DR. DANIELS: There's one.

DR. GORDON: There's one, Kuo et al. Can you go ahead and tell us, Susan, why this one has been suggested?

DR. DANIELS: This one is a research agenda that lays out some goals for research that are very important, but it's not an original research article.

DR. GORDON: Anyone want to make the case that it should be kept despite the recommendation of our staff to remove it? Alycia.

DR. HALLADAY: Sorry. I want to advocate for it to be removed. There's been a couple of these articles in past years that had been removed. The research agendas and recommendations for future research are not appropriate.

DR. GORDON: Now, I encourage members who are interested to read the article and see how it does or doesn't comport with our recommendations and we can always consider adopting some of those things in the future. But any comments to the contrary? I don't want to cut conversation off too early. Thank you, Alycia, for your perspective on that.

DR. DANIELS: We also can consider things like strategic plans and recommendations for mention in progress reports on the strategic plan in another context.

DR. GORDON: Now, the next one might inspire some discussion. Let's move on to that one. This was a commentary that some of you have brought to the attention of OARC, as well as to me personally. A commentary, A full semantic toolbox is central for autism research and practices to thrive. This article doesn't meet our criteria because it is a commentary and does not present original research is the recommendation by OARC staff. Would anyone like to make comments on this recommendation? In particular, those who would disagree with it being stricken from the list. For those of you who haven't read it, it is a perspective that has been presented to this group in oral public comments. But those of you who are interested I do encourage you to read it, it speaks to the need to consider the full spectrum of challenges and disabilities faced by many in the autism community. But I agree personally with the OARC recommendation that is not a candidate for the Summary of Advances. There is a comment sent to Steven. Steven, go ahead and read it.

MR. ISAACSON: Hello. Morénike added some comments to the chat. She said, the Singer et al. article is a commentary, not original, and contains a lot of incorrect information, they say it should be removed and does not meet the criteria.

DR. GORDON: Okay. Thank you. I'm not hearing objections except that, as noted, that we would like to try to scour the literature for an advancement that might be helpful to consider in the telehealth areas. We will remove those three, they will not be included in the final ballot. Having gone through that, now I would again open the floor to anyone who'd like to point out a particularly meritorious, or perhaps argue against voting for-- I'm not saying excluding-- but voting for any of the articles on our list. Again, you've all received the descriptions and I would just add a plea, there are a few in here whose nominators have not included a justification. I encourage you to go ahead and send us that justification, if you nominate an article. It's much more likely to get a vote if you explain to members of the Committee in language that they can understand the importance of the advanced.

Would anyone like to make comments on any of the other 80 articles that were nominated today? Now's your chance to nominate your favorite one, I mean to highlight your favorite one that you nominated. Julie. Thank you. Please.

DR. TAYLOR: Hi everybody. I'll say a word about an article that I submitted, that I thought was a pretty nice advance in the lifespan area. This is a Forbes article. How do autistic people fair and adult life and can we predict it from childhood? We're starting to see some of these longitudinal studies that have been following autistic children for quite a while. Yeah, the children are starting to grow up and we're able to look at some of the young adult outcomes and see if there are things that we can identify earlier in childhood that predict better outcomes, however we define that, in adulthood from people that we followed over time. In the study they had, I think, around 125, over 120, and what they found was that adaptive behavior and IQ in early childhood predicted likelihood of working and living independently. But I think, importantly, did not predict mental health, did not predict friendships and social relationships. I think understanding what does and does not predict mental health and friendships is really important, and really understanding the nuance of functioning and childhood, and what that might be a protective factor against, I guess, and what it may not be, I think is important. They relied on parent report for their young adult outcomes, which I think can be a limitation. I think the strength of that is that they had a pretty broad range of functioning of autistic adults in their sample because of that methodological choice. I thought that was a pretty nice study in the adults sphere, and I love when longitudinal studies, especially long ones like this, can inform what we might understand about adulthood.

I'll just mention something about the Goldfarb study, too, so this was looking at the impact of work-related loss due to COVID-19 and mental health for autistic adults.

It's a small sample, so I think they were under 25, somewhere between 20 and 25, I can look it up. But they did some rich qualitative analyses to try to understand when people lose their jobs, and when that's related to mental health challenges. What does that look like in a more in-depth way? It's a smaller study, I thought it was nice. I will say-- and I don't usually like to nominate or opening up articles that we've done in our group--We had a really similar finding with a sample of 150 autistic adults, where we track them over the first three months of COVID. The people that kept their jobs, their mental health tract similarly across that time, the people that lost their jobs had pretty significant mental health increases over that time. I think it confirmed what was found in the Goldfarb study with the smaller sample, as well.

DR. GORDON: Thank you, Julie. Karyl?

DR. RATTAY: Hi. Being new to CDC I feel less self-conscious about bragging about some of the papers that my team has submitted. One in particular, by Kelly Shaw and colleagues, has been described as a watershed analysis. Historically, with the ADDM network we've used median age of detection and had not seen--

DR. GORDON: Sorry, Karyl, can I interrupt you? What's the last name of the article authors so we can make sure we find it on the slides?

DR. RATTAY: It's Shaw. S-H-A-W.

DR. GORDON: I think we've got it up. Is it Progress and Disparities and Early Identification of Autism Spectrum Disorder? Is that the one?

DR. RATTAY: That is it, yes. Historically, with Adam we've looked at median age of diagnosis and hadn't seen significant progress. This study looked at, instead, cumulative incidence and found significant difference. For example, identification by 48 months using this analysis was four times as likely in 2016 in comparison to 2002, and it also, I think very importantly, revealed striking racial disparities in early ASD identification by race and ethnicity and co-occurring intellectual disability. We think that this was really eye-opening.

If it's okay, I wanted to mention two others that I think are significant. Wiggins et al., in that article is features that best define heterogeneity and homogeneity of autism and preschool children. What I thought was really interesting is this, they found heterogeneity more so around dysregulation and developmental delays, but homogeneity among sensory dysfunction, and suggests that that should be considered a core aspect of ASD phenotype. Then finally, Wiggins et al. looked at toileting resistance, and I can tell you as a primary care pediatrician this is really useful that they found a difference in presenting factors or underlying risk related to toileting resistance when comparing individuals with ASD versus individuals with developmental delay and toileting resistance. I think that's very helpful for the pediatric community and how to address toileting resistance among these populations. Thank you.

DR. GORDON: Thanks for those comments Karyl. Scott.

DR. ROBERTSON: Thanks, Dr. Gordon. I wanted to point, spotlight, an article in the interventions area and the article in the lifespan area. In the interventions area, an article I nominated was the Benevides article on occupational therapy services use and access among Medicaid-enrolled children and adults, both autistic people and folks with intellectual disability. It's very striking, as far as the change in services use and access for occupational therapy. I think you see a parallel to this for other related therapies, like speech and language therapy, where the drop-off in age as kids get older into adolescence and adult life is very striking, going from say, 20 percent to 36 percent. That shows an area where, I think, it's a real primary area that needs to be addressed, especially since therapies like occupational therapy could be very helpful. I would say, even in many cases, more helpful for folks as they get older for challenges and barriers in focuses such as executive functioning, just the engagement in school, and then transition to work and adult life. That there are so many areas of that field that would be helpful, and so it's concerning in terms of the drop-off there. But I think in many cases we had an idea of some of these drop-offs, but we didn't necessarily have data to back it up. I think it's helpful when we have data that aligns with what we've already been thinking in certain areas, but didn't necessarily have the data to justify our assertions about some concerning disparities. That includes, as I say, NHS folks get older and really need the services access. One of the other articles I wanted to--

DR. GORDON: I’ve got to interrupt because the numbers are-- really, you’ve got to give the numbers. I'll just quote from your justification,“"About 20-24 percent of kids access OT services and only four to six percent of adults”" It's a tremendous drop-off. Thanks.

DR. ROBERTSON: Yes. Thank you, Dr. Gordon. It is a tremendous drop-off. It parallels, for instance, as I say, the lived experience too, is that, for instance, I had occupational therapy in elementary school, did not have it in middle school or high school, and certainly have not had it as an adult. I think it's reflective of what we already had been knowing from lived experience. But yes, the drop-off is striking when you look at the specific numbers. Thank you for putting out the specific numbers.

The other article I wanted to point out was one of the ones that I nominated in the employment space for lifespan was a study about I think it's Whepley, I think is the first name. It's about interviews where they looked at biases between how folks who are autistic interview versus non-autistic folks, neurotypical folks, and it was very striking that they rated autistic people a lot higher when they were not using videos, but were using just text transcripts, versus when videos were used. Folks, in terms of atypicality, in terms of how that showed up visually, really created a bias for a lot of folks. I think that does align with some of the concerns folks have had recent times. In interviews, folks rate autistic people lower because they think there's something a little bit odd or quirky about that person even though they're highly qualified for the job. This is another area where I think now we finally have data start to back up some concerns that we've had about biases. I think that's blazed a good trail, as far as that we should be having more data on that area as far as employment-related biases and how we can address that, too, in terms of that can hinder access to gainful employment for autistic job and career seekers.

DR. GORDON: Great. Well, thank you very much, Scott. We have another comment, Stephen.

MR. ISAACSON: Hi, everybody. I have comments from Hari and Morénike regarding the toileting article, where it says toileting issues may tie into gut issues.

Hari says he used to have a lot of discomfort before and after a bowel movement as a child, whether it's hard to loose stools, so there's a negative association for the child around the toilet. He says we need more research around gut.

Morénike says that they agree with what's being shared about the OT, occupational therapy, article because of a lot of schools and education and special ed professionals heavily dissuade parents from pursuing OT when the kids get older. They say some providers are also more reluctant to continue OT referrals. Given that, they believe that this research was inclusive of a Medicaid-eligible population with minimal outside resources to obtain OT otherwise, and that's especially problematic. Morénike concurs with gut issues that I already noted.

DR. GORDON: Thank you both, Morénike and Hari. Yetta?

MS. MYRICK: Thank you, Dr. Gordon. I recommended in the interventions section. I think it's the next slide. Give me a second because I was trying to find my justification. Bear with me, everyone. It's the Steinbrenner, Patterns in reporting and participant inclusion related to race and ethnicity and autism intervention literature. This study was a large-scale, systematic review of intervention literature between 1990 and 2017. The authors found that only 25 percent of study--this is out of over 1,000, so 1,013 reviews included data related to race and ethnicity of their participants with minimal changes in their reporting patterns across the year. In the study with reported data, why participants had the highest rate of participation with a large gap between the newest, highest rates of participation among Hispanic and Latino, black and Asian participants. I definitely think, given our focus on the Strategic Plan, that this will be something that we should definitely include.

There also is the article from Dr. Zubler who does work with the CDC about the developmental milestones. Full disclosure. I'm the acting Ambassador D.C, so just want to highlight, I think this is in the infrastructure if my memory's serving me right, might be wrong. But I think that is also another important article to highlight because it's been about, I think, 15 years since the milestones have been updated and I took a really systematic approach in updating them, so I just want to highlight that article as well. Thank you.

DR. GORDON: That'd be great. Yetta or Alicia, if you wouldn't mind putting in a justification, you can email that to Susan because it's missing that article, the Zubler article is missing a justification. It'd be useful for members to be able to see that justification as they go to submit their thoughts. Dena.

MS. GASSNER: I can't open the video. I did want to just champion Harmen's study, H-A-R-M-E-N, on diagnostic experiences of autistic women. I think we're failing a lot of women in that regard. It's the second one down there. I also wanted to champion the article by Groenman, G-R-O-E-N, on menopause. Again, we're not doing enough studies on aging and autism, and De Mello, the leaky recruitment article. I think that's a fantastic article. I'm actually using that and the Doherty article on this same slide for my dissertation. I think they're important. Then, I think any research that we're seeing, like the Benevides article on how people are navigating through Medicaid and Medicare, is critically needed. I don't think we have nearly enough research on systems navigation and barriers to health care that result from that. Thank you.

DR. GORDON: Thank you, Dena. I appreciate those comments. Any other comments? Go right ahead, Stephen.

MR. ISAACSON: Sorry about that. Dr. Jenny, my fan, has a comment in the chat. They say, "Hi, I'm glad to see more original research on sensory sensitivities and that it's highlighted as a core feature of autism, such as the NIMH-nominated article, Lyons-Warren. It's all study under the category of biology. I hope that we can see more studies on this topic and how it relates to regulation and coping, but to also consider that sub-grouping as hypo- versus hypersensitivity misses more nuanced subgroups, such as those who have periods of hypo- and hypersensitivities. I, myself, and my children experienced both types of sensitivities and, sometimes, we would have periods of only hypo- or only hypersensitivities.”

Morénike also added a comment. They just want to note that the Steinbrenner article that Yetta was mentioning was a very sobering read and matches out of many families' experiences -- matches the experiences of many families of color, unfortunately.

DR. GORDON: I want to add, and thank both of you for those comments, Morénike and Jenny. I'll note the Shaft et al. article which is another one, nominated by NIMH and also nominated by NICHD staff, also focuses on sensory function and individuals with autism, and looks at sensory function not just from the hypo-/hyper- perspective, but also trying to categorize differences in sensory function in more subtle ways. I think that's another article in that vein for those of you to consider.

Well, I think we've heard quite a bit about a number of these nominations. We're going to go ahead and remove the three that we discussed earlier. All the rest are open for your consideration. Please, in the next, shall we say, a week or so, Susan?

DR. DANIELS: Yes.

DR. GORDON: Any additional, last-minute nominations, but particularly if you have something to nominate in the realm of telehealth. Susan and I will look it over, if there's any controversial ones that we think don't deserve to be nominated, but otherwise, we will forward them on. Please do include justifications, and those of you who nominated, and in looking over the nominations, your justification is not there, please go ahead and do that also in the next week or so, so that we can get out the nominations for you to vote on. Susan, just remind us about that protocol that we'll have.

DR. DANIELS: I will give you a deadline for drop-dead to get us the last nominations if you have any final ones, and Dr. Gordon and I will look through them and decide what to add to the list. After that, we will send you an email ballot and you can vote on that ballot. We will take the top 20. They will be drafted into summaries for the Summary of Advances, and all the others will also be mentioned in the volume toward the back of the volume. We will work on preparing that, and congratulations on getting a set of nominations together here in the last part of 2022 to reflect the research that has taken place in 2022. We will also be starting the 2023 process. We'll try to let you finish 2022 so it doesn't get too confusing. Then we'll get going on 2023 and then we will be caught up and you won't have to do multiple projects at the same time.

DR. GORDON: Well, thank you. I think that concludes our Committee business for today. Is that correct, Susan, any other --

DR. DANIELS: I have one other comment that I'd like to make on Committee business, and I don't know if I skipped a slide that I had prepared or if I didn't make a slide for this. But now that we're finished with the strategic plan, for the most part, and we're completing this version of the Summary of Advances, one proposal I have for the Committee about a future project is that we had a report on co-occurring conditions that was being developed by a working group of the IACC in the last iteration of the IACC. That report is, I would say, about 65-70 percent done. Dr. Julie Taylor and Dr. David Amaral were the chairs of that working group, and we had a number of outside experts that were asked to be on that working group. What I would propose to you is that this IACC look at this report, contribute to it, and help finalize that report on co-occurring conditions, as it could be highly impactful for the community, and it would be great to get input from this even bigger IACC on it. I wanted to see if the Committee is feeling favorable toward working on and completing that report with this iteration of the IACC. I'll take a comment from Scott Robertson.

DR. ROBERTSON: Thank you, Susan. I think that would be a great idea, I'm very enthusiastic about revisiting that. I think it was such tremendous work that we had with the work group discussion. I was glad to be part of that work group at the time and I'd be happy if -- I don't know what form this will take -- but I'd be happy to collaborate on that. Again, if you might do it by a short-term work group, or something, to work on finalizing that. I would also add to that, since there was a possibility at the time of the other work group that was held on homelessness, if there's a possibility, I don't know if that would occur after the co-occurring conditions document or otherwise, but maybe a short brief on that space, reflective of what had come out of that work group discussion. The workshop that was held on homelessness at the time, I think would be helpful. Maybe us connect back to any research literature updates that have happened, for instance, in homelessness that we know in this space, since that was held in

2019, I know there's been some additional advances in there. Is that a possibility, Susan, that in addition to the co-occurring conditions document that may be a short one could be developed on homelessness, potentially, too?

DR. DANIELS: In that working group, was actually on all of housing. One of the great things is that we have HUD on our Committee now. They were not a Committee member back then, as an agency. We have inside expertise in the IACC that could help us with doing some type of a policy brief on housing, if the Committee is interested in that. My suggestion would be, let's tackle the co-occurring conditions report first, get that finalized, and if we still have time-- which we might, because that report was already significantly developed already, so it really would be updating it with current research. What I'd like to do is reach out to the working group members we had previously, also incorporating our current Committee, which is a very broad committee, to put eyes on it and give us suggestions and feedback for that report so that we could complete it.

DR. ROBERTSON: I'm sorry if I characterized it wrong. You're right. It was broadly on housing related to community living. My -- I know that homelessness came up as a major topic, and there is my error.

DR. DANIELS: We had some work on homelessness that this Committee did with a session of IACC and, as we said, with ACL and HUD, very involved in the whole housing issue, I think that we could do a nice job with that, too. If it's okay, we would maybe put that on as a secondary project after we finish the co-occurring conditions. Is there a comment from Steven, or someone on the Committee?

MR. ISAACSON: Yes. Hello. Morénike wanted to voice their support for the co-occurring conditions topic, said it's very important, and would be in favor of pursuing it.

DR. DANIELS: Thank you. Maria Fryer?

MS. FRYER: Hi. Thank you, Susan. I also wanted to just extend my support for this report and to offer any assistance at all. This is, of course, a big part, a large part of the portfolios that BJAS, where people with co-occurring disorders are intersecting with the justice system. Also, just want to extend this to Scott and others around the issue of people living in homelessness. BJAS engaged in several projects and committees to continue to grow the body of work in connecting people and increasing access to housing. Especially, we know that a large percentage of this population is a co-occurring population. Of course, many of our law enforcement/mental health learning sites that partner with behavioral health and the community have created a great many programs to conduct outreach and connect people that they visit in their homeless outreach teams, two people, connecting them to housing and building those partnerships and building access and increasing the number of housing that's available. We've tackled it on a few different fronts. I'd be happy to help in any way I can.

DR. DANIELS: Wonderful. Thank you so much. Julie Taylor, would you have any comments as the chair of the working group? I would like to also propose that I re-contact David Amaral, and work with Julie Taylor, if she is willing to help lead the working group.

DR. TAYLOR: Yeah, I'd be glad to, and I'm really thrilled that the Committee is interested in wrapping this up and having a nice report and product from the work we had. Just as background, it was either one day or multi-days, Susan, I can't remember, workshop focused on physical health conditions, and then a separate, just as rigorous, workshop on mental health co-occurring conditions. We brought in a lot of experts, we brought in a lot of people with lived experience. I think we all learned a lot and we engaged a lot of people who really had deep expertise, and where things are at and the challenges, and how we might want to make things better moving forward. I'm really happy to help pick this up and help move this forward. Certainly, we'll like a lot of input from the Committee. I think, sadly, I don't know that things have changed a whole lot in terms of mental health conditions and in terms of how we support people that have significant co-occurring conditions. I think everything that we talked about a few years back is still going to be highly relevant to what's going on today. I'm really happy to continue to help move this forward.

DR. DANIELS: Wonderful. I agree that we've also done some work with the strategic plan trying to get some of the latest research on co-occurring conditions, and would be happy to try to integrate that into the report. I will, in an email, also ask members of this Committee if you'd like to serve on the working group, that we can expand on this report, but everyone on the Committee would have a chance to approve the final report when it's completed. Thank you so much for voicing your support for that project, and we will launch that as we're finishing up the strategic plan. With that, I think we are done with business for this morning and we have time for lunch.

DR. GORDON: Wait. We will adjourn until one o'clock when we will return for our public comment session. Look forward to seeing everyone then.

DR. DANIELS: Thank you.

DR. GORDON: People can stay on, is that correct? Just with the video and muting off, if you'd like and so that you don't have to worry about rejoining.

[Whereupon, the Subcommittee recessed for lunch at 12:00 p.m. and resumed at 1:00 p.m.]

DR. DANIELS: Yes. Welcome back, everyone. It's one o'clock, and it's the top of the hour, so we are ready to start the public comment session. Dr. Gordon, did you have a comment?

DR. GORDON: Nope.

DR. DANIELS: Nope. Just joining?

DR. GORDON: Just joining.

DR. DANIELS: Great. Yes, welcome back everyone from lunch. Hope everybody had a little bit of something to eat to give us energy for the afternoon session today. We are going to be joined by five public commenters today who are sharing in the oral comments section. They will be presenting in this order: Finn Gardiner, Stacey Blecher, Areva Martin, Joe Joyce, and Tom Frazier. I will call on each person, and then you're welcome to give your oral comment. We're going to go through all of the oral comments, followed by a discussion -- or a description of the written comments, and then we'll have a discussion period. I'd like to welcome to the screen Finn Gardiner.

MR. FINN GARDINER: Hi. My name is Finn Gardiner and I'm with the Autistic People of

Color Fund. I'm also here to present some comments from the Autistic Women and Nonbinary Network, as well. The Autistic People of Color Fund is devoted to fostering the inclusion and social integration of autistic people of color, people who have been negatively racialized, people who've experienced systemic racism, and are also autistic. We work with the Autistic Women and Nonbinary Network to direct policy research and community advocacy to advance healthy outcomes for disabled people, including high-quality and community-based services and supports, successful housing and health care, integrated employment, and inclusive education.

For research on autism, needs to focus on the needs and priorities of members of the autistic community. So often, research focuses on the priorities and needs of non-autistic people, which is a epistemic injustice, which is a principle that the philosopher Miranda Fricker introduced, and, I believe, in 2007, in which people who are systemically discriminated against are deprived the opportunity, are treated as deficient knowers of themselves, and are also treated as though they are deficient in gathering knowledge. That happens to autistic people.

The first thing that we need to do as autism researchers and advocates is to involve autistic people in autism research. For years, autism research has been dominated by the needs, priorities, and experience of non-autistic people. That means that our voices are often silenced and marginalized. For research to include our true needs, priorities, and concerns, it should include us from the start.

We encourage IACC to make a priority of research models, such as community-based participatory research and participatory action research, to address those inequities. There are organizations that are doing that right now, such as AASPIRE, or the Academic

Autistic Spectrum Partnership in Research and Education; the Human Services Research Institute; and Patient-Centered Outcomes Research Institute, or PCORI; that are all doing work that involves the input of people with disabilities, specifically autistic people, to become leaders in their own communities, to direct research that reflects our priority. Another important research topic is the mental health of autistic people of color, autistic immigrants, and autistic refugees.

There are some studies out there about the prevalence of psychiatric disabilities among autistic people, but very few examine the relationship of race, autism, and mental health. Their studies have shown that autistic people, regardless of race, are already more likely to experience psychiatric conditions, like depression, anxiety, suicidality, and psychosis. We suspect that systemic racism may exacerbate some of those psychiatric conditions. But we need more empirical research to find that out, because it's just not there yet.

We also call for the use of anti-ableist language and approaches. We want to see more research that is responsive to autistic people’s needs, that improves our short and long-term outcomes; and it reflects the priority of autistic people; consistently receive the least support, recognition, and access; people with chronic health conditions, autistic parents of autistic children, people who face multiple forms of marginalization. We need to see research that dismantled ableism, that dismantles the systemic prejudice against people disabilities. We also need to see more research about the effects of gender bias against women, both trans and cisgender women; people with feminine gender expressions and presentations; and anybody assigned female at birth; and neurodevelopmental disabilities co-occurring conditions, because often there are correlations between gender discrimination, people who are members of marginalized gender and health disparities.

We'd also like to see more research on school disciplinary policies and school-to-prison pipeline, and their effects on autistic students of color, because students with disabilities already, regardless of disability, are disproportionately likely to be expelled or suspended from schools that use zero tolerance disciplinary policies as our students of color. Autistic students are also more likely to experience restraint and seclusion, which can cause severe injury, death, and lasting trauma.

We'd also like to know more about the health care experiences of autistic people of color, LGBTQ autistic people, and autistic immigrants and refugees. These experiences can include interactions with doctors, nurses, and other clinicians; hospitalizations; accessibility in hospitals and clinics; communication barriers; lack of parity and insurance coverage; denials; affordability. There's already a lot of -- a huge body of research out there, about racial disparities in health care settings. We'd like to know more about how autistic people, especially autistic people of color, are being affected by these disparities.

We'd also like to know more about the rate and effect of housing, and unstable housing and homelessness, among autistic people, because there is some research out there that suggests that autistic people are more likely to be homeless or unstably housed than non-autistic people, but there aren't many studies out there. Moreover, most of this research is not from the United States. Most of it comes out of the U.K. There's social cultural context, especially regarding social services, is very different from that of the United States.

DR. DANIELS: Can I ask you to wrap it up for us then, but thank you so much for sharing this wonderful points. Do you have any final comments?

MR. GARDINER: We'd also like to see some research on alternative and augmentative communication, because there are a lot of people who do not have access to that and we'd like to learn more. But yes. If you'd like to see more of the concerns that we've raised about autism research, please consult our written commentary, as well.

DR. DANIELS: Thank you so much. Yes, I failed to point out to everybody that we have the written comments that were submitted for the oral commenters, as well as all the other written comments, in a packet for you all on our website, so you can access them. But thank you so much, Finn Gardiner for those comments. Next, I'd like to call on Stacey Blecher.

MS. STACEY BLECHER: Hi, good afternoon. I'm Stacey Blecher. I must admit I'm a bit out of my comfort zone here, as I'm speaking about a population that I do not embody personally, but I do thank you for giving me the opportunity to speak here today. I'm a board-certified art therapist in the State of Ohio. I have been working with autistic children age 5-22 at the Positive Education Program for the last decade. I'm also a wife to a husband who has been recently diagnosed as autistic earlier this year. Autism is all around me and as an art therapist, I find that it's truly a shame that there's not more services for autistic adults that are covered by insurance. Typically, mental health services for autistic adults that are covered by insurance, typically those are talking, and that doesn't normally work for many autistics. However, as an art therapist, I have found that the services that most benefit autistics are those creative art therapies or expressive art therapies.

Years ago, I ran an art therapy group for an organization called Autism Personal Coach for teens and adults. The group was really beneficial for those that attended. But between the financial strains on the attendees and the physical public space, it being noisy, it wasn't really well attended. The actual sessions that did take place provided the attendees the ability to express their thoughts, feelings without the use of words. It gave each person that opportunity to connect with one another in a very therapeutic way with no verbal mouth words, and at the same time still feel heard.

I don't fully grasp the autistic experience because I, myself, as I said, I'm not autistic. However, there are many times I can understand through my husband's experience. At the end of a long day, he might say, Can we just text? Or can we just not talk? His level of overwhelm at the end of the day, he just can't really find those words.

I think, as a country, that there's way more that we could be doing for the autistic population to provide services, not just in the area of heavily concentrated populations, but across rural areas, as well. Autistics need to feel and have greater access to all expressive therapies, providing support to this amazing population, whether it's federally funded or federally meeting medical necessity. I think as a society, we could be really great. Often, in the community, people who are seeking supports, and could be on a waitlist for upwards of a year or longer. Possibly giving access to these expressive therapies would provide access to a provided, a much-needed, service in those, even giving our technology advances. Autistics wouldn't have to necessarily leave their homes. They could just type versus text, or not have to show their face, but they could engage in the therapeutic process. I think that there is a lot of opportunities that could be gained just having greater access to these expressive arts and the expressive therapies for the autistic population. Thank you for your time.

DR. DANIELS: Thank you so much for sharing those comments. We will go to our next commenter. This is Areva Martin.

MS. AREVA MARTIN: I would like to thank the members of the IACC for allowing me to offer testimony today. I'm speaking to you as the founder and president of Special Needs Network, and as a civil right attorney, and mother of a young adult on the autism spectrum. For more than 16 years, Special Needs Network has been working to close the gap in services available to lower-income and BIPOC children with autism and other developmental disabilities. We provide direct services in the form of behavioral health treatment through our clinics and through our in-home service division. Those services are paid at a rate that is 30-40 percent less of what a private health insurance carrier would be paid for providing the same services. The legislation that allows for enhanced payments through Medicaid does not designate board-certified behavior health therapist eligible. You are all aware that federally qualified health centers are entitled to federal grant monies and enhanced Medicaid payments for certain license providers. These supplemental payments make it financially feasible for clinics to operate in poor and historically underserved neighborhoods. But a critical community of providers is left out of the current legislative scheme that enables those supplemental payments, the behavioral health specialist who provide critical services and interventions for those with autism and other developmental disabilities.

DR. DANIELS: Excuse me, can I interrupt you just for a moment? I don't know if you're aware that your camera was blocked. I'm sorry, I didn't want to interrupt your flow but yes, we want to see your face.

MS. MARTIN: No, thank you. Although some states don't have a licensing process for behavior analysts, certified behavior analysts are highly educated in their fields. Most have master's degrees, many have actual PhDs. Their education and expertise allow them to conduct assessments of children with behavioral health issues, write assessment plans, provide direct intervention services, and even supervise other clinicians providing direct intervention services. But under the current Medicaid provision and scheme, these experts are not considered qualified when delivering services to someone who has Medicaid insurance. This arrangement puts providers like Special Needs Networks and others at an extreme disadvantage, even as we deliver much-needed behavior health treatment to the most vulnerable patients in our communities. This reality is detrimental to our capacity to pay our staff, our clinicians, to expand our services, and even, simply, to operate at a level that is sustainable. The reality is preventing organizations from serving these vulnerable populations means fewer providers providing services for individuals with autism in our most vulnerable communities.

The Los Angeles Times recently covered the issue as it impacts Martin Luther King

Hospital. The hospital's emergency department is overwhelmed with patients who can't get help elsewhere because of a provider shortage caused by the low reimbursement for services, and the department has lost tens of millions of dollars because of the incredibly low Medicare reimbursement rates.

As behavioral health providers face their own crisis in being able to deliver services, Special Needs Network is requesting your help in communicating to the Office of Health and Human Services of the dire need to expand the definition of providers under Medicaid who are eligible to receive enhanced payments. This change would make available a larger pool of providers to deliver behavioral health treatment to our nation's most vulnerable patients, those that live at the intersection of disability, racial inequities, and poverty.

Today, as you know, one in 44 children are diagnosed with autism. That is a 244 percent increase over the year of 2000. The data is clear that individuals with autism, particularly those who live in poverty, face greater challenges as they age out of schools.

Earlier interventions also, as we know, benefits society as a whole. A National Audit Office research indicates they're supporting more people with high-functioning autism and Asperger's syndrome quickly becomes cost-neutral and can, potentially, lead to long-term savings from higher levels of employment and more people living independently. Such early intervention also reduces mental health and criminal justice costs, as people supported before they reach a point of crisis.

There is precedent for the advocacy that we are requesting. The Improving Access to Mental Health Act of 2021 proposes amending the current law that prevents clinicians from billing Medicaid for behavioral health care. If passed, this bill would allow clinicians to bill for 75 percent of a psychologist’s rate, and would also increase the reimbursement for clinical social workers from 75 percent to 85 percent of the physician's fee. If this bill is re-introduced in the new Congress, we see an opportunity to support the expansion of the bill in a way that would increase the reimbursement rates for those certified behavior analysts providing interventions and behavioral health treatment to individuals with autism.

This proposal is about advancing equity and racial justice. The current scheme creates a dual system whereby the wealthy have access to more providers and services, while low-income and poor people, particularly people of color, are receiving diagnosis, assessments, and intervention services 2-4 years later than their peers. Increasing provider payments, rates for Medicaid, will help improve provider participation, expansion, and access to care for those whose lives, for far too long, have been left behind and those who have been disproportionately impacted in a negative way by our dual healthcare system. Thank you.

DR. DANIELS: Thank you so much, Areva Martin, for sharing those comments. We appreciate it. Next, we will take a comment from Joe Joyce.

MR. JOE JOYCE: Thank you. Dr. Daniels, Dr. Gordon, and the rest of the Committee for allowing me to provide brief comments. I am providing this testimony on behalf of the Autism Society of America, and as a father of two adult sons with developmental disabilities.

My wife, Elise, and I are the parents of two individuals with significant functional limitations. David, age 24, has autism, and Matt, 26, has Down syndrome. Both have intellectual and developmental disabilities.

Developmental disabilities are defined in law as physical or mental impairments that begin before age 22, are likely to continue indefinitely, and result in substantial functional limitations in at least three major areas of self-care. In spite of these limitations, both of our young men are loved and valued members of our family and community. Elise and I were finally able to transition David to a home that we bought for him. However, it was a massive struggle to find direct support professionals and a licensed agency to operate the home. Many agencies declined due to inadequate provider rates to serve high-risk residents. We are fortunate to have some resources for this planning, but millions of families do not. Matt continues to live with us as we plan his transition. We know that David and Matt will not be able to care for themselves without significant support. We worry about what will happen to them when we are no longer here to take care of them and coordinate, and oversee, their services.

The home and community-based Medicaid Waiver is the program that most individuals and families depend upon to get the services they need to keep family members at home; get habilitation, behavioral health, and supported employment. However, the only service that states are required to cover is home health. Most other services are optional. States are also permitted to limit the number of people eligible for waivers, resulting in waiting lists that in some states are many years long. In addition, states vary in the way they screen and collect data on waiting lists, and they vary in the pay rates for direct support professionals. Waiting list totals across all disabilities for states is estimated to be over 800,000. Even more troubling, individuals wait, on the average, 39 months to secure services, with reports of some waiting 15 years. There is an urgent need to remedy this crisis, as the prevalence of autism is expected to increase by 15 percent or more over the next 10 years.

New data from Angkor finds that a significant shortage of direct support professionals has reached catastrophic levels. The longstanding workforce crisis exacerbated by the pandemic has led to closures of critically-needed services and the denial of access to community-based support. They can see rates for full-time direct support positions experienced a 45 percent increase.

My family experienced this shortage firsthand. During the height of the pandemic, David's day habilitation services, Hope Springs Farm, was completely closed for 12 months, putting a significant constraint on working parents. Many of the direct service providers sought employment elsewhere, resulting in a significant shortage of staff. We are so fortunate that Hope Springs Farm survived the crisis, thanks in part to federal government funding packages. However, due to the staff credentials required for high-risk behaviors, David has not yet been able to return to the day program at pre-pandemic levels.

In all the years that I've been involved in the Autism Society, I have never been more worried about the state of our nation’s service system for people with autism and other developmental disabilities. We receive way too many calls to our hotline related to individuals and families suffering without services. The administration and Congress must find the political will to help states provide these services.

We have provided recommendations in our written testimony for your consideration. We hope that you will use the influence of this body to do what you can within the agencies around this table, to make an impact and to make recommendations to Congress to improve services for those with autism. Thank you for your attention to this very important issue.

DR. DANIELS: Thank you so much, Joe Joyce, for those comments. We appreciate it. Finally, we will hear from Tom Frazier.

DR. TOM FRAZIER: Thank you, Dr. Daniels and Dr. Gordon, for the opportunity to speak today. As mentioned, I'm Dr. Tom Frazier. I'm a professor of psychology at John Carroll University and I'm an Autism Speaks board member. I'm speaking today on behalf of Dr. Andy Shih, who's the Chief Science Officer and Steward Spielman, who's the leader of the advocacy division at Autism Speaks.

In 2019, the IACC held a workshop addressing the mental health needs of people on the autism spectrum. Participants there discussed co-occurring mental health issues that affect many people on the autism spectrum, including things like anxiety, depression, suicide, self-injurious behavior, and other severe and distressing behaviors.

A recent Washington Post story highlighted the plight of an autistic teen who waited months for a psychiatric bed to become available in a facility that can provide appropriate care for him. The teen siezed and died days after being admitted to a psychiatric facility. The workshop, the newspaper story, and personal accounts, in their own ways and separate ways, speak to the distance between the mental health services, the community needs, and the services that the community receives.

But there is an opportunity here, and it's been provided by the recently enacted Consolidated Appropriations Act of 2023, to make a ground for autistic individuals with co-occurring mental health conditions with the most significant unmet health needs. The omnibus agreement directs NIMH to deliver, with the fiscal year 2024 Congressional justification, a professional judgment budget, estimating the additional funding needed to support opportunities to broadly accelerate research on severe mental illness, or SMI. That agreement goes on to specify that the budget should include efforts to expand existing scientific programs focused on improving things like early identification, accurate diagnosis, biomarker assessment, intervention development, and implementation of effective services, among individuals in the early stages of severe mental illness, or SMI. The omnibus agreement also urges the NIH to provide an update on its investment across the priority areas outlined in the IACC Strategic Plan in the fiscal year 2024 Congressional justification. This language, coupled with the new professional judgment budget for SMI, offers an unprecedented opportunity for the IACC to engage and articulate a path towards addressing some of the unmet mental health needs for our community, particularly for those with the most significant health care needs. The IACC should really seize this opportunity. Consistent with the language of the Omnibus, the IACC should identify time-limited, goal-driven investments that the funding identified in the professional judgment budget should address.

Countless individuals and families had waited for an answer to the lack of accessible quality mental health care. The time to address this real and growing concern is now. Thank you.

DR. DANIELS: Thank you so much, Tom Frazier, for those comments, and thank you to all of our oral public commenters today for your very timely words, as we have just completed our Strategic Plan within the IACC. We also will be talking about services, which was the topic of many of your comments.

Now, I will take us through what we received in written comments. With the written comments we received, we received 118 comments this round, and we have the names all written here. I won't read them, but you can read them off the slide. The full text of the public comments is available on our website, as I mentioned. You can go there if you want to read all of those, and they were provided to the Committee in advance. We have comments on these topics, so research and services needs, resources and policy implications, we have 47 comments on that topic. On research, services, and supports for adults with autism, 14 comments.

Inclusion of autistic perspectives in research, 12 comments. Educational needs and the teacher workforce training, eight comments. Addressing the needs of autistic individuals with high support needs, four comments. Mental health research services and treatment, four comments. Employment, five comments. The role of the IACC and the federal government, five comments. Potential causes of autism, two comments. Increasing autism acceptance and reducing stigma, four comments. Inclusion of underrepresented groups, five comments. Communication and AAC, two comments. Parent and caregiver support needs, two comments, and language regarding autism, four comments. We aren't summarizing them, they're in the packets and you're welcome to read them. But I know the Committee has already looked at these.

And now we have some time for discussion by the Committee of everything we've heard today and what you've read in your packets. We'd open up the floor to comments from the

Committee. I know that there was a lot to think about in the comments that you've just heard and seen. Dr. Gordon, would you like to start us off?

DR. GORDON: I was just going to say, it seems like a quiet group today.

DR. DANIELS: We've been working hard already, but there's a lot to take in.

DR. GORDON: Excellent. Dena, we can always count on you. Please.

MS. GASSNER: I'm just flat because I had this operation. I'll be back to normal in four months, you won’t be able to deal with it.

Anyway, I just wanted to thank Mrs. Martin for her comment. Specifically, when I look at our next topic of conversation, we have not documented the school-to-prison pipeline issues that primarily BIPOC individuals are facing. I'm really grateful for that.

I really appreciate your comments, Joe. I think issues with portability for both the military was addressed in our public comments, but also for siblings who are trying to take over care and keeping of their beloveds, for individuals who need to relocate for purposes of employment. We're actually dividing up a lot of families, because I know in my house, I couldn't live in the same state with my husband and get my son the services he needed. We haven't lived together for 15 years because of the gaps and services in the region he needed to stay employed in.

I would also want to point out that any conversations about self-harm that come to us, we need to continue to remember that it occurs across the spectrum. It's not just limited to people with high support needs. I even questioned the whole construct around this subjective observation that we put into the idea of who has the highest support needs. Clearly, when we get to the opposite ends of the spectrum, we can see that difference. But when we get to the middle, it gets a little messy. Trying to delineate these people based on what you think you know about someone, especially with language, can make it difficult to communicate. I'm not just responding in terms of non-speaking people, but people who have selective mutism or who shut down with people of authority.

Then the last thing I wanted to bring up is the prevalence rate increases, that have been asserted by multiple people in our conversations today, that came in. I believe what the research is showing is that we are doing a better job of diagnosing people of color, and we’re doing a slightly better job, not nearly as good a job, in diagnosing autistic women. We have to remember according to Lay et al. and Simon Baron-Cohen’s study on this, that there was a lost generation of individuals for whom there was no diagnosis available. Those people are surfacing now--it isn't that they haven't always had a developmental challenge. They've had unmet developmental needs their entire lives. It isn't as though someone is just like spontaneously disabled. It's that they'd been living with this their whole lives without a category of information to help them understand, not only for providers how they struggle, but for themselves. Internally having the self-awareness to understand how the lens of autism shapes their lives. I just want to be clear, yes, the numbers appear to be going up, but we have to remember all the factors that contribute to that increase in prevalence. Thank you.

DR. DANIELS: Thank you so much. Steven Isaacson, do you have a comment from one of our Committee members, or more than one?

MR. ISAACSON: Yes. Hello. I have a comment from Lindsay Neumacher. She says, "I appreciate Finn Gardiner's comments, and for reminding us how important it is to prioritize funding for research on the disparities and inequities, and service provision and outcomes, that autistic people of color, queer, and transgender autistic people and autistic immigrants and refugees face. As we approach Black History Month in February, it is an excellent time for us to recognize BIPOC autistic people in the community and encourage expansion on autism research, addressing the needs of this specific population. I would also like to express my appreciation to Joe Joyce for sharing his family's personal story, and for reminding us of how important it is to not leave anyone behind as we continue to prioritize discussions on improving autism services and supports. Every person deserves to live a life filled with dignity, respect, and connection to the accurate, adequate resources and supports needed, and it must include people with all dimensions of support needs.”

DR. DANIELS: Thank you so much, Steven and Lindsay. Jenny Mai Phan?

DR. PHAN: Hello. Yes, thank you so much for the oral commenters who came on and shared their perspectives as well as stories.

I would like to bring up maybe a comment, written comment, that was written into the IACC, because I know we often don't select these comments to be discussed. But there was one in particular that really stuck out to me from Shelly Hendrix McLoughlin. Just to dovetail on Shelley's comment about Shelley’s son's experience with the health care system and the hoops that Shelley and their son jumped through to find the right support. I could relate to this. For example, my son uses atypical idioms or phrases that he believes describe his emotions or experiences. But those phrases only make sense to him. There's a lot of decoding on my married partner, my sons siblings, his teachers, and myself that we have to do in order to best support him. The issues that Shelley raised are some of many that I have heard from other families where they referred to one specialist after another, continuously throughout their child's lifespan. In my experience, misunderstandings, and misdiagnosis or missed problems, can be avoided if families can also access communicative therapies along with the autistic person. Many of the times, parents or caregivers are dropping their children off at these clinics for therapy and they're not actually a part of the therapy. I know, as a mother to my children, I could benefit from being included in speech, language, and communicative therapies where my experiences as my son's mom could be considered and partnered in this type of therapy. Part of it is that I can help with decoding what my son is communicating. But I also want to highlight the importance of child assent being necessary as a part of therapy partnership, as well as child assent for the family member to be a part of the therapy. If the outcome goals are to improve self-advocacy, empowerment, agency, autonomy, independence, and quality of life, implementing child assent and their input in therapy, supports, and services has the potential to foster these outcomes. I hope that this is one of the catchall comments that I'm providing that could address some of the written comments that were put in. Thank you.

DR. DANIELS: Thank you so much, Jenny. Scott Robertson.

DR. ROBERTSON: Yeah, thank you, Susan. I appreciate the wealth of comments here from both the oral comments and the written comments. I just wanted to especially spotlight the comments about intersectionality and the BIPOC community. I think it's very valuable and it aligns with what we've been focusing on with the Strategic Plan and other key priorities. I think communication use, obviously employment is very important to us at the Labor Department. The fact by folks that submitted comments on related to employment, including the project that we're running in collaboration with Mathematica, is very valuable.

I also wanted to spotlight that there's a couple of other themes that struck out to me. One of which was on autistic people raising families, autistic people who are parents themselves. There was a report that the National Council on Disability had done on disability more broadly, as far as parents with disabilities and lack of supports for parents with disabilities as far as empowerment. I don't know if that's something in a future topic for a meeting, or some other way to consider, is autistic people and what it means for family engagement, support for family life, as folks move through adult life. Then, another topic that has really stuck out to me was the focus in terms of what was mentioned on the school-to-prison pipeline and criminal justice issues, which are often under-researched. We know from some recent research literature just this past year that autistic people face substantial barriers in the criminal justice system and often are not having access needs met when folks are growing through the justice system. Sometimes there's different challenges with socialization, communication, and otherwise may face barriers such as, say, longer sentences sometimes then non-autistic people, there was a study that was put out on that had that in their findings. I think it was in the UK in this past year. I'm glad the folks are spotlighting these issues in the public comments and is especially great to hear from so many autistic people too, there were, I saw many autistic people discussing their experiences and the intersection with, in some cases with, professional work in the public comments, that it's always great to see autistic people and family members sharing their thoughts and perspectives and viewpoints on these critical issues.

DR. DANIELS: Thank you so much, Scott. Are there any other comments. Yetta Myrick.

MS. MYRICK: Afternoon, everyone. Thanks to all who presented their comments here live. I think that a lot that was shared could be things that we think about when we do our next report, our update, a progress report. There are a lot of great nuggets, things that I think we should be focusing on. I wanted to just make a note of that. The other comment that stuck out to me was on page -- hold on -- page 42. I hope I'm saying this person's name right. It was a comment that was submitted. Myread Keogan, who says that, "I'm an autistic social worker. I notice not only in the social work field, but in the mental health field in general, there's little training on autism in educational institutions and places of employment. Research in this area and the benefits of training on autism will be very beneficial for the autism community so the therapists, social workers, and doctors can be more educated about this population." I just wanted to call this comment out and agree, based on my own lived experience and supporting my son who is transition age, in trying to support him, as we think about him.

He's 19 now and 22 will be coming up pretty soon, and thinking about what employment and what supports are needed. Also I think the other piece too, generally in the work that I do locally in D.C., around providers really having a clear understanding about what everyone is doing, where can you find resources like this. This is a challenge, I agree, and thank this individual for submitting this comment, because in order for anyone to be a functional part of society, we all need supports. It doesn't matter whether you're autistic or not. I think that making sure that people have an understanding about what autism is, that the individual is that individual. However, how can you support them? I think that that is something that's lacking in this bubble here, based on our experience, whether it's lived or professional experience. I think again, I don't want to bring up this dissemination piece as well. That is why, with the understanding that this is for the government, but families are not, individuals are not, researchers are not, going to be able to advocate and do the work that they need to do unless everyone is on the same page, or has a general knowledge or understanding about what's going on in the community. I just wanted to thank again that individual for submitting that comment. I really think that we need to be figuring out ways to look at this, because our family members, we as individuals, we don't stay young, we age and we become adults. How can we all be functional parts of society and support those individuals? I think really is something that we need to be looking into. Thank you.

DR. DANIELS: Thank you, Yetta. Stephen, do you have a comment to share on behalf of one of our members?

MR. ISAACSON: Hi there. I have a comment from Morénike. They wanted to share a resource on their website, that was also shared on the [Marion Robyn] document. It's related to public comments around neutral language. morenikego.com/inclusive-communication-resources. She sent me a Google Doc with further comments, but I don't have access to see it yet.

DR. DANIELS: Thank you. With the round robin document that’s accessible to anyone who’s attending this meeting or anyone from the public. It’s on our website in the meeting page. You can access that there. If it needs to be updated, we can update it after the meeting. Ivanova Smith.

MS. IVANOVA SMITH: Hello. I am Ivanova Smith and I just want to echo the comments made about supporting an autistic throughout the full life span. A lot of times we get focused on the idea that autistic people, we develop slower, we don't develop, or like a different diet. It really that we just developed differently. Our development changes over time. It may look different, like the way we age looks different. I think it's important that we look in research and how we age and how aging affects autistic people in different support levels, in like co-occurring conditions that autistic people may have that will affect their aging. What things are we more prone to in aging? We're more prone to Altzheimer’s, like that, a lot of people with IDD that are more prone to Altzheimer’s, but it would be good for my family and my future generations, my children, to know those type of things when I become older because I won't be able to tell them in the future, maybe. That is true for other people, as well. I'm just using myself as an example. But I just wanted to echo that idea that aging is really important to look at and to research, and that we need to support autistics throughout the whole lifespan, not just at certain ages. Thank you for those comments. People [predict] that. Thank you.

DR. DANIELS: Thank you, Ivanova, and we'll let this be the last comment. Stephen, do you have one more comment to share?

MR. ISAACSON: Yes. I have a long-form comment from Morénike. She says, "I want to share some information to help inform the ongoing discussion about language usage, the resources I've reviewed all indicate that rather than constituting censorship propagated by an allegedly non-representative fringe elitist who are out of touch with reality, the recent suggested guidelines are very much aligned with best practices in research, communication, and journalism, and multi-disciplinary science and disability fields and publications around the globe. Please note that the resources listed within the document I'm sharing were easily identified via an informal internet search conducted on my phone and under 30 minutes. They are inclusive of autism as well as other conditions. The majority of them were collaboratedly drafted by diverse teams of professionals and stakeholders, explicitly inclusive of profoundly affected individuals vary with various disabilities, including terminal ones and parents of children. Those that relate to autism included autistic individuals and families from all parts of the spectrum. Several also predate, in some cases by several years, the inclusive language guidelines maligned by some commenters in this and the last IACC meeting. This indicates that they developed organically and not as part of some neurodiversity-led conspiracy to undermine scientific communication, or trivialize anyone's experience. Rather, the opposite appears to be more accurate. I hope having data of this nature will reassure all parties that they suggested not-mandated inclusive language guidelines helped to foster rather than hinder accurate and objective communication between scientists, whether they are discussing extremes of typical human personality characteristics, clear pathology, or something in the middle.”

DR. DANIELS: Right. Thank you. We are at the time for our break. Dr. Gordon, I don't know if you want to take a five-minute break now or do you want it to be a little bit longer than that?

DR. GORDON: Yeah. We're running ahead or we're right on time?

DR. DANIELS: We're right on time right now.

DR. GORDON: I would say let's go till two o'clock.

DR. DANIELS: Okay.

DR. GORDON: I think that should do it and that may or may not allow another break later before our guest speaker.

DR. DANIELS: Okay, thank you everyone for your participation in the public comment session and we'll go to a break.

DR. GORDON: Let me add my thanks to the public commenters, really appreciate everyone giving us their input and giving us or their food for thought.

DR. DANIELS: Agreed. Thank you so much for sharing with us. We'll see you at two o'clock.

(Whereupon, the Subcommittee members took a brief break starting at about 1:50 p.m. and resumed at 2:00 p.m.)

DR. GORDON: I wanted to go ahead and introduce this next section. Where we are meant to have a discussion around services that are helpful and supportive for individuals and families in the autism community. Why are we having this discussion? First of all, you heard from almost everybody today, whether it be comments from the Committee members this morning or the public comments this afternoon, that there is a great need for a range of services for individuals with autism, for an understanding of the evidence-based and support of specific services for recognition, as several of you said, and most perhaps eloquently by Larry Walker, that we don't have evidence-based for a lot of what we do. But much as we try in the Strategic Plan to set out what's known and what's available, and what we need to know and what we need to provide. I think there's a lot of interest in this group in discussing what are available evidence-based services, where are the research gaps. This is meant to help us figure out what our role will be moving forward in trying to identify and clarify what we know, what we don't know in the area of services.

Second, as you saw and was highlighted in particular by -- now I've forgotten who pointed out that intervention research has been going down from a collectively amongst the funders in terms of funded research. We need more of that and how to identify the gaps and encourage people to fill those gaps with research is something that we're obviously, as a Committee, very interested in trying to do.

Third, there's a lot of interest amongst policymakers and especially amongst Congress in understanding what more can be done to support individuals with autism and their families and communities. In particular, to understanding what evidence-based approaches there are out there that could help those people in need, but which might be challenging to access, either due to lack of providers, lack of funding, disparities, or other reasons. I wanted to engage you all in a discussion that we'll start today, but not end today.

In trying to understand what are: Number 1, the evidence-based services available now? Number 2, what are the needs for additional services that we might have? Number 3, what are the barriers in accessing the services that we need now? The first part of that was presaged by emails that the IACC staff sent out to you on my behalf, to really identify evidence-based services that are most beneficial to improve outcomes. Then, how easily can those services can be accessed in the real-world and what types of coverages and access are available, what barriers to those services, are helpful.

Now, I note in here that we're interested in hearing from all of you. Those of you with lived experience in accessing services, and those of you with the research knowledge on the current landscape to understand what services have an evidence base. Before I open the floor -- which was hopefully seeded by the fact that you all were asked in advance to think about it-- I just want to note that, yes, it's important to think about what people need and what services might be available to meet those needs. But here I really do want to focus on identifying the services for which we have an actual academic evidence base for efficacy in order to understand, again, the gaps in terms of what programs we might need to identify that don't have that evidence base. But importantly, also, think about how we as a Committee can improve access to the things that we have proven work. Right. It's a separate issue of lots of things that are out there that may have worked for some people or may be working for a lot of people, but we don't have the evidence to support it, which suggests that we need to invest in research. I really want to start with that first piece about evidence-based approaches.

With that, I'm going to turn it over to Susan because she has set up the discussion in terms of requesting responses from specific members. I'm going to turn it over to Susan to get the discussion jump-started.

DR. DANIELS: Okay, well, we have about 25 minutes to discuss each question. We wanted to leave a good amount of time on the agenda today for discussion and for each question, Dr. Gordon is going to be requesting responses from three IACC members in the following categories: autistic individuals; family members; and researchers, clinicians, and providers, or other professionals. We recognize that many of you fit all three of those categories or fit two of those categories. The intent of that is just to make sure that we have a wide variety of perspectives, as Dr. Gordon just mentioned. After those first three comments, the floor will be open, and Dr. Gordon and I will try to do our best to distribute the conversation around and so may skip over the order in order to make sure that we get different people. Keep your comments a little bit brief so that everybody can have a chance and, of course, be mindful and respectful, as we always are, of others that may have different opinions from you.

With that, this is our first question. What evidence-based services are most beneficial for children and adults with autism?

DR. GORDON: Alright. I'm sorry Susan, did you seed individuals already, or you would just want me to select? Okay, so I'm going to ask people to respond to this question, and go ahead and raise your hand. What I'll do if you'd like to respond to this one -- And what I'll do is, as I said, is we'll start with one representative from each of those three categories and then open it up more broadly. But please just raise your hands and I'll go ahead and select the first speakers based on that. [I'm just touched], I can sit here for a while. Yetta. Alright. We have--

MS. MYRICK: I just thought, I know we are going out of out of turn. But in terms of answering your question, I would say that speech and language therapy, occupational therapy, PT, those services are often available. One of the things that I tell parents and colleagues here locally, we’ll tell parents to access services through, like if you're waiting for an autism evaluation, for example, but it's suspected, is to go through early intervention services and oftentimes, families can access those services for free or little or no cost here locally in D.C., and my understanding, across many of the states. Those are the main services that we oftentimes tell families about. Yeah, I will stop there.

DR. GORDON: Okay. We've identified speech and language therapy and OT and PT as services that are beneficial for children and adults with autism. Certainly some of those aspects have pretty good evidence base behind them. Julie.

DR. TAYLOR: I would say for services for adults, I think that vocational rehabilitation has a pretty decent evidence-base that VR services seem to be pretty helpful in terms of getting autistic adults into employment and into employment positions. Now those get phased out when somebody has been there for a little while. That's a real challenge, but in terms of an evidence base for getting people into employment, I think there's some pretty decent work with the VR databases in autism and other samples to show that for a lot of people that works reasonably well.

DR. GORDON: Julie, before you move on, I don't know if you have anything else to add, but before you disappear, let me ask you a clarifying question there. You mentioned, of course, that vocational rehab has good evidence to get people into employment. I think there's also evidence that it can keep people in employment. Is that correct, or no?

DR. TAYLOR: Well, so once somebody has been in the job for a certain amount of time, even if someone's getting a job coach on the job or etc., at least my understanding is that those services fade out.

DR. GORDON: Well, actually it-- so I'm not talking about access now. I'll get to that. That was the question I want to ask. The difference between whether those services are still available and whether it's been demonstrated. We've heard lots of speakers here in our group talk about employment programs that keep those services for their employees in the long term. My question is, when they are, is there evidence that those approaches are better than phasing things out? Or is that a research gap area?

DR. TAYLOR: Sky will probably speak better to this than I am, but I think when I think there's evidence that when the services are there, that helps you.

DR. GORDON: Anyone else who wants to answer that question, please feel free to raise your hand and we'll get to it even if it's out of turn. Thanks, Julie, did you have anything else to say, or no? Okay. We've heard from-- let's go to Jenny next. I think we've got with Jenny the three categories covered and there are several, I think, Jenny and Yetta both wear dual hats. But go ahead, Jenny.

DR. PHAN: Yeah. I won't repeat what Yetta or Julie has already mentioned, but I want to add to the bucket, complimentary and alternative interventions. It's a smaller literature base. However, emerging evidence are showing strong efficacy for helping children with emotion regulation and coping issues, such as--

DR. GORDON: I'm sorry, Jenny, I want to interrupt you because we trying to figure out-- complimentary and alternative could mean everything from, let's just say, it can mean a lot of different things.

DR. PHAN: Right? Yeah. I'm I'm targeting specifically art therapy and music therapy. There's evidence supporting these types of therapies with helping children with emotion regulation difficulties. I just want to add that to the bucket as evidence-based services for children.

DR. GORDON: Okay. People should feel free, I like, Jenny, how you start out by saying, I'm not going to repeat what other people have said. If you want to briefly say yeah, I agree with that, or no, I disagree with it, please do. But I like this idea that we're going to keep generating a list that is not repetitive. Thank you.

Alright, well we've hit the three major categories. I'm going to now just bounce among some of our different members, not necessarily in the order you raise your hand. I apologize if I do that, but I'm want to try to keep the diversity of a representative of the Diversity Committee. With that in mind, I do know that I'm going to go next to Scott Robertson. You may have things to say about some of the other comments that have already been made. Scott.

DR. ROBERTSON: Yeah. Thanks, Dr. Gordon. I want to say, briefly, that I concur. I do agree with what was mentioned by Dr. Taylor, as far as the vocational rehab services, though a lot of autistic people may or may not qualify based on various different reasons in the States. We are doing a little bit of research in that area. I can't say exact specifics, but we have been looking at VR in our [array S] project at DOL. We've also looked at the research literature as far as not only what's out there, but in terms of the quality of evidence, and there are a lot of gaps there. But I think the major one that you were pointing out, rightly so, is the retention aspect, it's very rare that autism research studies have focused especially on retention and helping employers. For instance, support retention and long-term supports and natural supports to help folks retain their jobs and advance in their careers. Most autism research on employment historically over the last, I'd say 30 or 40 years, has focused on simply obtaining jobs. That's important, too, obviouslyo for internships, apprenticeships, etc. But that retention aspect is sorely lacking in the research literature. Then we need more research unemployment services in terms of how to scale them up across the country, too, when we're supporting research translation to best practices. It's a scaling issue, just like a lot of other aspects of quality of life with employment, services, and supports is that we have some models, but we're talking about sometimes there's thousands of folks, not millions of folks, who need sometimes even just a small amount of services supports to make the difference in terms of whether they can not only attain a job, but retain the job and advance in their careers. That's really lacking in the research literature is that, how do we move up with scaling?

DR. GORDON: Thanks, Scott. Appreciate it.

DR. ROBERTSON: Thanks.

DR. GORDON: Alice?

DR. CARTER: Thank you. I really appreciate and don't want to take away from anything that anyone has said. But I do want to challenge the question a little bit because children and adults with autism are not a monolith. Children are not a monolith, adults are not a monolith. I think that we really need to be doing a better job of characterizing our samples and figuring out which treatments for which individuals at which time in life, and how are we sequencing treatments, also. But because I just think if we have a list of interventions that are evidence-based, we could run into a real problem, because they may not match the needs of a particular individual. I love this question, I love that we're talking about it, and I have a little concern about thinking about this as one list for everybody.

DR. GORDON: I appreciate that, Alice. As I said, this is the beginning of a conversation, not the end. It's a question that's meant to put together a list that we can think about in those terms. One way to think about this, though, is that without defining what the basis is, it's hard to know then how to apply it to individuals based upon their needs. But you're right, in general, when you're talking about "evidence-based" services as people have already mentioned, and you highlight here, the methodology by which things are proven to be efficacious has its challenges in terms of meeting individualized needs.

DR. CARTER: Well, I think the other thing is for research, as we tried to expand the evidence base, I just would really hope that NIH, NIMH will push for looking at moderators of outcome. If there's not a global effect, but there's a strong moderator, that will be seen as a highly successful trial because we've learned that this treatment works for this subgroup and not for that subgroup.

DR. GORDON: Fantastic. Actually, that was actually been pointed out in some of the summary that answers papers that we looked over today. Thanks, Alice. I'm going to go now to Steven who has a comment that was typed in, I would imagine.

MR. ISAACSON: Hi there. Yes, I have a comment from Morénike. They said, "What I struggle with is, exactly what we mean by evidence-based. Depending on the data source, it seems that there is not necessarily enough high-quality research of substantial size, double mass, etc., that provides adequate information for enough for the population for one to determine how accurate many frequently-recommended services are.

DR. GORDON: Thank you, Morénike. It's an excellent point that gels also with points made by Alice and others already. That's actually part of the exercise here is try to figure out where we do and where we don't have a sufficient evidence base. I don't know if anyone else would care to comment on what we mean by an evidence-based approach. I've already given my two cents about what I meant by it and asking the question. But if there's anyone else would like to make comments, it'd be fine. Let's see. Hari, your hand just came up. Did you want to speak to what we mean by evidence-based, or did you want to make a different point?

MR. ISAACSON: Hari did send a comment here. He said that EVT is based on testable autistic. That means that it's leaving a bunch of data points out.

DR. GORDON: Thanks, appreciate that. Absolutely. This is an issue that we definitely want to keep in mind. I'm going to go with Jennifer Johnson and see in particular if you have something to say on that particular topic. Otherwise, please, go ahead and move on to the next.

DR. JOHNSON: Can you hear me okay?

DR. GORDON: Yes, I can.

DR. JOHNSON: Okay. Thanks. I'm having technology problems today, so I am on my phone right now, that's why I'm going to keep my camera off. But in response to your question about what does evidenced-based mean. I don't know if I'm going to answer that question as opposed to, I guess, broaden or raise questions about what we would call evidence-based. Sometimes, I think what we do is only think about evidence-based services and supports are approaches, which obviously is important. It's important to know what's working and what's not working. But sometimes, what that does is it sometimes leaves out some emerging practices or promising practices, and always having to wait for the evidence to be there means that some services may not be in place as immediately as they might be needed. As we're talking about evidence-based services and supports, want to just put it out there the thought of also thinking about or including emerging practices or promising practices. That getting pure evidence of what works may be limiting in our understanding of what's supportive for people with autism.

DR. GORDON: It's a good point. Larry, I'd imagine you want to make a similar point. Larry?

DR. WEXLER: Sorry, I was unmuting. Not necessarily a similar point, when we're talking about are there evidence-based practices out there. I just want to remind folks of the Promise Project research project that the Department of Education did in conjunction with the Department of Labor, actually, and there were close to 14,000 subjects in that, randomly assigned. What they found was that for better outcomes, now, this was not just persons with autism, but rather, all persons with disabilities, but there was about 700 persons identified as autistic, that was part of the sample. Really, what they found for everyone was a braiding of practices that led to better outcomes. They're not surprising, paid or unpaid work experience, benefits counseling both for the person with the disability as well as the family. There was a large family component, financial and financial literacy as part of it. The combination of those three led to significantly better outcomes for, I'm calling them kids, but they were youth, young adults.

DR. GORDON: Thanks, Larry. I want to go now to Ivanova.

MS. SMITH: This is Ivanova Smith, and I just want to comment to say that any evidence-based treatment, I feel needs to be person-centered and respect that every autistic is different, and so our treatment need to reflect our differences and individuality, that it can look different for everyone, and autistic treatments, and whether it evidence-based or not, one evidence-based treatment may not work for one autistic but might work for another autistic really well. Just always keeping that in mind that we just always do respect individual autistic and their medical needs are different than other autistic medical needs, and to always practice a person-centered approach. Thank you.

DR. GORDON: Excellent point, Ivanova, and I would add and this is similar to what, I believe it was Jennifer brought up. There are research designs that allow one to ask what treatments work for which individuals. Even that, of course, is not the same level of individualization that one would expect when you're working with a provider whose job it is to care for one individual, but from a research perspective, there are ways to gain that kind of evidence support to tailor therapies. Jodie.

MS. SUMERACKI: Hi. Yes, and I sent this actually to Susan. I think it might be helpful for some people. There's a good resource, it's a little bit dated, it's from 2015, I think, on the Autistic Self-Advocacy

Network website, that gets into, even on page 2, it starts to talk about supportive services for individuals with autism, a guide for individuals and families. There's a nice introduction. On page 2, it gets into the background and it says that evidence-based. It gives a definition of evidence-based, talks about developmental approaches, and really gets into some interesting aspects. I sent that link along. It might be of interest for some people to read that. I think it does a good job.

DR. GORDON: Appreciate that. Thank you very much. We'll be sure to promulgate that as we contemplate where to go with this discussion in the future. Dena.

MS. GASSNER: Quickly, but gently, I'm going to speak as a social worker from the field, as compared to all the other hats I wear. I'm going to gently push back on Julie's comment about the effectiveness of voc rehab. I do think that there's a pocket of individuals who begin and end as a closed case with vocational rehabilitation, identifying that as success. I do have to say, speaking from the field, I actually got a text in the middle of the meeting from a parent, that there are a lot of individuals on the spectrum who can't fit into established programming, and because it isn't individualized, it is not as effective for them, and we don't have those numbers because they're considered people who dropped out of the program, rather than being a successful case closure. We don't even have those numbers in terms of how many people go to VR as for VR services, tried to work with the system. I had VR services on behalf of my son in four different states. If I were willing to let him be underemployed, he would have a job through voc rehab. But I want him to have a job that's commensurate with his expertise, and they don't know how to go in and ask for the order. I've also had tremendous difficulties with multiple agencies related to self-employment. The example I was given was, if you want to be a researcher, then that's not really self-employment, wouldn't you rather open a hot dog stand? I swear to you. I would predict that within the next few months, my son is going to drop from the VR program because they're not getting the job done, and he's been a client for a year and a half. I wish I could say he's a rare example, but again, working with people transitioning to Social Security, many of them are going that direction because they haven't had effective transition services from school all the way through these systems. I think everybody is doing their best and I think there's difficulties.

DR. GORDON: Dena, let me actually ask you to keep your professional hat on for a moment, and actually maybe even divorce out for a moment your experience with your son, although I think it's an integral to your professional hat. What we're really trying to do here is identify services for which there is evidence that will benefit individuals.

Not all individuals. Maybe not even most individuals. There are plenty of therapies that have FDA approval that get paid for by Medicare, Medicaid, that only work in a minority of individuals. Nonetheless, they are services for which one provide. If you are asked to help advise a company about whether they should provide vocational rehab services, and all you could do is provide vocational rehab services of the type that your son experienced, would you not want that company to provide it?

MS. GASSNER: How can I say this? I think that what we're seeing is growing pains. I think the VR system is used to working with people with more overtly-presenting issues related to autism, people with intellectual disability, people with higher support needs, people that fall in what might be that moderate range, the guy that works at the supermarket. But when we're talking about people who could work at a museum, people who could work in a hospital setting, all the way up to people who are going to be leaving the system, getting a PhD, they have not been able to yet develop the expertise to come up with evidence-based services. The model could theoretically work, but they just haven't updated to incorporate more complex, more nuanced employment-based needs in the workplace.

DR. GORDON: Right. But we're asking a much more fundamental question. I would push back against all of those folks. But I don't disagree at all that individualization is incredibly important, but we're asking a much more fundamental question. We're asking, what services do we have at all to offer that we know work?

MS. GASSNER: VR services work for some people, I will agree with that. I would say I don't think it works for the majority of autistic individuals.

DR. GORDON: Fair enough. I don't mean to endorse that statement, that's why I was pushing to clarify. I'm not keeping track of time, Susan. I don't know how much more time we have on this topic before we should move to the next question, but while you figure that out, I'll ask Alycia Halladay to speak next.

DR. HALLADAY: Great. Thank you. Sorry, it took a while to turn on the camera. I want to just reiterate what people have said about individualized treatments or individualized interventions, that not everything works the same way in other people, but tag on to Alice Carter's comment, which is that we need large studies with moderating variables to get to this. These studies that we have now, which are a few, maybe 20, 30, 40 people, depending, that show efficacy or not efficacy, isn't going to get to the question of what works in what people without these moderating variables. I also want to put a plug in for behavioral interventions, which have been proven to be very effective. Then finally, I want to just warn us to think about-- to stay away from interventions. I know what Jenny Mai Phan was referring to is not harmful, but many interventions, in fact, are harmful and can cause harm, either financial harm or physical harm, or even lost opportunities for other interventions. I want us to think carefully about what sorts of interventions we want to endorse, because while there may be anecdotal evidence, and in fact, they can in fact be harmful. I know that's not where she was going, but I just want to take a step back and warn us against these potentially harmful interventions.

DR. GORDON: Fair enough. Now, Alycia, I want to actually ask you to specify a little bit more. Not to put you on the spot if you don't feel like you have the expertise or want to. Behavioral interventions means a lot of different things. Are you thinking of one or two or three that you would like to name, or would you prefer just to leave it at that that there exist some behavioral interventions?

DR. HALLADAY: Am I on screen?

DR. GORDON: You're on screen.

DR. HALLADAY: I know this is a tricky subject, but I think that applied behavioral analysis falls under one of those that has an evidence base. Then of course, I know some people have some bad experience with it, probably with some of the interventions that the types that were delivered 40-some years ago, and of course, not every behavioral interventionist or every clinician is the same, but this has a strong evidence base. I think other methods of communication research like PECS, for example. Although the evidence-- it's tricky, because there's really not a strong evidence base on paper, but yet it's one of the more understudied interventions that has a strong evidence base. Those are just two.

DR. GORDON: Great. Then I would mention another one. This is not my area of expertise, so someone jump in and tell me if I'm off base, the Denver Start or [debit an] early start.

DR. HALLADAY: There's a lot of these what are called “naturalistic developmental behavioral interventions.” They can include Jasper, they can include ESDM, they can include SCERTS. There's a lot of them that are based in the practice of ABA, but they're delivered in more naturalistic settings, they’re child led, they are very flexible, they're not what people think of as ABA, but yet they're guided based on the principles of ABA.

DR. GORDON: Now, I just want to say we've discussed in this forum issues around ABA. I'd rather not get into that argument right now. That's not the purpose of this discussion.

DR. HALLADAY: No, I don't think so either.

DR. GORDON: Right, and that's one of the reasons why I brought up these other models that are, so okay. You're really talking about as a class of interventions that are aimed around behavioral modification and then have some evidence base for them. They may not be working for all individuals and they may have goals that aren't compatible for all individuals, but they do have an evidence base.

DR. HALLADAY: Some of those have actually been, and I'll let Alice respond, have been studied with moderating variables. That is important to know certain work for certain groups of people, certain IQ levels, certain language abilities, so that adds to the strength.

DR. GORDON: I want to make sure to move on for a moment. Susan, should we move on to the next question unless you want to take--

DR. DANIELS: Maybe will be best to move on to the next question, unless you want to take--

DR. GORDON: No, let's move on and just end. The next question may be relevant to those comments you're about to make. Again, this is the first discussion, really a “feel out the space” discussion about this to see where we want to move. The next part of it is important.

If we're thinking about the evidence-based services we've already mentioned, or others that you might have wanted to mention it until we ran out of time, which of these -- I really want to focus on which of these are widely accessible. For those that are not, what are the barriers to access? One of them, let's just say get it off the table, you already heard, is that vocational rehab, which isn't always suited for everyone, that's number one, and another barrier is that they get easier to initiate than to maintain. Let's hear from folks about which are accessible and what barriers prevent access. Go ahead. I'm going to go to the comments, to Steven, because I'd imagine that might have been one that was already put in there and is relevant to this question. Go ahead, Stephen.

MR. ISAACSON: Thank you. This series of comments from Hari. He sent these over email.

He's talking about state supports, financial supports. They stop when you enter a grad school program. He says that state supports stop when you become a PhD student, for example, and the grad school stipend, which is barely enough for non-disabled folks. Well, it would count as your income. He says he's still significantly disabled and will continue to need the supports. He needs a full-time one-to-one aide, independent living skills, or ILS services; in-home support services; behavioral support; and CBT, cognitive behavioral therapy support. He says a barrier is finances and the majority of autism services are expensive, with little accountability for the quality of the services. He says they can be a huge burden on desperate families, even though some of them might be covered by insurance. He says that, why are people who choose to enter higher ed are being punished for doing so?

DR. GORDON: It's an excellent point, Hari, and of course, not just people entering higher ed, but of course, as others have mentioned in the past, in before this forum, those who get jobs often lose their support, or even just those who age out of the support that children get. Financial access is certainly a barrier to getting services, and I'll just throw in there, I'm sure will capture it in the notes, that Hari also mentioned a range of different services that he finds valuable. Some of them I'm sure having evidence-based behind them, Paul?

DR. WANG: Yeah. Thank you, so in response to this question, but very much following on to the comments that we heard earlier from, I think Alice initially, that Alicia was just touching on, also Ivanova, on person-centered and on different forms of therapy. I don't have an answer here, but a follow-up question for children who are of school age, who have intervention, therapeutic support services through the school district. How much of a menu of potentially helpful interventions is there, or is it the case that children aren't just like plugged into the one approach that a school system has, or, if you don't like, how often can they avail themselves of other approaches? If that first interventional style or package or whatever you might call it, is not ultimately effective for them.

DR. GORDON: That's a really good question. I don't know if people would want to answer that. Yetta, did you want to respond directly to that?

MS. MYRICK: Yes, I did. My understanding, locally and nationally, is oftentimes there are set therapies that are available, unfortunately, to families, and there's not too much more beyond that. That really is a challenge, so it’s then on the families, if they have the resources, if they can link into Medicaid, to do other things. Maybe a family can access speech at OT or PT, which is why that's part of the reason why I suggested those thinking about this question. Because there are not a lot of widely available resources. If a family is thinking outside of the box and wants to explore other therapies, it's oftentimes on that family to do that, and we know that, depending on what people's socio-economic situations are, that then determines access or not.

DR. GORDON: Yetta, I want to unpack a couple of things that you said and then go back to the other trains of thought. One, in your experience of what you understand nationally, it can be challenging to get into individualized therapy. We can add to the barrier list the lack of ability to individualization, lack of flexibility in the application in many of these services?

MS. MYRICK: Yes.

DR. GORDON: Another thing that you snuck in there that you also said earlier is that speech OT, PT, and language therapy are often widely available, and I don't want to put words in your mouth, but that is what you said before. I believe that's also generally true, but especially in younger children who are identified early in terms of early intervention services?

MS. MYRICK: That's correct.

DR. GORDON: Please, again, if people feel differently, raise your hand and you can make that point along the way. I want to turn to Mercedes, have you next.

DR. MERCEDES AVILA: Thank you, and just briefly, when we look at barriers, myself also being a parent, by working in academia and working in pediatrics, advocating for children's services is a full-time job for parents. That's a barrier that we need to acknowledge on an ongoing basis. There are also cultural and linguistic barriers that prevent parents from even advocating in school settings. That's another barrier that we need to keep in mind, that not every parent has the knowledge or skills or ability to be able to advocate in a setting where some of us come from countries where we don't question the school. We believe that the school is doing what's best for our children, and then we come to a society, that might not necessarily be the case. Advocating is necessary to get basic services for our children. I would add that delays screening, especially we heard that testimony for communities that are racially and ethnically diverse. We know that children who are racially and ethnically diverse, they'll have a delay screening. They're not identified with autism early on and that delays access to services, delays everything in in their life. Especially again, when parents can't advocate. I would add, also, that we don't have enough professionals, or professions being identified, for screening for autism, which is another big issue in our society. I would like to see federal agencies and organizations advocating for other professions. We only have a few professions, and the shortage that provides a screening for a specific diagnosis in our country, and we that's not meeting the needs, there are waitlists six months, eight months waitlists, to be able to access a screening. Then this connects directly with the previous questions of evidence-based practices, because we know that the definition of evidence-based practice is a very biased one in our society, we know that many communities are not included in research. Many community voices are not heard when it comes to providing services. Again, we need to have a more culturally and linguistically responsive way to hear the voices advocate for community-based participatory action research, qualitative study that collects stories of communities accessing services, so we know better. These two connect, but there are so many barriers, especially for family with school-age children, and then it transition years. Then it becomes even more complicated because there are, as it has been mentioned early on, all the different variables. Thank you.

DR. GORDON: Thank you, Mercedes. Matt Siegel.

DR. SIEGEL: Thank you. This is a tricky question to answer because, I think, if we were really honest with the first question, what services are widely accessible and covered by health insurance, the answer would be almost none. The one that is probably most widely accessible and covered by health insurance, but it's not necessarily the one that we want to be turning to first in most instances, is medication. I think that's the truth. Then, if you go from there, most other things are not widely accessible. Quality ABA is not widely accessible and frequently not covered by health insurance, or you have to fight for it. CBT for anxiety and anger management, or variations on that, which has a good evidence base, very few therapists trained in those things are comfortable with people with autism. Speech pathology outside of school systems, very difficult to access. Speech pathology for social pragmatics and communication, very difficult to find. So not to be negative, but I think that's the perspective that I see, and the barriers are multiple for many of those different things. But they do include payment systems and reimbursement, and just to pick out one piece of that, a lot of work has been done nationally through advocacy to get various autism services, including ABA, reimbursed by commercial health insurance plans. However, that's still a struggle. There are age limits on almost all of those, and there's still a lot of work to be done there. Those are some thoughts, if I’m really being honest, from the field, or from the ground of what's widely accessible.

DR. GORDON: Let me explain, Matt. First of all, I really appreciate the honest appraisal of accessibility, and you identify at least two very important areas that serve as barriers. One is the lack of reimbursement, the other is the workforce issue. Again, when we think about policy, when we think about legislation, when we think about federal solutions, which is what this Committee is concerned about, identifying the barriers that prevent access to evidence-based services is something that we can potentially influence, and so it's useful to think about those, and so I really appreciate those comments.

Let's see. It looks like everyone who's handout has already commented once, so I will go at this point to the first person in line, which is Alice.

DR. CARTER: Thank you. I'll try to be quick because I have spoken. I just wanted to follow in on what Yetta said earlier and that you highlighted, which is the Part C early intervention system is widely accessible and free across the country. The problem is that it's incredibly unevenly distributed and there is not good incorporation of evidence-based interventions, and training in evidence-based interventions, within the Part C system. I think focusing on enhancing those systems and enhancing workforce development within those systems would be extremely beneficial, at least for the youngest kids and that includes screening for autism within the Part C system, which we've demonstrated not only works well in identifying where kids, but also addresses health disparities, and also, there are states where they've built in diagnostic services. There are really wonderful models out there that could be great, and then the other thing I think is, also making sure when we're talking about what's working, thinking about outcomes that matter to individuals like communication, like being able to communicate one's wants, needs, and etc. I'll stop there.

DR. GORDON: Great. Our newest member, I'm going to let her have what I think, given Susan has come back on camera, it should be the last comment for this session before we move to the third. I apologize again, I know there’s people waiting to comment. I’ve been trying to spread the answers around. Karyl.

DR. RATTAY: I think there is a little bit of a different approach or perspective in thinking about the increased burden of chronic disease. Looking at the lifespan, health promotion programs, and disease prevention programs, there are some that are evidence based for the general population, but have not been well studied for individuals who have any, really, special needs persons with disabilities, really have not been designed to address accessibility. Although they are available in pockets in different places, they're not widely available, and again, they're certainly not in an accessible way. I also think a lot about the whole lifespan and ensuring that we're also able to promote good health among persons as they age.

DR. GORDON: That's an excellent point, Karyl. I think it also echoes in a certain way, if you allow me, a little bit of poetic license. The comment by Alice, in that yes, services are available, but they're not necessarily well tailored to the evidence base and they're not well tailored to individuals with autism and, or to the individual, as others have commented as well in the past. Thank you very much for that.

I think I jumped the gun a little bit. I think we have a few more minutes left on this topic. I'm going to go next to Steven to read a comment from the chat.

MR. ISAACSON: Yes, hello. I have a few comments from Morénike. Yetta Myrick also commented that she'd like to agree a hundred percent with what Mercedes Avila said. Morénike said, "My understanding is very similar to that of Yetta’s, not just as a mom, but in my work as a former special educator, families do not get many choices, unfortunately, and when they try, there's a lot of pushback. There is a growing evidence base for parent mediated advocacy and empowerment training. They have proven to be effective in terms of improving child outcomes and family dynamics. Some of them are designed to be culturally competent: FACES is one targeted to black families of children on the spectrum; Parents Taking Action, which is a bilingual program for Latinx families." Here is another. Morénike said they fully agree with Yetta, Dr. Siegel, and Dr. Avila. "It's very challenging in a number of ways, and this is speaking from my perspective as a parent, as an autistic person, and from a professional experience, as well. One often does not get comparable services in the school district compared to what you can seek in terms of private pediatric rehab services and, like Dr. Avila said, less privileged parents are often unable to advocate successfully for their needs for various reasons, including cultural, language, and racial barriers. One might receive two or three times weekly OT, through private insurance or Medicaid, while schools district offers your child 30 minutes of OT every other month, and maybe 30 minutes of group ST provided by speech therapy assistant once a month."

DR. GORDON: Thank you very much for

those comments. I just want to shout out to one of our own of course, Julie Taylor, who conducts research on parent advocacy training, showing that they can have positive outcomes, particularly in transition period and lots of other work, as well, on that, in that area. We're going to go with Scott next.

DR. ROBERTSON: Thanks, Dr. Gordon. I wanted to add life coaching, too. I think it's an area where there's been promising practices and a little bit of research starting in there. Not covered by insurance, as was emphasized by pretty much everything out there for autistic people, and then just to concur with the fact of allied health services, social work, OT, speech and language therapy. In some cases, some of these things are covered by insurance, but folks are just not trained in autism and developmental disabilities. That means that folks do not have understanding of issues like executive functioning, and social communication barriers, and sensory motor issues, that autistic adults based at affects quality of life and bar employment, community living, education, etc. I think that training aspect and services, I think can't be separated on that, is we need more research that goes to that area.

DR. GORDON: I appreciate that, Scott. A little bit of word of caution with life coach. Life coach is something that is used, again, like behavioral therapy, to mean a lot of different things, and so when really needs to look at in terms of whether there's an evidence base in support of it, really look at what's being done. Certainly, one of the areas where there is a fair amount of research is on coaching of parents of children with autism and other caregivers. But, thank you very much for that comment. I think we'll take one more comment on this question before we move on to the last. Dina.

MS. GASSNER: I just want to talk about one elephant in the room, and that's privilege. I participated in Julie's programming on parent advocacy. While well intended, and I think it does serve some families well, it requires you to be able to participate in the training. Too many women are leaving the workforce to be available to do those things. I think a better solution to all of that is having systems navigators at every tier that intervention support is needed. I think that parents have an outrageous responsibility, because of the lack of services in home-based services, to try to serve their children as a volunteer speech pathologists, OTs, being someone's attorney should not be on that list of parent responsibilities. I have long advocated for that. I do agree that OT, PT, and speech is necessary. It doesn't end at 22. I think that an occupational therapy or physical therapy environment shouldn't look like little kids go there, if it's an adult service delivery model, that's very off-putting. I also want to say from recent experience, we had this beautiful thing that I teach. The group is child life specialists. They’re people in hospital settings who helped children who are struggling to cooperate with medical care because of fear and anxiety. We have nothing comparable for adults with disabilities. We assume that an adult with a disability that comes through the door autonomously is not going to need services. I think that I've had so many negative experiences in that position.

I also think our failure to train medical providers at the medical school level on how to be diverse in their expertise. I had my ankle reconstructed. I have tried to convince my doctor that I need a sleep treatment right now because I'm sleeping with a five-pound boot on. He's like, well, I can't do that. My mental health provider is, like, well, I can't do that. My general physician is saying, well, I can't do that. Well, the reason they can't do that is because none of them get that he's not treating my ankle, he's treating the whole person. If you don't know how chronic sleep issues are in autism, and you don't trust the individual to adequately and accurately report what they need, then that person is going to be marginalized and underserved. They need that translator in there, that person that can bridge the gap. I just think that's a huge barrier in terms of not having systems navigators, not having adult-oriented OT/PT spaces, and not having child life specialists that grow up.

I also think, lastly, that there needs to be intensive intervention at the time of diagnosis, regardless of age. We dump all of our resources in early intervention, which is wonderful, I believe in it. I think it's helpful for many students, but we have to realize that many people are coming to their diagnoses, not only late, but after a long, lifelong, experience with repeated traumas because they didn't have the self-awareness and the resources they need to be more successful. I'm looking at kids that are getting good services on the front end, have very good mental health at the backside. For people who never had that, in that void is where a lot of garbage grows. We need to help people unpack that at the time of diagnosis. We can't just give them a piece of paper and ship them on their merry way.

DR. GORDON: Thank you, Dina. Well, Yetta, if you can be brief, I can squeeze you in before we move to the next question.

MS. MYRICK: Yes, very brief. Thank you. Dena, a lot of nuggets there, just want to flag the safe initiative, which was in the round robin document last meeting, which is supporting access for everyone. There are four or five of us who served on that Committee, and we are looking at making sure that hospital settings, medical settings, are accessible to everyone. We recognize the point that you are making about adults, and there is going to be a little bit of information about that, but that's not essentially what the document was slated to be, but we do acknowledge that. I just want to flag that for everyone, that that will be coming out soon, without giving too much information. I also think that you are correct in terms of families having a lot on them, and it should not be family members’ jobs to case manage and do everything. However, I also think it's important to note that families, the individual, we are partners in care. I think that the more we wrap our heads around that and this person-centered approach, I think we will get closer in making sure that families have the supports, individuals have the supports that they need. I'm going to stop there. Thank you.

DR. GORDON: Thank you, Yetta. We're going to move on now to the third question. What are some unmet needs for which services do not currently exist or exist at scale? I think you’ve already, many of you have been discussing this. I'd ask you, as you contemplate answering this question, not to be repetitive with what's been said earlier. Let's just ask if there are additional unmet needs for which services --I shouldn't say if --unmet needs in addition those that have already been mentioned, for which services do not currently exist or exist at scale, should we be considering? I see a hand up already, so we'll go with Jenny to start.

DR. PHAN: Hi, thank you, Dr. Gordon. This suggestion comes from my area of work as a researcher and educator in human sexuality, also working with adolescents. I would like to suggest comprehensive sex and sexuality education supports and services. Specifically, direct supports and services are needed for autistic people. Right now there are pamphlets, online resources, ad nauseum, all over the internet that families can access. The issue here is not getting direct supports and services. It's a barrier, not just for families, it's also a barrier for developmental scientists working in this area who are trying to study children development and puberty, for example, and the influences of this sensitive critical period of development impact on the brain and behaviors. Which is an area of focus of my research. I think it's critical that not only autistic children get access to comprehensive sex education. If people are looking, the CDC has this wonderful guideline for comprehensive sexuality education from kindergarten to 12th grade that educators, if you're interested, you can look this up, but I think, more importantly, families need direct supports and services surrounding these topics about growth, development, sex, sexuality, consent, menstrual cycle, gender identity, hygiene, victimization, just to name a few, but there's lot. The other is these services may not be supported by insurance or Medicaid, and I think it is a critical conversation to have, that these direct supports and services be covered by insurance and Medicaid. Thank you.

DR. GORDON: Excellent point, Jenny. I

don't know how widely those services are available to individuals who are not on the autism spectrum. But there are clear specific issues here. That would be helpful if it could be provided for members of our community. Certainly, it also gets to the question-- that was not the question, the issue that was raised earlier-- in that where are those services exist, whether they be in school-based programs or from primary care providers, those programs and our providers are not likely experts in being able to provide those services to individuals and families are in the autism community. Next up, I'm going to go with Steven for another chat comment.

MR. ISAACSON: I have comments from Dr. Avila and also Hari.

Dr. Avila says that she completely agrees with Dina. She says we need more community health workers and navigators, especially for underserved and unserved communities. She said we definitely need effective and humane training for future health and allied health providers, including anti-racism training. That type of training is not happening effectively, and that's why we continue to see enormous health disparities and inequities.

Hari provided this comment through email. He said that most families or autistics he knows are in California, and so that's why the comments here are based on the experience around California surfaces. There's various recurring themes that adult autistic and families struggle with and that have problems with. He said it’d be nice to have regional centers provide the following supports rather than remain in asylum. He says that guidance on navigating critical health benefits, including info, planning, and navigation, would be helpful. Many of these issues with benefits are foreseeable, and often occur at predictable points, including Social Security, SSI, the ABLE accounts, and other critical financial planning tools. He said better guidance on real, person-centered planning would be helpful. Health promotion and life coach support, and health care advocate/navigator for tracking appropriate medical care, continuity of care, and embedding of critical supports for exams, and visits, and procedures. He also mentioned housing supports and supportive training for DSPs, direct service professionals, across daily living, dealing need domains, including health monitoring and communication, and other functional supports. Regarding the regional centers, he says that having specialized staff would be a more powerful advocacy voice for weighing in key community entities that make decisions affecting health. Like a vaccine, access, responsive Housing Authority programs, policies, and more. This is so that individuals can be better included in community life and have much needed supports.

DR. GORDON: Thank you.

DR. RATTAY: A couple of things, I know we're not supposed to repeat, but I also really wanted to re-echo comments about community health workers and care coordination. It's so critical, and there are so few, and they are not well reimbursed and supported at all.

The comment I really wanted to, or the point I really wanted to make is around emergency preparedness and response. I think we've seen that in multiple emergencies, whether they're weather related emergencies or the pandemic, whether it's across federal agencies or state or at the local level. We're not doing as good of a job as we need to in our planning and in our response to address the needs of people with disabilities, and that certainly includes people with autism. In our shelters, as an example, when people need to go to shelters, we need make sure that we're able to meet people's needs, when people need testing, vaccination, etc., we need to make sure that we're able to meet people's needs in those settings. Communication across the board, it's critical that we're able to meet people's needs.

DR. GORDON: Thank you, Karyl. Dena.

MS. GASSNER: I wanted to talk about the need for in-home supports. We have this distorted perception in many of our service delivery models, whereby we think if we train somebody that they're going to develop the skills as if they’re non-disabled. The reality of it is, for many of us you could train us in a specific area, all day long, for weeks and weeks and months, and we're still not going to be able to execute the task. I think that flips back to what we were saying about parents of different cultural backgrounds, different social expectations about interacting with systems, we're never going to inherently just understand that. Again, we’re talking about privilege. The few people who can get to that level of expertise really struggle, also. I don t know a single autistic adult who doesn't have something they could really use help with, in-home, whether it's cooking, whether it's help with purging a doom pile, whether it's help with organizing their daily functioning. For some of them, even that help may not need to be in the form of training, again, it may be ongoing, in-home support services. Denying that is keeping a tremendous number of people out of the workplace, or they get in the workplace and they can't maintain it. It should be based on functional limitations, not based on intellectual or cognitive test scores, which we often assign services based on that. It's a developmental delay. We're going to have pockets where training isn't going to fix my math LD, it's never going to get better. For that particular arena, maybe I need an accountant to work with me once a month on my banking, as an example. I really do think that we need to remember that you don't outgrow autism. You grow into supports and services to help you achieve your own personal best, howeve, that's defined, and the supports are not getting us there.

DR. GORDON: All right, thank you. I think what I want to do at this point is wrap up. I appreciate all the comments and input. We're going to distill down what's been said, not distill down, but report out what's been said in the minutes, as we normally do. What I'd like us all to think about is what role does IACC have in trying to elucidate what services that we have are available, and identify the barriers and communicate that in some way. To certain extent we do that in the Strategic Plan, but some of the comments made earlier about lists and individualization, etc., maybe that's what we want to focus on in terms of making broad statements, as opposed to specific ideas about lists or things like that. But we may have a role to play in terms of advising the federal government on existing services that have barriers that we want to try to reduce. Thinking about how we want to prioritize our efforts in that area would be useful as we move forward. Thank you very much for your participation in this really broad-ranging discussion. I really appreciate, also, the spirit of collaboration. We had folks across the spectrum of our membership today contribute and I really appreciate that very much. We're going to take another break and we're going to come back. Is that right, Susan? I think so.

DR. DANIELS: Yes, we have a break. The next session starts at 03:40, unless the core is ready to go.

DR. GORDON: Let's plan on coming back at 03:35, which gives us still a 20 minute break, which will be nice for all of us, I'm sure, after the last two-plus hours that we've been here. That way we'll be sure to be ready for Dr. Cook and Dr. Warren and their presentation on PCORI. I think you'll find that what they're bringing to the table is very relevant to the discussion we just had, and very relevant to the goals of the IACC.

We'll see you back here at 03:35. Thank you very much.

(Whereupon, the Subcommittee members took a brief break starting at 3:15 p.m. and resumed at 3:35 p.m.)

DR. GORDON: We welcome everyone back. We are joined today by Dr. Nakela Cook, who is the Executive Director of PCORI, assuming that position in 2020. Prior to joining PCORI, she served in several other positions, including Senior Scientific Officer and Chief of Staff at the National Heart, Lung, and Blood Institute, which is one of the other National Institutes of Health. We're also joined by Dr. Meghan Warren, who is a Program Officer on the science team at PCORI, where she manages a diverse comparative clinical effectiveness research portfolio, including PCORI research on intellectual and developmental disabilities, particularly irrelevant to our Committee's work. I want to thank you very much the two of you for joining us today, and I'll just preface your talk with one more remark, and that is that I had the pleasure of meeting you, Dr. Cooke, a little bit earlier this academic year, if we can still talk about an academic year being in government, but I'm really glad to learn of your personal interests and PCORI’s interest in expanding the work that you do in developmental disabilities. I'm really glad you could join us today along with Dr. Warren to talk to us about PCORI interests in these areas. Thank you very much and take it away.

DR. NAKELA COOK: Well, thank you so much, Dr. Gordon, and it's so wonderful to be here this afternoon. I hope you've had a productive meeting thus far, and it's just my pleasure to be here with all of you to speak with you who share a really strong commitment to the important research related to autism and to improving the lives of autistic people. We certainly appreciate the opportunity to share with you some of PCORI’s current work, and especially some of the highlights of our portfolio related to intellectual and developmental disabilities and autism spectrum disorder.

I know that there are so many ties between PCORI and this Committee, one of which is that several of you that are here today are members of your organizations, serve on various PCORI panels or committees, or have participated in our efforts to garner relevant input for our work. For that, I wanted to personally thank you. We also appreciate the engagement of so many of you in our recent strategic planning process and the vital feedback that you've provided at several points along the way. I'm sure today's meeting we will provide just another opportunity for ongoing productive collaboration.

Today we hope to cover quite a bit about PCORI in our portfolio in the next 30 minutes or so, and we're just at an exciting point and are now 12-year history at PCORI. I'm going to update you on our current research focus at a relatively high level and introduce our approach to research for those of you who may be less familiar with PCORI. And we've also recently refreshed our strategic plan, as I mentioned, which will guide our funding decisions and other work over the next several years. I'll be delighted to share with you some exciting components of the plan, at the heart of which are our national priorities for health, which you'll hear more about. As Dr. Gordon mentioned, I'm joined today by my colleague, Meghan Warren, who will be taking you into a deeper dive of our portfolio of research on intellectual and developmental disabilities and autism spectrum disorder.

Just a quick note that in 2019, when we've received our re-authorization from Congress, our reauthorizing law actually included a special provision to fund research on intellectual and developmental disabilities. While this had been a long focus for PCORI even before our reauthorization, it does allow us to take a long view of this work that we were really excited about.

Following our presentation, we hope to have about 30 minutes or so for some of your questions and comments and we look forward to a lively discussion.

But before I begin, I just wanted to mention a quick note on language. I know that there are different perspectives within the autism community regarding terminology used, and we'll be using terms like autistic individuals, individuals with autism, as well as both autism and autism spectrum disorder, or ASD, interchangeably throughout this presentation, really in an effort to be inclusive.

Let's begin just by touching on PCORI mission. This is a very brief mission, but I think it's a bold and really important one. PCORI’s mission is to help people make better informed decisions about their health and health care through research that's guided by patients, caregivers, and the broader healthcare community. We really do this, primarily, by funding comparative clinical effectiveness research, or CER. CER projects address questions that are important to patients, to caregivers, and other healthcare stakeholders through studies that generate the evidence that's meaningful to those who need that information to make health and health care decisions. Finally, we also have a very unique focus, of PCORI, and dissemination and implementation on facilitating the uptake of research results such that they're accessible and useful to those who can use them to make better health care decisions.

I did want to speak just briefly, before getting into the detail on our plans for the future, about the approach that makes the PCORI funded research different from most research and health and health care, and at the core of this approach is engagement. We define engagement as the science and the art of robustly bringing together, and meaningfully involving, patients, caregivers, family members, advocates, payers, purchasers, clinicians, communities, and many other stakeholders throughout the research process, all the way from identifying the areas of focus for research funding, to planning the study and designing the research question, to conducting the study and participating in the research, to reviewing applications for funding, and, ultimately, to disseminating and implementing study results. Patients and other stakeholders are represented, as well, on PCORI's five advisory panels, which provide guidance to us and to our leaders on funding priorities and other strategies. We believe that including the voices and lived experiences of patients and others helps to ensure that we are funding the studies that are examining the issues and the outcomes that matter the most to them.

At the bottom of the slide, you can also see that we have identified six key principles that we've determined to be really essential to effective engagement. These include: reciprocal relationships when roles and decision-making authority are defined collaboratively and clearly stated; co-learning regarding the research process and patient-centeredness; partnership and valuing all members of a multi-stakeholder research team; and transparency, honesty, and trust, which are enhanced when decisions are made inclusively and information is shared readily with all research partners. When Meghan comes on to discuss more of the specific aspects of engagement, she'll talk about how it relates to the development of topics in our funded studies in just a few minutes.

PCORI developed a range of approaches for different types of evidence products that help us to meet our mission, helping people make more informed healthcare decisions. These include some shorter-term types of evidence synthesis tools, such as horizon scanning reports and evidence map. They take about a year or so to develop. You'll see one example here on this slide, which is our social needs evidence map, which summarizes what's known about interventions that address non-medical needs that may not be traditionally attended to by the health care system, but nonetheless, contribute to health status, such as programs that aid with transportation, housing stability, or food security. This type of evidence map gives us an understanding of the existing interventions and the status of that evidence related to those interventions. You see here as well that we support systematic reviews and other evidence products like topic briefs. That's located in the middle of the slide. These can take from about one to two years. You'll hear shortly about a relevant topic brief a little bit later in the presentation. At the end of the spectrum here, you see the funding of phase trials and broad-pack pragmatic studies, which can take up to seven years to complete. This approach across a spectrum of different evidence, products, and activities allows us to balance that need to be nimble and responsive and a rapidly evolving healthcare environment, providing information on what may be known, while also pursuing the need to fund research that generates the data that can only come from rigorous long-term studies.

At PCORI, we also have an array of funding opportunities that we pursue for research, primarily on that longer end of the spectrum on the slide that I just discussed, as well as research-related activities. Related to research, as you can see here, we have focused research funding opportunities that are generated from topics that emerged from our engagement of patients, and caregivers, and families, and advocates, and others from the stakeholders in the health care community. But we also have open solicitations for topics related to our national priorities for health and our large clinical trials, ranging from smaller studies of about $5 million to larger studies of about $22 million. Just as important as the research that you see those funding opportunities for are the research related activities that we fund. These are the things that we believe make us a little bit unique in the research ecosystem. We fund opportunities for engagement that's focused on capacity-building, dissemination and stakeholder convening, as well as dissemination and implementation projects that help take PCORI-funded research results into specific settings and up to scale. You're going to hear more about how we're utilizing these approaches in our portfolio related to intellectual and developmental disabilities in just a little bit.

Engagement, as I mentioned, is at the heart of everything we do at PCORI. This was also true of our work around our recently approved strategic plan. At every stage of the process, we sought and incorporated feedback from across the stakeholder community, including many of you that are here today. This plan has some distinct features that will bring a new focus to our work over PCORI's next phase. One of these features is this holistic approach that you see pictured here on the right, in which four essential elements of our work come together to help us achieve our national priorities for health. These are: our funding of comparative clinical effectiveness research, really PCORI's bread and butter work; but also our stakeholder engagement; dissemination and implementation; and investments and research infrastructure.

At the core of our strategic plan are five national priorities for health. These are mutually reinforcing goals that will drive our funding and other initiatives and help us to improve patient care as well as health outcomes. These priorities were developed with input from a wide variety of stakeholders over a period of more than a year. There's one priority that I'll point out here that's devoted to the goal of achieving health equity. We also consider health equity to be woven throughout all of the priorities and through everything that PCORI does. We're also recognizing the critical concepts of equity and inclusion encompass more than race or ethnicity or gender, or even demographics, and really intend our approach to be inclusive of all groups, such as the autism community. These priorities also reflect on evolution in our work, with an emphasis on health and on the multitude of factors that really influence health, rather than focusing on health care alone. This means that we have a stronger focus on the whole range of factors that contribute to an individual's health beyond the clinical interaction, including things like social determinants of health, and all of those elements that contribute to a person's health everywhere they really live, work, learn, and play. In the context of research related to autism spectrum disorder, this would also include things like managing life stage transitions, which we continue to hear is so important for this community.

This shift in our approach is also going to require us to strengthen some of our existing partnerships and develop some new ones beyond the formal health care system. Such as in the fields of public health or education or housing, and really putting a premium on collaboration and on engaging with all audiences and communities to help us improve the health of all.

As we move forward in implementing our strategic plan, we've also developed a high-level framework for our immediate next steps that will guide our funding and other work driven by the input that we received in our strategic planning efforts. We identified this set of early topics for focus and these topic themes, which as you can see here, include things like mental and behavioral health, amongst many others. They were approved by our Board last year and are starting to be incorporated in our funding announcements. These eight themes really relate to high impact and hybrid and health conditions, as well as particularly vulnerable populations of children and youth and older adults, and they include urgent issues such as violence and trauma, substance abuse, and mental and behavioral health, as well as a widespread of conditions like cardiovascular disease, pain management, and sleep health. But as with everything that PCORI does, these things were developed with significant input across our stakeholder community and they are intentionally broad and will be further refined with continuing input from our stakeholders. The things also intersect with, and are in addition to, our work that's related to intellectual and developmental disabilities, as well as several other workstreams ongoing at PCORI. We'll also continue to address other priorities in our research funding through our broad funding announcements.

In addition to the topic and theme framework that I just mentioned, I also wanted to emphasize the fact that that framework will help ensure that all the work that PCORI is funding, related to two research priority areas that were emphasized in our reauthorized law, are not siloed but really are integrated across those themes and more. Those two priority areas included, as I mentioned before, intellectual and developmental disabilities, but also research that addresses maternal morbidity and mortality. You'll also hear more from Meghan Warren shortly about our engagement awards, our evidence products, and funding opportunities that we're investing in related to intellectual and developmental disabilities.

Finally, I just wanted to mention one other provision that was in our re-authorizing law, which encourages research that we fund to capture the full range of outcomes, including the economic impact and other burdens of patients use of medical treatments and services. This includes things such as out-of-pocket costs, transportation, or childcare. We're really excited about the opportunity to help inform patients’ choices by what they need to know about the economic and other burdens related to different choices and interventions.

This concludes my brief overview of PCORI and our high-level plans for the coming year. Now, to take a closer look at our portfolio related to intellectual and developmental disabilities, I'm going to turn it over to my colleague, one of our senior program officers, Meghan Warren. Meghan, you're up.

DR. MEGHAN WARREN: Thanks, Nakela. Thank you all for the invitation to talk about our intellectual and developmental disability focus. What I want to talk about is our approach to this and also our work we've done to date. --Sorry about that.--

Before I start, I wanted to let you know how we're defining IDD at PCORI. We wanted to keep this really broad so that we're as inclusive as possible when we're looking at funding announcements. We use the term “developmental disability” that are disabilities that originate at birth or in the developmental period and cause impairment in physical learning language and/or behavioral areas. Intellectual disabilities are under the umbrella of developmental disabilities and specifically involve limitations to cognitive function and adaptive behavior. With our work, when we're trying to develop topics of interest for research funding and IDD, we use an iterative approach where we focus on background research, literature reviews, and stakeholder engagement, and each one plays a role into the other. Background research may include government documents and clinical practice guidelines. Literature reviews have a focus in systematic reviews in meta-analyses. But in the IDD population, we also consider other study designs because of the state of the evidence in this field. Then, of course, a critical piece is stakeholder engagement, and that includes self-advocates and their caregivers and family members, clinicians, researchers, government agencies, community agencies, and other groups that Nakela talked about. The iterative approach to this is when we have conversations with our stakeholders that may require us to go back into the literature to find something further. Or literature prompts us to seek out additional stakeholders to make sure that we're fully aware of the topic. Once we have a topic that's important to stakeholders, it's necessary for further research and can be answered with a CER question. We then move to a funding announcement.

With our work in IDD, we have four goals. One is to fund high-priority research, and those can be the short and long-term projects that Nakela spoke about. Building capacity for PCOR or patient-centered outcomes research. There are engagement awards and our PCOR network, dissemination and implementation awards to take work that's done from PCORI studies and implement them more broadly into clinical and other practice, and enhancing efficiency and research design. There are methodologic guidelines and our funded method studies.

The next couple of slides I want to talk about some of the funding announcements that we've done specific to IDD. This first one is an engagement award that was issued in 2021 and it's to build capacity for PCOR and CER, so PCOR, patient-centered outcomes research, and CER, comparative effectiveness research. This was an engagement award announcement that was trying to build support for education, knowledge, competencies, sharing of work between self-advocates and researchers, and trying to build this capacity for stakeholder engagement with PCOR and CER. The topics that are listed here are some of the areas of focus of these awards, and these were really identified as the critical areas that require additional comparative effectiveness work.

In all of our research awards, we do have a specific callout for intellectual and developmental disabilities. Since our re-authorization that has been one of our areas of focus. We had some more specific areas of focus. In 2022 we had a specific area of focus and caregiver-delivered interventions and that was looking at evidence-based, or commonly used, caregiver-delivered interventions. Of note with this, outcomes could include outcomes suggest focused on the person with IDD, or could focus on the person with IDD as well as the caregiver delivering the intervention. We committed $20 million for that area and, currently, the applications are under review.

In 2020 and 2021, we had an area of focus and improving care transitions in individuals with IDD. This is looking at models of care to support transition of health care from pediatric to adulthood. This was the first topic that we issued after our re-authorization and focus in IDD because this was really the most important topic that came up in all of our engagement activities that we had done. We had $12 million committed to this area and we funded three studies that are all ongoing.

Finally, in 2021 and 2022 we issued a funding announcement on comparative effectiveness of interventions targeting mental health in individuals with IDD. These interventions could be pharmacologic and/or behavioral interventions. Again, this was a topic that really was identified as really important to the IDD community, and really had an adequate evidence base to come forward with a funding announcement specific to it. We have $40 million committed to this area, and so far we funded two studies. I'll talk about one of them in a little bit.

Since 2012, PCORI has awarded $112 million to fund 87 comparative effectiveness research studies and research support projects with a focus in IDD. The research support projects are those engagement awards that I talked about. We also have had some methods awards and infrastructure awards, but that's not the focus for today.

As far as the number of projects, our engagement awards are smaller in scope and shorter in length, and we've funded 56 of those projects with a total investment of $11 million. Our CER projects are larger in scope, and longer as Nakela talked about, and we’ve awarded 28 of those projects with a total investment of $101 million.

We funded projects in IDD in 27 states and D.C. But it's important to note that's the institution, or the organization, that was awarded. There could be data collection and research participants in other states. For example, if we had a study that was funded in Arizona, they may have study participants in Arizona and Utah that would be part of that. That's why we have 27 states that are in dark blue that received awards, but there may be a far greater reach.

When we look specifically at autism, we funded 14 engagement awards in autism only with a total investment of $3.2 million. For our research awards, we've funded five with an investment of about $27.5 million. Then, those other awards and methods and other things, we have a small amount of money with two awards.

All told, at PCORI, currently, we've awarded 20 projects with a total investment of just over $32 million. That's about 30% of our overall IDD investment. It is important to note that these are projects that are solely focused on autistic people. We also have a large number of studies that are in people with intellectual and developmental disabilities, and those certainly include people with autism, but are not solely focused on people with autism. Research awards, the median sample size for these is 300, but you can see there's quite a range of the size of the studies in these five research awards.

The next few slides, I want to talk about some examples of studies that we've funded so that you have an idea of what we mean by engagement and what we mean by CER. The first one is an engagement award. This was funded in 2021, so it's ongoing. For all of these slides, at the bottom of the slide, I included the link to this study on our website if you would like to get more information. Our first engagement award is building capacity for CER/PCOR participation among black, indigenous, and other people of color, adults on the autism spectrum. This study was proposing to increase the capacity of BIPOC autistic adults in Massachusetts in Texas, as advisors, as experts in CER and PCOR. This perspective of autistic BIPOC individuals is really critical for studies, but it's often not utilized. This study worked to educate these autistic adults on CER and PCOR, and also identified outcomes that were important to BIPOC autistic individuals. The outcomes of this project will be a toolkit for BIPOC autistic adults interested in partnering with research as experts, as well as a toolkit for autism researchers on how to engage BIPOC autistic adults. Again, this is in progress, so we don't have those toolkits yet.

The second study is a research study and this is completed, Improving Classroom Behaviors Among Students with Symptoms of Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder. In this study, it was a randomized trial of 24 schools with 148 third graders in Washington D.C. It compared a new program called Unstuck and On Target to usual care to improve student learning and behaviors. The Unstuck and On Target teaches students how to plan, set goals, and be flexible. The outcomes were observed behaviors, observed problem-solving skills, and parent reports about the student's behavior. As Nakela mentioned, all of our studies have a strong stakeholder engagement component, and in this study, parents and parents of children with ASD and ADHD, school staff, and clinicians provided input on the measures for this study, the study protocol, the retention of participants, training, and then interpretation of the results. Additionally, the schools in this project were low-income schools, and so how to best adapt some of the materials for low-income populations in Spanish-speaking people. The results of this study, when all of the students were compared together, executive functioning did not differ between the programs, but amongst students with ASD, the Unstuck and On Target program, improved classroom observed executive functioning behaviors, as well as parent report executive functioning and student problem-solving. This study now has a dissemination and implementation award to try to implement this intervention outside of those 24 schools that were originally under study.

The final study I wanted to talk about is one from our most recent funding announcement in mental health. This has been awarded and they haven't started yet, but it was awarded to the University of North Carolina at Chapel Hill. It was comparing cognitive behavioral therapy versus mindful based therapy in 300 autistic adults in North Carolina and Virginia with co-occurring anxiety and/or depression. The outcomes for this study include anxiety and depression symptoms, overall sub-clinical severity, quality of life and well-being, functional impairment, use of emergency services, and acceptability and feasibility of the treatments. The engagement partnered with a PCORI-funded stakeholder engagement group made up of autistic individuals, family members, and clinicians, and they'll help with shared leadership and decision-making for this study. Again, for all these studies, I have the website on the slide so you can keep track of these studies moving forward.

Finally, as Nakela said, we do have some short-term evident projects. In November 2022, we published a topic brief on treatment for insomnia and other sleep disturbances among persons with developmental disabilities. The link is included in this slide that will take you to that topic brief.

On the right panel of this slide, is a white paper on methodological challenges in IDD research. In March of 2021, we had a workshop on the challenges, and hopefully some solutions, in conducting research in IDD. Some of the things that we talked about in this workshop were some of the comments heard earlier in the discussion, about what outcomes are most appropriate and how to address the wide heterogeneity within IDD, and then, also, within autism and some other conditions, and how we can come up with patient-centered research that really addresses the wide heterogeneity. This is a really nice document that involved a lot of stakeholders in the discussion.

I think now we have some time for questions and discussion. Our PCORI IDD website is included on this slide, as well as an email address if you have any questions for us. Thank you and I look forward to your questions and comments.

DR. COOK: Wonderful. Thank you so much, Meghan, for that detail on the portfolio and looking forward to hearing people's questions.

DR. DANIELS: Josh, did you want to moderate or would you--

DR. GORDON: No. Go ahead. But let me just say thank you very much, Dr. Cook and Warren. I know there'll be a lot of interest, especially, thank you for highlighting some of the studies you're doing in autism. They are addressing questions and concerns that we've been talking about even today. It's really wonderful to see this work being funded by PCORI. I'll turn it back over to Susan, who will moderate the Q&A with our members.

DR. DANIELS: Thank you so much for this great presentation. We really appreciated hearing more in-depth about your work and look forward to the questions. First, we'll take a question from Dena Gassner.

MS. GASSNER: I don't have a question. I wanted you to know that I'm part of Brenda Maddox's training team on the topic that you funded, so I want to thank you for that. I also wanted you to know that I'm not a young career researcher, but an early career researcher at a very old age, and I am using many of the PCORI constructs, if you will, in my dissertation. I have a community advisory board that's helping me come up with my questions for my qualitative study. I'll be compensating those people. I want to shout out to PCORI that one of their mandates is that they always have advisory people involved in their research, and that they are properly compensated, which is a breath of fresh air, because so many self-advocates or early researchers give away their time to research, but they get a gift card for a Starbucks coffee. For a grant to not only mandate compensation, but to mandate a living wage compensation, is a breath of fresh air. I have done three different PCORI projects. I was with [asset], that was my first project, and I just want to champion you for your person-centeredness and magnifying the voices of marginalized individuals. I don't know, I just think it should be the example of how research is conducted around the nation. I want to thank you very much.

DR. COOK: Thank you for your lovely comments and we really strive to achieve those goals. It's wonderful to hear the affirmations from others that we're meeting the mark, but there's always work to do. We continue to push forward.

MS. GASSNER: Well, I appreciate your efforts and I just wanted you to hear that, because I don't know how often that happens.

DR. COOK: Thank you.

DR. DANIELS: Thank you so much, Dena. Yetta Myrick.

MS. MYRICK: Good afternoon. Thank you for your presentation. Like Dena, I'm going to give high praise to PCORI. I'm not a trained researcher. I am a parent who has all this lived experience and literally got into research by one of the studies, the second study that you shared about improving classroom behaviors, I actually, amongst students with autism and ADHD, I served as a stakeholder advisory board chair and that was the first research study that I worked on. I learned a lot and can't help but think that participating in NIH studies with my son, and then having the opportunity to be on that stakeholder advisory board with PCORI, has gotten me here. Currently, I am also working on one of the engagement grants, the Building Capacity in African-American ASD Community for Patient-Centered Outcome Research with Allysa Ware through Family Voices, and just really excited about the work. Again, just want to really thank you all for providing this space for us to do work that, oftentimes, does not touch people who are lower resourced, people of color, and so on and so forth. Thank you.

DR. COOK: Well, we should really flip the thank you to you for participating and leading in the way that you have, because without people like yourself, none of this would be possible. We are equally as grateful.

DR. DANIELS: Thank you so much, Yetta. Scott Robertson.

DR. ROBERTSON: Thanks, Susan, Dr. Warren and Dr. Hook. This research is amazing. I want to share my compliments, too, as I enjoyed hearing everything that you all spotlighted in there. I wonder if you've considered putting some of the best practices that you have, the best and promising practices, for how we approach research, bringing in the community and paying autistic people and other folks who identify as self-advocates, if there was a way to maybe compile some of that into the best practices that you do that could help us, I think, enhance the work we do in supporting research across the governments and outside of government, as well. Because everything you highlighted, I think is wonderful and should be emphasized, I think, an awesome research across the board and in other disability-related research, including bringing folks from the community to help be equal partners in the research process and help shape what's happening with it. It's all excellent. Thank you for funding so much. I didn't realize that the portfolio was at large, that it's 32 million, that's a pretty significant investment. We appreciate that.

DR. COOK: Thank you so much for that comment and as well as your appreciation for the work. Maybe I'll mention just a couple of things that we have been doing, and Meghan may have a few others. We have really strove over time to find ways where we can publish what we've been learning, from our efforts and engagement, as well as start to make those learnings really accessible to those that are trying to work in the way that is really much more of this patient- and stakeholder-engaged approach to research.

There are a couple of things that you can find on our website as resources which we'd be happy to surface. One is that we have an engagement rubric that is really a guide for the way in which our multi-stakeholder research teams approach to the work and the funded projects. It provides some of those best approaches to how you may take on engagement and research. The other thing that we've done is we've put together a couple of forums on our website where you can go for a training, in terms of how you may think about approaching a multi-stakeholder research team, and really understanding what that means, ways you'd have to communicate differently, what it means in terms of even thinking about the way in which you set up the times for meetings, the structure of meetings, things of that nature to really fully engage patients and others in the work. We've also started to pull together opportunities where we think about the lessons learned that we've had and our funding opportunities to understand more about engagement. We have, actually, a portfolio of projects that we're currently soliciting around the science of engagement, which will help us to learn a little bit more about the process of engagement, some of these best approaches and the outcomes that are achieved from them in a very rigorous way, because we've been observing things over time that we're collating, but we also want to make sure that, in this rigorous approach, we're able to gather that information and create a body of work, really, from this laboratory of engagement we've been conducting for the past 12 years, and anticipate being able to continue moving forward. There are some things to come and some things that already exist, and maybe some of your points, we could also take it to heart in terms of how we could really expand the opportunities to share these learnings even further. Meghan, is there anything else you'd want to add?

DR. WARREN: Yeah. Just a couple of things. I'll echo the working with multi-stakeholder team, that resource that we have on our website, it is probably the number-one website that I share with the projects that I manage, part of my portfolio. I share it with prospective applicants, awarded applicants, anyone who's thinking about applying to PCORI, I really share that very liberally, because I think the resources are truly spectacular, and it's a really easy-to-follow module. I think the other thing that is related to Dena's comment, we do have a compensation framework for stakeholders, and we do value that, and those resources can be really helpful in understanding considerations and how to engage people that are critically important to the research conduct.

MS. GASSNER: Just to chime in on that, I just have to say I'm involved in another project, and they wanted to pay us for three months' work, all at the same time. Knowing that many of their stakeholders get government benefits. I had to explain to them that we appreciate the compensation, but it needs to be teased out to a monthly basis so no one goes over their limits. PCORI already gets that.

DR. DANIELS: Thank you for sharing all those wonderful resources. We'd be happy to add more of those to the website for this meeting afterwards. If you send me some of those links, I can add them. I know, certainly, in our office we hear a lot of questions about stakeholder engagement. We'd be really interested in hearing about any future events, or webinars, or papers that you may be putting out about stakeholder engagement, because there are a lot of questions in the community and we'd be happy to help you disseminate those. Alycia Halladay.

DR. HALLADAY: Hi, thank you for a great presentation. I had a question around-- Since you do have a focus on intellectual disability, how you envision individuals with intellectual disability participating in projects that may require a little bit higher cognitive function. Things like economic costs, things like complex emotional issues. How do you ensure that everyone, because they should and could be engaged, how do you account for that in the intellectual disability framework?

DR. COOK: I'd be happy to start us off, and I think Meghan probably has more to add, and it's such a great question. One of the things that we think is critical, as you heard even in our presentation, is to really understand lived experience in order to contribute to even how best to engage, or how best to involve, certain groups and individuals in our work. I think one of the ways in which we strive to do that is by first listening and learning in order to help inform, and encourage that even in the conduct of the studies. I think even in populations where we may not know how best to make things accessible, etc., it's about engaging and asking in order to learn that, and to provide frameworks that move forward. That's what we encourage of the multi-stakeholder research teams, as well. But Meghan, did you want to add to that?

DR. WARREN: Yeah. I think as a program officer, we're in really close contact with the people that we award projects to. We do, after award, the researchers are required to submit an engagement plan to us. We monitor and we discuss their progress, challenges, modifications to that. We're able to pull resources from other projects that we've had, other projects PCORI has had, and then we have engagement officers at PCORI with an expertise in engagement. We can use, we can pull our colleagues in to help, to hopefully address some of the issues as they arise, rather than waiting until the end of the project to say this didn't work well. I think our frequent communication with our study awardees and really trying to stay proactive-- Because there could, of course, so many of our studies are trying to address health care issues in the United States. We could have a study that not focused on IDD. There could be study participants in a trial that's comparing two medications for asthma that include people with asthma. Making sure that the breadth of the participants in that project are addressed at the very beginning.

DR. HALLADAY: Sorry, I wasn't clear. I just want to follow up with them. You're talking about after the person has received the award. I'm talking about even earlier on in the LOI stage, because the LOI stage for PCORI is very competitive. If you don't have a comprehensive plan for patient engagement that in fact the reviewers for the LOI approve of, then your LOI is pretty much shot. I've actually been involved in some applications that involve things like economic costs, and cost benefit of certain things, that our engagement plan wasn't strong enough, because the individuals with a cognitive disability were not participating on the same level. I just wanted to throw that out too, but I know there's people waiting.

DR. COOK: I may have one quick thing to add here, which is that I would also encourage in that scenario to consider things like our engagement awards, which as Meghan mentioned, are smaller scope but allow for some of the capacity-building, some of the relationship building, some of the information sharing that will help to build a bit of that ability to build the necessary skills to be involved in the CER projects that may--

DR. HALLADAY: Yeah. No. I was talking about the engagement awards. Yes. So there's been some challenges with people, a lot of people, who are family members of people who are intellectually disabled, who I've been involved in half a dozen application LOIs where the engagement of those who are cognitively disabled wasn't equal to those, that or was different, and the reviewers didn't like that. I just wanted to bring that to your attention that there may need to be some adjustments for the role of people with cognitive disability.

DR. COOK: Great, Thank you for raising that. I will definitely also consider that we have technical consults where this information is very helpful for us to hear back so we can think about how we can help support others. Thank you for that.

DR. DANIELS: Thank you so much. Jenny Mai Phan, can you provide your comment for us for your questions?

DR. PHAN: Thank you, Dr. Daniels. I just want to echo what everybody else has already said in terms of how PCORI is really leading the field in its mission and practices for funding research. I've had the honor and privilege of learning that process with the review and the carry out of people being funded by PCORI. I also love that PCORI has an area focus on adolescent health, and that there are some significant interests among investigators on adolescent health, and that adolescents youth are engaged in the engagement process so that they have a say in their own health outcomes. Of course, PCORI has a number of funded projects and lifespan, health outcomes issues.

I just have a question. I'm not sure if it could be addressed now or later. Has there been interest in intensive longitudinal studies looking at long-term health outcomes in autism? It's a topic that comes up a lot during these IACC meetings. I was just curious to hear if that's a topic that comes up with the PCORI?

DR. WARREN: I'll start here. The examples I gave happened to be randomized trials. We do have some observational studies, which would be longer-term studies. We have had discussions in our IDD work about how long should these studies be followed up. Especially, as you said, in the adolescent as they transition to adulthood. Those are current discussions that we're having.

DR. COOK: Yeah. I would also mention that, traditionally, our length of studies have been in that more three- or four-year time frame, but we've recently realized the need for longer-term studies. That's where you see some things are up to the seven-year time frame, even for some of our clinical trials. These are the active discussions that open up new opportunities, as we learn what's really necessary for different types of things that we're trying to take on that are importance to our community. Thank you for raising it.

DR. DANIELS: Thank you. Dena Gassner.

MS. GASSNER: I just wanted to say to Alycia that there's many things that we do, I'm on teams where we have people who are non-speaking. I'm on teams where we have people who have ID and they don't read. Whenever we're generating collaborative work with them, we make video recordings on voice thread, or we make a plain-language version and the contributing community advises us on how to word all of that. Actually, I'm borrowing a lot of those strategies for my dissertation because I don't want intellectual level to be something that keeps people out or a learning disability in reading or whatever could be happening.

DR. HALLADAY: I get where you're coming from. I think the challenges is that in the LOI, which is very competitive, it's been my experience after doing several of these, that there's an expectation that the individual who has a cognitive disability, is non-speaking. Well, non-speaking can be different, but especially with intellectual disability, that that person is able to contribute in the same manner as other people, including those who may have normal cognitive function, which just really isn't the case. Take the case of economic costs, for example, you cannot expect somebody with an intellectual disability to be able to estimate the cost of living. That's not really their job and it's out of the scope. For situations like that, you may not be able to engage all the stakeholders in the same way. I just wanted to alert PCORI that that's the case when you work with intellectual disability, and that there should be some way to adjust for that at the LOI stage, because that's been a point of contention in many of the LOIs, which don't have the advantage of being able to describe the plan. They want to know who's going to be involved and when you're writing the LOI, you're very honest about the roles that people can make. Once you get that award, then you move into a completely different situation. But just getting the award becomes very challenging in that way.

MS. GASSNER: Thank you.

DR. COOK: Alycia, I would just say that, please do contact us offline. We'd love to talk further about that, and we have that venue for that technical consult to work through how we can approach those things together.

DR. DANIELS: Thank you. Are there any other questions from our Committee? Paul Wang.

DR. WANG: Fantastic. Thank you for telling us about the scope of all of your activity at PCORI. So much of that as the other commenters have mentioned is relevant to us. I'd like to ask you, looking forward, how can this group, how can this Committee, be of service to you in your priority setting? If I may be so bold, should we have a member of PCORI on this Committee?

DR. COOK: Well, we'd love to stay in touch for this type of dialogue. We've been eagerly awaiting an output of the Strategic Plan that you've all been working on. I think that's going to be incredibly informative for our work. The other place that we find the relationship between this Committee and PCORI to be really valuable is through the opportunity for, and that ongoing engagement that we talked about, whether it be related to when we were developing our strategic plan or when we're trying to refine some of our topic themes, and really understand the needs within those themes related to autism research and things of that nature, is that we would love to use this Committee and the members of it as a resource for that kind of input into how we guide our priority setting and approaches that we recognize may be right for PCORI to take on. Hopefully, this is just that way in which we're re-introducing ourselves and to the Committee as we continue to have these types of opportunities to work together. I appreciate you offering that willingness because we were certainly hoping that this is part of that collaboration but a springboard to much more. Meghan, I saw you smiling, did you want to say something?

DR. WARREN: I'd say the PCORI-wide initiatives that we have, but then also with some of our IDD-specific topic development and how we work in there, that would be great to have a continued relationship because this is such a broad group of experts that would be great that we could collaborate with and get feedback from.

DR. DANIELS: Thank you, and we would really encourage you to stay in touch with us. I also wanted to highlight that PCORI has been a really great partner with our Interagency Autism Coordinating Committee portfolio analysis, and all have been submitting your data to the portfolio analysis for a few years now, and we really appreciate having you within the landscapes that we are tracking for autism research, so thank you for your continued partnership on that. Ivanova Smith.

MS. SMITH: I just wanted to respond and comment. I want to thank you for your presentation and also want to [inaudible comments]

MS. MYRICK: Ivanova, maybe turn off your camera because you're breaking up.

MS. SMITH: --Disability as I did research stage. When they see things more accessible for people with intellectual disability by making plain language documents, making ways for people to explain things in meetings in a more accessible way, and helping self-advocates have all access to research opportunities, and having IDD researchers try to figure out a way to make becoming a researcher accessible for a person with intellectual disability. I think we really need to work with academia to make that more accessible, so we can hear more from people with intellectual disabilities. Thank you.

DR. COOK: Thank you so much for sharing that perspective. One of the things that we have strived to do with PCORI is that we have what we call lay abstracts that we published on our website, that really is trying to make sure that we're putting research findings in lay and accessible language, and so we work very closely with them, lots of experts to try to help us do that. We'd love to continue those efforts in terms of making the results of the work accessible, but also, if there are ways in which we can partner to think about the accessibility of those with intellectual disabilities as part of our work we certainly welcome that, as well, so we really appreciate you raising that.

DR. DANIELS: Yetta Myrick.

MS. MYRICK: Quick question and follow up, Dr. Cook. When you write those lay abstracts and you have those experts, do you also have a stakeholder group that reviews those documents before they go up? I just wanted to confirm that.

DR. COOK: Yes. There are, I would say, maybe multiple steps in that process. Part of what we have to do at PCORI is actually make sure that we report our results publicly and not just rely on publications, and so we have what we call a peer review process to review the research results and help us with the interpretation of the findings, and that includes a broad stakeholder component, in addition to traditional researchers involved. It has a stakeholder component within the peer review process. Then we also have a translation component, which is what I was referring to, which is a center that we fund to really work through the translation of those results to be accessible and published in that plain language. That process actually has mostly an expert team that's focused in translation, that helps us with those activities. Does that help in terms of responding to your question?

MS. MYRICK: Yeah, it does. Thank you so much. I appreciate it.

DR. WARREN: Can I add one other thing, Yetta? We also put this on, we also have an expectation with our researchers that their dissemination is not only scientific peer review journal academic articles. Their dissemination covers the full scope of stakeholders for this study. We have that piece as well, to try to make this as broadly applicable and broadly communicated as we can.

MS. MYRICK: Yes. I can say that happened in both the projects. Project I'm working on now at the project before. Thank you.

DR. DANIELS: Thank you so much. It looks like we have probably finished the questions here and we're out of our time. We really appreciate both you, Dr. Cook and Dr. Warren, being here, sharing with us your wonderful work, and talking about some different collaborative opportunities. We would love to stay in touch and work on those with you. Doctor Gordon, do you have any final comment?

DR. GORDON: No. I do see a hand up by Alison Marvin. I don't know if she's in preparation for the Round Robin or if she would like to make one more comment or question.

DR. DANIELS: Sure. Alison.

DR. MARVIN: No. Just getting ready for that Round Robin.

DR. GORDON: Let me thank you again doctors, Cook, and Warren, for coming. Really appreciate it. You can tell that we are actively engaged and interested on this topic. If you were interested in having someone from PCORI join us on a regular basis, please just get in touch with myself or Susan, and we can help facilitate that.

DR. COOK: Thank you so much. We're so pleased to have been here today. I appreciate the invitation and we'll follow up.

DR. GORDON: Great. Susan, I'll turn it over to you for the Round Robin.

DR. DANIELS: Thank you. Now we have some time for Round Robin updates. We have about 18 minutes and we'd love to hear from our members about the things that you've been working on in the last few months. Just pointing out that we have a Round Robin document that is on our website that everyone can access. But feel free. Some of you might want to verbally share some of the same things or different things. We'll start with Alison.

DR. MARVIN: Hi, thank you so much, Susan. First, I'd like to direct everybody to the newly redesigned ssa.gov website. The reimagined website with books that focus on customer experience and the improved self-service capability allows people to skip calling or visiting the office. We do recommend people do that. It's designed so people can go in there and it makes it easier to find what you want to do. I think it's very good and people should take a look at it.

The second thing, SSA has made a second round of awards for the Interventional Cooperative Agreement Program, the ICAP. Projects under ICAP are cooperative agreements with states, foundations, and other non-federal groups and organizations for the interests and ability to identify operate, and evaluate research related to disability insurance and supplemental security income programs.

Now you know that, I'll let you know who the winners are. Those awards were made to Mathematica and Westat. For research, that will include participants on the spectrum. Mathematica will conduct a randomized controlled trial to assess the impact of unemployment intervention for youth with disabilities who are transitioning into the adult workforce. That's very appropriate. Westat will conduct a randomized, controlled trial to assess the impact of combining supportive housing with individual placement and IPS-supported employment services for recently homeless people experiencing a range of disabilities. If you want to read more about that, just check the link in the round robin document.

Now, actually, we're soliciting for a new grant administrator for our small grants program. This is the point where I would normally say we're going to be launching our draw and trying to get people to apply for grants. But now we're looking for the grant administrator. That's the analyzing relationships between disability rehabilitation and work. If you've research organizations, universities, associations of research organizations, universities, [USAIDS, IDocs,] the grant is going to be posted under grants.gov and there's a link in the document.

Lastly, just a quick plug for the Able Age Adjustment Act that was signed into law. This will raise the ABLE account qualifying age of onset of disability from 26 to 46 as of January 1, 2026. These ABLE accounts are tax advantaged savings accounts that are available to certain individuals with disabilities. One advantage of an ABLE account is that the first $100,000 in an ABLE count is exempted from the SSI individual resource limit, which is very important. Thank you so much and have a great afternoon, everyone.

DR. DANIELS: Thank you so much for those timely updates. We'll give an opportunity to Judith Cooper to share on updates.

DR. JUDITH COOPER: Thanks. Yes, I just want to remind everyone about a webinar that's coming up next week. On the afternoons of January 24th and 25th, NIDCD is going to be hosting a virtual webinar open to all, no registration needed, entitled “Minimally Verbal, Non-speaking Individuals with Autism - Research Directions for Interventions to Promote Language and Communication.” Just a word, quickly, about the purpose of the meeting. It is to identify research needs and opportunities for improving both language and communication outcomes for minimally verbal, non-speaking children-- autistic children-- as well as adults. The webinar's going to focus on three main areas: novel interventions, research designs and methods for intervention studies, and meaningful outcome measures, which we expect is going to foster the development of critical research studies addressing the communication needs of this population. Our planning committee, as well as the participants who you'll see on the webinar next week, include individuals on the autism spectrum, non-speaking persons with autism, parents of non-speaking autistic children and adults, as well as clinicians, educators, and researchers who, for many years, have experience working with this group. In addition, we're also going to have some presentations about interventions and findings related to non-autistic but other non-speaking populations, so that maybe we will learn from and can inform our approaches in autism. We feel very certain that our discussions and our goals next week will reflect a spectrum, a breadth of perspectives, a breadth of opinions. That being said, regardless of perspectives, I believe there is a common goal for NIH's next steps. That is to identify intervention research approaches that will enable all children and adults with autism to develop and utilize effective communication. We hope you can join us. Thank you.

DR. DANIELS: Thank you so much, Judith, and we have the link on our website, as well, and are happy to disseminate that. It also went out at our newsletter to everyone. Hope that people can attend that webinar. Alycia Halladay.

DR. HALLADAY: There I am. Sorry. I want to make sure my camera’s on. Hi, everyone. Thank you for allowing me to speak. I wanted to highlight three things. The first of which is the ASF announced the recipients of our most recent pilot grant mechanism. It's actually new mechanism. We don't normally give out pilot brands, but we did. They called for ways to improve inclusion of individuals who are minimally verbal, or have extreme cognitive disability, or both. They include a study on a new, non-invasive way to detect brain activity during sleep; an understanding of who is using IACC devices and what sorts of training or support they need, because we know way more people need one than actually have one; an examination of self-injury in a large, community-based setting across the state of Pennsylvania; also, an examination into the predictors and a possible treatment of a phenomenon known as neuropsychiatric regression. Those of you who know of the [family make Germans] syndrome community know that this is a pervasive problem. It's probably more problematic than we're recognizing across the autism community. But it seems like girls, anywhere between the age of 15-25, start to experience catatonia, other manic-depression, even psychosis. It’s obviously incredibly debilitating. You can learn more about them on our website, including better summaries that I’m giving now.

We were happy to organize a meeting before it got too cold in Minneapolis of the Baby Siblings Research Consortium. This is 50 researchers and growing from around the world who study individuals who have a younger sibling with autism. The early signs and symptoms, all the way from birth to age of diagnosis, both biological and behavioral, can be monitored. We talked about the biological and behavioral signs of autism that are present, and also specifically talked about how to support families in a variety of ways, and how to communicate better with health care providers to ensure that diagnosis can occur as early as possible.

Then finally, I want to mention that we have our 10th annual Day of Learning on March 30th in New York City. It's going to be hybrid, so even if you don't live in New York City, you could still attend. There will also be a short, celebratory cocktail hour afterwards, if you can participate in person. Go ahead and save the dates and registration is going to open literally in the next couple of weeks. That's it.

DR. DANIELS: Thank you so much, Alycia.

Yetta Myrick.

MS. MYRICK: Thank you for giving me the floor again, three things for me as well. To address Jenny's point about sexuality and DD earlier, I wanted to share that through my non-profit, I work with a sexuality educator here locally named Marsha Stepensky, and we offer a sexuality and DD workshop. We normally hold them on Zoom, so they will be open to people all across the US. We're working on a schedule, but I anticipate we'll restart in the spring, and when that information is available, I will share that out.

Dena mentioned I'm training on anti-racism. Another project that I'm working on -- I know, so many things -- is the Family Voices United to End Racism Against Children and Youth with Special Healthcare Needs and Their Families. It's not autism specific, but we have developed a toolkit through the work that we had done in the midst of all the things that have happened in the past few years in relationship to George Floyd's murder, disproportionate numbers in the African-American and black community, as it relates to COVID, and so on and so forth. We have the toolkit available. I will make sure that you all have access to that website, but we have resources on anti-racism, how to do work in your states. Know that it was originally developed for the Family Voices Network, which is a national network of family-to-family health information centers. But I think that that information is vital to support folks who are interested in doing anti-racism work. We're now piloting in three states, Massachusettes, Oregon, and Nevada, them actually putting together a town hall based on the work that we did in the first year, year-and-a-half of our work.

The third thing I want to share in relationship to the PCORI Engagement Award that I mentioned I'm a part of earlier, that we're going to be conducting trainings for autism researchers on engaging the African-

American community. Late February, early March, we are in the process of finalizing flyers. I anticipate it's going to be 40 spots available, so if folks are interested, please reach out to me directly, but I will get that information to Susan and team. Thank you again for giving me the floor.

DR. DANIELS: Thank you, Yetta. Paul Wang.

DR. WANG: Thanks, Susan. A quick mention of three funding opportunities from SFARI. The first two both relate to DEI, and we have offered these opportunities for a number of years now, they're continuing. One is to support the recruitment of members of underrepresented communities as subjects in research related to autism. The second one is to support the recruitment of scientists who belong to underrepresented communities into the autism research community. The third funding opportunity that we have is a new one, and we think it's going to be especially relevant to sensory issues, which were mentioned earlier in this meeting, as well as motor, and possibly sleep, issues. The title of this RFA doesn't refer to sensorimotor or sleep, but instead it's cross-species research. We just think that sensorimotor and sleep will be especially relevant, because the neurobiological substrate of those functions is much better conserved across species, meaning between people and animal models of autism, then the neurobiological substrate off more complex functions, if you will. Again, we think there will be very high relevance to sensorimotor and sleep issues. Thank you.

DR. DANIELS: Thank you, Paul. Scott Robertson.

DR. ROBERTSON: Thanks, Susan. I wanted to highlight a couple of your updates for us that appear in the updates posted online. One of which is the Job Accommodation Network, as jan.org, which is a project that's been longtime funded by us at the Office of Disability Employment Policy, is hosting a free training webinar on accommodation solutions for neurodivergent workers. Workplace accommodations for folks, during National Autism on April 13th at 2:00 PM. Eastern time. Completely free webinar, folks can register for it with the link in the updates document posted online. I don't know, Susan, is that something you could also potentially share?

DR. DANIELS: Yes, and everyone here, if you have events coming up, that you want us to share free events, please send them our way and we can add them to our list on our website.

DR. ROBERTSON: Great. Then what I also would like to highlight is our project on research support services for employment of young adults on the autism spectrum, which is our long-term autism project that runs in conjunction with Mathematica, is continuing to release new resources from its work and publications. One of the resources that was recently released discusses barriers and facilitators to employment and careers for autistic young adults, which summarizes what we've learned from the listing sessions that were held in spring 2022 with autistic youth and young adults, family members, employer, service providers, etc., folks, and governments. Thank you, Susan, if I recall right, you participated there. We learned a lot from those sessions and that discusses the overall in terms of lessons learned, such findings from that.

Then the other resource that we have posted online to you at the RAS website -- again, this link to their online and their updates document --describes evidence on the effectiveness of programs, models, and strategies to support employment and outcomes for autistic young adults. That is reviewing, if you will, the evidence and the quality of the research literature on employment for empowering folks. We will also have more resources to the project forthcoming, I would say, likely in the next several months, certainly within the next year, year-and-a-half, you'll still continue to see things coming out from this project. It probably might take until the next meeting, because there some other things that we have under works for neurodiversity at work in autism, too, that are coming up down the pipeline too I just don't have the specifics to share yet. Thanks.

DR. DANIELS: Well, keep us posted. Jennifer Johnson.

DR. JOHNSON: Hi, I know we're short on time, so I just wanted to highlight a few things that are included in the updates document. I wanted to highlight them because it's work that we're doing that's addressing many of the issues that have been identified and discussed today. One project I want to highlight is a project that we launched last year that's building off of work that we've done previously to address the needs of people with co-occurring intellectual and developmental disabilities and mental health disabilities. It's a national center, that again launched last fall, so we will be sharing more information about that project as it unfolds. We also funded the National Center for Disability, Equity and Intersectionality. This also builds off work that we have done in the area of health equity to address the ableism and discrimination that occurs in medical decision-making. We'll continue that work and then expand into other areas related to equity. We've also continued work that our grantees are doing to help people with disabilities get vaccinated. We've had additional money go out to target community-based organizations that will, again, help people get vaccinated. Then, also in the updates are few resources and new projects that have been funded by the National Institute for Disability, Independent Living, and Rehabilitation Research that are specific to autism. I encourage you to take a look at those. Thanks.

DR. DANIELS: Thank you, Jennifer. Dena Gassner.

MS. GASSNER: This is a quickie. I'm one of the trainers on a project with Stony Brook, where we have been granted a pretty substantial chunk of change to do training for mental health clinicians for the State of New York on intellectual disability and autism without ID. It's free for clinicians, so if anybody in the state of New York would like to participate, I put it in the chat so we can forward it. I just didn't get permission to put it in the round robin until last night, so I just wanted to make sure I could do that.

DR. DANIELS: Yes. If anyone has something they forgot for the round robin document, you can just send it to us and we will add it into the document for this meeting. I think that concludes the round robin, so we're ready to conclude the meeting overall.

DR. GORDON: Thank you, Susan, for

putting together this excellent meeting. Thank you to the entire IACC staff and to all of the members of the Committee. A lot of wonderful conversations today, and we'll be continuing those in the future. Made a lot of progress. Proved the strategic plan, set up for a vote on the summary of events. This is a really a productive day. Thank you very much to everyone.

DR. DANIELS: Thank you, and I will be following up with emails about some of the action items we talked about during the meeting, including the summary of advances in the co-occurring conditions working group. Feel free to email us and stay in touch, and we will hopefully see you in person in April, but we'll keep you posted on that. Thank you again for your engagement today.

(Whereupon, at 5:00 p.m., the Subcommittee adjourned.)