INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, APRIL 17, 2024

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

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PROCEEDINGS

DR. JOSHUA GORDON: Good morning, and welcome to this meeting of the Interagency Autism Coordinating Committee. I'm Joshua Gordon, director of the U.S. National Institute of Mental Health, and chair of the IACC. Sitting next to me is Dr. Susan Daniels, the National Autism coordinator, and the executive secretary of the IACC.

Welcome to IACC members, to members of the public, those of you joining us in the room, those of you watching videocast and those of you members who are joining us, the -- our various hybrid modes.

I want to start this meeting off by recognizing that this month is Autism Acceptance Month. We're very pleased when the White House announced this occasion and announced the change from awareness to acceptance, which I think is a positive movement and appropriate for our nation, which is increasingly aware of autism.

But for lots of reasons we've heard

about over the years of the IACC, the idea of acceptance of autism is still something that our society is working on. We here at NIH, as well as everyone around the table, are committed to the idea of increasing acceptance and inclusion of autistic people.

As well as ensuring that the research necessary to improve the lives of individuals with autism and their families and communities, as well as the services that we know are effective in improving those lives are available and directed to ensure this acceptance and inclusion improves.

We know that there are both strengths and challenges associated with being autistic, caring for individuals on the spectrum and with regard to those who participate fully in including autism, and individuals with autism in their communities.

For the month of April, we take this time to celebrate those strengths to call attention to those challenges, and to reinforce our efforts to support the health and well being well being of people on the autism spectrum.

We began our own IACC and NIMH celebration of Autism Acceptance Month with yesterday's event, which I think we'll hear a little bit more about later from Susan. It was a really wonderful event. And thank you to those of you in the room who attended yesterday, and to those who attended online as well.

Today, we're going to be focusing our attention on international autism activities. We're going to start with the presentation about autism efforts at the World Health Organization. We'll hear from our National Autism coordinator address ICC business.

And then in the afternoon, we'll hear a series of presentations and panel discussions on autism activities around the world, including presenters joining us from the United States Canada, Peru, the U.K., Egypt, Kenya and Australia. We look forward to hearing from this diverse group of experts about this diverse set of activities.

I also want to take a moment to mention some recent updates regarding committee membership. We welcome Dr. Sunny Patel to the committee as the new member representing SAMHSA. He will be replacing Dr. Anita Everett. Sunny, would you like to introduce yourself?

DR. SUNNY PATEL: Thanks, Josh. My name is Sunny Patel. I serve as a senior advisor for children, youth and families. Oh, can you hear me in the room?

DR. GORDON: You're a little bit quiet in the room. I don't know if you're quiet online as well. But we can see you, hello.

DR. PATEL: I can try to speak louder. My name is Sunny Patel. I serve as a senior advisor for children, youth and families here at SAMHSA. And I'm a child and adolescent psychiatrist by trade.

DR. GORDON: Thank you very much. Welcome to the group. We're also in the process of having Ms. Deirdra Assey [spelled phonetically] from the Department of Justice -- I hope I got that name right, I apologize if I got it wrong -- join the IACC, replacing Dr. Brooke Mount. Deirdra, would you like to introduce yourself? I hope she will be able to join us later. Deirdre, if you're trying to speak, you're on mute. All right. We'll have her introduce herself a little bit later if she joins.

We've also heard the great news that IACC member Hari Srinivasan recently received an NSF Graduate Research Fellowship. This is a very prestigious award given only to a small number of graduate students in science from throughout the country. And so, we congratulate Hari on this achievement. Congratulations.

With that, with those notes, I'm going to turn it over to Susan for some additional opening remarks, the roll call, and the approval of minutes from January meeting. Susan.

DR. SUSAN DANIELS: Thank you, Josh. It's wonderful to see everyone here. We welcome our online audience and our in person audience today, and are really looking forward to this special series of presentations from different places around the globe. And thinking about our collaboration and partnership with so many different countries that are working to increase the health and well being of people on the autism spectrum.

So, looking forward to the program. And I will defer to maybe tell you a little more about our special event a little bit later when I have a slide or two about that. But we did have a very nice event yesterday. And thank you to those of you who attended. So, I will go ahead and do the roll call in a minute.

I'd like to make some housekeeping announcements. So, just reminding members who are attending in person, you can raise your hand physically in the room, if you'd like.

You can also use the raise hand feature in Zoom. And also, the people who are online, you can use raise hand in Zoom. And members attending virtually, stay muted and keep your camera off if there's a presentation going on. But if you're speaking you can turn on your camera, and of course speak.

And anyone in the room or online from the committee who wants to make a comment in writing, send your comments to "send comments here," and they will go to Steven Isaacson, our neuro diversity liaison, who will be happy to read those comments out loud in the meeting. And just reminding everyone to keep your comments somewhat brief so that we have time to hear from as many people as possible with each segment of the meeting.

So, with that, I will start the roll call. And -- oh, sorry. There were a few more housekeeping notes. Letting everyone know there is closed captioning available in Zoom for members of the committee and people on videocast.

We do have a sensory room down the hall and we ask that nobody use that for anything noisy. So, that's going to be reserved all day long for anybody who just needs a quiet place to rest. And feel free anyone in the room if you're getting -- you know, you need a little break, feel free to use that room.

And there are restrooms in the main lobby here. If you've never been in this building, you can just walk out to the main lobby and they will be there. And elevators in the building will be undergoing annual inspections and maintenance today.

I think most of our audience won't be accessing the elevators anyway because you need to be escorted. But maybe that's a note for federal employees who are hoping to get to your office. And please silence your cell phones.

All right then. So, with the roll call. We'll start with Joshua Gordon.

DR. GORDON: Present.

DR. DANIELS: From ACF. Allyson Dean.

MS. ALLYSON DEAN: Hi, good morning.

DR. DANIELS: Good morning. ACL, Jennifer Johnson, or an alternate, Amanda Reichard. Kamila Mistry from AHRQ, or alternate Justin Mills. And some folks might be joining us in a few minutes. CDC, Karyl Rattay.

DR. KARYL RATTAY: Present.

DR. DANIELS: Thank you. From CMS, Jodie Sumeracki or alternate Melissa Harris. I believe they had a meeting today that they told me about and I don't know if they've sent any other alternate. Is there any other alternate present for CMS? All right. From the FDA, Tiffany Farchione.

DR. TIFFANY FARCHIONE: I'm here.

DR. DANIELS: Thanks, Tiffany. From HRSA, Lauren Raskin Ramos.

DR. LAUREN RASKING RAMOS: Present. Good morning.

DR. DANIELS: Good morning. From Indian Health Service, Barbara Roland, or Bobby [unintelligible]. From the NIH, Dr. Bertagnolli, Jane Simoni.

DR. JANE SIMONI: I'm here.

DR. DANIELS: Thank you. For NICHD, Diana Bianchi, or Alice Kau. For the National Institute of Deafness and Other Communication Disorders, Debara Tucci.

DR. DEBARA TUCCI: Yes, I'm -- hello. I'm here and Judith Cooper is also in the room.

DR. DANIELS: Wonderful. Thank you. From NIEHS, Richard Woychik, or Cindy Lawler.

DR. CINDY LAWLER: Cindy Lawler, I'm here. Good morning, everyone.

DR. DANIELS: Good morning. And NINDS, Walter Koroshetz or Kristi Hardy.

DR. LAURA MAMOUNAS: This is Laura Mamounas. I'm covering for both of them.

DR. DANIELS: Yes. Thank you so much, Laura.

DR. LAURA MAMOUNAS: Good morning, everybody.

DR. DANIELS: Good morning. Great to see you. SAMHSA, Sunny Patel.

DR. PATEL: Present. Thank you.

DR. DANIELS: Thanks. From Department of

Defense, Nicole Williams.

MS. NICOLE WILLIAMS: Hi, present.

DR. DANIELS: Oh, thank you. From Department of Education, Christy Kavulic.

MS. CHRISTY KAVULIC: Hi. I'm present.

DR. DANIELS: From the EPA, Elaine Cohen Hubal.

MS. ELAINE COHEN HUBAL: Yes, good morning.

DR. DANIELS: From HUD, Leah Lozier.

MS. LEAH LOZIER: I'm present. Good morning.

DR. DANIELS: Good morning. From Department of Justice, Deirdra Assey. From Department of Labor, Scott Michael Robertson for Taryn Mackenzie Williams.

DR. SCOTT MICHAEL ROBERTSON: Scott Michael Robertson for Office of Disability Employment Policy, ODEP.

DR. DANIELS: Thank you. For SSA, Allyson Marvin.

DR. ALISON MARVIN: Good morning.

DR. DANIELS: Good morning, Alison. And

for the VA, Matthew Miller or Scott Patterson.

MR. SCOTT PATTERSON: Scott Patterson here for VA.

DR. DANIELS: Thank you, Scott. So, now I'll call up public members. Maria Mercedes Avila?

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

DR. DANIELS: Thank you, Alice Carter.

DR. ALICE CARTER: Here Hi.

DR. DANIELS: Hi. Sam Crane. Aisha Dickerson. Thomas Frazier.

DR. THOMAS FRAZIER: Present.

DR. DANIELS: Thank you. Dena Gassner.

MS. DENA GASSNER: Here. Thank you.

DR. DANIELS: Morénike Giwa Onaiwu.

MALE SPEAKER: Morénike is here.

DR. DANIELS: Thank you. Alicia Holiday. Craig Johnson. Yetta Myrick.

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

DR. DANIELS: Lindsey Nebeker.

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

DR. DANIELS: Good morning. Jenny Mai Phan. JaLynn R. Prince. Camille Proctor.

MS. CAMILLE PROCTOR: Good morning, present.

DR. DANIELS: Good morning. Susan Rivera.

DR. SUSAN RIVERA: Present.

DR. DANIELS: Matthew Siegel.

DR. MATTHEW SIEGEL: Here.

DR. DANIELS: Laura Ivanova Smith.

MS. LAURA IVANOVA SMITH: I am present.

DR. DANIELS: Thank you. Hari Srinivasan.

Helen Tager-Flusberg.

DR. HELEN TAGER-FLUSBERG: Present.

DR. DANIELS: Julie Lounds Taylor.

DR. JULIE LOUNDS TAYLOR: Present.

DR. DANIELS: Paul Wang.

DR. PAUL WANG: Here. Good morning.

DR. DANIELS: Good morning. And did I miss anybody? All right. So, we are done with the roll call. And I believe I will turn it back to you, Josh.

DR. GORDON: Minutes.

DR. DANIELS: Oh, that's right, the minutes. So, you all received a copy of the minutes. They're in your packet. And you also received them from us via email. So, everyone's had a chance to look at them. Does anyone have any comments on the minutes? All right. I'm not seeing any -- are there any on Zoom? Okay. So, is there a motion to accept the minutes?

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

DR. DANIELS: Thank you. A second? JaLynn, thank you. All in favor of accepting the minutes as written, please raise your hand. And we're good on Zoom. All right. Anyone opposed to accepting the minutes as written? We have any online? No. And anyone abstaining? So, it sounds like we have accepted the minutes unanimously. Thank you so much. And we will put those online after the meeting. Thank you.

DR. GORDON: Thank you, Susan. Thank you, members for participating in the roll call and for approving the minutes. I now have a bittersweet announcement to make, which many of you received by email. I am proud to have served for the past seven and a half years as chair of the IACC in my capacity as director of the NIMH. And I'm -- as I said, I'm experiencing mixed emotions to announce that I'm stepping down from my position at the National Institute of Mental Health effective in June of this year.

And therefore, I'm going to be also stepping down from my position as chair of the IACC. It's been, for me, a wonderful educational and emotional experience chairing this committee in the three incarnations that we've had since I took over in 2016. I have learned a tremendous amount from you at the table, from you online, from everyone who's participated in our meetings.

There are many, many moments that I experienced a true increase in my own understanding of the experience of individuals and families and communities, addressing the needs of individual autism, of the needs of those individuals, the needs of the families, that have truly revolutionized my own ideas about what's important in this illness.

I came into this job as a psychiatrist, yes, but a neuroscientist with relatively little experience in -- actually, with relatively little direct knowledge of individuals with autism, with relatively little knowledge of their needs, of what was important to them. And I leave this job with much more knowledge.

Along the way, we have done a really -- a tremendous amount of work together. We have revised their strategic plan. We've included budgetary recommendations for that plan and research space. We provided advice to the Secretary, to Congress. We've covered a number of different issues that are important to the community. Those issues have been heard and acted upon by various federal agencies. And perhaps more importantly, by the many agencies and organizations that are represented around the table that are throughout our society.

I am most familiar with the changes at NIMH that have resulted from input in this panel. We now have a robust -- to small still, but robust research program addressing the needs of adults with autism. We have now a very robust and sizable program, trying to understand how we can help individuals with autism negotiate the transition from youth to adulthood.

We have continued our wonderful neuroscience and genetics work, which I know can sometimes be controversial. But we are continuing to focus that more and more on understanding the issues and problems that individuals with autism face, as opposed to the issues and problems that our scientists might think those individuals would prioritize.

It remains a work in progress, but it's one that I can tell you has deeply affected our scientific community. And it's deeply affected that community because of the work done around this table. We will continue to enhance that from a research perspective and from a services perspective over the coming years due to your work.

And although this committee will sunset this summer, once the Act expires, we know that there is vigorous attention in Congress to renewing that Act, and to re establishing the committee. And I know it will continue to work over the next years with the leadership of Dr. Daniels, as well as the leadership at NIMH that continue.

I want to take a moment to thank you all around the table, members of the IAC past and present. People don't realize, I think, this is not the only thing you do coming to D.C. to meet here or meeting virtually. There is a lot of work that goes in behind the scenes, writing, editing, participating in workshops, arguing back and forth.

Negotiating and trying to make sure that we put our best foot forward on in terms of expressing a consensus about the needs of the community that can be acted upon by government and by private agencies alike. So, I want to thank you all for the hard work that you've done and wish you continued success.

Now, while I am leaving, NIMH and the IACC will continue to enjoy the leadership of its many, many scientists, physicians and administrators whose goal is to make sure this works. You have an amazing team at the Office of the National Autism Coordination that facilitates these meetings, led, of course by Susan. But the others are around the room and I want to thank them for their hard work over these years. You recognize these faces around the room because this is a stable group that will remain stable after my departure.

And finally, I want to introduce you to

the person who will oversee the IACC moving forward in June, both towards the end of its current tenure and into the next one. She's my deputy currently, Dr. Shelli Avenevoli. Shelli is, among many other things, a trained clinical psychologist and researcher with knowledge of and specialty in child development. So, she is well acquainted with many issues.

Shelli has attended many IACC meetings in the past. And when she hasn't attended, then following it online. And is more than capable of directing the NIMH and the IACC once I depart. There will be a national search for my successor that will be starting soon.

The NIH director, Dr. Monica Bertagnolli, who you met at the last meeting, will be the selecting official that is -- she will name my permanent replacement. But in the meantime, we have Shelli to safeguard the efforts of the IACC and the NIMH.

So, I'm wondering, Shelli, if you would

like to say a few words.

DR. SHELLI AVENEVOLI: Good morning, everyone. It's my pleasure to be here. And as Josh mentioned, I've been following the IACC and attending the meetings for more than a decade, under Dr. Gordon, under Dr. Ensel [spelled phonetically] from the inception.

And I've just -- like Josh had mentioned, I've learned so much in that process, and so much from all of you. And I know the membership changes, but in many ways that's been great to sort of broaden that knowledge base.

And the one thing I've really appreciate it is just a steadfast commitment and the teamwork that you all do towards the greater cause. Which is to promote high quality research for those on the autism spectrum, as well as promoting the needs for services and representing people.

I also have appreciated Josh and Susan's incredible leadership. During this time, I know it is a great loss to lose Josh, but he'll always be here in spirit. And I think he set a wonderful tone and that's a tone that I want to ensure that we maintain. Susan and I both working very closely together.

So, with that, I'll conclude and just say I really look forward to getting to know all of you just a little bit better instead of being in the audience. I'll be here at the table and listening and learning and helping direct and answer you questions. So, thanks.

DR. GORDON: Thank you, Shelli. Thank you all again. And I wish you tremendous luck as we move forward. But we have another meeting to get through today together, lots more to learn and to accomplish. So, with that in mind, I'm going to take a moment to introduce the introducer for our next speaker, Dr. Leo Cubillos.

Leo is here? Come on up, Leo. We're going to have him at the podium? Yeah. Dr. Cubillos is the director of the NIMH Center for Global Mental Health Research. Psychiatrist, scientist and expert in global policy, who oversees our many interactions and our research across the globe, as well as our research that is focused predominantly in lower and middle income countries around the globe.

He is also our liaison with the World Health Organization. So, I've asked him to join us today to introduce our next speaker. Leo.

DR. LEO CUBILLOS: Thank you, Josh, so very much. Thank you for introducing the introducer. Susan, also, thank you for inviting me, Josh and Shelli to attend and learn from this meeting. In particular, from our esteemed international colleagues will also be sharing, you know, their experiences. I will be taking attentive notes.

It is my distinct pleasure to introduce Dr. Chiara Servili. Dr. Servili works at the World Health Organization as a technical officer in the Department of Mental Health and Substance Use in Geneva, in Switzerland. She serves as a technical focal point for the joint program between WHO and UNICEF on mental health and psychosocial development and wellbeing for children and adolescents. This is a program that -- as I understand it started in 2020. It should carry on until 2030.

Dr. Servili focuses her work in the promotion and protection of mental health of children and adolescents throughout the world. In her capacity in WHO, she also provides technical advice to WHO member countries. And by training Dr. Servili is a fellow physician with training in neuro psychiatry, in Italy, Master's in public health in the London School of Hygiene and Tropical Medicine, and a PhD in the University of Modena in Italy.

Before I give the floor to you, Dr. Servili, yesterday, we were talking and she said something that I haven't stopped thinking about since yesterday. She said, "Leo, we talk a lot about brain development in children and adolescents. But we don't talk enough about brain health in that population." And I just want to thank you, Dr. Servili for that, you know, few words. They mean a lot to me and they'll be resonating my mind. The floor is yours.

DR. CHIARA SERVILI: Thank you very much for these kind words and introduction. And I'm really pleased and humbled by the opportunity of being here with you today and sharing a bit of what WHO is doing in terms of advocating and increasing actions, accelerating changes within countries. Going backwards. You want to do it yourself.

In few words, the approach of WHO, when we think about how to improve outcomes and particularly health and well being in participation for persons with developmental disabilities. We can summarize it in three key areas or words. We want to deepen values and commitment in countries including the financial applications. We want to reshape environments for persons with developmental disabilities. And we want to strengthen systems and services broadly within health and beyond the healthcare system.

The latest -- I want to enter into the definition of terminologies here. If you have very burning questions, I'm happy to respond. But we frame the work around autism in the context of a public health approach that targets broader groups of persons with developmental disabilities.

And the latest product released by WHO providing the vision around the approach to accelerate action in countries is a joint project with UNICEF. It's a global report on children with developmental disabilities. It addresses children and young people but in the context of a life course approach.

And it was developed with support and collaboration with Autism Speaks and many others here in the room international collaborations, including persons with developmental disabilities.

When you articulate the need to act on developmental disabilities in the context of the many needs are also you know, within health, we highlight how communities -- how -- and, you know, particularly how the latest global estimates provide us, you know, the global prevalence on developmental disabilities.

We talk about the increased likelihood and risks of noncommunicable conditions in these populations, including for mental health conditions, and for instance, obesity and others. We talk about the increased risk of institutionalization. So, human rights probation also within the health care and poor quality of care. And we talk about how this leads to higher rates of premature mortality in this population.

The resources are very scarce. You know, if we think about, you know, the latest estimates we have from the Mental Health ATLAS [spelled phonetically], that is 0.02 occupational therapies per 100,000 population as a global estimate. And the global spending, we know that for mental health is 2 percent. And, you know, we don't have a figure particularly for developmental disabilities that is well below that percentage. And this is not enough.

We -- with the report, we have a specific purpose and attention to inequalities in health. You know, to say that there is -- out there, you know, enough data, you know, for us to recognize the need to have specific attention in broader policies that address the health needs to this particular population.

Because of, as I say, you know, the higher incidence of some conditions, including obesity, diabetes type 2, respiratory health conditions, as well as mental health. And these all contribute to the poor health outcomes across the life course.

And when we look at what are the determinants of these inequalities in health outcomes, of course, you know, in certain cases, there will be contributing factors at individual level, including genetic type of issues. But well beyond that, you know, we need to consider, and it's demonstrated that there are social determinants that have any impact.

And this includes, you know, poverty, you know, exposure to violence and social exclusion. But also poor access to health promotion and care across the life force of poor quality of care as reported and documented, and inappropriate inpatient stays for persons with developmental disabilities across the life course.

We have lower access to education. We know that that is related to health and participation. And we have lower access also to recreational activities and sports. And that contributes to wellbeing and health for every one of us.

So, when we think about, you know, what is the approach we want to see implemented in countries, we have an ecological approach to the work on developmental disabilities.

Recognizing the most proximal factors and individual level in families, but also the more distal ones together as with policies and societal level type of actions. And outcomes are articulated as development for children and adolescents, as well as health, well being and participation.

We have opportunities out there. The Conventions on the Right of Persons with Disability and the SDGs. Targets are not new, but are still there, as, you know, requirements for member states and countries to act upon. Inclusive -- you know, to create inclusive environments and inclusive health care.

And we have increased country's demands and readiness, so that we see every day in our interactions, also, with the ministers of health, particularly, you know. A few years ago, you know, we would be directed in our interactions to other ministries is no longer the case. I think there is increasing recognition and accountability within the

Ministry of Health, for developmental disabilities. And we had a strong bias on disability -- of, you know, the disability community, and neurodiversity.

So, the global report wanted to take that opportunity, and, you know, go to countries, so with some clear distill messages. So, I want to apologize here, because I think you know, the next slide -- so we'll be providing a summary of those key messages that are emerging from the global report.

They're not new for you. But those are, you know, the key messages as we were able to distill, you know, to make sure that we're still having a base, either in evidence or in country level experience and implementation. And that could be articulated in a way that could make sense and catalyze some action at country level.

It's important to note that the global report provides an actual framework. It articulates ten key actions, really, you know, for member states to have something concrete that they can look at and then implement. And the global report in every chapter refers to the different action points so, you know, to articulate better, what are the approaches.

It is not a finished agenda. There is much work that needs to be done, you know, to ensure that these actions are articulated and are available and that member states are ready to implement them. But this is a starting point in terms of making them available for them to integrate across their action plans. I will highlight some of these actions in my next slides. So, I won't enter here into each one of them.

So, there is a focus action on policies. And we want to go beyond commitments and legal international commitments to really implement legal and policy changes. We take, as a starting point, the Conventions on the Right of Persons with Disabilities to see, you know, what did they commit to.

And, you know, we recognize the four areas, you know, or legal requirements. You know, we want achieve non discrimination and equality for persons with disabilities, including autism. And we want to make sure that there is freedom from violence and degrading treatment, including within the healthcare.

We want achieve comprehensive access. And this resonates with our, you know, commitment towards universal health coverage. And, you know, the Convention on the Right of Persons with Disabilities articulates a human right-based care approach, you know, highlighting also the requirements of financial support and the rights to education.

We want to achieve independence and autonomy, including the right to live in community and access community-based resources. And we want to achieve meaningful effective participations across the different areas of life. The Article 33 in the

Convention on the Rights of Persons with Disabilities reminds us that it is important to make member states accountable with independent monitoring of the implementation of the CRPD.

And but, you know, we know that the situation is far from being, you know, at the stage where we can claim that we will have been able to implement the recommendations. So, you know, it trained in the Convention on the Rights of Persons Disabilities. And when we look at what has been documented so far in terms of implementation experiences of creating this human rights-based policy framework, we see that there is, you know, some consistent gaps and reporting of challenges.

So, they're really consistent across regions and across countries. So, you know, from high-income countries to low-middle income countries, there are reports of lack of -- you know, the difficulties include lack of coherence in policies, inadequate enforcement of legislations and monitoring of implementation of policies, as well as inadequate investments in community based systems.

And these leads to persistent human rights violation, low coverage of services, long waiting lists to access services, and inappropriate use of residential care and nonstate facilities.

We have been looking at good practices across different countries in implementing and developing policies. And of course, you know, we have been looking at the U.K., for instance. And I could talk about, you know, very, you know, good examples that, you know, that we could take from that experience.

But what strikes me is also that despite the focus attention, and the dedicated efforts and investments in the U.K., you know, in February 2023, there were 245 people with a learning disability and autistic people receiving inpatient care. Of whom, more than half had a long stay of two years or longer.

Then, you know, we look at the implementation experience to distill, you know, what we could convey as, you know, some good practice approaches to policymaking. And we have three that we are articulating for countries. So, one is, of course, you know, the twin-track approach to policymaking recognizing the need for mainstreaming inclusion, while having targeted policy provisions for empowering care in support.

So, mainstreaming inclusion across different policies related to different sectors. And then targeted provision, explicitly targeting the population of persons with developmental -- with disabilities.

Then we have, you know, recognition of -- the application of a health in all policies approach also in this area. So, we talk about improving health outcomes. We need to have all the policies that are relevant to health outcomes, and not only the health policies, talk about this population, and the health consideration that relates to improving those health outcomes in this population.

And of course, you know, we need to make sure that policies reflect real life concerns, and involve in meaningful participation of persons with disabilities and developmental disabilities.

The second aspect that we highlight with countries is about transforming care systems and services. And we know that there is a wide variety of interventions that can have benefits according to what the evidence says to us. And we categorize them in two broad areas.

Those intervention that are aiming to promote the health capital, the functioning and the skills. And an example is, you know, interventions for prevention of other health conditions in person with developmental disabilities. And we have also those interventions to remove barriers and promoting access to resources. A critical aspect is making sure that interventions and services are designed in a way that they are embracing a person centered, individualized approach to care.

Even when we plan and design services, so we consider the twin-track approach. Again, you know, thinking about what are the barriers of physical, attitudinal, and others to access mainstream interventions. What can be targeted actions and initiatives as an example. The annual health checks for persons with, for instance, intellectual disabilities is a good example, or improving sex education for adolescents, productive learning strategies and accommodations.

And you know, the other track is action interventions in healthcare to improve outcomes with targeted interventions. And we want this to be embedded in the existing services. For instance, in wellcare visits -- wellcare services, in school health services or in youth one-stop services within the community. And the focus is developing integrated community-based service network, and eliminating long term institutional care.

The WHO has over the past few years, having quite a bit focus on this particular aspect of the work. So, we tried to articulate the need to enhance capacities of nonspecialist providers, also in the primary healthcare setting, to be better able to integrate early detection and continuous support for children and young people with developmental disabilities.

We want to build a stepped care approach and build tiered care systems recognizing that we need to make available different care options with different level of intensity linked through care pathways. But flexible enough to reflect the evolving needs and the preferences and choices of persons and families.

We looked at ways of -- you know, we keep saying we need to connect care pathways across sectors. One example, I think, is their individualized service plans. When we look at the evidence of their implementation experiences, it seems that many countries including the Nordic regions, have integrated this approach. It is less well-documented how this has been evaluated and sustained over the years.

I want to highlight, very briefly, about harmful care practices, you know. As we work across regions and countries that, you know, we are often confronted with the situation. I'm talking about involuntary care restraint measures. And also, inappropriate prescribing of medication, for instance, inappropriate prescribing of anti psychotic medications, to manage difficult behaviors.

And in situations where it is a substitute for the absence of psychosocial interventions, or other environmental level type of interventions. And we look again at good practices. And what we can say is that we probably need strong leadership and care facilities based on national policies or district level policies. We had a strict monitoring system. And we need trained staff on management, for instance, difficult behaviors. And this would help us, you know, really, you know, with avoiding harmful care practices in our services.

WHO as I mentioned, has given quite a bit of focus on enhancing the nonspecialist competencies for early detection and for provision of care support with entry point in the primary health care system and in community. I just want to mention the mhGAP program is WHO guidelines.

It's broad is addressing mental, neurological and substance use condition, but it includes a specifically developmental disabilities. And there is an update version that was released December last year. It includes a new recommendation, specifically also for autism and intellectual disabilities.

And I know that Andy [spelled phonetically], she will be talking more about this. I just want to flag that the WHO with support from Autism Speaks, developed -- the WHO can give us this training package, again, as an as an approach that could help countries enhance competencies of non specialist providers to provide evidence based approaches to parenting for children with developmental delays and developmental disabilities.

And it has been currently being integrated across the implemented [unintelligible] within research and outside of research in many countries. In some countries, it's also, you know, being integrated within the primary health care approach in high-income and low-income countries. An example is Italy or Peru.

One of the late -- a chapter of the report and an action area is about participation. And participation is recognized as an important outcome very much linked to health and wellbeing and development. And when we say participation, we consider participation in terms of developing opportunities for participation at the individual level, you know, within family, in services and communities, and also interventions to address barriers.

I think I mentioned a bit of these already. But I just want to highlight the opportunity of promoting participation within the workplace environment, as well as enhancing opportunities within the digital space. Again, looking at what can be done, you know, in the digital environment and the digital space and how to enhance digital literacy for persons with developmental disabilities.

These are the actions that articulate what can be done to trigger change. We know that change needs to be monitored to make member states accountable. So, the report is providing a structure for monitoring and evaluation. And with specific examples of indicator taking as much as possible for what indicators are already being used in the context of countries.

And when relevant, articulating that in the context of collecting data for this indicator, it is appropriate to look at indicators to disaggregate data to make available information for this particular population.

Unfortunately, monitoring evaluation would be stronger if we had a World Health Assembly resolution dedicated to this topic. It is not currently the case. So, we had a resolution dedicated to autism that was passed by the WHO in 2014, but it's over now.

And I just mentioned that this is the area of monitoring. But it's not -- we don't have a dedicated resolution that is requiring member states to report back on actions specifically on autism at this stage. It is in the broader context of brain health.

I think the last piece of my presentation is about resource priorities. I saw that this group also had been reflecting quite a bit on research priorities in the context of the U.S. In the context of the report and the global research agenda, we looked at what could be derived as a key recommendations. And I had just two slides highlighting some of the aspects.

Research priorities, recognize the need to invest more in optimizing functioning participation, also beyond childhood. And documenting health inequalities and approaches to address health inequalities. We want to be better able to monitor system performance. And looking at interventions to improve access to lifelong services for health promotion.

We also know that, in many cases, trials that tests interventions, looking at early childhood development outcomes and mental health outcomes, very often exclude persons with developmental disabilities and autism. And so, this is something that requires action.

We want to be better able to have an informed approach to individualized care service development, to be better able to say what component of an intervention, what frequency and intensity and timing would benefit specific groups of -- sorry, children and caregivers, but beyond is persons with developmental disabilities.

And, you know, how can we scale up while sustaining standards of quality? We have increased evidence on the potential of digital technology but more, of course, you know, needs to be done. And, of course, you know, keeping in mind the requirement of improving participation of persons with developmental disabilities in research.

The next step is countries' action. We are very active with our partners, including Autism Speaks and others, with facilitating the uptake of the priority actions within countries. Even today, there was a planned conference in Egypt, where the global report was being presented at the presence of the Ministry of Health.

And we have -- as has been mentioned by Leo before, the joint program with UNICEF that provides us also increased potential for impact in countries working jointly. In the context of broader actions for mental health with the focus on children and young people, but also specifically in the context of improving development, and psychosocial well being for children and young people with developmental disabilities. We're currently having an active, you know, priority focus in 13 countries, but more to come. And I'd like to thank you for this opportunity.

DR. GORDON: Thank you, Dr. Servili. We now have time for questions or comments from members of the IACC. Please raise your hand on Zoom, or enter into the chat and we can have Steven read them, or raise your hand in the room.

And actually, one good way for me to be able to keep track is if you want to -- besides -- again, I see you. But others just raise up your card like this and put it -- in that way, I'll keep track of the fact that you still have a question. Please, Yetta, get us started.

MS. MYRICK: Good morning. Thank you for your presentation And for your work. This is a comprehensive report And I appreciate that. Of course, it's focused on children and young adolescents. Is there any thought about how this work can be transferred over or into the adult sphere, right? Like that is the black hole, right?

DR. SERVILI: Yeah.

MS. MYRICK: I don't think I'm saying anything that you don't already know. But I'm just curious if there are plans to move the work forward to figure out what's going on in the adult world?

DR. SERVILI: Should I respond directly or -- yeah, no, thanks. Absolutely. You know, and we're about this huge gap. We have opportunities to expand the work and given the context of brain health agenda. And, you know, for instance, so we at WHO is very active working on dementia. And we know that this is such, you know, an entry point also to work out, you know, with that spectrum of, you know, the life coarser.

And the other opportunity is we want to be able to have more dedicated attention to this population in the context of WHO's work on mental health in the workplace. We would like -- we are planning to host a technical consultation on neurodiversities as a starting point to help us articulate how we can bring in more intentionally that perspective. And have more interaction on this scope on prioritizations of, you know, work for WHO in that space.

It's not the first time that we have been engaging with, of course, you know, adults on the spectrum before. And also in the context of the resolution on autism a while back. But I think, you know, this is an evolving work and field. And that we would like to reconvene to have more dedicated discussions on how to take this stream of work forward in with a more intentional life course perspective.

MS. MYRICK: Thank you. Appreciate that.

DR. GORDON: I don't know if there's questions on Zoom. Someone pointed that out. Please go ahead, Scott.

DR. ROBERTSON: There's a question that Dena has [inaudible].

DR. GORDON: Yeah. Please, Dena.

DR. GASSNER: Hi. Sorry to be away. I just wanted to, you know -- how can I say this. I wanted to suggest that in any avenue where you're looking at adult services, you continue to raise up autistic leadership and that decision making. We have seen such growth on the part of the IACC because of the shift from autistic people giving public testimony to actually engaging on the committee.

Honestly, looking around the table, I would recommend that for any of our agencies here. But also, as you're in the baby steps of planning this future engagement on life course, I think you would find it wildly informative, and extremely supportive.

And I'm Dena Gassner, by the way. And I have some materials that might be very helpful in terms of preparing environments and settings to make sure that those people can meaningfully participate. Thank you so much for your presentation. It's really well done.

DR. SERVILI: Thank you very much. And I need to admit, you know, one of the reasons I wanted to be here in person was to learn from this experience and from your work. So, you know, very well taken and looking forward to more engagement.

DR. GASSNER: Thank you.

DR. GORDON: Scott.

DR. ROBERTSON: Yeah. I would like to say also, thank you for your wonderful presentation. It was very informative and very helpful, I think for the work that we're doing in the you're in the federal government. I'm a senior policy adviser and an autistic person at the U.S. Department of

Labor. And we especially appreciate that you emphasize this part of the social determinants of health vocational training.

I don't know if you could talk a little bit more about how employment, and for instance, transition and skills development for adolescents and young adults fits into that as far as what you emphasized on vocational training. And we would also be interested in connecting with you and your colleagues potentially, in the future, and on virtually works easier as far as over an online platform. Thank you.

DR. SERVILI: Yeah. thanks very much for this. I think, you know, one clear opportunity that we have not taken yet is adapting what WHO has in terms of promoting, for instance, social emotional learning in the context of the school to adolescents. To make sure that that is accessible and is tailored to really, you know, benefit adolescents with autism, for instance.

You know, there is a very strong

recommendation in the guideline of WHO, on the requirement for every adolescent to access social and emotional learning in the context of schools. And we're working also closely with UNESCO to make sure that this has been implemented. There is a set of comic books and teachers guides that articulate the social and emotional learning skills for young adolescents in the school environment.

But we have not yet taken the step of looking at it from this perspective. And making sure that whatever needs to be done is done in the context of the approach, the document, the implementation. The way we approach countries and teachers and school managers to make sure that in benefits that, you know, the community of autistic adolescents

DR. GORDON: Dr. Servili, the overarching plan that you presented highlights many of the evidence based approaches that our research has supported and many of the needs and concerns that people around the table have expressed at the ICC. But, you know, where -- we don't know a lot about is how that's how these practices are promulgated by the WHO and taken up by other countries.

We're going to hear this afternoon from a number of different countries to develop their autism plans. But could you just tell us something about the levers that you have. You did mention, for example, that for some programs, there can be monitoring efforts, where you -- I imagine, try to pay attention to what countries are actually doing.

And that that is not a lever you have currently in the autism space. But can you tell us what activities you do engage with help countries, like those are going to hear from today, develop their plans and evaluate them?

DR. SERVILI: Yes. Thanks. I think you know, we are working at different levels, you know, with member states and countries. So, one level is to require countries to report on a core set of indicators. And this happened in a contest, for instance, at the Mental Health Action -- Mental Health ATLAS, which is linked to the WHO resolution on the comprehensive mental health action plan.

We also have resolution on brain health. Autism is actually one of the priority condition within that plan. So, we will be collecting some data. The other opportunity, you know, is working more with member states and countries directly on the ground. And we are doing that, you know, not with all countries, but in some countries.

And in that context, our approach currently is looking into mapping services as an entry point to understanding what is the current situation. Not only, you know, availability of services, but access uptake. You know, what is the reported quality, perceived quality of the services and so on.

And that is, you know, the starting point to have policy dialogues, you know, within countries to reflect on what are their own priorities. And then, you know, come with some dedicated funding to implement those that we call catalytic actions. We cannot, you know, sustain, you know, scale up comprehensive action plan in countries with the current level of report resources we have for country work.

But we can sustain some catalytic actions and help them come to the stage of recognizing the priorities as well as develop action plans, you know, within governments and with sectors with engagement of persons with developmental disabilities and the different civil society organizations. So, that, you know, is the current approach that we are undertaking at country level.

DR. GORDON: Let me just say from my own personal experience having visited some of the many countries -- member states that are engaged around other aspects of world -- the World Health Organization, mental health, it can be transformative even with relatively little resources.

So, WHO, for example, has developed a curriculum to teach lay healthcare workers how to deliver some very simple mental health interventions: widely-available, low-cost drugs for depression and psychosis; simple, short cognitive behavioral therapy for anxiety.

And I've seen those practices in action in very low-resource settings delivered by -- as it's people without any medical education and talk to the folks who've received that care. And it's really transformative. It is absolutely transformative.

So, are there similar kinds of curricula that you're working on or that you have? In autism, you mentioned for example, the provider care training.

DR. SERVILI: Yeah.

DR. GORDON: I think, you know, it may not be obvious to everyone that an -- a parent with autism doesn't necessarily know the best way to parent a child with autism. And that they can learn, just like we can all learn, lots of different tricks and tools and approaches that work for parenting or for any other skill. Besides that, are there other programs that you have that educate --

DR. SERVILI: And I take this opportunity, you know, to reflect on this experience with -- the tool that you were referring to is the mhGAP, the Mental Health Gap Action Programme. Developmental disabilities have been part of it since the very start.

What has happened, although, you know, on the ground, is that, you know, either countries were not including that modules in their approach, not giving priority to that. Or, you know, I would be asked to facilitate training in countries only to discover that those non-specialist providers would never, you know, have interactions with families or children with developmental disabilities.

It was not in their task. They were dealing with either adults, or, you know, they were not considering that as part of their duties. This is, you know, a while back.

Currently, we have experienced a shift in this situation. You know, there is really a readiness and demand. So, currently, you know, last year alone, I think we trained over 2,000 people with this approach only on modules related to developmental disabilities, behavioral conditions because of the demands of countries to address this specifically in the context of the child mental health programming.

So, it's coming. And it is there in updated version of the mhGAP guidelines that was released, I think it was December last year. There are, I think, eight new recommendations related to autism and neurodevelopmental conditions.

And we are in the process of updating the other tools to reflect this change and implement it in countries. And it will be talking about the parenting approach that you just alluded to.

DR. GORDON: Thank you. Are there other questions or comments from members of the Committee? And please, online, raise your hand. Sorry. I see there's a couple. I told you to do it, and now I can't even remember they're doing that. All right. We're going to do, Paul and Susan and then Yetta. Paul?

DR. WANG: Thank you, Servili. Thank you very much for coming over here and sharing the results of your work and that of so many other people. It's daunting just to think about the volume of work and thinking and insight that must have gone into this. Congratulations. To -- some of this kind of global perspective and a plan for global action is going to have enormous impact.

Along the lines of thinking globally and acting locally, I wonder if you have a perspective for us here in the United States. You cited some specific examples, Peru, the United Kingdom. Some better, some lesser examples.

What do you think we do well here even if we still have room for improvement? And surely, we do. And what areas do you think that we perhaps lag surprisingly given the resources that we have at our disposal?

DR. SERVILI: It's a difficult question [laughs].

DR. WANG: [laughs]

DR. SERVILI: But, you know, first of all, you know, what you do well, I think, you know, you said, you know, I mean many things of course, you know. But we truly look into your experience, you know, when we think about ways of changing the environmental perception of autism. You know, you're really leading the way.

And we are trying to, you know, reflect on this on what are the key ingredients that can be, you know, taken to make this change happen quickly, you know, in other countries where, you know, there are massive human rights violation still and stigma and exclusion.

What I would like to see happen in the future is you leading the way also for us to have a common narrative around autism. In the context of the development of the Global Report, we struggled with different perspectives.

You know, those, you know, doctors from lower-income countries wanting to have disorder in the title is not there. You know, others wanting to have, you know, more, you know, nuances in the terminology.

So, it was, you know, an evolving conversation and learning experience for all of us. But it took some time. And I would like -- you know, I'm always looking at, you know, experiences such as, you know, the one of your Committee and your work, you know, to pave the way for us to have an easy job, you know, where we can find that common understanding and narrative that can ensure that we have -- we build on synergies rather than, you know, deal with fragmentation in this field.

And, yeah, maybe I can also mention, you know, one other thing I've been struggling with when looking at the evidence is the issue of managing how, you know, countries deal with entitlements to services.

You know, one approach that, in the context of the mhGAP, we have taken is the transdiagnostic approach. Recognizing that, you know, for instance, when we talk about environmental disabilities, we recognize that we want to avoid that waitlist reflects in not having access to early interventions.

But then it comes in the issue of how do you access services in the context of, you know, regulatory system that provides you access to services based on diagnostic -- you know, a diagnosis.

So, this is something that we are grappling with at the moment. And if you have an experience to share any perspective, any thought, they would be very welcome. Because this is, you know, very important, particularly in countries where the capacity to make a diagnostic assessment are limited. And we don't want that to, you know, to be a problem with ensuring early access to interventions at whatever age that comes.

DR. GORDON: Thank you. Susan?

DR. RIVERA: Thank you so much for this really comprehensive overview. And since it was so comprehensive, I wanted to invite you to go a little bit deeper into one specific thing that caught my eye.

Which is, you talked about a prioritization for digital literacy for people with developmental differences. And so, I wanted to just know a little bit more about how that's defined and what the WHO is doing in those spaces.

DR. SERVILI: Yeah, this is an exploratory space for us. But in the context of the Global Report, we had a very deep looked at -- look at the literature defining areas and opportunities for participation.

And also -- so, we intentionally look at the digital space because even in the context of young persons' mental health promotion, we look at the digital space as one of the spaces where we recognize there are opportunities and risks.

And when we look at what are -- what is the experience and evidence, you know, telling us about the digital space and inclusion and risks and opportunities for autistic persons and person -- particularly, I think there is mostly research on autistic persons and someone -- person with intellectual disabilities.

What we learn is that, you know, we can focus of course on creating -- you know, having -- making sure that there is an inclusive perspective in the creation of software and tools. But there is also the element of ensuring digital literacy, because that is a particular obstacle and -- in this population.

WHO has no tool to improve digital literacy in the context of persons with autism. It is itself paving the way in a way, you know, to ensure that whatever we produce is more inclusive.

So, we have now new guidance on how to provide webinars and produce documents and so on. But nothing specific on digital literacy, you know, in the way that could be, you know, immediately used for this purpose.

DR. GORDON: Yetta?

MS. MYRICK: Two things. So, one, want to flag the caregiver skills training that you all developed. Because you were asking what's something that has been done, like, in this sphere to support the community.

I do recognize that it's only for 2- to 9-year-olds. And when I found out about it a couple of years ago -- my son is 20 -- I was like, oh, this would have been great when he was younger. Right? You know, how things go.

The other thing I was thinking about when you were talking about the strengthening participation slide. And there was information about, like, families and there being, like, training. But the one piece that

I didn't see was navigation. Has that come up as part -- in part of the discussion around how to strengthen?

DR. SERVILI: Yeah. You mean care navigation?

MS. MYRICK: Yeah, like basically having someone to help the family or the individual themselves, right? Like navigating services. Like, it's one thing to train folks, right? But people learn differently.

And I think there's a -- at least in what I've heard locally, in some cases nationally too, like, there's a challenge in families being able to navigate the systems themselves. Which I mean, of course, it's like chicken -- which comes first, the chicken or the egg, right?

DR. SERVILI: Sure. Yeah.

MS. MYRICK: Like, we need the systems to change to support, you know, the individual.

DR. SERVILI: Yeah.

MS. MYRICK: I get that. But again, if we're really truly focusing on individualized, you know, care and support for the individual, then that means that there need -- if there needs to be a -- different ways to support them, right?

To have things in place so that people can learn however they need to learn. Whether it's the family supporting the person, whether it's the individual, you know, supporting themselves, right? Like we --

And in truth, right, like, none of us in this room, anyone that's listening, like, we don't do anything alone, right? Like, there are -- we have support all over the place, right?

DR. SERVILI: Yeah.

MS. MYRICK: And so, I think another piece as I'm talking and this is coming up, and I think I need to say it is that when we think about autistic individuals, right, like, yes, they might need support. But we also need support too. And so, how do we, again, like, think in terms of how do we integrate folks in a meaningful way, right?

Like, I say this, you know, and believe this deeply that my son is not the challenge, it's the systems that we have to navigate, right? And so, again, with that thought, how -- what are we putting in place to support that navigating of systems until systems are working in a manner that's smoother and easier where it may -- it's more intuitive, if you will, to navigate them.

DR. SERVILI: Yeah. No, thanks for the question. I think, you know, the care navigation model has emerged, you know? So, you know, clearly mentioned in the report is one of the good practices that should be implemented in the context of planning and designing services.

MS. MYRICK: Okay.

DR. SERVILI: The -- there is an opportunity now with the update of the mhGAP program to integrate it as one of the training elements for primary healthcare providers, for instance.

I think you know what is working more is the care navigation approach driven by dedicated professionals within the primary health context. So, I think, you know, we're not yet there in many lower-income contexts. That, you know, we could try, you know, to articulate that more in our messaging to countries.

But certainly, we can try to enhance the competencies to promote -- to empower families and persons to navigate services within the context of the training of mhGAP. And also, wanted to say, you know, that working with families has been a great, you know, experience, you know, for myself and the colleagues, you know, within WHO.

Because when we started working with developmental disabilities, what we were facing was the non-readiness of governments, the high turnover, and not clearly defined tasks or readiness for care providers in the health facilities to take on, you know, those additional tasks that were seen as very complex, very difficult, and so on.

But then there were families up there, you know -- out there, you know, requesting our support and be there for life. And we took that opportunity, you know, to start off with enhancing and empowering families for them to become advocates as well as, you know, providing, you know, the support and liaising with services as much as is useful.

And yeah. So, that has been, you know, a bit of, you know -- so, you know, why we have given that much focus on parenting. And in the context of the report, when we look at participation elements, you know, the family component was also clearly there.

You know, with recognition that enhancing mental health, not only empowering parents, but addressing mental issues of caregivers is important to promote participation as well as enhancing the expectations of participation that parents have for their child or son or daughter, you know, in every context.

Because that was also perceived to be critically, you know, significant related to the level of participation in communities of -- irrespective of the level of impairments.

DR. GORDON: All right. Thank you very much, everyone. We really appreciate the wonderful questions and discussion. We especially appreciate the great presentation. Thank you, Dr. Servili. And we're going to take a break now for 10 minutes. We're going to be back at 11:25 a.m.

(Whereupon, the Committee members took a brief break starting 11:10 a.m. and reconvening at 11:25 a.m.)

DR. GORDON: We're going to go ahead and get started. If people can take their seats, please. As I said, please take your seats. We're going to get started. Our next activity is the National Autism Coordinator Update.

So, I'm going to turn it back over to Susan, who's going to give us that update and then move us into our Committee business. Again, if we could rejoin the group. Thank you very much.

DR. DANIELS: Thank you. All right. So, we're ready for our update. So, this is just an overview of the items we're going to cover in the update. Whoops. Oh, I skipped ahead.

So, wanted to give you an update on a few items from across the government. So, President Biden issued his proclamation on World Autism Acceptance Day on April 1st. And we have the link for you for that proclamation.

And we also wanted to let you know, as Josh mentioned earlier, that HHS has officially changed its designation of April to National Autism Acceptance Month. So -- and you've probably noticed on ONAC's webpage too that we've all changed to Autism Acceptance Month. So, I think this is a wonderful movement forward.

On April 2nd, 2024, the United Nations held its virtual observance of World Autism

Awareness Day. And they had a special event, "Moving from Surviving to Thriving: Autistic Individuals Share Regional Perspectives." And we provided the link for that in case anyone wants to watch it.

And a few other events that have happened, on April 2nd, the Indian Health Service posted a message celebrating Autism Acceptance Month. And they had a webinar on applied behavior analysis for the community. And that is available as well.

And NIEHS on April 11th held an event featuring Eric Garcia, who is the author of "We're Not Broken: Changing the Autism Conversation." You may want to view the recording of that. We also do have a webpage on the ONAC web -- or the IACC website.

I also wanted to point out that for Autism Acceptance Month that Josh and I authored a co-authored a blog for Autism Acceptance Month highlighting the importance of including lived experience perspectives.

And this is all lessons that we've learned from the IACC and from the wonderful work that members of our Committee, and especially those with lived experience, have done together. And how we can create that synergy to move things forward. And hopefully, setting an example not only just within autism, but for other fields that need the benefit of lived experience.

We had a special event yesterday that I hope many of you were able to attend. But if you weren't, we will have the recording up in the next few days. So, we hosted a special event called "Sound Tracks: An Artistic Journey to Belonging."

And this was a hybrid event that featured autistic photographer Blair Bunting, autistic violinist Laura Nadine, and neurodivergent filmmaker John Schaffer. And we showed a film that featured -- that was created by John and -- with the participation of Blair and Laura. And talked about their experiences on the spectrum and with their art. And this was all sponsored by First Place Arizona's Mulzet Center for Expression.

And so, we also heard from Denise Resnik, who's a former member of the IACC, about the work of her organization and their efforts to highlight the contributions of autistic people to society.

So, the recording will be posted. But it was -- I found it to be a very moving and beautiful event. I hope that many of you who weren't able to watch it will go back and see it. But really wonderful work and a great celebration of what people can accomplish and contribute.

So, I wanted to point out that we have a new report that will be coming to the IACC website soon. So, this is the FY 19 -- 2019 to 2023 report to Congress on federal autism activities. And this is required in the Autism CARES Act. The report is done, completed, and it's been submitted to Congress.

But it takes us a little while to get the formatting and everything ready for the web. So, we anticipate this will be out very shortly. And it's a comprehensive report that covers over 25 different federal departments and agencies across the U.S. government that are working on issues related to autism and disabilities.

And includes descriptions of federal programs on biomedical research, education, health, employment, housing, disability benefits, justice, and disability services. And provides updates on progress made under the Autism CARES Act of 2019.

And it also has some information that was specifically requested by Congress on the incidents and prevalence of autism, the age of diagnosis and interventions, and the effectiveness of new and existing interventions, as well as home and community-based services. And so, you'll be seeing this soon. But you can see the cover here. So, we look forward to releasing that.

Also, other updates from the White House, President Biden in his State of the Union Address urged Congress to add funding for Medicaid home and community-based services. And his budget for the fiscal year 2025 includes funding for special education services and provider training. And we have the remarks available for you there.

And he also signed a new executive order that will create more registered apprenticeships in the federal workforce. And I can see Scott happy on the other side of the table there about that announcement.

And I have a few updates from other federal advisory committees that are working in the disability space. That we always, of course, want to make sure that we're working together and we're not duplicating effort but we're working in a way that builds upon each other's work and collaborating.

So, with the Interagency Committee on Disability Research, which is a Committee that I actually sit on for the NIMH -- and there are other agencies here at the table that sit on this Committee -- has been very active recently.

They officially launched their Interagency Rehabilitation and Disability Research Portfolio Database online. And this is a searchable government-wide database of disability, independent living, and rehabilitation research.

And so, maybe in some ways similar to the autism research database that we have on our website that's only autism. So, you can access that through the link here. And it features research from many different agencies. And it was -- it took several years for them to launch this. So, it was exciting to see it come out.

There is also a new toolkit on participatory action research that was released by ICDR and a new toolkit on surveying the landscape of disability data and statistics. And it's a tool for interagency collaboration.

Also, FDA has proposed a new ban on electrical stimulation devices. And they've issued a press release on this. I wanted to mention the Government Accountability Office releasing a report on strengthening federal autism interagency coordination. This was a report that was really focused on the efforts in the ONAC and with the IACC and the work that we do.

And the report highlighted that they have a new set of standards that they're using to measure interagency collaboration that has eight priority areas. And that out of the eight, they determined that we have met six. And this was without us knowing what those criteria were because they're new. And the other two that we have partially met.

And so, we have a few -- a couple of recommendations before us to make some improvements to meet those other two recommendations. And so, we will be -- in terms of they mentioned tracking of autism activities.

And as you know, we track a lot in this Committee. We go down to the individual project level with our portfolio analysis. But we will be presenting the data in a new way so that it can be more easily determined how this tracks with our Strategic Plan. But we definitely have those data.

And they also want to know more about our process for avoiding duplication of effort and how we interact with other agencies. So, I will be reaching out to other agencies with plans for a more obvious plan of how that will happen. So, stay tuned for that.

And with the Census Bureau, they also announced their next steps on the American Community Survey disability questions. And they've made a statement.

So, some non-governmental activities that are upcoming or have just recently happened, the inter -- the INSAR meeting. The International Society for Autism Research is going to be holding its 2024 annual meeting in Melbourne, Australia. And so, maybe some of us will be at that meeting together. Looking forward to interacting with international colleagues.

There was also a recent meeting of the Autism Science Foundation Day of Learning on April 4th. And there was a profound autism summit on April 5th. And so, we have the links for those.

And a couple of other recent activities; an AIR-P webinar, "Introduction to Plain Language Writing for Academics and Researchers." The National Coalition sets Roadmap to improve healthcare for those with IDD. And a report on the "Case for Inclusion: Transforming Temporary Progress into Long-Term Sustainability." So, we've provided those links for you there.

And in terms of legislation, many of you probably heard there was a hearing in February that included the Autism CARES Act. And that was the first hearing on this topic. It went smoothly.

And now the act is moved to the next stage to be considered further. But there's no -- as far as I know, there's no new action as yet. But I know that there's been a lot of activity on the Hill about this. And we look forward by July to have probably heard more about what's happening. But it is moving.

There were also a couple other hearings in February. One that was on disability employment. And in January, one on entrepreneurs and employees with disabilities that involved autism as well.

So, if you need -- oh, I -- this is just to say that we have a written document, as you know, that we always put together for the National Autism Coordinator Update that's more detailed. And so, you can access that in your folders or online. So, that is the end of the National Autism Coordinator Update. Is there anything that you have questions about? Paul?

DR. WANG: I did have a question about the FDA proposed ban on the electrical simulation devices if Dr. Farchione is still on. I know there was a previous ban that I believe was vacate or annulled through the court system. And I wonder what has changed and what competence there is that any ban would be upheld.

DR. DANIELS: Tiffany, are you on the line, or Martine? They may have stepped away. But we can circle back to it and ask later if they're back online.

DR. GORDON: Anyone else have a response to that? All right. Well, we look forward to learning more from Tiffany.

DR. DANIELS: Sounds good. Anyone else? Any questions? All right. Then we will move on to our Committee business. And we have, quite a bit to talk about today in Committee business. So, this is the outline of what we're going to discuss. And I'll start with an exciting ONAC staff update.

So, Dr. Oni Celestin, here to my left, has been appointed as the deputy director of the ONAC. And so -- and you can imagine I'm very pleased about this. It's going to be a wonderful help to have a deputy in the office.

And she will be assisting me with all aspects of planning for the IACC as well as overseeing many of the different activities we have in the ONAC. So, welcome to that new role, Oni. And yes, so you will all be hearing from her more as well in her new role.

I also wanted to let you know that the 2019 to 2020 Autism Research Portfolio Analysis Report is now available. And we did send out an email to Committee members about this. And we are also working on 2021. And that's actually pretty well underway right now. So, we hope that one will follow not -- in not too long.

But the 2020 report provides comprehensive information about autism research funding across federal agencies and private research organizations in the U.S. And this was the 12th and 13th year of funding data that we've collected and the ninth report we've put together. Because sometimes we publish more than one year together just for efficiency.

And the report provides trends in autism research funding that span all the way from 2008 to 2020. So, we try to keep track across the years as to what's happening. And aligns research projects with the objectives and recommendations of the IACC'S Strategic Plan.

And this report also includes analysis of the cross-cutting objective on autism in girls and women, and an examination of autism projects that are focused on racial, ethnic, geographic, and socioeconomic disparities. And so, you can find the full report at that link.

We also for the first time published an at-a-glance summary. That's a short 4-pager that has some of the key figures and graphs in it so that you can get a quick look at what is in this report. So, you can access that online.

And just to give you a little overview of what's inside. We had 14 different federal departments and 16 private organizations that contributed their autism research funding data to the report.

And we are really grateful to all of you, and in the agencies and organizations, that took the time that it takes to curate all of this information and submit it to us so that we could create this report.

And, there were five federal funders and four private organizations that were new additions to this year's report, which was really exciting. And as you look through that list -- just as a little note -- you'll see organizations like FRAXA and TSC Alliance just reminding the Committee that our office looks carefully at each project.

And we only count projects that are related to autism. So, we don't, for example, count the entire, Fragile X or TSC portfolio. We only count the projects that are related to autism so that it's very focused. So, there we go.

And the famous pie graph. Here is our pie graph for 2020 about the distribution of autism research across the seven areas of the Strategic Plan. And you'll see that the largest portion of funding address the underlying biology of autism, which is question 2.

A reminder that the pie is bigger. $418.9 million spanning over 1,500 projects. And funding for research in the areas of services and supports, which has been an important area emphasized by the Committee as well as lifespan, question 6, have increased in recent years. And they're approximately doubled since 2016. So, still maybe a smaller portion but rapidly increasing.

And so, our next steps with the portfolio analysis report we're -- as I mentioned, we're currently working on 2021 and 2022's dataset. And we'll continue to identify additional U.S. autism research funders for inclusion in the reports. If you see a funder that's not listed there and you would like us to look into it, please let us know.

And the next iteration of the report will evaluate progress using the latest Strategic Plan that you all developed. So, thank you for that. I don't know if there are any questions about the par.

So, if not, I will move on to mention that in 2016, our office conducted an international portfolio analysis report that involved the U.K., Canada, Australia, and the U.S. And this allowed us to compare portfolios across countries and look at the similarities and differences and gaps.

And it fostered international collaboration and identified global trends in autism research funding. I don't know what is going on now. Why it's -- suddenly we're in completely the wrong part of this presentation [laughs].

[laughter]

DR. GORDON: This is why you have a deputy.

DR. DANIELS: Yes, [laughs] controlling the remote.

DR. ONI CELESTIN: I'm controlling the remote right now [laughs].

DR. DANIELS: [laughs] Oh, there we go. Thank you so much. The remote sometimes doesn't like me. So, what we would like to do -- upcoming in the future, as you know, the Committee is going to be going on hiatus at the end of September when the Autism CARES Act expires. But we hope, of course, it's going to be renewed by Congress.

And during the period while we're working on appointing the new Committee, ONAC would be interested in doing a new international portfolio analysis report to give us a new snapshot on what's going on globally and focus on the 2023 research dataset.

And in addition to Canada, the U.K., and Australia, we would really love to connect with other countries. And we have the opportunity of making those connections at the upcoming INSAR meeting, and of course, through this meeting that we're having here today with many international partners.

And I wanted to ask the Committee if you would be supportive of the ONAC taking this on while we are on hiatus and working toward this type of report, hopefully to present the new Committee.

So, it doesn't need to be a formal vote. But can I see a show of hands around the table of who's in favor of us doing such an activity? Oh, there's a comment. I'm sorry. Go ahead.

MS. MYRICK: Really quickly. I think that's a great idea. Especially in light of thinking about the plans that we've developed and even the Summary of Advances. We're getting a lot of papers that are outside of the U.S. So, I mean, you have my vote. I know you didn't ask for it yet. But I think that makes sense to me.

DR. DANIELS: Okay. Great. And I'm sorry, I should have stopped for comments. Do you have comments?

MALE SPEAKER: I just wanted to say that I concur. And we've had a lot of engagement on neurodiversity and related focuses for improving access to employment for people with disabilities in international work recently.

And I don't know if maybe offline I could help connect you to some of the -- it's a contact that I had that maybe it could help expand in terms of what you're looking at for that report. But I think it's a wonderful idea.

And I think it really also helps build upon what we're doing today in terms of this discussion today about international policy and practice issues that relate to autism and cross disability issues. So, thank you for doing that, Dr. Daniels.

DR. DANIELS: Absolutely. Any other comments? Susan?

DR. RIVERA: I love the idea too. And my hope is that it will include broader than just European partners.

MS. MYRICK: Absolutely.

DR. RIVERA: So, I think that's really the part that we have a lot of work to do on. Making sure that other continents are involved. I mean, Australia will probably be pretty well represented. But Africa would be, you know -- so, I know that's hard work. But I would be very much in favor and also willing to roll up my sleeves.

DR. DANIELS: Yes. And so, we would appreciate if any of you have some context. We know that there's some contacts in this room. And as you noticed, our program today includes the Global South. We intend to be as inclusive as we can of people from around the globe. So, we will be working on this.

It may end up taking a little longer if we have a lot of different participants. But I -- I'm sure it'll be worth the effort. So, we are willing to make that effort. Any other comments?

MR. ISAACSON: We have two comments or questions online. In addition, Hari says it's an excellent idea.

DR. DANIELS: Great. Any other comments?

MR. ISAACSON: Dena has their hand raised.

DR. DANIELS: Oh, okay. Dena?

MS. GASSNER: Yeah. In looking at this and in looking at the pie chart we previously looked at, I would like to emphasize as an if IACC goes forward, that we make a conscious effort to add an element related to the -- I guess I would just say policy.

You know, our earlier speaker talked about systems navigation and training parents. And as a social worker who's done that for 30 years, I'm going to say we need to stop training parents and we need to start focusing on what we're getting out of various agencies in regard to outcomes for autistic people.

We need to start providing systems navigation support. Asking families to learn to mastery, you know, seven or eight systems over the lifetime of an autistic person is an outrageous ask. We're teaching people how to use the bathroom, how to do personal hygiene. We're helping them with academics if they're able to do schoolwork. We're teaching them how to be safe in the community.

And we need to take that pressure off of parents and create harm-free systems navigators throughout the lifespan of the autistic person. I think it's some -- an additional element I'd like to see us add to our Strategic Plan in terms of getting information from the agencies around this table.

I don't want to call anybody out. But I've asked for information, and it comes in the form of tables that are not accessible when we basically just want three or four numbers about what the outcomes have been with people engaging with systems here in the U.S.

But I know that systems access is problematic around the world. And so, I'd really like to encourage us to stretch a little bit and start focusing on how are people benefiting from, or in some cases failing to benefit from, the infrastructure of various agencies.

Whether we're talking within the U.S. or outside the U.S., those systems navigation barriers are prevalent. So, you know, sorry to get on my platform.

But, you know, I would for one thing, like to have all the agencies that are sitting around the table give us basic information about how many autistic people are asking for your services, what their outcomes are. And if they're not getting successful outcomes, what the agency feels those breakdowns are about. So, you know, thank you for hearing me make my pitch [laughs].

DR. DANIELS: Thank you. And we would be happy to try to incorporate maybe some qualitative information into that report as well. Oh, thank you. So, Tom Frazier.

DR. FRAZIER: Sorry. I just forgot to lower my hand. Apologies.

DR. DANIELS: Oh, okay. Helen?

DR. TAGER-FLUSBERG: I appreciate you expanding the funding landscape beyond the United States. It strikes me though that you do it by individual country. And the European Union is a major funding agency that's kind of not bound to a specific country. And they --

You know, go look at an -- the INSAR program, they really are a major player in this field. And so, I'm hoping that as you work on the next portfolio, you'll be able to incorporate that.

DR. DANIELS: Thank you. That's a wonderful suggestion. We certainly will look into that. JaLynn?

DR. JALYNN PRINCE: Expanding on a couple of things that had been mentioned previously. I see that there is still a small amount for lifespan issues. And I know that a few years ago we were asked to give testimony about increasing it from 2 percent to 4 percent.

But when you realize how much of life is spent as an adult on the spectrum, this is not very reflective of the work that needs to be done. And as we're seeing different types of health issues coming into adulthood, and we have no information recorded in quantity or surveillance to see what is happening as somebody breaches into the geriatric aspects of life.

And we were a little bit slow getting into adulthood anyway. And now, we're going to be looking at aging. And I don't see enough information, enough funding. And if there's any way of encouraging any more research in these particular areas, I think it would make life better for many people and also save a lot of money.

And as you're realizing too, that the caregivers of many of these adults are passing away. They're not going to have that advocacy, but they may be dealing with lifelong issues that we have not looked at as comorbidities as well. Thank you.

DR. DANIELS: Thank you. And yes, you as a Committee did include recommendations toward research on aging in your latest Strategic Plan. And I'm sure the next Committee will also build on that. Lindsey?

MS. NEBEKER: So, I am very encouraged and I do support this effort in, you know, expanding this globally. I do have a quick question regarding funding. Will this effort have any impact on any of the set aside funding in the future for our own -- you know, our efforts in directing our own research?

DR. DANIELS: You mean in terms of the U.S. portfolio?

MS. NEBEKER: Yeah.

DR. DANIELS: We always -- when -- the year that we did the international report. So, we always collect the U.S. data anyway. So, we did publish both the U.S. Report and a Global Report. So, we'll plan to do that.

MS. NEBEKER: Okay.

DR. DANIELS: So, we won't be missing anything. And we do it with our in-house team. So, we -- it -- we get paid anyway to be here and do this work.

MS. NEBEKER: Thank you for clarifying.

DR. GORDON: If I could just make one comment as well. Absolutely, you're right, JaLynn. We need to continue to increase support for lifespan research. There's an issue about capacity in the field, right, that we've discussed in the past. That we're working on from a research perspective at NIMH.

But even despite that issue, just, you know, from 2016 to 2020, which is the latest data, we doubled the number of projects on lifespan issues across the portfolio. It's still only -- it's only 4 percent.

You're right we only went from 2 to 4. But that's a pretty substantial increase given the capacity of the field. Let's keep an eye on it. Let's see what we can do to continue to get more interest in pursuing those kinds of issues.

DR. PRINCE: That's the difference. I appreciate that tremendously. But with the proportion of the number of people that are now adults on the spectrum and that proportion it is still lagging behind. And I'm grateful for all of the work, and I know people around the country are. But there is such a need.

DR. GORDON: Absolutely, 100 percent. I'm just making -- I guess, just to be more explicit, you know -- and this happened with our first announcements in this area, right -- we could say, "Well, we want to spend -- you know, we want to triple it, we want to quadruple it in the next year."

But the projects that are going to come in aren't going to be good enough to actually -- it's -- it -- you know, so, it's one thing to say we need to increase, another thing to cultivate the field. We're in violent agreement on this though.

DR. PRINCE: I hope that some of the comments here will be heard across the country.

DR. GORDON: Hope so too.

DR. PRINCE: And that it can stimulate more research and more thought in this particular area. And thank you very much. You have been doing wonderful things.

DR. GORDON: Go ahead, Julie.

DR. TAYLOR: I had a clarification question and a comment about the pie chart. Obviously, there are studies that can fall into more than one of those buckets. So, let's say a lifespan study that was about services or a lifespan study that was an intervention. Are those getting put in -- I mean, granted --

Let's just -- let me just say that all those buckets are small. So, it's not as if putting those all in the adult bucket is going to make that bucket bigger.

But I was curious, where -- is the adult kind of bucket there? Like, anything adult, regardless of whether it could fall into one of the different? Or is it -- or would we expect that percentage to go up just a little bit if we pulled the adult studies -- I mean, a little bit out of the adult studies that maybe we're falling into services or falling in different direction? Does that make sense?

DR. DANIELS: So, anything that's adult, we are pulling into question 6.

DR. TAYLOR: Okay. Oh, so that's everything.

DR. DANIELS: That's -- I'm confirming with my team back there in the left-hand corner. They meticulously code all of this or recheck the coding from agencies and organizations. But anything adult is -- that's primarily adult is going there.

If it's something that covers all ages, it's not probably going to go in the adult bucket. But if it's really focused on adolescents and adults, it will be in that bucket already. So, we do carefully look at that.

DR. TAYLOR: And my other thought -- and maybe this is not the thought we want to bring up now with the Committee sort of winding down a little bit. But I do feel like we've seen a lot of people moving in the -- to the -- transition to adulthood sphere.

And I think that the work of this Committee in particular was really instrumental in that with really targeted requests for proposals and money set aside to pull -- not only to sort of pull mid-career researchers into this area -- many of whom have stayed -- that came from other fields.

But also, I mean, before I joined the Committee, we applied for an intervention grant on transition to adulthood. And I had not done intervention work before and don't know that I would've necessarily taken that leap on my own.

But there was funding to do -- or an idea that we thought could be a really good one. And so, we did. And now that's become a major part of the work that we do in my lab.

And so, it might be that, you know. I think there are people that are interested, but the -- sometimes the proposals aren't as compelling because people don't have as much of a history in that area. And there also isn't as much of a history to draw from. That makes it harder sometimes to compete with more established areas of research in more general calls.

So, I think something that could make a difference down the road, you know, if the next iteration of the Committee wanted to do that was to think about, you know, recommending specific calls for proposals around the aging sphere, just like we did for transition to adulthood 10 years ago that I think have really made --

I mean, there's a lot more to be done. But there's certainly a lot more people doing that work than there were 10 years ago. And I think having dedicated funding towards that made a really big difference.

DR. DANIELS: Do you have any comments on that?

DR. GORDON: I agree.

DR. DANIELS: Wonderful. Have I missed anybody or are we good?

DR. GASSNER: It's Dena. I just wanted to piggyback on that really quickly and just say, I think when we're looking at hard science research, we need to start being accountable that those projects are directly impacting the lives of autistic people.

I think there's a lot of biological research that's being done that is not having immediate effect. It's not translational. And I think when we're looking for funding, we need to start diminishing the funding access for projects that are not immediately beneficial.

We have a crisis on our hands. It's not the increase in diagnosis. It's the recognition of the numbers of people who are struggling. And I see all this money going to projects that do not have immediate implications.

Whereas the lifespan work at Vanderbilt that, you know, Julie's talking about and other groups are working on in terms of aging and transition to adulthood, the needs are desperate and dire.

So, I would say, when we look at how we're spending money, we need to really start making a big shift here and making sure that the research is having direct benefit.

DR. DANIELS: Thank you for that. So, I think maybe I just wanted to see, around the table and on Zoom, how many people on the Committee are supportive of the idea of doing a look at international research on autism? Looks like pretty much everyone in the room. And how about on Zoom?

DR. GORDON: Makes sense.

DR. DANIELS: We're good? Okay. On Zoom is there --

DR. GORDON: We had a good number.

DR. DANIELS: Okay. We definitely have a quorum. So, wonderful. Well, we will proceed with that as the Committee goes into the next phase. Oh, do you have a comment, Steven?

MR. ISAACSON: Hari has a comment. He says, "Focus on translational research, please."

DR. DANIELS: Thank you. And so, we will be working on that. Thank you so much. I'll move on to the next item, which is the 2023 IACC Summary of Advances Status. As you know, you voted now on the articles to be included in the 2023 Summary of Advances.

And we are in the process of preparing those summaries and the draft publication. And we should have that for you to see by July at the next meeting of the IACC, is basically the short, story about that. So, that is in preparation. Did I skip or are we good?

DR. GORDON: [inaudible].

DR. DANIELS; Okay. So, now we are going to move into the Summary of Advances discussion. These are the guidelines which you all are familiar with about what kinds of studies we're looking for in the Summary of Advances. And I will turn it over to Dr. Gordon.

DR. GORDON: So, we received a number of nominations from the CDC and from NIMH. I don't recall -- yes, I think that's all that we've received so far. So, I want to encourage everyone to consider nominating articles, research reports that you would like to see considered for the Summary of Advances between now and July.

But in the meantime, we now are open for discussion on any of the nominations that were presented, and comments or questions from members of the Committee. I'll just take the -- a moment to say that there are some really wonderful reports in here that are worthy of consideration. I won't pick out any favorites at the risk of biasing everyone.

But we look forward to continued discussion on these at the next meeting. Susan, what is the plan for 2024 given that we're only going to have the Committee in session through the summit?

DR. DANIELS: Right. So, the Committee, actually, your terms go all the way to September 30th. And we may get a reauthorization before that. We hope for that.

Something that I was going to note for you, and I can note for you now that we have the option of extending the term for another 180 days. So, we usually do, do that only to finish prior Committee business. So, we will not hold any new meetings or do any new business or write new Strategic Plans.

But when we have projects that we need to finish such as the Summary of Advances and also this report on co-occurring conditions that we're all going to be working on, I will be reaching out to you via email. And if needed -- if I need to do a little Zoom with you to try to get something done, I'll do that to help us just complete our business.

So, be expecting that you'll get an email that will ask you about extending your term briefly so that we can finish that business. And so, we'll take care of this then.

DR. GORDON: Right. So, in other words, keep your nominations coming. Thank you. All right. I'll pass it back to you, Susan.

DR. DANIELS: Thank you. And thanks to everyone for your nominations. So, where are the rest of us? We're not supposed to be at round-robin updates. But [laughs] I'm sorry. Did they get blacked out?

DR. GORDON: We have just the RFI left to discuss?

DR. DANIELS: Yeah. So, yes, we're presenting the RFI.

DR. GORDON: Moment of technical difficulty, folks.

DR. DANIELS: Just a moment.

DR. GORDON: The next item moment item up is the request for information that we're going to present the data from, right?

DR. DANIELS: Yeah. So, we're going to, yes, be talking about this last report. So, as you know, you all decided that we would combine the activity of doing an update on the Strategic Plan with the co-occurring conditions report that was started by the previous Committee.

And the status of that is our team has been working with the draft. And Julie Taylor was co-chair with David Amaral on that working group.

Prior, we have been working on updating the draft, trying to get it current with the latest research and also some of the priorities that this Committee identified, particularly with regards to equity which was not as much of a focus back in 2018 and '19 and now is in very sharp focus across the entire federal government and around our country.

And so, we wanted to make sure that some of these newer areas that you identified in the Strategic Plan are rolled in there. So, our team has been working on getting that draft ready for the Committee to review.

And a part of this process was also doing a request to the -- request for information to the public to gather public feedback on what's really important to people in terms of co-occurring conditions, making sure that we're including the expanding range of conditions that people are identifying as issues in autism.

And so, we have received the feedback. We got over 1,200 responses from the public, which I've shared with what -- which our office has shared with the Committee, and it's up online. All of those responses are available.

And Dr. Celestin is going to be going over the results of the RFI with you to share that information. So, I'll turn it over to you.

DR. CELESTIN: Thanks, Susan. We're just trying to get the right slides pulled up.

DR. DANIELS: So, yes, with this RFI we were able to pull in quite a bit of information on a really wide variety of conditions. And we had a couple of workshops back in 2018 and '19 that were related to physical co-occurring conditions and mental health co-occurring conditions.

And in the RFI, we also expanded to make sure we explicitly included other developmental disabilities and other kinds of disabilities that might be co-occurring conditions. And we hope that we will have expanded the range.

And we did hear from a number of different groups and even conditions that were not previously identified as key before, now are in the RFI.

Are there any questions about this report and the processes? So, in terms of the

-- oh, are we getting the -- looks like the slides are coming up. You ready to turn that over to you? Are you ready?

DR. CELESTIN: Yeah, we're ready.

DR. DANIELS: Okay.

DR. CELESTIN: Okay. Sorry about that. So, as Susan mentioned, on behalf of the IACC, ONAC released a request for public comments to help us identify priorities related to physical and mental health conditions, as well as other conditions that commonly co-occur with autism.

The comment period was open from January 3rd to February 14th. It actually opened a few days early. But we did accept all the comments that came in. And it was posted on the Federal Register, the IACC website, as well as other agency websites. It's not advancing. Oh, there we go. Okay.

So, the -- in the request for public comments, there were seven questions that we asked the community. The first was, what are the most significant challenges caused by co-occurring physical health conditions? The second was challenges caused by co-occurring mental health conditions. The third was challenges caused by other conditions that co-occur with autism.

The fourth question was, what additional research is needed to help address co-occurring conditions for autistic people? The fifth question was, what could be improved in autism services and supports to help address co-occurring conditions?

The sixth question was, what lasting impact has COVID infection and illness had on co-occurring conditions? And the seventh question was, what lasting positive negative impacts have societal changes due to the pandemic had on co-occurring conditions?

So, we had these seven questions. We also asked people to provide their demographic information. And based on how people answered the questions, we decided to shift our analysis a little bit.

First of all, we received over 1,200 responses. So, this was a lot more than we were expecting. And we were very pleased with that. The complete text of all the responses is posted on the IACC website. So, if you'd like to peruse, you're welcome to.

We did review and -- we did read and review all of the responses. And our preliminary analysis of the responses is going to be presented here today. We'll have a fuller analysis in the report on co-occurring conditions.

So, as I was saying, we analyzed the responses and sorted them into six categories. First was to identify the demographic of the response -- of the respondents. So, whether they're an autistic individual, a family member, service provider, et cetera.

The second category was types of co-occurring conditions that they described. So, we lumped physical, mental, everything together -- physical and mental health conditions together. A lot of people had difficulty separating out the impact from their physical health condition versus the impact of their mental health condition. So, we just decided, excuse me, to combine all of those together.

The third category was the impact of co-occurring conditions. This includes things like emotional challenges, difficulty finding providers.

The third -- the fourth category was research needs. The fifth category was service needs. And the last category was impact of the pandemic.

So, first, the demographics of our respondents. People were able to choose more -- as many demographics as they would like. So, we had 54 people who identify them -- 54 percent of people who identify themselves as autistic individuals.

57 percent identify themselves as family members, 23 percent as a health service provider or educator, 7 percent as

researchers, 6 percent as representatives from advocacy organizations, and 6 percent as other. And we had 39 percent who identified themselves as members of multiple groups.

This is just a word cloud representing how often different co-occurring conditions were mentioned. The top ones, as you might imagine, were gastrointestinal, sensory and motor challenges, anxiety, sleep, ADHD, communication.

And we have that represented here as well. So, the top 10 conditions identified were sensory and motor, anxiety, sleep, ADHD, GI, mood disorder such as depression or bipolar disorder, communication challenges, self-injurious or aggressive -- self-injurious or aggressive behavior, learning and memory difficulties, and suicidal ideation.

We decided to pull some quotes just so you guys could see the types of things that people were saying. And we'll have more quotes in the report. But we have just a few here for now on the impact of co-occurring conditions.

So, we have this person who said, "The most significant challenge has been finding medical providers who believe us." This next person is talking about their child saying she masks extensively at school and she comes home broken.

This person here says their co-occurring physical health conditions cause pain, and pain can be difficult for them to communicate, which results in delays in care and delays in intervention.

This person says, "Professionals often do not see beyond the autism diagnosis." The next person says, "When I can't remember or focus on my daily routine, I get more stressed out and more dysfunctional." And this leads to a meltdown, and they're completely drained of energy and burnt out.

This last quote is talking about their son and says, if he hasn't had a good night of sleep, it affects their whole family and no one in the household can have a good night of sleep. And it means they all have a hard day the next day.

So, our -- the -- our accounts for the impact of co-occurring conditions, the most commonly mentioned was difficulty finding providers.

Next, communication issues, social challenges, bias or stigma, employment or financial challenges, executive function difficulties, inaccessibility or lack of accommodations, academic challenges, difficulties with daily living skills, and reduced health and wellbeing. And these were the top 10 impacts.

Next, we asked people about their priorities for research. And we aligned the responses with the seven areas of the Strategic Plan, the two cross-cutting topics which were sex and gender issues and reducing disparities, as well as an additional category for the inclusion of lived experience in research.

And so, the top category mentioned here was biology -- the underlying biology of co-occurring conditions. Next was interventions for co-occurring conditions. Increased services and supports. Understanding the impact of sex and gender on co-occurring conditions. Lifespan issues. Better screening and diagnostic tools. Inclusion of lived experience in research.

Promoting equity and reducing disparities. Understanding the genetic and environmental factors that contribute to co-occurring conditions. And better infrastructure and prevalence.

We also have some quotes here about service needs. One person mentioned that a care manager or navigator to help would -- is needed badly. The second person mentioned that doctors and professionals should have mandatory training on how to work with autistic patients.

This third man -- third person mentioned that trying to get care for her son, but the departments that she's trying to work with won't work with each other. And this last person mentioned, insurance needs and reduce burden of paperwork for obtaining insurance coverage.

So, when we categorize the responses for service needs, the top mentions -- the top item mentioned was provider training. Followed by more benefits and insurance coverage. Increased accessibility of services and interventions. Better and more personalized services. Systems improvements such as navigation. Support for caregivers. Training for autistic individuals. And acute care or crisis management.

Finally, we wanted to -- we asked about the impact of the COVID-19 pandemic. Some of the quotes here are, "Increased remote work and healthcare has been the single best thing that has ever happened to my physical and mental health."

This person says their son was a happy child, then he was isolated. His anxiety increased. He could not see his therapist, so his OCD became debilitating. He's not the same child he was before.

This third person says, "Before COVID-19, we had an incredible support system of providers. We lost those providers due to in-person services being suspended. And we have not been able to find replacements."

The last quote is, "It's scary because we are now seen and treated as second-class citizens because we're considered disabled. I don't want to be the last person in the hospital to be seen because I have so many comorbidities someone thinks I'm better off dead."

So, when we categorize the responses, we identified both positive and negative impacts of the pandemic on health and wellbeing. The top seven impacts were, benefit from remote technologies, new or exacerbated health challenges, hardships due to increased isolation, decreased availability of services, disruption of routines or regression, benefits from reduced social obligations, and hardships due to lack of in-person services.

So, as I mentioned, we'll have a fuller analysis of the RFI, the request for public comment responses, in the co-occurring conditions report. Now, I'll turn it back over to Susan.

DR. DANIELS: Thank you, Oni. So, yes. So, as I mentioned, we're currently updating the content of the report. So, our next steps are going to be trying to incorporate some of the full RFI analysis into the new draft.

And so, in late spring -- so, after this meeting, we will be sharing the draft with you for your comments. And in July, our plan will be to discuss that draft. And then after that last meeting, we will continue in the office working on the draft.

And we'll share back a second draft to the Committee. But that will have to be by email because we won't be having an in-person or a hybrid meeting at that point.

And we'll try to gather your additional feedback. And our goal is to get this published in 2024. And so, with the 180-day extension, that should be enough time for us to complete the report.

And while we recognize, we will try to be as comprehensive as we can. There -- there's -- there are always chances in the future to expand upon it. But I think getting something out there that is representing the Committees' gathering of information on this will be really helpful to the field and helpful to the next Committee. So, we look forward to working on that with you.

Do you have any questions about that process or any of the work that has gone on so far? And we're thankful to Julie for her leadership on this. And she will be working with us on this draft as we move forward.

And we will acknowledge the previous working group or the working group that helped put the initial draft together. So, we will include, you know, acknowledgement of both Committees and the working group in the draft, as well as any other people we need to pull in for any expert opinions on some of this. So, we look forward to working with you. Question, Yetta?

MS. MYRICK: So, not really a question, just a general thought. And thinking about what I've heard today and thinking about this -- like, the next steps, a recommendation about how we build capacity, right? This is a huge challenge, I think not just in research, but in the community at large.

So, when you all are drafting -- and I'm even thinking about what Julie you shared earlier about how researchers specifically, right, like, might not have been doing this work unless there were very specific recommendations.

So, I just want to, like, pull that out again. And my brain is, like, going back to how do we build capacity? How do we build capacity across all these various sectors.

So, I'll leave that there. But I think it's so very important.

DR. DANIELS: Yes, thank you. So, we will -- of course, anything that we get from this report, we will hopefully incorporate in the next full Strategic Plan with recommendations. Julie?

DR. CELESTIN: Steven.

DR. DANIELS: Oh, Steven, sorry [laughs].

MR. ISAACSON: Hi, there. We have two comments. One from Dena. She asks, "Can we get a link for others to continue with the report?" And we have a comment from Morénike. They concur with Yetta; capacity building is essential.

DR. DANIELS: I didn't understand the first one, a link?

MR. ISAACSON: A link for others to continue to report.

DR. DANIELS: A link to continue to --

MR. ISAACSON: I think the question is the RFI still open?

DR. DANIELS: No, the RFI is not open. It's closed now. So, that is completed. If the new Committee wants to do another RFI later on the same topic, that's an option for them to do.

DR. TAYLOR: When we're thinking about capacity building too, I think it'll be important for us to -- I'm saying this now so we remember for later [laughs] -- to think about reimbursement issues.

I used to think when I was first kind of thinking about this work, that lack of capacity was because providers -- a lot of providers aren't comfortable, you know, treating people with disabilities or people who are autistic. And I'm not saying that that is not an issue.

But we're finding more and more and more that providers would be just fine treating autistic people. But when people are on public health insurance, like Medicaid, the reimbursement rate is low enough that they can't have very many people in their practice and feel like they can pay their bills.

And so, at least sort of anecdotally, that is seeming at least in our area, to be a bigger issue than sort of training providers about how to treat people with IDD. And we've got all kinds of ways that we can do that. And we've got toolkits put out there.

But if they can't afford to treat a whole lot of people with IDD or people who are autistic in their practices, then sort of the toolkits and the trainings are sort of for naught.

DR. GORDON: It's an excellent point, Julie. And maybe another item for thinking about inclusion in the report is, you know, there are modification codes for billing that account for complexity of the case. For example, that allow providers to bill more for a service when it is merited.

And whether those could be used or whether there might be additional codes that we would want to try to get CMS to adopt that would permit billing for the increased time that it takes to see someone with a neurodevelopmental disability.

Or on the autism spectrum, the comments were made, "It's hard for pain to be expressed." Well, to ferret out that pain then takes more time and effort by the provider even if they do have the right training. So, I think that's an excellent point along the workforce development piece.

DR. DANIELS: Yes. And to comment on that too, there was a -- as you recall from the physical health workshop that we did, we had a whole section on provider-patient interactions. And so, that is a part of this report that's being developed. So, we'll take note of those points. Thank you. Is Aisha next?

DR. AISHA DICKERSON: Hi. This might be backend, and it might not even matter now. But as I was watching the presentation and I saw that long bar for biology, it occurred to me that maybe biology is such a general term that perhaps we can parse it out into separate little sections, like animal studies versus brain imaging or something like that.

Just it -- I probably thought about it before and never mentioned it. But in seeing it on the slide, it occurred to me that when people say biology, it's so broad. And I don't know if that's something that we can do in this upcoming report, but maybe in the future. And I just thought, let me say it before I forget. So --

DR. DANIELS: Yes. So, in the portfolio analysis report where we take project-by-project and analyze the data, we actually do have subcategory coding for each of those categories. So, biology is broken up into -- I don't remember if it's 10 different subcategories, something along those lines. And so, we do have that in the portfolio analysis report.

In something like this that's going to be more of a narrative report, we don't necessarily have that. But we can consider that comment and see if there's anything that can be done to break that up.

But you're right. It is a very big category that includes a lot of different things. Everything from molecular studies to some very, you know, larger biological studies or cohort studies and so forth are all included in that. So, that's true that it is a general category. And then does Scott -- did you have your part up?

DR. ROBERTSON: Yeah, I had my part up. Thanks. I just want to say that I appreciate the great work that you all already done on --

DR. GORDON: If I could just interrupt you. Now, people --

DR. ROBERTSON: Oh, sorry.

DR. GORDON: No, no, no. People could just take their last comments briefly. We're running a bit over.

DR. ROBERTSON: Okay. I'll try to stay brief. Is -- I just want to say I appreciate the analysis you've already done in the mix of the qualitative and quantitative data. And I hope the qualitative thoughts can be integrated just as well as the quantitative data.

And I also appreciate that work in terms of thinking about the practical policy practice kind of changes that could happen. And I think that could maybe help inform future recommendations and maybe help support in terms of hopefully when the Committee is reconstituted maybe in 2025, it could learn from what has been done in terms of the focus in this -- for this co-occurring conditions. So, thank you for the analysis so far.

DR. DANIELS: Yes, thank you. Tom Frazier has a question on Zoom.

DR. FRAZIER: Yeah. I just wanted to quickly highlight the earlier comment about reimbursement as a blocker. In adult services and day programs we see the same thing, even though there are different rates depend -- that are modifications as Josh pointed out.

The rate differences aren't enough oftentimes for programs to accept children with, for example, profound autism, severe challenging behavior or other kinds of co-occurring conditions.

So, the -- even when there are differences in rates, it's really important that we actually make those differences big enough and useful enough for the more challenging population to make sure that they can get the services they need.

DR. DANIELS: Thank you for that. Paul?

DR. WANG: Yeah. I just wanted to offer a personal perspective that cuts across a number of topics here from the co-occurring conditions to the Strategic Plan, the types of research. I apologize I'm going to bucket biology sort of into one thing.

I would love to see more translational research, more research on services, and community-based supports and things like that. In fact, 20 years ago I changed the direction of my career. I moved from the ivory tower of academia to the for-profit drug industry because of -- well, at least partially [laughs], because of that reason.

At our last meeting, I spoke out in support of research on a particular research paper for nominations on the value of navigation in helping children reach a diagnosis, navigating that whole odyssey, and now getting to treatment. So, I hope there's no question about the value that I personally put on that type of research.

At the same time, I want to offer my opinion that basic research is of critical importance and absolutely must continue. What I learned when I worked in industry is that in our capitalistic society, we know enough to make a difference -- a practical difference.

For profit industry is going to jump all over it. They are going to make it happen. That's the beauty of the United States. Unfortunately, science is still full of gaping holes that do not allow us to make a difference for issues that are enormous importance to autistic and the autistic community abroad.

And just drawing on co-occurring conditions, I'm going to mention two things quickly. Sleep and sensory integration. Sleep is like such a fundamental thing. We're all experts on sleep. Most of us do it every night [laughs] for a lot of hours. And yet, we really do not understand what drives sleep. Why do we feel sleepy? That is still not understood.

And it is important that -- we just absolutely cannot do translational research with an expectation of immediate impact for autistics unless we fill that gaping hole in basic research. Similarly, for sensory processing, sensory integration, there's just so much. The brain is just too complicated.

We are basically much closer to ignorance about the brain than we are to full understanding of the brain. And we need that basic research to continue. And we need the gorilla of federal funding to continue to support basic research.

I work at the Simons Foundation. I was trying to figure out the weight of gorillas versus, like, other kinds of primates. We need the gorilla of federal funding for basic research. Simons Foundation, I think we're sort of like a bonobo.

We're very capable. We're pretty cute. But absolutely we need federal funding of basic research to continue on a very large scale. It's not going to have immediate impact. Hopefully, it will have enormous impact down the line.

DR. DANIELS: Thank you, Paul. And, Yetta, did you have --

MS. MYRICK: Yes, I have. Okay. Really quickly, just a resource. So, Got Transition, which is the National Resource Center for Transition, has a -- and this goes back to the billing piece -- a 2023 coding and payment tip sheet for transition from pediatric to adult healthcare.

So, I just want to flag that for folks as a resource because I think that's important. And full disclosures -- we have to disclose these things -- I was on their Health Care Transition Family Advisory Group for a number of years. I did not specifically work on this project, but I just want to share that.

DR. GORDON: Yeah. Thank you for sharing that. And as I mentioned, these things are big drivers of supplied -- you know, raising reimbursement rates, finding ways for providers and caregivers to know how to get reimbursed for their services really, really crucial.

It's not going to change things overnight because we got to train people. It takes years. But, you know, the shortage areas in medicine are not a surprise if you look at reimbursements. The shortage areas in care more generally for behavioral health and for autism, not a surprise if you look at the reimbursements.

So, really, really important. And thanks also, Tom, for your points about we have to make sure that they're adequate. Any last comments on that? We're -- we -- the next and last phase of the morning is the round-robin updates.

And given that we're just a few minutes over, what I'm going to say is that we all have them in our folders and receive them in advance. And they are posted on the website for the general public. So, I encourage you all to look at -- there are updates --

There was a request for information. Yes, we could make it more digestible. And we'll have to make sure that our federal agencies keep -- are being kept to the fire to make sure it's simpler.

But there are updates from every single federal agency at the table, as well as from many of the public members of the Committee. So, I encourage you to look at those. And with that, I think then we can break for -- we can conclude our morning. We're going to break for lunch. The time we are due back I think is 1:30 p.m. Is that correct?

DR. DANIELS: [affirmative]

DR. GORDON: So, we're going to do -- be done back here at 1:30 p.m. Those of you online, please rejoin us just a couple minutes early. Those of you in the room --

DR. DANIELS: It's actually 1:40 p.m.

DR. GORDON: Yeah. But the timing is wrong, right, because we have oral comments at 1:30 p.m.

MR. ISAACSON: It's 1:40 p.m., yeah.

DR. GORDON: Yes.

DR. DANIELS: Oh, it should be 1:40 p.m. actually. She said that the 1:30 p.m. is a mistake.

DR. GORDON: Yeah, I don't think so [laughs]. I think we should be back here at 1:30 p.m. unless there's a reason why the video cast won't work at 1:30 p.m. because we have public comments and a break at 2:00 p.m. So, I'm a little concerned given the capacity of this Committee for responding.

DR. DANIELS: We have one.

DR. GORDON: So, I would say let's be back at 1:30 p.m. We will aim to start sharply at 1:30 p.m. We may not make it, but we'll do our best. There are lunch options. For those of you in the room, please, if you don't know, please speak to the staff. Thank you very much.

DR. DANIELS: Thank you.

(Whereupon, the Committee recessed for lunch at 12:40 p.m. and resumed at 1:30 p.m.)

DR. GORDON: All right. Well, thank you all for coming back a few minutes earlier than planned. I want to make sure that we have the full time for committee discussion, as usual with the oral comments, and that we get to our esteemed afternoon panelists on time. We -- with that, I'm going to open the public comment session. As usual, we ask for members of the public to pre-register in advance to give oral comments and limit those comments to three minutes.

We have one oral commenter who has asked and is joining us virtually. And then we will have a summary of the written comments as usual prepared by the IACC staff. So, with no further ado, I'm going to ask our oral commenter to turn on their camera and unmute their phone -- unmute, sorry, their audio. And the oral commenter is Dr. Sharief Taraman. I'm sorry if I'm missing the pronunciation there. But if you would -- yeah, there you go. Excellent. You have three minutes for your comments.

DR. SHARIEF TARAMAN: Excellent. Thank you all for allowing me to make some comments. And I did provide written feedback as well. As mentioned, my name is Dr. Sharief Taraman. I am a pediatric neurologist and have a board certification in clinical informatics.

I was a former division chief of pediatric neurology here in California at Children's Health of Orange County. And have my academic appointment as an associate professor at University of California Health

Road Irvine. And then I also am an affiliate professor in the School of Engineering at Chapman University.

I think the main hope that I'm reaching out to the IACC regarding is something that I -- has been disturbing me for some time now. When I became the division chief at Children's Health of Orange County, despite having two autism centers within our county -- which are phenomenal autism centers and neurodevelopmental centers.

We were experiencing, within my division, a huge urge and request from the pediatricians in the community to evaluate children for neurodevelopmental delays. Because they could just simply not get an evaluation and get a diagnosis within the autism centers and the neurodevelopmental centers within our area. And simultaneously, as a division chief trying to rectify that situation by recruiting a shortage of specialists as we know exists in my own practice. My initial first few years of practice were focused primarily on children under the age of five who had neurodevelopmental disorders.

And then after that first five years period, what I began to see is, you know, the slew of just pediatric neurology patients. And in that, what I had started seeing as a trend was older individuals, mostly persons of color, children of lower socioeconomic status, children of immigrant families presenting at 8, 10, 15, 19 years of age with some concern that would ultimately result in an autism diagnosis. And the families and the patients expressed to me their frustrations that they had been trying to get an evaluation or understand what was going on much, much earlier.

And really in retrospect, looking back at records, you know, an earlier diagnosis was definitely achievable. And many of those families, the vast majority of them, did not benefit from early interventions, including things like speech which don't require speech delay, which don't require necessarily a diagnosis to evaluate but often were being treated in isolation and were lacking efficacy.

And so, this trend was very disturbing and -- but also motivating for me. And I think as a -- someone who understands informatics and looks for system level approaches to address problems within the healthcare system, which is very dysfunctional, I took to that approach. And so, presently, I'm also the CEO of a company called Cognoa. Which has gone through the FDA to develop a diagnostic using artificial intelligence to support primary care physicians. As well as specialists to kind of rethink how we evaluate neurodevelopmental disorders and how we potentially diagnose autism.

And as a member also of the American Academy of Pediatrics, both prior president of a local chapter and a board member of California and serving in national capacity.

You know, the American Academy of Pediatrics really has focused on, can we help alleviate some of our specialty shortages? And really, reprioritize our availability of specialists to focus more on treatment and allow primary care physicians to help and take on a portion of the diagnostic process, evaluating neurodevelopmental disorders and autism.

DR. GORDON: Dr. Taraman --

DR. TARAMAN: And, obviously, there's lots of stats. So, I won't go through them.

DR. GORDON: Yeah. I might just ask you to wrap up, please.

DR. TARAMAN: Yes. But I would hope that the IACC -- excuse me -- really looks at strategic planning and how we can support policies that look at things that have gone through the FDA. And have looked at how we can support our primary care physicians, specifically, pediatricians in the evaluation of neurodevelopmental disorders, including autism. Thank you for your time.

DR. GORDON: Thank you for that comment.

We appreciate you joining us today. We will have an opportunity to have discussion as a committee on this and the other comments. But first, I want to turn it over to Susan for presentation of the written comments before opening up to the Committee.

DR. DANIELS: We have our written public comments here. We only received nine this time around, probably partially due to our RFI, which, as you know, was very extensive. And we got 1200-plus comments.

So, we had nine written public comments that were not about co-occurring conditions that came in in the last quarter. So, we have three comments that are on research and service needs, resources, and policy implications, including from Mackenzie Purcell, John Poulos, and Nicole Corrado.

We had two comments on mental health research services and treatment from Lisa Morgan and Fran Stanley. We had two comments on the role of the IACC and federal government, including Anthony Tucci and Jinny

Davis. And addressing the needs of autistic individuals with high support needs, we had one comment on this topic from Tiffanie Smith. And inclusion of autistic perspectives in research, we had one comment from Tosha Brothers.

And all of these comments are in your packets. We also have them up online for anyone in the public who wants to read the full text of these comments. And the Committee had them in advance to review.

So, we really appreciate all of you who sent in your written public comments. Thank you for sharing your perspectives. And I'll give time back to the Committee to be able to have a discussion. Thank you.

DR. GORDON: Great. Thank you. So, now, we will open the public comment session up for committee questions, comments, and responses. Please, again, raise your cards, or raise your hand on the Zoom. Paul.

DR. WANG: Yeah. Thank you. I just want to respond to Dr. Taraman's comments. Not to say whether I disagree or agree with the content of his comments. I think it's important to explicitly make clear that Dr. Taraman has a financial conflict of interest. His statement is biased by his financial conflict of interest. I actually think that the Committee should adopt a policy as to whether we would accept that type of public comment in future meetings.

DR. GORDON: Paul, can you state more explicitly what the conflict of interest is you perceive it as?

DR. WANG: As Dr. Taraman said, and as is reflected in the materials for the meeting, he works at Cognoa. In fact, the website shows that he is, I think, the CEO of Cognoa. And he mentioned that Cognoa has a product along the lines of what he described. So, it is a commercial product. It is for sale, and that is the nature of his conflict of interest.

DR. GORDON: Okay. Thank you. You know, we can certainly look into requirements for disclosing conflicts of interest. We have to be careful with prohibiting people from making open comments. And we -- but we can certainly look into the -- and [unintelligible] disclosure of conflicts of interest where they are.

And I appreciate very much, Paul, you bringing that to the attention of the Committee, as well as to those viewers to help inform their thoughts about that comment. Let's see. I have Scott -- oh, no, sorry. Dena is next.

MS. GASSNER: Yes. I just wanted to respond to the comment that came in from Jinny Davis. Jinny, thank you for your comment. I did want to let you know that I and my son both are recipients of Social Security Disability, as are many of the members of the IACC. I'm afraid you may have the misinformation or misunderstanding that that's not possible for IACC members.

And I also wanted to encourage you to go ahead and apply as a member if the Committee continues to progress. We have many members who are getting government benefits on the IACC. So, trust me when I say that there's a lot of representation here. And I just wanted you to be aware of that. Thank you.

DR. GORDON: Thank you indeed. Scott and then Lindsey.

DR. ROBERTSON: Yeah. I just wanted to say that I appreciate the written comments that are on quality of life focuses for employments. There's a comment from John in the written comments on -- that -- from ASN that emphasizes especially retention and attainment of jobs and career outcomes for autistic people across the life course.

And I think we could really do a lot more to build on what we've already been doing in the employment space. So, we appreciate seeing that continuous input from folks across America in terms of especially autistic people, about what we could be doing even better on employment work, including employment research. Thanks.

DR. GORDON: Thank you, Scott. Lindsey.

MS. NEBEKER: I just wanted to briefly acknowledge a couple of the written comments. One of them -- it's sort of related to the same thing. One of them coming from Lisa Morgan, who had addressed the needs of autistic people who are in crisis being able to have access -- adequate access to supports without feeling like -- that they might have a harming experience due to their communication differences and sensory issues. Because there still needs to be more specific training for -- there's first responders, emergency room professionals, and the crisis center workers. And I think that's an incredibly important issue to have conversations on still.

And the other person who -- where this is kind of all related is the comment from Tiffanie Smith who has a non-speaking, autistic son. And there -- she talks about the struggles to find a provider who can address all of the accommodation needs for her son.

And also, about difficulties of finding a provider or dentist for adults who are non-speaking and need more substantial supports. And so, I wanted to -- I know we've had this -- we've had conversations like this before. But I think it's always good to continue to remind ourselves that regardless of where -- what point people are in the spectrum, that we really need to continue focus and increase on autism-specific training for first responders and people that work in the hospitals.

DR. GORDON: I excellent point. Thanks, Lindsey. I'm sorry, I didn't quite hear what you said at first. Whose fear of what that you were --

MS. NEBEKER: I'm sorry. What was -- what did you say?

DR. GORDON: [laughs] Sorry. Maybe you don't remember [laughs]. You opened up your comments about that issue where being aware of individuals in their fear of -- and I just didn't hear the word, right?

MS. NEBEKER: Oh, yes. Because there are some people who might be in crisis. But because of sometimes the history or the trauma history involved of going into hospitals or clinics and not being treated appropriately by staff or just some of the trauma experiences from it. So, that's just --

DR. GORDON: Right. So, fear of interactions with the very people who are trying to come and help them and creating, you know, an unfortunate feedback loop.

MS. NEBEKER: Right.

DR. GORDON: Thank you very much. Appreciate the comment and appreciate you highlighting the comments from the written comments. Any other questions or comments from -- oh, sorry. Yetta.

MS. MYRICK: Thanks again, everyone, for sending in your public comments. I think it really helps to push our group forward, right, and making sure that we are getting on the -- as much on the ground information.

As Dena already stated and I agree with, you know, there [laughs] are many diverse people here on IACC who are serving on this committee. And would invite you, just like Dena said, if you're interested in nominating. Because I think there was something specific, Jinny, about, you know, I don't necessarily have like the capacity to -- you know, I don't have all the things necessary to apply.

But I'm sure there's someone -- if you have submitted a comment, I'm sure there's someone in your state that would be willing to write a letter of recommendation for you that you can self-nominate. That's actually what I did, full disclosure, and reached out to people in my -- in D.C. to support that nomination. So, just want to be transparent there.

The other thing as well that was highlighted in Tiffanie Smith's comment about, you know, the access to adult services. We -- if you are listening today [laughs], we have been talking about that. We've been talking about how providers can -- how we can build capacity. How we can figure out ways for providers to be compensated for their time right there. It's a lot of work to be done. And I just want you to know that I see you and I hear you.

The other thing, as Lindsey was talking about, you know, these traumatic experiences that could be happening in medical environments. Right? Want to call out specifically in the Round Robin document. And there are actually four of us who are members of the consensus panel for the SAFE initiative.

So, Morenike, Matthew Siegel, as well as Lauren Raskin Ramos and I all served on the consensus panel for the SAFE initiative. And this is looking at developing healthcare standards for youth and -- with neurodevelopmental disabilities. There is a consensus statement. It was published this month.

So, please, go to the website, if you've not already. Look at the Round Robin document. And specifically, look under my name for that information. But I think it's so important for us to be sharing, you know, whatever supports need to be put in place to help everyone across the states, right, to get appropriate supports when they are in the medical setting. And again, you know, thank you all for your comments.

DR. GORDON: Thank you, Yetta. And I'm glad, again, that you brought up that there is an IACC website, iacc.hhs.gov -- sorry, .hhs.gov. And on it are all the materials for the meeting, including the written comments. So, if any of the summary that we just gave you or comments from the IACC members on those written comments makes you want to learn more about what our contributors had to say, please do visit the website and look at that.

And I just want to say thank you to all

the IACC members who've spoken, even those who didn't. Because clearly, you can see from these comments that we read them [laughs], that we know what's in there. And that we actually have read them, have seen them, have heard them, and really appreciate this input. With that, unless there are other further comments -- ah, yes, please, Jenny.

DR. JENNY MAI PHAN: Hello, everyone. I actually want to highlight Tiffanie Smith's comment especially, as I very much relate to the experience of -- a lack of providers to address high support needs for your child.

I'm someone who has moved around a lot with my family. And I have one child with high support needs. And because we have moved around, we also have, you know, dealt with the challenges of finding enough providers and the right providers to address some of the concerns that my son and I have raised with our primary care physician.

The move towards telehealth has really helped address this problem where you -- if you live in a place that does not have a provider who can address the concerns that you're raising. I want to applaud all the providers and scientists in the field of autism for expanding telehealth so that families like Tiffanie can access this support.

With that said, there are so many barriers that many families today are still facing to access telehealth care. And I'm not saying that's the best care for Tiffanie's child, but it might. There are many opportunities for us to improve in telehealth. But also, for families to have that care covered by their health insurance or by some kind of healthcare financial -- that aid that they're receiving.

I think that there needs to be a mechanism in place for these families because there are so many families like Tiffanie in the U.S. who need that mechanism in place for them. So, I just want to echo her comment and raise that as a committee member. Thank you.

DR. GORDON: Thank you, Jenny. And I would just add to your comment of -- regarding telehealth is that there is a body of evidence supporting the use of telehealth for a wide range of mental health applications, including autism, both in terms of treatment, but also in terms of caregiver support. So, thank you very much for raising that response.

Oh, I understand that Tiffany Farchione is on the line and can address the question from earlier today around the FDA. Right. So, if -- I don't know who asked the question, but if you could restate it, about -- the question around the ban of the equipment for ABA.

DR. WANG: Yes. Paul Wang here. Thank you, Dr. Farchione. We were curious what the confidence was that any new action from the FDA would be upheld if it is appealed to the court system since the previous ban was overturned.

DR. GORDON: And can we just restate what the --

DR. WANG: The ban on electrical stimulation devices being used in autism.

DR. FARCHIONE: Yeah. So, I'm sorry. I actually -- I responded to the previous chat that I don't have any additional information beyond just what's in the public domain. I haven't been involved in that decision. You know, we -- my division was consulted previously. But I think that they're just relying on our previous comments on that. So, I don't have any insight into that, unfortunately.

DR. GORDON: So, thanks for responding, Tiffany. My recollection -- and this is hazy and not my area of expertise -- was that there was a process issue with the prior ban. And therefore, it could be solved with the new effort. But I don't know if anyone else has more information about that, whether I'm right or wrong. I don't want to provide information to the public that's inaccurate. So, Scott.

DR. ROBERTSON: I recall that with the court decision just a broad kind of aspect was that there are restrictions in terms of the way FDA's powers or whatever, I think, under the law to regulate the practice of medicine. And I think that that was sort of in conflict in terms of what the court had decided.

And it sounds like maybe -- I assume that maybe this new effort is probably taking that into account. Because one of the confusions I think that was raised at the time was that if they had restricted it entirely rather than just in certain circumstances, then it would've been an easier lift.

And I don't know if they're taking a little bit of different approach. I haven't seen the exact text of it. But I remember that being out in the public sphere around the court decision. And I think I had taken a look maybe at the text of the decision at the time that the FDA is restricted on regulating medicine itself.

DR. GORDON: Great. All right. Thank you, Scott.

DR. FARCHIONE: Yeah. I mean -- and I'm happy to try to look into this further. But again, it's, you know, kind of outside of my particular area. I would be more involved with like office of regulatory policy and, you know, some of our legal folks more so than my group. But I can certainly look into it and try to provide feedback to the Committee.

DR. GORDON: Thank you. Greg Robinson from the Autism Self-Advocacy Network has something to say about it. We need you to come here and use the microphone.

MR. STUART SPIELMAN: Yeah. Stuart Spielman, Autism Speaks. Greg and I can both talk to this.

DR. GORDON: Yes, please.

MR. GREG ROBINSON: So, as the Committee has said, there was a previous final rule banning the use of electric shock devices that was overturned in the court on the basis that the FDA did not have the authority to ban devices for a specific use and that [unintelligible] to the practice of medicine.

That is something that Congress has now addressed in the 2022 omnibus, incorporating language clarifying that the FDA does have the authority to ban a device for a specific use.

So, the FDA's new NPRM is largely a -- substantively, it's the same proposed rule using this -- based largely on the same evidence, updated for the new information that we have since 2022 but reaching many of the same conclusions. And as a result, with the clarification of the authority using that rationale for -- to promulgate a new ban.

MR. SPIELMAN: So, Greg and I -- Stuart Spielman, Autism Speaks. So, Greg and I were actually talking about this before the question came up. And we were talking about the common period on the new rule, which ends on the 28th of May, I believe. So, the short answer is that the FDA's authority was changed subsequent to the court decision.

DR. GORDON: Great. Well, thank you very much, and appreciate that. And this does belong in the discussion of public comments as this -- the practice of using these devices has been one that has inspired many public comments in the past. So, thank you very much for that discussion. And I'm going to turn it back over to Susan. I think we take another break, is that correct?

DR. DANIELS: Yes. We will be taking another break. We'd be happy to update the Round Robin document to have a direct link to where those public comments can go in case there are public members of the Committee that want to use the link. So, with that, I think we can --

DR. GORDON: Oh.

DR. DANIELS: Oh, do we have more?

DR. GORDON: Please, Helen, and then Lindsey.

DR. TAGER-FLUSBERG: So, I'm extremely

sympathetic with Paul's -- the concern that Paul's raised. The truth is, it's something that's bothered me since I've been here, which is that public comments oral but particularly in the written comments, often contain reference to things that are not just non-scientific but in many cases, very anti-scientific.

And I do think that there's a concern that we don't flag this. Okay? So, much as if you were to write certain inflammatory comments on Twitter, they will be marked as inflammatory. I -- well, they should be -- supposed to be. I would think that given the prominence of the IACC, the fact that we are here to represent science, we ought to be doing the same, that we should be marking.

And you can simply, with an asterisk after every comment that is -- does not -- is not based on science as the way we would understand it, to say that this is controversial and not supported. The scientific evidence is questionable. I just think that's the way we should be handling all our public comments.

DR. GORDON: Appreciate the opinion, Helen. And I certainly, of course, share the importance of ensuring that the information that we as a Committee promulgate has a scientific basis. And I welcome the discussion period as an opportunity to identify any comments that do have that. And we have used this space as the opportunity to discuss that in the past, including I think even at the last meeting.

So, if there's any particular comment to which you're referring of the nine written ones, you're welcome to introduce that here. I think we can also think about a way to allow for a committee response in a more formalized way that gets posted on the website as well.

I would say that it is not our job, nor are we empowered to do it, to -- and you're not suggesting it either -- to edit the documents or prohibit the posting of that information. These are public comments and they represent public opinion, however, informed or not it might be. Lindsey, last comment and then we probably should get ready for our [unintelligible].

MS. NEBEKER: This is going to be quick. I know that we're getting into a very interesting discussion this afternoon on global leadership. And it's going to be -- I know how, you know, large our committee is now, and how we love to be engaged in our questions and feedback.

So, in case I don't have the opportunity to do so for the remainder of the day, I just want to take a moment to express my sincere appreciation to Dr. Gordon for his seven years of service as the chair of the IACC and for his leadership at the National Institutes of Mental Health.

Dr. Gordon, it has been an honor and a pleasure to work with you during my last few years as a member of this committee. Not only have you been present at the quarterly full committee meetings and subcommittee meetings, but behind the scenes, I have also noticed how proactively engaged you are in participating in addressing concerns and ideas and how you take in the time to listen even if a concern or idea is only expressed by a few members at a time.

I appreciate your willingness to be open-minded and take into consideration the diverse lived experiences from individuals and families in the autism community. As you stated earlier this morning, there's a lot to learn and a lot to take in. And I recognize the energy and the investment it takes to facilitate these conversations. And as most of us can probably agree, we can -- we have a -- still have a lot to work to do, and gaps we need to address.

But even though we will miss working alongside with you, I am also thrilled to hear about your transition back to your leadership involvement at the Columbia University Irving Medical Center in New York and to spend more time with your family. So, on behalf of my colleagues at the IACC, I wish you the best of luck and continued success.

DR. GORDON: Thank you very much. I meant what I said earlier. And I really do appreciate your heartfelt words and the silent and not so silent applause. Thank you really very much.

DR. DANIELS: Well, we can take a break at this time. So, we will be coming back for the panel sessions. We want to -- we are not going to move straight into it because we have some people logging in on Zoom. And we want to make sure that they're present so that we can start at the right time that we said that we were to start. So, you'll have a little break.

(Whereupon, the Committee members took a brief break starting 2:00 p.m. and reconvening at 2:15 p.m.)

DR. GORDON: Okay. Folks, we're going to get started again. We've got our afternoon session already teed up. Confirm everyone's online that needs to be. So, people could just take a seat, and I would say finish up. Or you should really just end your side conversation, so we can get started.

All right, folks. So, our last two sessions of this meeting are actually held jointly with the Canadian Autism Leadership Summit, which is happening today in Ottawa, Canada. This summit is organized by the Autism Alliance of Canada, which seeks to inform policy and practice at a national level -- sound familiar? By bringing members together, identifying priority issues, and developing meaningful ways to address them.

The network includes a broad and diverse membership of autistic people and their families and support persons, as well as clinicians, researchers, policy influencers, service providers, and organizations from across Canada. Again, sound familiar? They really are our Canadian counterpart. Due to our shared interest in learning about autism activities around the globe, we decided to collaborate in these sessions.

And I really want to actually say that Susan was, of course, the main impetus at driving the collaboration today. And I want to thank her for her hard work, as well as Andy Shih, who I will introduce in just a moment, who helped put us all together as well. This portion of the IACC meeting is going to be streamed live in Ottawa. Hello, Ottawans and other Canadian colleagues. So, they can watch and participate.

Some of the speakers are here in Rockville with us. Some are in Ottawa, and others will be joining us virtually from locations literally around the globe. So, I especially want to thank anyone for whom this is the middle of their night for coming today, whether you're here in person, in Ottawa, or in your home country.

To kick us off, our first presenter will be Dr. Andy Shih, the chief science officer of Autism Speaks. He will be speaking about the global advocacy efforts of Autism Speaks. But I also want to acknowledge that, Andy, thank you for your help in assembling the sessions this afternoon, in helping Susan and our counterparts in Canada.

DR. ANDY SHIH: Thank you, Dr. Gordon. I want to thank first Dr. Daniels and Dr. Gordon and committee members for inviting me. I last shared Autism Speaks international efforts with this committee over a decade ago. And it's wonderful I had this opportunity to provide an update about progress in various priorities and activities.

So, the Global Autism Public Health Initiative is a broad programmatic umbrella for our public health work. At its heart, it is a community participatory research and advocacy program, where in addition to facilitating high impact research to inform program policy development, we serve as technical advisors to country government. And NGOs committed to enhancing support of our community.

We make sure that autistic people and their families are at the table, and that their voices are heard. And we prioritize implementation and help source expertise, support community-based knowledge co-production, and facilitate dissemination of sustainable solutions. For example, working across these four pillars, interconnected programmatic pillars of research, capacity building, advocacy, and policy. We facilitate and support prevalence studies, development of national strategies, training programs, and policy recommendations. Oops. Okay.

Earlier today, you have already heard Dr. Chiara Servili presentation on WHO UNICEF Global Report on Developmental Disabilities. I'll take the next 10 minute or so to highlight two other gap related programs for you. The WHO Caregiver Skill Training program, known as the HCST, and the Advocacy Leadership Network, or the ALN.

The update I'm sharing with you today is largely the work of these wonderful people I'm fortunate enough to call colleagues and friends over the past decade or so. I'm also immensely grateful to the many, many, many leading researchers, clinicians, and advocates, including some in this very meeting that have been incredibly generous with their time and expertise. And helping community stakeholders in Autism Speaks to better support autistic people and their families around the world.

The WHO Caregiver Skills Training program or CST is a caregiver mediated intervention developed by WHO with support from Autism Speaks. The program empowers caregiver with skills they can use in daily routines to promote development, with an emphasis on social communication, daily living, and positive behavior. Today, it has been implemented in over 35 countries. The program involves nine group sessions. Oh, sorry.

So, the scope of the WHO CST program is

really for children -- caregivers of children aged 2 to 9 years old who have developmental delay or disabilities, with a specific focus on caregivers of children with delays or impairments in social and communication domains.

It's important to know accessing the program, a diagnosis is not required. Because as Dr. Chiara said earlier today, in many parts of the world, having an official diagnosis can be extremely difficult. And we don't want that to be a barrier for accessing health. The aim is to increase caregiver skills to promote their children's development and wellbeing through joint engagement in play and home routine.

The program involves nine group sessions and three home visits. In a group session, the facilitator, often a non-specialist, uses illustrated stories, demonstration, and role play to teach strategies. The content of each session includes strategy to understand behavior, teach skills, and everyday -- for everyday life and caregiver's wellbeing. A very important component in the program is delivered through the home visits.

When facilitators have an opportunity to coach caregivers to implement the CST strategy while interacting with their children during play and other everyday activities. During home visits, facilitator can also support a caregiver to set specific goals for their child. The field testing -- I'm sorry.

Okay. So, the content of the program is really naturalist developmental behavior approaches, performing shared engagement, and communication. For example, we have element of JASPER or Joint Attention Symbolic Play Engagement Regulation developed by Connie Kasari. Also, PRT, the pivotal response treatment behavior intervention built into the program itself. We also have emphasized positive parenting approaches for promoting positive child behavior and management of challenging behaviors.

And finally, we promote caregiver problem solving and wellbeing. Even so, you know when the -- when caregivers are at their best, they can do their best for their children. There's also eLearning CST that's now available. Like everybody else, we thought about digital strategy during the pandemic.

And our colleagues at WHO were really terrific in leading the way to develop an e-learning component for this program. So, the self-directed eLearning for caregivers based on the CST is total eight hours and it's self-paced. It supports low bandwidth. So, it's suitable for mobile devices. It's currently being translated into Arabic, Chinese, Spanish, Hindi, Marathi, Yoruba, and Portuguese. It's also used to support hybrid delivery of CST. And for more information, you can turn -- go to WHO and just search for caregiver skills training program, and you'll get all the information you need.

So, this is CST sites worldwide from

2016 to 2024. We color coded them to indicate different levels of progress. Some are just starting the planning. The orange countries are just planning -- starting. The greens are where we have finished the training of master trainers. Master trainers are really the lead in each country. They're the ones who eventually going to take over the program and run the program in their own country. And at that time, WHOs and Autism Speaks will withdraw.

And as I said -- mentioned earlier, while others have been very successful implementing -- in the pilot implementation already started scaling up. Today, we have trained over 250 master trainers worldwide. In the U.S., we have taken a similar approach, as you may recognize. Many communities in the U.S. really struggle with the same factors that low income countries struggle with around the world.

So, currently, there are eight sites in the States, with additional sites in planning phase. So, the field testing in this country has been a very rich learning experience for us. It has informed the finalization of the package, indicated [unintelligible] a high level of feasibility of implementation. It was very well received by the caregivers and can be adapted for remote delivery to improve caregiver skills and interaction with the child.

There are perceived confidence in parenting skills, as well as reduction in stress. Pilot RCT in Italy indicated increased child communication gestures. Our [unintelligible] skill evaluation of CST in context appropriate care model is ongoing in Ethiopia and Kenya, the SPARK program, and is being co-led by one of our panelists today, Dr. Amina Abubakar, who you will hear from later.

Our aim of the CST program is to become part of the -- in the U.S. and the worldwide, in the near term is to explore incorporation of CST in the U.S. programs and systems. For example, Head Start, Part C Early Intervention, PTICs, and as well as HMOs. The longer term -- what we aspire to is broad, nation-wide accessibility, of this program. No matter where you live, how much money you have, and who you know.

And globally, we want to continue to work with our partners supporting WHO, increase the number of communities and countries implementing CST globally via broad, multi-stakeholder collaborations. Ultimately, we aim to facilitate, enhance, and sustain global CST accessibility, implementation, and innovation through an online community of practice that are already up and running at this point.

So, I want to change -- switch gears a little bit and talk about Advocacy Leadership Network. I should first say that of all the sites I mentioned about CST, about half of those sites were -- are in existence because of the work of the Advocacy Leadership Network. Advocacy Leadership Network is a network of accomplished international leaders. They are self-advocates, families, professionals, and policy makers.

We use social media to keep in touch in real-time. And we have biennial meetings, in-person meetings, and virtual working groups to facilitate knowledge exchange and collaboration. We focus on advocacy, dissemination, implementation, and research. And some examples of high-impact work that we have done together, including facilitating the passage of UN as well as World Health Assembly resolutions, and the implementation of CST program in many, many countries. As well as what Dr. Chiara mentioned this morning about the Global Report for Children with Developmental Disabilities.

I'd like to give you some eye candy -- some visual history of this group. So, this is when we first started in 2010. Relatively small group, not terribly diverse. By the time we moved on to Washington D.C. in 2016, you can see the complexion of the network had changed dramatically. We also enjoyed the participation of Congressman Chris Smith as our representative of many country embassies in the Washington D.C. area.

By the time we got to 2018, we started diversified activities we have in these networks. So, when our ALN member in China Women's Development Foundation decided to co-fund the meeting with us in 2018 in China, we built in a CST consultation -- technical consultation with this meeting. And as you can see [laughs], it's really a lot of fun. It's terrific. A lot of learning and a lot of foreign momentum coming out at that meeting.

By the time of 2020, this is actually literally a few weeks before the world shut down -- the pandemic. The network has grown large enough that we started to implement these regional activity -- regional meetings. But this was actually our first African regional meeting that we held in Adis Ababa in Ethiopia. And again, working with WHO, we incorporated consultation for the Global

Report on Developmental Disability into this event itself.

And last but not least, this is when we finally got back together after pandemic. This was last year in Long City [laughs]. It was a very joyous occasion. We had even more members coming in. For example, country from Mongolia were there now. And many more self-advocates had joined us. It's -- really feel like becoming more mature, kind of global community network, working together trying to advance the interests of our community.

And this is just a picture representation of the countries represented in the most recent gathering in New York City. So, near-term goals for us going forward is that we're actually working with the advocates in this network to produce advocacy training package by and for autistic adults. And we talked about this, this morning.

But I think one thing that we are very cognizant of is that because of different settings, different environments, different infrastructures, different resources, how this package is implemented and what the emphasis going to be may vary from region to region. We're interested in launching the African Research Consortium for Neurodevelopment Disabilities.

In Adis Ababa, we had a first taste of bringing some stakeholders together. Our recent interaction with them suggests that they're still super enthusiastic about this opportunity. And we are going to start holding a regional meeting again next year. And the biennial meeting, of course, the entire network will be planning sometime next year. I'm not sure where or when -- where yet, but it might be here in D.C. And that's it. Thank you very much.

DR. GORDON: Thank you. We're going to hold questions and discussions till the end of the first half of the afternoon. So, I want to thank Andy for the discussion from a global perspective of both intervention and advocacy efforts. Our next three speakers will move from the global scene to a relatively local scene. They're going to be talking about their efforts in each of their countries to develop a national strategy for autism.

We're going to hear from representatives of Australia, Canada, and Egypt this afternoon, or I should say in this session this afternoon. So, let me welcome the first speaker Pru McPherson, the director of Autism Policy in the Foundational Support and Early Childhood Reform Branch of the Australian Department of Social Services. Pru, thanks for coming.

MS. PRU MCPHERSON: Thank you. And good afternoon, everyone. Thank you, Dr. Gordon, Dr. Daniels, and the whole committee for having us here today. We're really excited to present on the work that Australian government is doing in this space. I'm going to try my very best to stick to time. But I'm hoping I'm not going to go too much over.

So, first of all, I just wanted to say the Australian government acknowledges the Aboriginal and Torres Strait Islander people throughout Australia, and their continuing connection to land, water, culture, and community. I come from beautiful Yuin Country, which is on the far south coast of Australia, which is where I live. And I work on Ngunnawal Country in Canberra. I'm also privileged to be on your traditional lands here today.

Just wanted to also acknowledge autistic people, their families, carers, and support networks. And representative organizations in the autistic and autism community who have worked tirelessly and campaigned long and hard for the establishment of the Australia's National Autism Strategy.

Just a very brief statement on language. So, we understand that people use different words to talk about autism. And that each person will have their own way of talking about autism and themselves. Some people in the autistic community in Australia like to use autistic person, which is identity-first language. Some like to say a person with autism, which is person-first language, and some are fine with using either.

The Australian government uses identity-first language to talk about the National Autism Atrategy. And this means we'll usually use the term autistic person or autistic people. Just an overview of what I'm going to cover today. The National Autism Strategy is being developed in three phases.

So, I'm just going to take you through each of those phases, hopefully, briefly. Share the context, vision, and goal of the strategy, the next -- the -- phase 3 of the implementation and next steps. Just to note, in my presentation, when I use the word department, I am talking about the Department of Social Services, as Dr. Gordon said. The department improves the economic and social wellbeing of individuals, families, and vulnerable members of the Australian community.

The department's work is wide ranging, with the ability to connect with Australians. The department makes a difference through social security assistance and support for resilient families and communities. And improve choice and control for people with disability and support for carers, and support for safe, stable housing.

By way of background, in 2019, the Australian Parliament's Senate Select Committee on Autism was established to inquire into services, support, and life outcomes for autistic people in Australia. The Committee delivered its final report on the 25th of March in 2022. And the report included 86 recommendations. A key recommendation was to develop a person and family-centered National Autism Strategy. Co-designed by the community that should form the centerpiece of efforts to improve outcomes for autistic Australians.

In 2021, Australia's national policy

framework for disability was launched; Australia's Disability Strategy, which is a 10-year strategy. The ADS vision is for an inclusive Australian society that ensures people with disability can fulfill their potential as equal members of the community.

In 2022, the Australian government committed to the development of the National Autism Strategy to improve life outcomes for autistic Australians. The Australian government -- sorry.

Development of the strategy is being led by the Department of Social Services reporting to the Minister for Social Services, who's the Honorable Amanda Rishworth. Development was -- the Australian government also committed to the development of a national roadmap to improve the health and mental health of autistic people.

The national roadmap is being led through our - through a separate but connected process. And led by the Department of Health and Aged Care reporting to the

Minister for Aged Care, the Honorable Mark Butler. It is important to note in Australia's federation model, the National Autism Strategy is an Australian government strategy and relates to areas of Australian government responsibility to improve life outcomes for autistic people. It does not relate to issues which states and territories are responsible for.

So, just some examples. The Australian government is responsible for delivery in the areas of employment services, the federal justice system, general practitioners, the pharmaceutical benefit scheme, aged care system, and the veterans care system, as well as universities. States and territories are responsible for delivery in areas of public, social, and community housing. Public hospitals, community health services, public transport services, public primary and secondary schools, kindergartens and preschools, and jurisdictional court systems and correctional centers.

Any areas of joint responsibility between the Australian government and state and territory governments, for example, in the space of mental health supports and services, disability advocacy services, and community infrastructure, the strategy will guide the Australian government's engagement.

The final strategy expected to be a whole-of-life plan for all autistic Australians build on the understanding and recognition of autism within key professions and the wider community. Develop a coordinated approach between all levels of government and service areas supporting autistic people. Consider ways to make education, employment, and health services for autistic people more inclusive and accessible. Provide better support for parents and carers, and establish a national autism research agenda. Development of the strategy will also align and take into account a number of other Australian government initiatives and reviews.

And the role of the National Autism Strategy is to ensure that parts of the system are responsive to the needs of autistic people.

So, the phased approach that I talked about earlier, phase one, was development stage from October 2022 to July 2023. The phase undertook an evidence-based development, which included gathering and analyzing current research data and evidence and early consider -- and early consultation. The phase also established the National Autism Strategy Oversight Council with an autistic co-chair, a majority of autistic members to inform and guide the work of the National Consultation's plan for phase two on the development of the strategy.

Phase two -- sorry, phase two was the national consultation period, which went from August 2023 to April 2024. Involved a co-design national consultation and engagement exercise involving people with autism and their families, the autism sector, and researchers to ensure the voices of autistic people and the wider community were heard. Phase three will be the agreement and launch of the national strategy, which will occur by the end of 2024.

I'll just talk a little bit more detail about the stages. This -- so, phase one. This phase undertook an evidence-based development, which included gathering and analyzing current research data and evidence. The department was conscious, the autism community, the autism and disability sector, researchers, professionals, and the broader community had already shared and highlighted the key issues over a number of years regarding the experience and life journey of autistic Australians.

Therefore, the first step, it was important to review what we had already heard. This step meant people didn't have to retell their story to government. We did this by developing a discussion paper titled "What we have heard moving towards the development of the National Autism Strategy" to test what we had heard. To build strong evidence base that will support the development of the strategy, research papers were commissioned by the disability representative organizations to provide further information.

A disability representative organization program provides systemic advocacy and representation for Australians with disability.

The program provides the capacity for all people and their representative organizations to have their views communicated to government regardless of the type of disability, gender, cultural background, age, or membership. Papers were commissioned around key issues facing First Nation autistic people, the experience of autistic women and girls. Engaging with the autistic people with an intellectual disability, and some lessons learned for the development of the National Autism Strategy.

The Minister for Social Services, the

Honorable Amanda Rishworth, also held a number of meetings with international representatives where the National Autism Strategy was discussed. These included Italy, United Kingdom, Israel, New Zealand, Zambia, Saudi Arabia, Canada, and Poland. As I mentioned, phase one also included setting up the governance arrangements to guide the development of the strategy.

In May 2023, the Minister for Social Services appointed members to the National Autism Strategy Oversight Council. Which included an autistic co-chair and a Department of Social Services co-chair, a majority of autistic members, including eight autistic community and sector members, two autistic research and professional members. And six Australian government members from the health, education, employment, and disability portfolios, as well as Australia's Department of the Prime Minister and Cabinet.

The Oversight Council is supported by four working groups focused on key outcome areas. These include social inclusion, economic inclusion, diagnosis services and support, and health and mental health, which has been led by the Department of Age -- Health and Aged Care. Working group membership comprises of members of the autism community, the sector, research and professional sector, and the Australian government.

The Oversight Council's role is to guide and inform development of the strategy, taking account of the information received through the national consultation and engagement. The Oversight Council assists the government to make sure that the ideas, thoughts, and experiences of autistic people, their families, and carers play a strong role in informing the vision and objectives of the strategy.

The National Autism Strategy Oversight Council members was selected through an open expression of interests, which was run by the autistic community. I'm delighted also that the co-chair of our oversight council, Clare Gibellini, is here with us today and will be sharing her experiences later in the panel discussions. That brings us to phase two.

Listening carefully to the community was an essential step in developing to what goes into the draft strategy. The department engaged a third-party provider to undertake a national consultation and engagement process. The consultation process was undertaken from September to December 2023 around Australia.

The consultation process involved a broad range of engagement activities, which were co-led by autistic people and/or local trusted organizations that were co-facilitated by autistic people. In most of the consultations, they were actually led by autistic people. There was a release of the discussion paper, which I referred to earlier, a public submission process and guided questionnaire and 18 open public community consultations, as well as 21 Autistic Voices forums where only people who identified as autistic were able to attend.

We held a webinar. We held yarning circles, which is engagement with our First Nations people. And an online ideas wall, which was similar to a discussion wall where you could post ideas and comments and people could comment back on those. We had 45 targeted focus groups and small stakeholder groups, and 14 one-on-one interviews with individuals and families to gather more in-depth personal stories. This provided an opportunity for people who have barriers to contributing in group settings.

The consultation process also included methods of engagement for harder-to-reach cohorts. This included First Nations communities, culturally and linguistically diverse communities, autistic women and girls. People who communicate through methods other than spoken language, autistic people with an intellectual disability, people with co-occurring health conditions. Regional and remote communities, autistic people in out-of-home care, LGBTQI+ communities, and autistic people in the criminal justice system.

Materials produced to assist the consultation and engagement were accessible, varied, and flexible so that all people could participate. This included people being able to provide their views to government in a form they chose. For example, they could do it via phone, in writing, by video, and we even received some artwork.

There was strong engagement from the autism community across both -- most of the capital cities. Most of those were oversubscribed, and the regional areas was also strong. We received positive feedback on the breadth and depth of the engagement activities, which has enabled autistic people to contribute to the consultation in a method which best suits them.

There were more than 2030 contributions to the National Autism Strategy engagement process. And we have our population far smaller than the USA. So, we're very pleased. We had more than 1,300 people involved in quantitative discussions. Around 550 people made a submission by sending written, audio, or video file by completing the guided questionnaire. Around 180 people contributed ideas to the Open Online Ideas wall.

The largest number of participants in Open Community Events and Autistic Voices forums were autistic people, followed by family members and informal carers. It should be noted that people do not fit into these cohorts exclusively, and participants may be both an autistic person and a family member or carer of autistic people.

So, the themes that came from the consultation included inclusion; systemic societal and attitudinal change. Acceptance; a better understanding of autism across all parts of community to create a more autism informed Australia and a sense of belonging. Recognizing autistic strengths where people have a strong voice, strength-based and neurodiversity firming practices. Recognition of individual diversity and capacity. Acknowledgement that every autistic person has their own experience and aspirations and can participate freely and equally in all areas of life.

Better quality of life and improved standard living -- standard of living. Systems and supports in place to provide for basic need to ensure access to health and mental health services stay -- to stay well. And equal opportunities for autistic people to participate in society, access housing, access justice services, and thrive in education and employment.

So, this has led us to develop the first national autism strategy. It's important to note that the draft strategy has not yet been agreed by the Australian government. Following feedback through a second public consultation process we are currently undertaking, the strategy will be further refined. And expected that it will be presented to the Australian government by the end of 2024.

Currently, the draft strategy is open for public consultation. It's an eight-week consultation period ending on the 31st of May. I'm going to go really quick now because I'm getting a very big windup sign. I just wanted to share with you the draft vision for the strategy.

The vision is for a safe, inclusive society where all autistic people are able to fully participate in all aspects of life in line with the international human rights. The draft strategy's goal is to improve the life outcomes for all autistic people. And both these statements are currently being tested through the public consultation period.

We have a set of guiding principles that set out how the strategies foundations will be put in place. In partnership, nothing about us without us. The strategy is co-designed, co-produced, co-reviewed, and co-delivered with autistic people, their families, carers, and support networks. Oops. It's -- sorry. It's accessible based on universal design.

The development and implementation of the strategy will be co-led by autistic people and the Australian government. It will be accessible and based on universal design principles. Self-determination and autonomy. The strategy will foster freedom of choice, control, and support for autistic people to make their own individual decisions about all aspects of life. The -- aligned and accountable outcomes.

The strategy and actions will align with other key government strategies. The strategy will be measurable, accountable, and evidence-based.

Acceptance. The strategy will reflect that every autistic person has unique strengths, abilities, and attributes. The strategy will seek to foster community understanding and acceptance of all autistic people for who they are and for many contributions to Australia.

Rights. The strategy will uphold the rights of all autistic people to be respected and safe from all forms of discrimination, vilification, violence, and abuse anywhere in their lives.

Individualized and holistic. The strategy recognizes that there are different aspects to a person's identity that can overlap and shape their diverse needs, abilities, and experiences. And that other factors, such as socioeconomic status, where they live, income, education, and the extent of support networks can also have an impact.

The strategy promotes an individual and neurodiversity affirming holistic person and family-centered approach to meeting these needs. And diverse communities across the whole of life, such as disability, race, gender, sexuality, culture, age, body-shape, size, and religion. The strategy contains 24 draft commitments under the themes mentioned earlier.

The commitments relate to areas of Australian government responsibility. I promise I'm hurrying up. Under social inclusion, autistic people and their families and carers and support networks experience disproportionately high rates of social isolation, discrimination, abuse, and violence. Commitments under this theme seek to ensure everyone has the opportunity to participate fully in Australian society.

The commitments aim to provide equal opportunity for people to learn, work, connect, and collaborate with each other, and have a voice, including those who are non-speaking or minimal speaking. When people are equally included, they can participate. Provide easily accessible information about community services, events, and facilities that -- and providing low sensory spaces supports the inclusion of autistic people in their community.

An inclusive economic -- sorry. An inclusive economy ensures that all parts of society, especially poor or socially disadvantaged groups, have full, fair, and equitable access to market opportunities as employees, leaders, consumers, entrepreneurs, and community members. Commitments under the economic inclusion focus on providing employment and financial security to improve outcomes for autistic people, including providing jobs and career opportunities. I'll do one more, and then I'm done. Oh, yeah.

The third area is diagnosis. And we've got diagnosis services and supports. I'm just rushing through now. And the last area is that we do include commitments on ongoing governance arrangements, exploring how autism research can be best applied to policy. And development of a robust evidence framework, including a theory of change, program logic, outcomes framework, and evaluation. Thank you. I'll leave it there. Thank you very much.

DR. GORDON: Thank you very much, Pru. Next -- our next speaker is Mark Nafekh, the director general of the Center for Health Promotion in the Health Promotion and Chronic Disease Prevention Branch at the Public Health Agency of Canada. Welcome, Mark, and we see you up on the screen. Thank you very much for joining us.

MR. MARK NAFEKH: -- event today. I'm Mark Nafekh. I joined the public health agency in 2020 as the director general for the Center for Chronic Disease Prevention and Health Equity. And I'm currently the director general for the Center for Health Promotion. And I lead the team at the Public Health Agency Canada that is focused on autism.

I am an older, yet young at heart male, wearing a blue suit, red and blue striped tie, and striped shirt, with thick black rim glasses. And sporting a very short haircut. It's not because I'm balding. It's a -- it's fashion.

So, in all seriousness here, the government of Canada is committed to helping and supporting the needs of all persons with disabilities in Canada. Including neurodevelopmental conditions such as autism, and those who care for them and provide much needed support. How autism is understood in Canada has shifted significantly in the last few decades.

We now better understand the importance of shifting away from the medical model of autism. And instead, recognizing the importance of a person-centered and strengths-based approach that emphasizes inclusion, self-determination, quality of life, and equitable opportunities. We also know that since everyone has different experiences and characteristics, the type and extent of supports needed can vary considerably across the life course and should be adapted to individual needs.

Addressing the complex and diverse needs of autistic people in Canada requires a coordinated effort between all levels of government sectors, autistic people, their family and advocates, as well as service providers. To help guide these efforts, the Public Health Agency of Canada is currently finalizing two documents, which will be released in the coming months; a framework for autism in Canada and Canada's Autism Strategy.

The autism framework and strategy were developed collaboratively with provinces, territories, those with lived and living experience, caregivers and families, indigenous partners, and other stakeholders. They were also informed by doing a scan of what other countries have done and examining best practices.

The framework for autism in Canada will outline broad overarching principles and best practices to guide national autism policy programs and activities in Canada at all levels of government. Whereas the strategy will be a multi-year action plan that outlines federal specific short and medium-term initiatives and builds on existing federal programs and measures. It supports the federal implementation of the framework.

The autism strategy will be updated over time to reflect evolving needs and priorities of autistic people living in Canada. In 2022, we engaged the Canadian Academy of Health Sciences to lead an assessment on autism, which included a comprehensive scientific review, as well as broad and inclusive consultations.

The challenges and opportunities identified by the Canadian Academy of Health Sciences through this assessment were instrumental to the development of the strategy and the framework. The Public Health Agency Canada also hosted a national conference on November 15th and 16th, 2022. Where we brought together the views of autistic people in Canada, their families and caregivers, advocates, provinces, territories, and indigenous peoples.

The discussions and information sharing from this conference are also guiding the development of the framework and the strategy. What we're doing in Canada is informed by commitments on the international stage. The World Health Organization and its partners have identified strengthening the capacity of countries to improve the health and wellbeing of individuals with autism as a priority.

The framework for autism in Canada will respect the principles laid out in the United Nations Convention on the Rights of Persons with Disabilities, which is an instrument outlining how those with disabilities must be able to enjoy the full spectrum of human rights and fundamental freedoms.

The framework and strategy are informed by best practices that draw from recent advancements on autism initiatives internationally. For example, we look to England, who shows that development and implementation of capacity building, professional development, and education is best done by working with autistic people in drawing on the expertise of those with lived and living experience.

The United States who demonstrate the value of enhanced and ongoing meaningful involvement of stakeholders in the development, implementation, and evaluation of a national autism strategy. We've clearly heard and seen that there is a great value in engaging those with lived and living experience on an ongoing basis.

Not only in helping to articulate the priority areas for action, but also in the implementation phase, where we ensure that there are appropriate governance mechanisms and a system for sustained support. There are five priority areas identified within the framework and the strategy, which we have put up here on our slide.

I won't go through -- I will go through the priorities. And even though they're numbered, they're not numbered in importance as they are -- they all hold significant importance. So, one priority is screening, diagnosis, and services. A second is financial support; a third, data collection, public health surveillance, and research; a fourth, public awareness, understanding, and acceptance; and the fifth, tools and resources. And along with those priority areas come areas of focus, which we look at building an implementation plan around and measures activities and whatnot.

The key federal measures described within the strategy will reflect the Government of Canada's convener role, fostering collaboration to improve information sharing across federal, provincial, and territorial jurisdictions. We are really looking forward to publishing the strategy in the framework in the coming months, giving us the tools to move forward with this important work. This will be advanced through different governance mechanisms.

So, a challenge particular to Canada is that of shared responsibility for services and supports, particularly when it comes to social services, education, or medical care. Roles and responsibilities for the delivery of healthcare services are shared between provinces and territories and the federal government. The federal government provides health and social transfer payments to the provinces and territories, while provinces and territories have control over how health, education, and social supports and services are delivered in each jurisdiction.

We recognize that each province and territory has unique needs and different approaches to supporting autistic people in Canada and their families. The Public Health Agency of Canada will continue to work collaboratively with provinces and territories on autism priorities. One way we continue to work collaboratively with provinces and territories is through the federal, provincial, territorial working group on autism, which is established in April 2022, and includes representation from all provinces and territories.

We have been leveraging our convening role to share information on autism priorities, gaps and needs, and challenges and opportunities. And moving forward, we look forward once we have released those documents to broadening the voices at that table.

We also recognize the importance of collaborating with our partners in other government departments. We'll advance federal action on the strategies priorities through our interdepartmental steering committee on autism. For example, the Public Health Agency of Canada will ensure the voices of autistic Canadians are considered in the Disability Inclusion Action Plan led by the Employment and Social Development Canada, which includes federal initiatives seeking to help persons with disabilities find and keep good jobs, advance in their careers, or become entrepreneurs; support employers as they develop inclusive workplaces; and aid organizations and individuals who support persons with disabilities and employment. PHAC will also continue exploring distinctions based in indigenous-led approaches to addressing autism related priorities for indigenous communities.

It is important to note for certain populations in Canada -- in particular for indigenous communities -- we lack sufficient data on autism. This creates challenges in developing policies and providing the appropriate supports needed. The Public Health Agency Canada, in collaboration with other federal government departments, will partner with national Indigenous organizations through the engagement protocol agreements that exist. And these agreements provide funding to national indigenous organizations to facilitate and engage with communities, which can later inform policies, programs, and services.

And of course, to make sure we're moving ahead with strategy, we need an implementation plan -- which I mentioned earlier -- that has clear objectives, deliverables, milestones, accountabilities, and investment sources. This is the next step once the strategy and the framework are published. And this is something that we are going to continuously go back to. This is something that is going to provide us with a more holistic platform in addressing the needs for autistic individuals in Canada.

It is important that the implementation plan be co-developed and informed by multiple partners and stakeholders, including by autistic people, their advocates, caregivers, family members, and advocacy organizations. And we will do this through a network -- a national autism network. One of the first steps of this network will be to create advisory committees to consult on the implementation plan, whose expertise and perspectives around the table will be invaluable. This will enrich the implementation plan and create a stronger strategy.

The advisory committees will also provide input to other committees like the federal, provincial, territorial working group and the interdepartmental steering committee that I mentioned. This will ensure a coordinated approach across the country. Most importantly, this implementation will require diverse expertise and perspectives. By involving experts and people with lived experience while fostering cross-committee collaboration, we can ultimately ensure a continuity of actions that support autistic individuals, their advocates, caregivers, and family members.

By working together, we can ensure autistic individuals in Canada are heard, understood, and accepted. So, in conclusion, I'd like to thank the Canadian Autism Leadership Summit Organizing Committee, my fellow panel members, and members of the audience for this opportunity to speak to you on behalf of the Public Health Agency of Canada. And I'm very optimistic and excited for the road ahead of us. Thank you.

DR. GORDON: Thank you, Mark. Our next and final presenter of this first session of the afternoon is Professor Menan Abdelmaksood Rabie, the general director of Hospitals and the General Secretariat for Mental Health and Addiction Treatment in Egypt. Dr. Rabie?

DR. MENAN ABDELMAKSOOD RABIE: How are you everybody? Thank you very much for this interesting presentation. I'm really -- I really enjoyed them all. Thank you very much for the invitation.

We had very good steps with Autism Speaks and with -- okay. Sorry. I'm still driving [laughs]. I'm about to reach home.

We have very good steps with Autism Speaks and with WHO about dealing with autism about early detection of autism and maybe soon, presidential initiative about autism so -- about prevention and early detection of autism. Let me tell you. This is the photo of our General Secretariat of Mental Health and Addiction Treatment, which is the main body responsible for giving -- providing the treatment, prevention programs, and awareness programs in Egypt. Egypt is a country in between Africa and Asia. And it currently has about 100 -- it's a big country. With a big -- such a big country, it's not very easy, but we are trying to start our steps. Next slide, please. May I have the next slide, please? Yes.

Thank you. Our vision is to give the child and adolescent the best service available in the best way possible. In the country of Egypt, we have 15 child and adolescent units all over the country. And many of our governorates -- the Egypt have 27 governorates. We are present in about 17 of them. And in 14 of them, we are having these units. The units present the child and adolescent services in general, and we have daycare for autism in three or four of them. And the others are coming very soon, "inshallah." Next, please.

Yeah. The story started 2012, when we

started to train our trainers. We started by having such a plan with the Embassy of Slovenia. They helped us to start this implementation plan. We created like a model for service. And we have the national recommendations for the issue as a whole. Next, please.

This is the start. We started by three clinics in three of our governorates in Abbassia in Cairo -- Cairo is the capital of Egypt -- also in Mamoura, which is one of the big cities in Egypt. It's a coastal city. It's in -- on the north coast, which is in -- on the Mediterranean Sea. And the third one is Assiut, which is present in the Upper Egypt. This is the third region of Egypt. So, we are covering three important regions with different social standards and different characteristics of the populations. And soon, we also -- recently, we also added Port Said. Next, please.

Actually, the autism awareness campaigns started as soon as we started our plan. 2012, we had this -- as you can see, this is the pyramid and the Sphinx on Egypt -- in Egypt. They were lighted blue. And of course, you can see the sign of autism -- the solidarity with autism at the right side done by human people by human bodies. And then we had, like, a bicycle ride like you can see on the down left photo.

And our hospitals usually celebrates the autism patients and their families like you can see in the down right two photos, one of them with Dr. Hisham Ramy, the former secretary general, and the other one is myself with the team of the Child and Adolescent Clinic and also with the -- some of the patients and some of the, you know, people who are intended to help such patients. Next, please.

Then we started to have a legislative frameworks to include the autism in the national law of -- with -- of people with disability. And this is currently the situation in Egypt. And actually, we are very happy that we are -- the persons -- the authorities who are responsible for deciding which people -- which of the patients are really in need for this services. You know, Egypt provide services -- sorry.

I reached home. I'm sorry. Very -- I'm really sorry. It's night here in Egypt. Yeah. We started this legislative framework. And actually, in Egypt, we, like, the General Secretariat of Mental Health and Addiction Treatment, is the body responsible for deciding which patient takes which extra service because of its -- of their disability. Next, please. And here is Dr. Andy and Dr. Khalid Saeed. Those -- we are really grateful to both of them because they started the CST Program in Egypt 2016 with mhGAP of the WHO and, of course, the Autism Speaks participation. Next, please.

This was our roadmap, to translate and adapt the CST training program, to perform the CST training of master trainers, and to practice with families then to train facilitators. This is actually all happened. "Alhamdulillah." Maybe in a small scale, but it's already happened. Next, please.

These were the first trainers. We trained about 20 of the CST trainee to be trainers for other persons who will deliver the program and the service. This was in Egypt, and this is the building of our Secretariat of Mental Health. Next, please.

This is [unintelligible]. Then we started practicing with families. And this time, like you can see masks on the face, this was the start of Corona -- of COVID-19 pandemic. But yet, we struggled to start the training [inaudible] practice with families in this -- in three governorates, Cairo, Alexandria, Assiut, which are those with the daycare facilities so we can find patients and families. Next, please.

Then we shifted -- as we all did -- to online trainings, especially with newly submitting trainee who were very eager and very enthusiastic about starting the training, mostly because it's really effective. And it's really -- you can see that it improves patients and improves the family conditions. Next, please.

The WHO Caregiver Skills Training for online delivery and supporting the caregivers for children with developmental disability with the WHO was all during the COVID-19 era. And the online adaptation was completed. And currently, we are starting to prepare for publication and printing. Please, next.

The real breakthrough was to engage our Minister of Health, Professor, Dr. Khaled Abdel Ghaffar, to present by himself the word -- the Egyptian -- the word of Egypt. And in this word, he illustrated what happened in Egypt and what we reached until then. Then he announced that Egypt is preparing for a presidential initiative for the early detection and prevention of autism and, of course, either for the patient or for the caregivers, getting support and providing care. Next, please.

As you can see, on the right side, this is the site of the platform -- the Egyptian platform, National Mental Health Platform of Egypt. And on this platform, in the lower most icon, we can see, "check on your child," right? "Check on your child," right? On this icon, you can press and find many scales, many tools. One of them is the tool to check the development of the child, mainly social, mental -- social, psychological development. And we also provide the M-CHAT on this. So, it's available for everybody. It's online, and everyone in Egypt can reach it on the internet. Next, please.

Being supported by our Minister of Health and Population, we started to reach out for primary care facilities. What you can see on this slide was the training performed for 37 of the primary healthcare facility staff to start involving them in the story of autism, in how we can reach -- we can early detect problems with autism, how we can give the initial support for patients and families and how to involve the families in the treatment of autism -- or sorry, the care and multiple procedures and multiple tricks to help the patient not to be in a severe case of autism. Next, please.

This is the referral pathway we teach them -- we give in the training to reach out. Starting from the family who comes to the primary care facility with the child suspecting him to have autism, reaching to -- giving them the initial assessment tool as you could see it in two slides before this.

Then we try to help them also to start doing some activities to help the patient not to be severely affected with this. And many of the cases can even get rid of the autistic traits or autistic symptoms. Then if the case is severe or continuing in spite of the activities for prevention, we can then refer the patient to a tertiary care facility, which are our hospitals, and then the daycare will continue with the patient until he gets better with his daily activities and with scholastic achievement. Next, please.

As regard with the building codes, we started like a prototype of an autism center. This is a center in Abbassia Hospital, which is in Cairo, which is the capital of Egypt. As you can see, on the left side, we have -- this is the entrance of the of the center. And we have a waiting area.

We have cameras -- CCTV cameras. And you can see in the middle, the two areas of playing rooms. One of them is an open room, which is the above one -- the one above. And the one below is a closed area for the winter, because in Egypt, winter is really cold. On the right side, you can see the table on which the patients are giving -- are getting their initial assessment and the daycare. And in the middle, this is the office of the doctor who received the patient. And above this is the center from inside. Next, please.

We are trying to propagate this example to many of the governorates of Egypt. We are currently working in Sohag, which is another country -- another -- sorry, another city in South Egypt or Upper Egypt. We are working the same in Mamoura, which is in the -- on the coast -- on the north coast. We are trying to start it also in El Zaqaziq which is a hospital in Al-Sharqia Governorate, which is in the east part of Cairo. And we are involving to Upper Egypt again with Assiut and its other centers.

We are planning to have these centers all over Egypt with the prototype you saw in the last photo. Within maybe five or six years, we can cover Egypt as a whole, "inshallah." The problem actually, maybe we need more support about the human resources. This is a real challenge in Egypt.

This -- the photo you can see is that we were lucky enough that the center was inaugurated with two of our ministers, the Minister of Health, Professor, Dr. Khaled Abdel Ghaffar and Her Excellency -- His Excellency Ghaffar and Her Excellency, Professor, Dr. Nivine El-Kabbag, the Minister of Social Solidarity. So, as you can see the whole Egyptian government is supporting autism. Next, please.

This was the last event about autism this month. At the early -- at the first of April, we had most of the Egyptian monuments lighting up with blue. As you can see the left -- on the left side, this is the new museum of Egypt. It's beside the pyramids. You could see that they were lighted in blue.

On the right side, this is one of the journalist -- journal coverage. Actually, more than 20 Egyptian journals and -- had this announcement of International Autism Day, which is really a happy event for us because this is really what we hoped for long ago. On the left down photo, I'm greeting -- with my dear colleague, Dr. [unintelligible] and Dr. [unintelligible], we are getting the actor -- the Egyptian actor who played the role of an autistic child -- an autistic young man. This is an Egyptian series, which was produced maybe a few months ago. And it's -- the name is "Special Situation -- Special Case," "Hala Khasa" in Arabic, which is a "Special Case." And this very actor worked to present the autistic traits very good. And he's an adult as you can see.

So, he played it. And he really achieved a very big success, and everybody was talking about "Hala Khasa." And they started doing like he does and talking like he -- he has some of the special movements somebody can see in our dear autistic patients. Actually, this is a real success in the track of awareness for all Egyptians especially, and I think also for all Arab countries. Next, please.

And we are lucky enough that tomorrow -- actually tomorrow we are having this huge, I think -- "inshallah." It will be a very huge conference. It's the second Pan African conference, and the third mental health -- child and adolescent mental health conference. It's about autism. Autism is the main talk. It's the main item, main theme of the conference. And we have maybe about more than 80 speakers from Egypt and other countries.

We have very high delegates from many of the countries. Autism Speaks is with us. WHO is with us. UNICEF is with us. And actually, many of the ministers of Egypt are there. And we have one of the ministers from Africa.

I think this will be a very good conference. I wish you can join. Even if we have an online activity, I will try to let you all know. Next, please.

Yet, we have some challenges. Actually, the building request is one of the main challenge -- as I told you -- because the human resources in Egypt are not very well paid, actually. So, they try to find payment -- better payment in other countries, either European countries or Arab countries, the Gulf areas in specific. The efficient supervision system is very important. But yet, the control over the whole country is not very easy, especially when we deal with other departments.

If we are talking about the mental health department, that will be not very difficult. But dealing with the primary care, secondary care, universities, other ministers who have centers like the Ministry of Social Solidarity, it's also presenting the service, so controlling all of this is not very easy.

And it really needs good armamentarium of people and of tools and of course, the continuous learning, keeping up with advancement in research, especially because of the rapid turnover of doctors and psychologists in Egypt. Because, as I told you, they are not very stable in their workplaces. And usually, they tend to change jobs. And of course, establishing effective partnership to ensure resources are effectively utilized.

This is the end of my presentation. And actually, I'm very grateful for you to listen to me in such a difficult circumstances. And thank you very much and have a happy International Autism Month, April. Thank you very much.

DR. GORDON: Thank you, Dr. Rabie. We now have time for questions or comments from members of the IACC. And I don't know if we have the capacity to take questions from the Canadian assembly. But if we do, we can do that.

If I might ask those -- Dr. Shih and McPherson, if you would come up and join us here in case you have questions directed to you. And please go ahead and -- members of the IACC -- and raise your hands or your placards if you'd like to ask a question or make a comment.

Yetta, please go right ahead. And I see Dena [unintelligible].

MS. MYRICK: Thank you for your presentations. What struck me is there is a lot of similarities across some -- sort of some of the things that you all heard that are happening here in the U.S. I'm hearing these things in your countries as well. Specifically, for you, Dr. McPherson, could you speak to lessons learned in engaging autistic self-advocates -- so, autistic persons -- to use the language that you all use, as well as others with related lived experience cares and language they use as well? I might have to adopt that. I like that. And like what were the lessons learned in working with them to establish your plan -- your strategy?

MS. MCPHERSON: Thank you for the question. I think the Australian Government was very committed to working with the autism community given the level of lobbying that they had done for a national strategy. Part of the lessons learned was probably time. Needing to give the autistic community time to absorb what it was that we wanted to come and talk to them about, and give them time and space to be able to collect their thoughts and to be able to present their best self when they will come into the consultation.

Also, really, put a lot of time and energy into making sure the room setup, the -- what we were doing was accessible. It was able to enable people to be able to come. They knew exactly what they were coming for, where they were going with the extensive what to expect guides that were sent out before the consultation. So, people knew where they were going, what to expect when they got there. Made sure we had sensory rooms like fidget toys on tables, those sorts of things. People were able to contribute in a manner that suited them.

So, we had tables that suited people that were happy to collaborate. We had silent tables. And we had people that were able to if you prefer a one-on-one discussion. And we had conversation cards so people could write down answers as well. So, I guess the lesson learned is to think far and wide about how you're going to consult with the community and also to provide the manner in which the community can come and talk to you in a variety of ways. I mean, we got some fabulous artwork as a submission to the strategy for things that the autistic community wanted to say. And that was really lovely to be able to provide an opportunity for people that communicate in art to be able to do that as well.

DR. GORDON: Thank you. Dena?

MS. GASSNER: Thank you, everybody, for your discussion today. I'm especially excited about what's happening in Australia because there's so much autistic leadership plugging in. So, thank you for that. Dr. Shih, I wanted to address two questions to you and then just make an observation.

First of all, let me talk for a minute about the M-CHAT. I have some grave concerns about the M-CHAT because it's looking for very overtly presenting manifestations of autism. So, as your countries are coming around to using just different instruments you're adopting from the U.S., please do some painstaking work at looking at whether they would be able to identify less overtly presenting cases of autism. I fear that we leave a lot of people behind. And it's actually the vast majority of the population that I have concern for based on the stats.

But back to you, Andy. I'm excited about your Advocacy Leadership Network. But as I look at the other work that you're doing around the world, I was concerned -- or at least I wanted to offer you an opportunity to convey how the Autistic Leadership Network is influencing your work in other countries. And second to that, I was wondering, as you describe -- continue to describe parent training efforts and initiatives around the world, what is the relationship in that parent training to -- I'm sorry, to bring up the elephant in the room but -- to ABA.

DR. SHIH: Thank you, Dena, for that question. So, the way we work with the local advocacy community in each country is exactly as has been described in other process as well. I think the first thing we do is not to assume that the priorities that we have in the U.S. or any other country, the same as the priorities in country trying to serve. And indeed, I think, you know, our experience has been that it depends on level of resources and the development of the understanding of the autism community in these countries, that there are different paths to this -- to the goals and objectives for our community.

I think the challenge often with these -- not the challenge, I think the issue often with working in other territory is that you don't want to impose your values, right, and your -- what you think is the best practices at their populations. What you can do is to make recommendations, and you share options for them to decide. Because certain things -- for example, what may be considered best practice in the U.S., may not be at all feasible in a low-income country, for example. So, I think that sensitivity to the community and what is realistic for them in terms of achieving progress, I think, is first and foremost in the work that we do in collaboration.

In other words, we support local leadership. We don't leave, right? So, that's the -- I think the fundamental there. Now, in terms of CST, Caregiver Skills Training Program, I think the -- what I've been impressed by -- about by the CST is that even though in the ideal world it's best if it can be adapted by country government and sustained and incorporated into his care systems, but oftentimes, I will say majority of time, the member states are not ready for that step, right?

So, what we do is that we work with advocates in smaller communities, try to facilitate change, try to facilitate access and opportunity to better support autistic people and their families. And hopefully, using those evidence, that we -- it would demonstrate to influence national program and policy. So, I hope that answer your question. You know, I think that the main point is that because countries are so different, even though the challenges are many times the same, the solution necessarily have to be feasible and meaningful for that country.

DR. GORDON: Thank you. If there are no other questions in the committee, I did want to -- sorry? Oh, sorry, Scott. He was blocked by the camera. Please, Scott. I was going to ask one, but you go ahead.

DR. ROBERTSON: There was -- my comment was mostly just that I think the presentations are -- were excellent. And it's really helpful for us learning about the strategies, especially for connecting out to autistic people and our families.

And I wonder, Dr. Gordon and Dr. Daniels, if that's something also in between period when the -- while the IACC is being reconstituted, maybe [unintelligible], for instance, some of the lessons learned from some of these strategies globally if other things we could be doing here in the U.S. among the agencies ourselves and give some maybe input to when the IACC reconstituted in terms of what we're looking at, because I think there's some really good -- great approaches and strategies could really enhance the work that we're doing in the United States.

So, I think it's very bidirectional here. We're learning from other countries. They're learning from us. And I'm very excited with what was shared in the presentations. It's excellent.

DR. GORDON: Thank you, Scott. It's an excellent suggestion. Actually, I wanted to turn and ask Mark to give him the opportunity as well to talk. You did mention in your presentation the involvement of individuals and families. I'm wondering if you might have anything to add about how that works into the Canadian plan?

MR. NAFEKH: Yeah. Absolutely. So, today, I mentioned two governance mechanisms that have been informing the development of the framework and strategy, which we plan to release soon. But once they're released, we want to change the nature of the -- our discussions at those tables to be more inclusive and to be driven by the voices of autistic individuals, their families, caregivers, and I mentioned a network. It sounds like it might be similar to the leadership network that was mentioned earlier, but I'm not sure.

We'd be more than happy to learn about experiences with leadership network. But our network -- our intent on the development of our network is that the network or the governing body of the network would establish advisory groups that could take each priority area as a focus. And we can start framing our conversations at those tables around the priorities and move into action. So, we want to make sure that the -- I'll say -- the autism community is driving things and is a voice at those tables.

DR. GORDON: Thank you, Mark, for that response. And I want to give Andy a chance to just say anything about that, given that he referenced the network that you've established through Autism Speaks.

DR. SHIH: Yeah. So, thank you, Dr. Gordon. So, yeah. I mean, I think that's the most important value of this network that we have, because they are our teachers. They understand their systems. I think they learn firsthand where the bottlenecks are. So, they know much more than we do in terms of how to navigate those system and what needs to be changed and what to provide in knowledge and information and sometimes external support to facilitate those changes that they want to happen on their own country.

DR. GORDON: Thank you very much. Let me just close this session by thanking all of the speakers. Really wonderful to hear all of the work that's being done across the globe. We have a panel this afternoon that's going to really focus on research and advocacy and continue this conversation.

Let me also just say to our Canadian colleagues, it may be known to some of you in the room, but Canada has long been a leader and really teaching us in the United States and the others around the globe in how to involve the voices of lived experience and mental health research in general. And I personally have benefited from the relationships that we've established with the Canadians in this regard, specifically with Global Challenges Canada, but with lots of others as well.

We're going to take a short break so that we can get set up for the afternoon's panel. It is 3:43 p.m. We're going to take a -- we're going to be -- try to be back at 3:50 p.m. to start the panel. And if the panelists who are here in the room can come up, and we'll make sure we get you a spot at the table set up. Thank you again. We'll be back in just a few minutes.

DR. DANIELS: All right. We heard him,

3:50 p.m. [laughs].

(Whereupon, the Subcommittee members took a brief break starting 3:43 p.m. and reconvening at 3:50 p.m.)

DR. GORDON: All right. Thank you everyone. If we could all take our seats? People in the back, if they could come back to the table? We're going to try to get started.

We have a wonderful panel this afternoon. We want to make sure to be able to hear from everybody. And again, it's an international group, so I want to welcome back. We're going to hold now a -- as a second half of our afternoon -- a panel discussion to learn about research services and advocacy in five different countries.

We have the U.K., India, Peru, Kenya, and Australia represented here. I'm going to turn it over to Susan, who is going to co-host the session and introduce our guests.

DR. DANIELS: Great. Well, thank you so much, Josh. And we're just so delighted to put together all of this. I really want to thank our collaborators at the Autism Alliance of Canada. I've been working closely with Dr. Deepa Singal, who's the scientific director there, with Jonathan Lai, the executive director, and Karen Bopp, the chair of their board -- co-chair of their board.

And this afternoon, I will be co-hosting this session with Karen Bopp. And so, I don't know if she's going to be up on the screen in a minute here to help me co-host this panel. But we're really excited to hear from five different countries.

Hoping that we're going to hear a little bit about the comparisons and contrasts between our different countries in our approaches to autism, the levels of advocacy, the different types of advocacy going on in our countries, and thoughts about how we can keep moving forward with implementation and collaboration.

So, our panelists today are Dr. James Cusack, the chief executive of Autistica in the U.K. And I know we've hosted James a few times before, and we're really happy to have you here today. Dr. Gauri Divan, director of the Child Development Group at Sangath in India. Dr. Liliana Mayo, who's on from -- she's from Peru, but she's on Zoom, and is the founder and chief executive at Centro Ann Sullivan del Perú. And Professor Amina Abubakar, director of the Institute for Human Development at Aga Khan University in Kenya. And Ms. Clare Gibellini, the co-chair of the National Autism Strategy Oversight Council in Australia. So, we are really excited to have a diverse panel and look forward to hearing from you today.

DR. KAREN BOPP: All right, everybody. They -- Am I on?

DR. DANIELS: Yes, you are, Karen.

DR. BOPP: Susan?

DR. DANIELS: And if you'd like to introduce yourself, we'd love to hear from you and for you to share a little bit about the Autism --

DR. BOPP: Am I on?

DR. DANIELS: -- Alliance of Canada.

DR. BOPP: This one. All right. They already have started without us. So, we're going to start the sound. And we're going to be looking at these panelists.

DR. DANIELS: Karen, can you hear me?

DR. BOPP: I can hear you, Susan can you?

DR. DANIELS: Yes. We can hear you.

DR. BOPP: Great.

DR. DANIELS: So, I sort of gave you just a brief introduction. I introduced you as the co-chair, I mean, of the board at the Autism Alliance of Canada, but I wanted to give you a chance to introduce yourself to our --

DR. BOPP: Great.

DR. DANIELS: -- committee, and to tell us a little bit about the Alliance before we get started.

DR. BOPP: Great. Thank you, Susan. Thank you to you for inviting us to this very important meeting today. And my name is Karen Bopp. And I am the co-chair of the Autism

Alliance of Canada along with my co-chair, Rebekah Kintzinger, who I think just stepped out. And apologies, we were in a big, live, large, beautiful meeting room here in Ottawa. And so, people are coming in and out, and we're just getting settled back again.

The Autism Alliance of Canada, formerly CASDA, the Canadian Autism Spectrum Disorder Alliance, has been -- we started this summit 10 years ago, the Canadian Autism Leadership Summit. And the Autism Alliance has been moving forward the agenda to create and push for and advocate for a National Autism Strategy for the last 15-plus years.

And we are thrilled that we are very close Our legislation is requiring that the National Autism Strategy and Framework to be tabled in October of this year. And so, we are here really to learn from other countries and from you about how we can continue to move forward together. So, thank you, Susan, for having us today.

DR. DANIELS: Thank you. And do you want

to say anything about the meeting that you have going on there, Karen? And what is going on for our committee to learn?

DR. BOPP: Sure. Yes. The meeting here today is the 10th Annual Canadian Autism Leadership Summit. And obviously, we started 10 years ago. And we are here today to basically connect and learn about the national -- what we can do and what we need from a National Autism Strategy. And once that strategy is tabled, and we have the priorities that are set out in front of us already -- but we're going to be looking at how to implement.

How can national strategy be implemented at the provincial and territorial level? In our country, there are things that are run -- obviously, in many countries -- things that are run federally, but many have the services and supports and the direct frontline services are run provincially. And so, it's trying to figure out how best we can action a National Autism strategy and leverage that, so it actually makes a difference to autistics in Canada from coast to coast to coast.

DR. DANIELS: Fantastic. Well, we are really excited that you're having our meeting. At the same time, we're having our meeting that we could collaborate on this joint effort. And so, with that, we'll start with the first question.

I'll ask the first question to our panel. And then you can go down the line and answer anyone who would like to answer this question. But this one, I definitely want to hear from you all. Can you each please introduce yourself and tell us about your role in the advocacy community or role in the research community in your countries or government? So, we'll start with Dr. Abubakar?

DR. AMINA ABUBAKAR: Good afternoon. I'm sorry. Good afternoon. I'm Amina Abubakar, Professor Aga Khan University. I'm a developmental psychologist by training. My key work is around research on autism and other neurodevelopmental disorders, mainly within East Africa. But also, we really work around advocacy very closely with parents-led groups and around creating pathways for care, because there's quite a big gap in terms of care needs mostly. Thank you.

DR. DANIELS: Thank you. Clare?

MS. CLARE GIBELLINI: Thank you. Hello, everyone. I'm Clare. I'm an autistic woman and the co-chair for our National Strategy in Australia, no pressure.

MS. GIBELLINI: But I also just want to quickly acknowledge the Piscataway and Nacotchtank people, the first people of the region that we're meeting on today. I come from the land of the Whadjuk people of the Nyoongar Nation in Beeloo or Perth, which is about as far away from everything else as you could possibly get. So, in terms of my advocacy work, first and foremost, I'm a mom. I have autistic children, and I'm obviously autistic myself.

But in my sometimes paid jobs, I'm actually a first responder. I'm a volunteer first responder in my community, what you guys would call wildfires -- volunteer bush firefighter. And I spent a lot of time preparing community for -- in -- with specific focus on autistic folks to get ready for disasters and disaster preparedness, particularly as climate change becomes more prevalent, so doing a lot of work in that space.

And I also spend a large part of my time in policy work, in particularly focused around employment and entrepreneurship. And again, I have a special interest in supporting autistic folks because we all know just exactly how poor those of outcomes for our community are. So, I wear a lot of hats. My kids call me a hat rack, but that's okay.

I'll pass it over. Oh, you got one.

DR. GAURI DIVAN: Yeah. Hi. So, thank you very much for this invitation. I'm Gauri. I'm a developmental pediatrician. And I work for non-profit in India, which is called Sangath. And so, as -- we actually started Sangath as a very traditional, center-based, child development center, which we realized over time that we were not meeting the needs of the families in a very holistic manner. And so, what we've done over the last, I would say, 10 to 15 years is really change our stance from a service delivery organization to a public health research organization.

I lead Child Development Group as a developmental pediatrician. And what we've been thinking about is how do we develop innovations in resource poor settings. So, we know that we have a lot of gaps. And so, we've been thinking very hard. And as an organization, we work across the life course.

And I work with young children and their families. And we always try and hear the voices of the people that we're trying to develop services for in the most scalable and, you know, just the most pragmatic manner in many ways. That's it.

DR. JAMES CUSACK: Thank you, Gauri. Well, hi, everyone. I just -- before I get started, I was just reflecting on the fact -- I think Josh I was at your first meeting?

So, there's some sort of a symmetry to that. I've got to see for was -- if you ask me, although very sad to see you go. I'm James Cusack. I'm, first of all, here today because I'm autistic. So, I discovered that when I was 12 years old, but I was identified with it for about the age of 3. That led me to become interested in what autism was and how it is that we can support autistic people.

So, I did a Ph.D. and a postdoc. I worked in autism policy around developing Scotland's first autism strategy. I worked directly with autistic people before joining Autistica, which is the U.K.'s leading autism research and campaigning charity. Really what our job is is to try and really find and support and develop breakthroughs which really enable support and better lives for autistic people in the U.K.

I'm also a member of the board of INSAR, the International Society for Autism Research. And we're very much looking forward to having that meeting in Melbourne and also listening to your keynote actually as well. So, great to be here.

DR. DANIELS: Thank you so much. And Dr. Mayo, I'd like to give you a chance to introduce yourself.

DR. MAYO: Buenas tardes, amigos. My name is Liliana. You have a new friend in Peru. I'm an advocate and practitioner dedicated to enhancing opportunities for people with intellectual and developmental disabilities, including autism in Peru.

My passion stems from 40 years of direct involvement in educating and empowering families to foster independence and productivity in their loved ones. This experience has shown that when families and professionals work together in a team, what I call the power of two, people with autism can lead an independent, productive, and fulfilling life.

And all this passion started during my internship as a clinical psychologist. For asking too many questions, I was sent as punishment to special education. And the punishment transformed into my passion when I met a little girl with autism and changed my life. She showed me how much she could learn when we give her opportunities and when we believe in her. That's when I started the Center Ann Sullivan in the garage of my parents' home. And what I want for my country is that every child with autism has an opportunity to be independent, productive, and family when we work with their families. Thank you.

DR. DANIELS: Thank you so much. And I will give the privilege of the next question to Dr. Bopp.

DR. BOPP: Oh, great. Thank you, Dr. Daniels. So, thank you, all of you, for joining us here today. The question I have is

-- or that we have here is can you share some background on the perception of autism in your country, the major challenges that are faced in your country, and how your work is helping to address those challenges? So, I don't know which -- who we want to go to first.

DR. DANIELS: Would you like to go in the same order?

DR. ABUBAKAR: So, thank you. So, in terms of some of the major challenges we face in our country, for a second, if I reflect back around eight or nine years ago, maybe ten now, when we started working in the area of autism, the first thing we did was to start raising awareness. And we went to the regional director in charge of Disability Mainstreaming -- it's a department in Kenya -- and said, "Well, in April, it will be a world -- you know, there's a day for autism awareness, and we would like to celebrate it and raise awareness." And he asked, "What's autism?" You know, there was just like no services, no recognition at all, as something that needs to be addressed.

We have made some movement. There's a lot more work happening now, but it is still really very low awareness. Whether it's healthcare workers, teachers, there's lack of diagnosis. One of the key challenges parents experiences is that they really don't know who to go to, who to give them answers. And we know parents who take years moving from one person to the other, sometimes spending all their life savings, just trying to understand what's happening to their children.

And really, one of the key challenges around autism and neurodevelopmental disorders is stigma. You know, quite a lot of it would go around perceptions of causes and sometimes very negative perceptions. That means that children and their parents, sometimes many mothers get stigmatized, get blamed, and then parents hide their children.

So, that's one of the key things we

really have been trying to fight here, that you need to take out your children for proper medical care, for support, for management. And I would say really, like, you know, like, there's just so much -- such a huge gap in terms of, you know, addressing the needs of children with neurodevelopmental disorders. But specifically with autism, it's really a latecomer in our settings.

What have we been trying to do? I would say we have worked across three different aspects. One is research. So, as a researcher, I've been very keen on culturally appropriate, contextually relevant approaches, but also open source, you know, accessible tools and services. So, we've been working, thanks to support from Autism Speaks, towards developing tools that can be used at different settings.

Actually, we are working on three steps. One is a community identification tool. So, generally, if a child -- how early can we identify children who are falling behind so that they can get the care they need? We are working on a screening tool but also a diagnostic tool that is simple and can be used with primary healthcare workers. But we've also looked at some of the available tools and tried to adapt them. Of course, those that we need to pay for are a huge challenge, and we've kind of given up on that.

We do work around understanding some of the risk factors, so both genetic works funded by the NIMH and -- but also environmental, looking at some of the social risk factors. We do research, and we are working closely with Chiara and the team on, how can we use some of these open-source WHO tools, like CST, to support families? And from the pilot work we've done with CST, we know that it's really been helpful. Families find it quite acceptable to them. They're very receptive.

I think one of the things that really attracted me to CST was the fact that mothers said, "By bringing us together, you empowered us to look for solutions." So, it was really beyond the skills to the awareness and really providing them a setting to work with. But also, we work very closely with parent support groups. We work closely with government officials, adult advocacy, and we really try to -- not necessarily for us to lead. So, if a parent support group, a parent-led group starts an activity, we try to join in to give them our technical support. So, I think because of time, I'll just stop there, but that's the kind of work we've been trying to do within our setting. Thank you.

MS. GIBELLINI: I don't know if it's comforting or disturbing, but many of the challenges that I've heard from other countries today, they're echoed. We're facing the same challenges. Despite the work that we've done with the strategy, you know, we're still battling the stereotypes. We're still, you know, when you're open about your diagnosis, you're automatically less than. It's not necessarily safe to come out to your employer that you're autistic and things like that.

I mean, I'm pretty lucky I work in the disability sector, but I'd find it very hard to work somewhere else because of the stigma that follows us there. You know, in Australia particularly, we have a National Disability Insurance Scheme, which is fantastic, but it only supports about 10 percent of our population. And so, we have this issue where 90 percent of folks with disability are going unsupported in Australia. It's an expensive scheme.

So, at the moment, the autistic community is facing a lot of rhetoric about how much we cost and how we're somehow seeking diagnosis to get access to that scheme. So, we're trying to push back against that perception because that's actually quite harmful. Because what is being said is that we are pushing to get that autism diagnosis so that we can get access to the scheme.

But the inference behind that is that we might actually not be autistic. We're just trying to get that label. And we as a community going, "Well, actually, no. It's just because we're getting better about understanding what autism really looks like. That's why we're having an increase in diagnosis." So, there's a bit of things going on there.

You know, we still obviously have horrible employment outcomes, shorter lifespans, all of those sorts of things. Challenges, of course, you know, if you've got all of those really poor outcomes in all areas of life, it's almost impossible to afford a diagnosis. So, you continue to go unsupported.

We don't have a lot of -- you know, particularly for our aging population, there's this really weird thing that autistic people get old. I know. It's random. But it happens. But they're not supported. At 65, magically, you'd seem to not be needed. So, you know -- and lots of extreme marginalization.

Australia is a very big, very sparsely populated place. So, it's not like we have a lot of big centers that people can get to to get access to diagnosticians and things like that. So, for those living in regional and remote areas, access to any type of support and services is really, really challenging. I could go on all day, but I also recognize the extreme privilege that I come from living in a country like Australia that has got a lot of resources too.

In terms of what we're doing, well, we do have the National Disability Insurance Scheme, which for those who are significantly impacted, that is a fantastic resource. Has a lot of work that needs to be done to improve it but I have personally seen friends and loved ones have great outcomes from that.

I think my hope is that the strategy will go a long way to addressing some of the issues that we face around the perception of autism and the capability and the capacity and the contributions that autistic folk make to the community. My hope is that we can improve access to the diagnosis and the supports that then follow.

There are a lot of reforms happening in our country, all rolling on top of each other at the moment. Personally, with my work, especially working in the disaster risk reduction space and the emergency management space, we're slowly making some gains around understanding of at-risk communities having been labeled a problem to be solved.

Actually, we're starting to now see emergency management systems at all levels start to see us as a tool that can be harnessed to build community solutions. Because guess what? All day, every day, we have to work in agile, flexible, creative ways in systems that don't work for us when things are good, right? So, we already know how to do that when everything falls apart.

So, we're actually really valuable to those systems as a tool rather than a problem to be solved.

So, we are starting to get better seats at the table. The fact that we have an autistic co-chair of something like the strategy, and we have co-leadership at every level really challenged the government. It's been really challenging, but at the same time, it's actually then starting -- you're starting to see a bit of a ripple effect where other government departments are going, "Oh, well, hey, maybe we can too." So, yeah, lots to do, but some good things are happening.

DR. DANIELS: Thank you.

DR. DIVAN: So, I'm just going to -- I think, you know, there's just so much similarity. In many ways, I would say every setting is a low-resource setting, but I think what we have been pushed in, I think, countries like Kenya and India to do -- is to really innovate.

So, I would really -- I'll try and just read the story of the three questions that you've asked me together. I think the first thing we really were finding in the Child Development Center was this increase of help-seeking for children with autism. And so, we decided that -- So, we kind of got together with the consortium in India. It was funded by Autism Speaks. And we did the first prevalence study for neurodevelopmental disorders.

And it was not surprising that we found it at 1 percent. So, I think, you know, we have everywhere in the world, so there's no denying. But you do need prevalence rates to actually try and push policy to give you anything. So, that was really the first step.

And then as we started exploring the parenting experience, we really found that there were two big gaps. And so, we call them the detection gap. It's like how do you get to services? How do you understand the differences? And much of what Amina said is very similar to India.

There's a very general low awareness. We don't really have any kind of child development tracking or surveillance for young kids. Kids go regularly for immunization. And at the back of the card that they use, which is a national card -- actually, they're all developmental milestones, but nobody has taught them to use that section of the card. They're just following whether they have the immunization jab. So, it's really there is an awareness, but there is no tracking.

There's also, I would say, the stigma, but I think it's also important to understand that in contexts like India, there is stigma without any benefits. So, getting an autism diagnosis doesn't give me anything as a parent, because it's not linked to any kind of services around the world. And so, that is an additional problem in, actually, for families to be reluctant to get a diagnosis or even reveal a diagnosis to the educational systems.

Then of course, there is the treatment gap, and I'll say that there are two big areas here. One is, of course, like many parts of the world, we have a lack of specialist care provisions. But I think we also, in the area of autism, are uniquely hobbled by a lack of evidence-based interventions. I think this is really a problem for the science that we need to start thinking about more closely. In terms of services for adolescents and adults, I would say it's almost totally missing. So, it's zero in contexts like India. Families are struggling, individuals are struggling, but there's really nothing the state is providing.

In terms of the work that I have been doing with the team that I work with in Sangath and internationally, I think we've looked at these two areas, detection and intervention, and at these two gaps. So, with the detection work, we've been trying to develop tablet-based tools that are, again, open source, that actually are going to be not requiring Wi-Fi.

Because actually, that's the other thing, that in many parts of the country, there's nothing like Wi-Fi. We're trying to keep them language-free. We have 22 official languages in India. So, we can't have them linked to language. And we're trying to use eye tracking. We're trying to use fine motor skills on the tablet, and we're trying to -- very nascent at this point, using parent-child interaction videos to try and see what that can give us in terms of children's behaviors and the dyadic behaviors within a parent and child.

And so, that's the area of detection. All of this work fundamentally is underwritten by this idea called task sharing. So, what we've been doing in Sangath as an organization is really realizing we don't have specialists. And how do we hand things to nonspecialists? So -- whether they're detection tools or whether they're interventions.

So, one of the pieces of work that we've been doing is we've taken an intervention developed in the U.K., developed by speech and language therapists, and we've developed a supervision and training cascade, which is -- we've just completed the trial for workers who had never heard the word autism before.

So, it's been an interesting journey, but I think we now have a very good methodology of taking a very specialized intervention into a nonspecialist's hands. Of course, all of this comes with the idea that we don't -- that nonspecialists work under supervision. So, it's not like we're just training people and setting them up. There has to be a specialist at the top. But we're very much hoping that this model of both detection and intervention can really allow us to scale up services as we gain more evidence in both settings.

DR. CUSACK: Hi, everyone. So, I think

it's really interesting. I think in terms of the life outcomes of autistic people, there's real consensus amongst all of us on the panel so far. And I'm really sort of trying to reflect here on the specific challenges that the U.K. might have.

I think one of the areas in which we're making a huge amount of progress in -- is in terms of changing attitudes and in terms of building destigmatizing narratives around autism and improving representation.

So, we've seen a great number of autistic women reveal that they're autistic, people from different backgrounds revealing that they're autistic, and actually just the idea of being autistic being destigmatized as well, which I think is -- which is obviously extremely positive. It's coupled with a neurodiversity narrative, which is becoming more prevalent in the U.K. But then that also brings an interesting set of challenges.

So -- and alongside that, we're getting better at collecting data. We're getting better at collecting data, I think, largely because a lot of the work that we've been doing to advocate for that, really pointing out the evidence from Sweden and other places around life outcomes, showing this is quite a serious issue that needs to be treated with seriousness, which means that we now have really good data on things like diagnostic waiting times, which is really good.

But unfortunately, sometimes you have to discover the bad news before you get to the good situation. So, the data says right now, that before the pandemic, waiting lists were five times smaller than they are now. So, that means they've grown five times. And at the moment in the U.K., we have 172,000 people waiting for a diagnosis. If you look at prevalence estimates, there are meant to be 700,000 people in the U.K. So, that is an enormous, enormous waiting list that we're experiencing. It has doubled in the last -- it's grown by 50 percent in the last year. It's doubled in the last two years.

So, this is like a real profound crisis that the U.K. finds itself in. And for me, it's very easy, as someone advocating for this issue, to suggest that people can spend more money. But speaking to the points we made earlier around lifespan research, we know we don't have the workforce to change that.

So, even if we implement the guidance as recommended, it's unimplementable. So, what we really do need is really wide systems change in terms of how we think about supporting autistic people but people with neurodevelopmental differences more generally, I suspect.

And what we're beginning to really ask ourselves is what does that look like? Because what we're definitely doing and what I think we're beginning to see from sort of health data is we're definitely becoming more sensitive to the needs of people with different neurodevelopmental conditions or different forms of neurodivergence.

But what we haven't done is adapt our systems and our ways of supporting people to reflect that. So, that's the price of success. You know, the data shows that, like again, there's real issues. We've got really great data from the Office for National Statistics on employment outcomes, but the data isn't great, if you see what I'm saying.

So, what we're really looking to do is to change -- as much as the data is not great, the outcomes aren't great, the story the data is telling isn't great. But we've got some -- we've got a huge opportunity there. We've got a very strong autism strategy. But the implementation is poor.

And we have really strong consensus amongst self-advocate groups, autism charities, and the government around the principles of what needs to be done. But there's a sort of lack of commitment from the government in terms of implementation.

We are really, you know, in terms of autism charities and self-advocates, classically insider lobbyers, but we are really having quite a difficult time with government ministers in certain areas in terms of implementation, but making some fantastic progress in areas like employment where they are seeing real significant opportunities, actually, in sort of the broader social and economic environment, which I think is really, really positive.

So, lots of challenges. Some of them are kind of the price of success really, which is better attitudes, better awareness and understanding. But with that comes a downstream -- a whole set of other new problems as well.

DR. DANIELS: Thank you. And we'll go to you, Dr. Mayo.

DR. MAYO: Peru is a nation of 34 million. Awareness of autism is increasing, but there is still a perception of low expectations of what they can achieve. The stigma of autism remains prevalent, and resource areas vary significantly particularly in the outside of urban areas.

Despite progress, such as the 2019 national plan for individuals in the autism spectrum disorders, which established the implementation of actions across multiple sectors, health, education, labor, and social inclusion, the national plan prioritizes services for detection, early diagnostic care, treatment, and health for people with autism.

But still, a significant challenge persists, as with all my other friends from the other countries. Early diagnosis is a critical issue. As of 2020, only 2.6 percent of individuals with autism have been officially diagnosed, indicating a considerable gap in detection and availability of mental health resources.

Approximately 80 percent of individuals with autism are unemployed, reflecting barriers to labor inclusion, and persistent workplace stigma. Although family training is part of the national plan, its implementation has been inadequate according to the evaluation of the plan in 2023.

So, what we are doing at the Ann Sullivan Center, we are collaborating with the plan, but especially our initiatives are awareness and training. Over the past 10 years, we've conducted video conferences in other countries, reaching over 49,000 professionals and family members, aiming to improve understanding of autism and supporting inclusive environments.

Our supported employment program has successfully helped over 200 individuals with autism in all the spectrum. Many of them don't talk, don't read, don't write, but they work. So, they work and for many years are financial providers for their family and even act as caregivers for their parents in time of need.

Through all our programs for families and a school of families that I would like to invite you, we provide monthly training to over 500 families, equipping them with the skills to prepare their children for life. In research and development, in partnership with U.S. academic institutions, we focus on developing effective methods for family training.

When I see my friend Sandro, a 42-year-old who defied autism -- who defied doctors' expectations despite his autism, I'm reminded of the little boy, a five-year-old who they said had no hope. Now, he's working 28 years for an international company. He has transformed his life from living in a straw house to a cement one, managing his finances, and caring for his father who has Alzheimer's.

It's all because we set high expectations, taught him with a functional national curriculum, and worked with a team with his family to prepare him for life. This is the future I envision for all individuals with autism in Peru and around the world. Muchas gracias.

DR. DANIELS: Thank you. So, our next

question for our panel is can you tell us about the roles that parent advocates, autistic self-advocates, advocacy organizations, and the government are playing in addressing autism in your country?

DR. ABUBAKAR: Thank you. I'll start by to the best of my knowledge, I think there is very little work with autistic self-advocates, and I think that's really something we need to work on. Maybe largely because I think there's very little work with adults. And I've been thinking the whole day, are we even identifying and working with adults in Kenya? I doubt it, and this is something I'm going to, you know, look around and see. So, I can say very little is happening there.

Parents are doing a fabulous job, you know. They're really quite a number of strong advocates, voices for their children, advocating for services, raising awareness. Like this month, you'll find they have fun, they have friends, and, you know, very many things to raise awareness.

And also, organizations. So, like, for instance, when we started the work, we set up a stakeholder group, a little WhatsApp group that now has really grown where people invite each other for different things. And we're finding that academic institutions, parents, and government officials are really working closely around how best can we support children, how best can we support families?

So, one, for instance, the Kenyan government has this very tiny little amount, I'm trying to translate it. I don't know if it has changed, but it's less than $20 a month to support children. Yeah. It's tiny but it's really helpful. And many parents, especially in rural areas, don't actually know that if you go and get a disability card, then you can access this money, but also you can access certain services.

So, you'll find that sometimes these three groups between parents, advocacy organizations, and the government, we go out and run clinics in the community for identification to support them because you must get a medical diagnosis. And sometimes parents don't actually have the money for that medical diagnosis. So, you get people to volunteer to be able to do that kind of diagnosis so that they can go for their disability card.

So, I would say in Kenya, some of the things really that are currently working a lot is around creating awareness and acceptance, trying to do more community level identification, and supporting parents to be able to access services but also at a certain level of -- I don't know if it's called policy development. For instance, a few years back, teachers were not trained in any way to support children with autism. Now, through a lot of advocacy, we now have a curriculum where teachers can be trained. So, that's some of the work that's happening in our country. Thank you.

DR. DANIELS: Thank you.

MS. GIBELLINI: I'm pretty proud of the advocacy space that we have in Australia. We're a pretty noisy bunch and we're not backward in coming forward. I mean, the big thing is we have a strategy. We're having this conversation because of parent advocates and self-advocates and the organizing and the lobbying they've been doing for years.

Aside from the strategy, a lot of the work that the groups are doing is raising awareness of, you know, autism is not one thing. It looks very different. It's very dynamic. It changes. We're talking a lot about the different impacts, and we're self-organizing into sort of groups in different subject areas.

We've had a lot of impact on the language that we use. I mean, Pru talked to you earlier about the language of the strategy. That's come from lobbying and advocacy from our community about the way that we want to be identified. And, you know, a lot of the way that we've organized and the way that we work with government has been really helpful as well.

We're very fortunate. Whether it's population, I'm not sure, but we seem to have better access to decision-makers in government than happens in a lot of places around the world. And I feel very grateful for that because, you know, that's how you have those really frank and fearless conversations that we need to have sometime.

The community, the advocacy community, the self-advocacy community, parents, et cetera, we haven't always been as collaborative as we could have been. So, there has sometimes been tension between parent advocacy groups and self-advocacy groups and things like that. And I don't think that that's unique to Australia, but --

[laughter]

-- I didn't think so, you know. And that tension still does exist. But what I think has been really valuable is that things like the strategy, everybody has been invited to have their say. Nobody has been, like, kept out. So, that's been really good.

What I'm also really proud of, particularly from the self-advocates in our community, a lot of us, we don't get paid for it. Like a lot of it is done on a voluntary basis because we really care. But I'm seeing older folks like me starting now to reach out to young leaders and support young leaders through their self-advocacy journey. We have self-advocacy training in different formats throughout the country.

And, you know, it's not perfect. And there's always going to be that power imbalance because people who get seats at the table kind of like to hang on to them. But we're seeing a lot more development of young leaders in that space as well. And that's really heartening. Because one day, I don't want to do this anymore. I want to go live on my farm with my alpacas. And someone else can do it.

So, I'm really proud that I'm seeing

like even a change from when I was at school to when like I have a 25-, 23-, and 11-year-old, the conversations they're having with their friends and being open and out about it. It's very different to when I grew up. And that's how you bring young leaders to the fore.

So, again, recognizing we have an extreme amount of privilege in Australia, but that's the kind of really powerful change that we're seeing. Thanks.

DR. DIVAN: So, again, like Amina said, I think self-advocacy is very nascent in the context of India. And I think it's very closely linked to stigma. So, I think there is no good reason for us to be saying that we're autistic if we are because it doesn't get us any benefit or any room at the table.

Parents, of course, I think like most disability movements across the world, have been at the forefront of actually demanding services. So, just as a little part of history in 1995, the Persons with

Disabilities Act had no mention of autism. And it was only through parent advocacy that the National Trust Act was passed in 1999 in India, which looked specifically at autism and a few other disabilities.

In 2013, they launched a very large national program, which is supposed to screen children from zero to 18. But again, implementation is patchy. But the 2016 Rights for Persons with Disabilities Act includes autism. It's on the table. It's in the books. And it has very clear directions for care and education.

So, I think parents have really pushed in terms of the legal frameworks of where we are in India. Most of the services actually have evolved also from parent-led groups. So, we have Action for Autism in Delhi. We have the Autism Society of West Bengal. We have Jyot School in the state of Goa. All of these initially started as mothers who realized their children were neurodiverse, had no services. What do we do? Got trained up and have started services. So, unfortunately, or fortunately, we've had these wonderful parents doing this work, but I think it needs to move beyond parents to actually public services that provide high levels of care and evidenced care.

So, I think that's where we are in terms of service provision and advocacy. But it's really heartening to hear that you actually have self-advocacy training, because I think this is the kind of thing that it would be amazing that if we can identify people in the context of the subcontinent, we can actually have them supported by people internationally to build up skill sets, which would then really create a louder voice in demanding services.

DR. CUSACK: So, it's really interesting to hear people's -- everyone's perspectives and particularly yours, Clare, around the social politics of trying to find consensus within a community before you go and advocate for change.

And I think really the key thing for me about this is that you've got to be serious about delivering change and be serious about understanding what change involves. And that involves finding some form of middle ground normally and consensus building and working with people that are serious around consensus building.

And that's really how we at Autistica have approached things in the U.K. So, we're working with autistic people, family members who are willing to understand that we as an organization are going to listen to everyone and try and balance the range of different views that exist. And then from there, really develop solutions which can serve all autistic people and their families. I think that's absolutely key.

One thing for me that I think is a real [unintelligible] to autism and neurodiversity more broadly as it comes to culture wars type issue not just within the field but in society more generally, I think we have a responsibility as a field to help try and build consensus and to really focus on sustainable, sensible, evidence-based, effective solutions which ultimately improve people's lives. Because that's ultimately what we're about.

And so, that's what we at Autistica have tried to do. And that's how we try to plug into the autism strategy and how the coalition that we've developed and worked within has tried to do.

And we've had some really amazing successes working with politicians. We worked with a politician called Robert Buckland on a review on autism and employment. We've managed to come up with some really brilliant evidence-based solutions around the issue of autism and employment, including the development of something that Autistica had developed called Neurodiversity Employers Index which is helping to support all employers to think about how they are accommodating neurodiversity within their workplace.

We've worked with the NHS, which Susan was initially involved with, on the development of an annual health check, which should be -- we should be able to roll out by hopefully 2025. That wouldn't be possible without building a coalition of people that are really focused on specific issues. And it's one reason why we have our 2030 goals at Autistica, which are really around real change which we think we can deliver.

Because having a hopeful focus and showing to policymakers and working together, this is the responsibility of all of us in this room, in this field, to show that this is not too hard, to show that this is achievable, and to show that we do have solutions. Because if you speak to politicians and if you speak to decision-makers, their real anxiety is this is too hard, and we can't solve this.

Because, of course, they want to be great. Of course, they want to make a difference. Of course, they came into this genuinely in most cases to do that. But if they think it's too hard and if they think there's no solutions, they'll walk away. And that's where our responsibility is to help them to develop those solutions. And so, that's what we really try to focus on in terms of building that coalition with autistic people, people or parents and different organizations in the government.

DR. DANIELS: Thank you, James. And Liliana.

DR. MAYO: Okay. Over the past 40 years, our center has significantly advanced autism advocacy. And Andy Shih came to Peru 10 years ago, and I think that helped a lot. Only it was during a period of the presidency that then the first lady that was sponsoring all these conventions went to Yale. So, it was not good. But we have kept fighting. People with autism are increasingly stepping into roles as self-advocates in Peru, presenting at conferences or internationally and engaging with leaders in government and business.

Imagine how I feel when a government like Panama or the University of Chicago invites a student and her parent to help educate other parents and empower their students as self-advocates. In Peru, people not only talk about autism but show us. We want to learn from a parent. We want to learn from a person with autism. Thus, when we train in our country, we always bring a team consisting of parents, their children, and a specialist from our center. Our students and families are very honored and happy when we tell them they are traveling to teach other families.

The shift towards self-advocacy among people with autism is profound, especially when they share their employment experience and what having a job means to them with businesses that want to hire people with autism. Parents are becoming effective advocates for their children's needs, equipped with knowledge from lawyers on how to assert their rights. This empowerment has touched various sectors, including education, healthcare, business, and law, creating a shift in the Peruvian society towards autism.

Although there is more to be done, we see positive changes. For instance, companies employing people with autism celebrate the World Autism Awareness Day with employees wearing blue and copying activities in government offices.

It was a deeply emotional moment for the team in our center when Delta Airlines sponsored four of our students to visit Atlanta, and they were invited to speak at the CDC. Listening to them address so many distinguished scientists filled my heart with immense emotion. Experiencing this profound exchange where I, the professional, becomes the student, and they become my teachers was the greatest reinforcement for our work. The voices of our students and their parents have become crucial in advocating for potential change in the Peruvian society.

DR. DANIELS: Thank you. And I'll hand the baton back to my colleague, Karen, in Canada.

DR. BOPP: Great. Thank you so much. I mean, I just want to comment on what we're hearing from you all. There's such, you know, changing perceptions of autism. This all seems to be sort of at different stages positive changes in all of your countries.

The common thread though, as you know, as we're seeing is the role of the autistic individual, self-advocates, co-conspirators, parents, caregivers, family. And it's really their lived experience and their voices getting in front of government and getting in front of decision-makers themselves that is making that change and that difference. So, it's so encouraging to hear that every one that spoke today has that underlying right there is the voice is the foundation, not something that's sort of extra. And it's the voice is direct. The voice is direct to the decision-makers and the most direct we can get.

So, the last question we have for you all today is what progress do you hope to see with regards to inclusion and support for all autistic people across the life course in your country in the next five years? What do you really want to see changed over the next five years?

DR. ABUBAKAR: Thank you. I think I'll pick on three things. One is early identification and an easier pathway to care so that parents, families, and individuals with autism don't have to spend, you know, a lifetime looking for the support they need.

I think the other one is really having autistic adults but even children speak for themselves, have a voice on the decisions and how they would like to be -- to work within their community society but also economic inclusion. I think across all different forms, you know, economic inclusion is really bad in our setting. And this, I think, would be really nice if we can work towards ensuring the nice transitions from school to the workplace. Thank you.

MS. GIBELLINI: I'm not as restrained. I've got a shopping list.

[laughter]

I think, you know, I've got a long list of things that I hope that we can add to this current strategy that we're developing and beyond. I'd love to see greater awareness of the intersectionality of our lives. We're not just autistic in one segment. It's we're autistic and queer. We're autistic and parents. We're autistic and First Nations people. So, a better awareness of the intersectionality and how that actually impacts the way we interact with things like employment systems and health systems and housing and all of those sorts of things and education.

I'd love to see better fit for purpose diagnostics, you know, that reflect some of that intersectionality so that we actually get diagnosis that is accurate and reflective of people's different experiences and the way that we present. I'd love to see more equitable access to the resources. And I'd love, of course, to see the resources reflective of the need.

Because sometimes I think that there are these conversations around profound autism versus -- I don't want to -- anyway, I'm not going to go down that road. I promised I wouldn't. But I don't think the problem is how we are autistic. The problem is the resources that are available, and it pits us against each other. So, I'd love to see that change. I'd love to see inclusion, of course, economic inclusion, social inclusion, inclusive architecture. When spaces are set up that are sensory friendly, it isn't just us that benefits, right? A lot of people do.

And to take it one step further, I would love to see autistic leaders on boards and not just the not-for-profits, the corporate boards. And because I really think the change is often pushed from the top down, but we spend a lot of time focusing on the capacity of people to push up, but we've got to see it come from the top down as well.

I want to see more openly autistic doctors and allied health professionals. I want it to be safe for those people to say, "This is who I am, and this is part of me." Because that can only give us better outcomes.

I want to see more of us in the spaces that I work and play in, in the emergency management space, in the defense forces. Because, you know, often we're excluded from those spaces, but we have a lot to give. That's probably as far as I'll go on my shopping list, but yeah, those sorts of conversations are things that if I had all of the resources in the world and all the money, then that's what I'd love to achieve.

DR. DIVAN: So, I'm going to just maybe speak to this more as a researcher and not as a passionate self-advocate or parent in that

I really feel what I would like to see in the context of India is for more evidence to inform what the country does. Because we put so little money into health.

When I look at the bucket for mental health, it's smaller. If you look at disability, it's like a drop in the ocean. So, if we're going to use that money well, it needs to be on evidence care.

And I think I'm very hopeful because Jan. this year, a technical committee for a national strategy on autism was just brought together in India under one of our premier institutes. So, I think there is -- the conversation is starting. We're trying to look at what are the different policies in place? How do we think they'd be implemented at the moment? What are the gaps? Let's look at the data. And then let's try and fill these gaps with strategies that have evidence.

And then there are a number of organizations like the one I work in which are really trying to also develop pathways to care. So, how do you not get stuck in this kind of diagnostic bottleneck? Are there things that we can do trans-diagnostically in the community that can be delivered as a first step to support families, which doesn't need very specialized help but still needs -- which still can be evidenced in what we're delivering on the ground.

So, I feel for me as a country -- I mean, for me as a person representing India, what I would really feel is we really need to look at the resources we have, mapping them properly. I mean, much of what I actually heard this morning from the Committee being done now in India in a much more systematic way so that we can actually be actioning it with evidence.

DR. CUSACK: So, just very briefly, I think one thing to recognize is that to do this, all of this, and to achieve all of this change, it's very nice to hear all the positive warm words about autistic people, which is great. But, you know, we need all of the expertise, right, to make this change and to make this happen. So, everyone is really, really important. I think it's really important that we acknowledge that as we build these solutions.

So, for me, for the change that I'd like to see in the U.K. over the next five years are really our 2030 goals, that we have at Autistica -- which ensure that autistic people get the right support, that we double the rate of employment as stated in 2020 for autistic people, to ensure that autistic people have proven treatments and access to treatments for anxiety, to ensure that every autistic person has an annual health check, to see measurable change in attitudes towards autistic people by 2030, to ensure that public spaces are more accessible for autistic people by 2030.

And those are our goals. We've got plans on our websites to achieve them. And that is really what we are focused on as a charity. I think to do that, we need to see an increasing -- I think there's a little bit of fear around the word "neurodiversity." I think we can have a discussion around neurodiversity, which is -- encapsulates the experiences of everyone and leads to better, greater personalization of support for everyone. I think that will really help to build a better world and also help to build social change, social understanding, and actually move decision-makers as well.

And then finally, one thing that I've really been reflecting on, which I think would help us in the U.K., but I think would also help globally, is to begin to sort of develop some sort of -- I'm big on indexes at the moment. We've got a neurodiversity index, an attitudes index. But also, could we have some form of global index which helps us to understand what good looks like globally and actually how well each country is doing?

So, Chiara, you talked about this a little bit in more qualitative terms, but could we begin to measure this and actually learn from the different examples of different nations? Because I think there's huge opportunities there, and I'd love to be able to implement that in the U.K. but also to see that implemented globally as well.

DR. DANIELS: And Dr. Mayo?

DR. MAYO: Peru is currently facing numerous challenges, including corruption, violence and economic. Despite this, our team at the center believes that loving our country involves doing our best in our work. We remember what President Kennedy used to say, "Ask not what your country can do for you. Ask what you can do for your country." So, we're doing our best.

But what we would like in our government to change in the next five years is first to increase training and coaching for educators in schools and provinces to better support over 5,000 children with autism included into regular schools where teachers currently have not received training of how to educate them.

Second, enforcement of existing laws for the inclusion and support of individuals with autism. Third, employment opportunities within government office too, enhanced dissemination of information in hospitals about early intervention campaigns such as Learn the Signs, Act Early, ensuring parents to receive the critical information at birth. Expand use of virtual technology to provide extensive training to parents and teachers in the provinces, eliminating the need for them to travel to the capital always.

Furthermore, the COVID-19 pandemic has significantly strengthened our team's capability in utilizing virtual education to support parents and their children. In collaboration with the Seaver Autism Center for Research and Treatment at Mount Sinai, we have done our research to evaluate the efficacy of our program in a 60-week family center intervention delivery, virtually, through our curriculum to Latin families in New York that have children with autism from three to five.

The results show improvements in both children and caregivers with parents learning to manage challenging behaviors and children learning to perform tasks with minimal or no assistance. The research is being written for publication. So, I think the government has the tools for using more virtual education to give massive training for parents and teachers. Muchas gracias.

DR. DANIELS: Thank you so much to all of our panelists and to Karen Bopp in Canada for co-leading this session with us. We really learned so much from all that you shared, and I think achieved our goal of demonstrating the full spectrum of all the way from awareness to acceptance to implementation of all of the various levels of work that need to continue in our world. So, thank you so much. And then I'll turn it back to Dr. Gordon to help close us out.

DR. GORDON: I want to add my thanks to the panelists both here in the room, in

Canada and in Peru. One of the better vacations I took with my family was to Peru. And it's wonderful to learn about the healthcare system there as well. And I've actually visited Calcutta with some of the founders of the organization there that is seeking to establish autism care for the community there.

It's been a wonderful day. I appreciate everyone for joining us, for listening and for participating actively. We do have one announcement. I believe, JaLynn, you want to announce the event that you're having on Friday to the community?

MS. PRINCE: Thanks. There we go. Yes. We have Autism After 21 Day that has been declared in Congress and is being celebrated here in the U.S. And it is emphasizing the talents, abilities, and challenges of adults with autism. And I quickly need to say I've been in your country starting 20 years ago as a global photographer. And as I was trying to photograph aspects of autism, it was very difficult because parents were hiding their children. As I have gone back over the last two decades, I have seen huge increases in acknowledgement, growth in the awareness, and even people knowing what the word autism is. So, if you wonder if you're making any difference, there's been a huge difference that has been made. And thank you so very much.

DR. GORDON: Well, thank you all. On that note, from awareness to acceptance, we'll close today's meeting of the IACC. Thank you to everyone who's been joining us on the webcast. Thank you to our Canadian colleagues for joining us for the afternoon. We really appreciate your participation, your guidance for the seminars that we've had and for this panel. Thank you, Susan. And best of luck to everyone.

DR. DANIELS: Thank you. And thank you to all the staff that have taken part in this meeting and helping us to have a successful meeting. I will be following up.

DR. BOPP: Thank you so much. I will keep the closing remarks.

DR. DANIELS: Oh, I think we were hearing Canada. Sorry. But yes, thank you so much to the ONAC staff, to Rose Li & Associates and NIH Events Management and CIT for supporting us today.

And I'll follow up with the Committee. I heard questions about the future and the next steps of the Committee, and we didn't have time to do more on that today. I do plan to talk about it in July, but I can also send you an email to follow up. So, thank you so much.

(The Committee adjourned.)