INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JULY 10, 2024

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 10:00 a.m., Shelli Avenevoli, M.D., Ph.D., Acting Director, presiding.

FEDERAL MEMBERS

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SHELLI AVENEVOLI, Ph.D.
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National Institutes of Health

DEIRDRA ASSEY, M.A.
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Behavioral Health and Justice Systems
Bureau of Justice Assistance
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Designated Federal Officer
Science Advisory Board
U.S. Environmental Protection Agency

JUDITH COOPER, Ph.D.
Deputy Director
National Institute on Deafness and Other Communication Disorders
National Institutes of Health

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Inclusion and Disabilities Services Specialist
Office of Head Start
Administration for Children and Families

JENNIFER JOHNSON, Ed.D.
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Office of Special Education Programs
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WALTER KOROSHETZ, M.D.
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Program Manager

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PUBLIC MEMBERS

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

ALICE CARTER, Ph.D.
Researcher/Clinician; University of Massachusetts Boston

SAM CRANE, J.D.
Self-Advocate, Advocate; Autistic Self Advocacy Network

AISHA DICKERSON, Ph.D.
Researcher; Johns Hopkins University

THOMAS W. FRAZIER, Ph.D.
Parent, Researcher; Autism Speaks

DENA GASSNER, M.S.W.
Researcher, Self-Advocate, Parent; Adelphi University

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Self-Advocate, Advocate, Family Member; Marketing Consultant, Independent Contractor

JENNY MAI PHAN, Ph.D.
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CAMILLE PROCTOR
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HARI SRINIVASAN
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JULIE LOUNDS TAYLOR, Ph.D.
Researcher; Vanderbilt University Medical Center

PAUL WANG, M.D.
Researcher; Simons Foundation

AGENDA

PROCEEDINGS

DR. SHELLI AVENEVOLI: Good morning, everyone. Welcome to the July meeting of the Interagency Autism Coordinating Committee. It's a pleasure to see you. I apologize that I had to be virtual today, but it's great to join you.

I did introduce myself at the last IACC meeting. I'm Shelli Avenevoli. I'm currently the acting director of NIMH. As many of you know, Dr. Joshua Gordon has stepped down from his position at NIMH. And so, now, I'm serving as the chair of the IACC as well as the acting director of the NIMH. And as I've said, it's really a pleasure to join you today.

I did introduce myself just a little bit at the last meeting, but I thought for those of you who may not have been there, just briefly, I am a developmental psychologist by training, with a particular passion for youth mental health, understanding the causes and improving the lives of young people.

And during my tenure at NIMH, I've really had the opportunity to work in a variety of places. I've been here 23 years now and both in the intramural research program as well as running some programs in the extramural research program, with the focus particularly, as I mentioned, on youth mental health, suicide prevention, and maternal health as well.

So, while I am new to the chair position, I'm very familiar with the activities and the reports of the IACC, and I've been attending these committee meetings for a long time. So, I'm looking very much forward to working with all of you today to carry on the important work of this committee.

And I'd also like to take this opportunity to thank Dr. Gordon for his service as chair of the IACC over the last eight years. And of course, a big thank you to Dr. Susan Daniels for her continued service as executive secretary of the committee. And thanks to the whole team as well, Oni and team as well.

So, we're very excited for today's agenda items. We will start the morning with an update from the National Autism Coordinator as well as the round robin, followed by presentations from members of the Federal Interagency Workgroup on Autism, or as we like to call it, FIWA.

We will also discuss committee business this morning. And then in the afternoon we will hear public comments and have a series of presentations and panel discussions on the topic of family caregiving.

So, with that I'd like to turn it over to Susan for more remarks and the roll call.

DR. DANIELS: Thank you so much, Shelli. I'd also like to welcome everyone to this meeting of the Interagency Autism Coordinating Committee, which will be our last one for this iteration -- the last full committee meeting that is.

As many of you know, the Autism CARES

Act is in the process of reauthorization, and we hope that it will be reauthorized before the sunset date of September 30th, 2024.

And in the meantime, we'll be working on close-out activities to finish all the projects that are remaining for this committee. And we are just so grateful to the committee for the work that you've done over the past three years.

So, now, I will transition over to giving you some committee member updates. I'd like to welcome our newest committee member, Ms. Deirdra Assey, from the Department of Justice. Deirdra, would you like to say a few words and introduce yourself? If you're here?

MS. DEIRDRA ASSEY: Hi, everyone. My name is Deirdra Assey, and I am a policy adviser with the Bureau of Justice Assistance, one of the funding arms of the Department of Justice. This is my first meeting, and I am very excited to be here.

DR. DANIELS: Thank you so much. We'd

also like to welcome Dr. Bryan Bloomer from the Environmental Protection Agency, who is serving as an alternate for the EPA today. Bryan?

DR. BRYAN BLOOMER: Yes. Thank you very much. My name is Bryan Bloomer, and I'm a long-time employee at the EPA. I've worked in extramural research funding as well as the intramural programs for air pollution and climate change, chemical safety and safe and sustainable waters.

I'm really grateful for the opportunity to support Dr. Hubal and Rebecca in being a part of this committee today and offering my experience, in addition to my professional experience, my personal experience as a father of two people who are diagnosed on the autism spectrum. So, thank you very much for the opportunity.

DR. DANIELS: Thank you, Bryan. Finally, I'd like to note that some of our committee members have professional updates. So, Dr. Jenny Mai Phan is now a research assistant professor and assistant director of Community Engagement in the Center for Adaptive Systems of Brain Body Interactions at George Mason University. Congratulations, Jenny.

And in addition, Ms. Sam Crane is now an independent consultant and serving on the board of the Autistic Self-Advocacy Network. Congratulations, Sam. And now, I'd like to turn it over to Dr. Oni Celestin, the ONAC deputy director for some housekeeping announcements.

DR. ONI CELESTIN: Good morning, everybody. Some housekeeping notes for our members attending in person. Please raise your hands to be recognized to speak. And during the votes that we'll have during committee business, you can just raise your hand in the room. And when you'd like to speak, please turn on your tabletop microphone and turn it off when you're finished.

For our members attending virtually, you can use the raise hand feature in Zoom to be recognized. For voting, please use the Zoom polls that you'll see in Zoom. Stay muted and keep your camera off during presentations and breaks. And you can turn your camera on during discussions and unmute yourself to speak.

For members who wish to comment in writing, please send your comments in Zoom, to the person labeled Send Comments Here. That's Steven Isaacson. And he'll read your comments out loud to the committee.

And as always, please keep your comments brief so that we can hear from as many people as possible during the discussions.

For those who would like closed captioning, that's available in Zoom for committee members, as well as on Videocast for members of the viewing public.

In the room, there's a sensory room available down the hall, for those who might need a sensory break. Please do not use that room for any kind of noisy activities or during the lunch break.

We also have a Zoom room down the hall for those who might need to step out to take a call or a meeting. And we'll have space available for lunch as well.

There are restrooms in the main lobby. And please silence your cellphones to not disrupt the meeting. And I'll turn it back over to Susan.

DR. DANIELS: Thank you. All right. So, now we will go through the roll call for the committee. And we do have many members who are online today. So, feel free to unmute yourself and turn on your camera when I call your name. So, first, Shelli Avenevoli.

DR. AVENEVOLI: Present.

DR. DANIELS: Allyson Dean from ACF.

DR. ALLYSON DEAN: Good morning. I'm here.

DR. DANIELS: Anyone else from ACF?

Jennifer Johnson from ACL.

DR. JENNIFER JOHNSON: Here.

DR. DANIELS: Kamila Mistry told me she might be joining a little late. Are you here yet, Kamila? From AHRQ. I think she'll be joining us soon. Oh, Robyn --

DR. ROBYN SAGATOV: Hi. Robyn -- yes, Robyn Sagatov from AHRQ is here. Kamila will be joining in a bit.

DR. DANIELS: Wonderful. Thank you. From CDC, Karyl Rattay or Stuart Shapira.

DR. STUART SHAPIRA: So, Stuart Shapira, I'm here as the alternate. And Karyl will join at 11:00.

DR. DANIELS: Thank you so much, Stuart. From CMS, Jodie Sumeracki for Melissa Harris. Oh, is not going to be here today. Tiffany Farchione is not going to be able to join us today, but do we have Martine Solages?

DR. MARTINE SOLAGES: Hi. Good morning. I'm Martine Solages from FDA.

DR. DANIELS: Thank you. From HRSA, Lauren Ramos.

MS. LAUREN RAMOS: Present.

DR. DANIELS: Thank you. Indian Health Service, Barbara Roland.

MS. BARBARA ROLAND: Good morning. I'm

here.

DR. DANIELS: Thank you, Barbara.

MS. ROLAND: Thank you.

DR. DANIELS: From the NIH, Dr. Monica Bertagnolli, but probably the alternate's -- Jane Simoni is in the seat next to me. I think that she will be here a little bit later today. The National Institute of Child Health and Human Development?

DR. ALICE KAU: I'm here, Alice --

DR. SUSAN DANIELS: Oh, Alice Kau?

DR. KAU: Yes. I'm attending as an alternate for Dr. Bianchi.

DR. DANIELS: Thank you so much, Alice. The National Institute of Deafness and Other Communication Disorders?

DR. JUDITH COOPER: Yes, good morning. Judith Cooper, I'm here representing our Director, Deb Tucci. Thank you.

DR. DANIELS: Thank you. The National Institute of Environmental Health Sciences?

DR. CINDY LAWLER: Hello. This is Cindy Lawler, and I'm, representing as an alternate for Rick Woychik, National Institute of Environmental Health Sciences. Good morning, everyone.

DR. DANIELS: Good morning. Thank you. The National Institute of Neurological Disorders and Stroke?

DR. KRISTI HARDY: Hi, I'm Kristi Hardy. I'm attending as an alternate for Dr. Walter Koroshetz. And I'm also in Scotland, so I hope that my wi-fi holds. I'll probably be muted and with my camera off.

DR. DANIELS: Thank you, Kristi. SAMHSA, Sunny Patel?

DR. SUNNY PATEL: Present.

DR. DANIELS: Thank you. Department of Defense, Nicole Williams?

DR. NICOLE WILLIAMS: Hi, everybody. Present.

DR. DANIELS: Good morning. The Department of Education, Christy Kavulic or Emily Weaver? And EPA, Bryan Bloomer?

DR. BLOOMER: Yes, I'm present. Thank you.

DR. DANIELS: Thank you. For the Department of Housing and Urban Development, Leah Lozier?

DR. LEAH LOZIER: Good morning.

DR. DANIELS: Good morning, Leah. Department of Justice, Deirdra Assey?

MS. ASSEY: Good morning. Present.

DR. DANIELS: Thank you. The Department of Labor, Scott Michael Robertson, I think may be joining us a little later because he's --

DR. SCOTT MICHAEL ROBERTSON: Yeah --

DR. DANIELS: Oh, there you are.

DR. ROBERTSON: Good morning. I'm planning to try to be in person this afternoon but just virtual this morning. Thanks.

DR. DANIELS: Oh, great. Thank you. All right. SSA, Alison Marvin?

DR. ALISON MARVIN: Good morning. This is Alison Marvin.

DR. DANIELS: Good morning. And the Veterans Administration.

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

DR. DANIELS: Thanks, Scott. And now, I'll go through the public members. Maria Mercedes Avila.

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

DR. DANIELS: Good morning. Alice Carter?

DR. ALICE CARTER: Hi, good morning. I'm here also.

DR. DANIELS: Good morning. Sam Crane I think will be joining us in a little bit.

MS. GASSNER: She's taking someone to school. So, she'll be here briefly.

DR. DANIELS: Great. Thank you. Aisha Dickerson? Tom Frazier?

DR. THOMAS FRAZIER: Present.

DR. DANIELS: Thank you. And Dena Gassner told me that she may or may not be -- oh.

MS. DENA GASSNER: I'm here.

DR. DANIELS: Thank you.

MS. GASSNER: Thanks, everybody. I'll be popping in and out today. It's dissertation time.

DR. DANIELS: Good morning. And good luck to your dissertation. Morénike Giwa Onaiwu maybe will join us a little bit later. Alycia Halladay. Craig Johnson.

MR. CRAIG JOHNSON: Good morning.

DR. DANIELS: Good morning. Yetta Myrick.

MS. YETTA MYRICK: Good morning. Happy summer. I'm here.

DR. DANIELS: Happy summer. Lindsey Nebeker. Thank you. Jenny Mai Phan.

DR. JENNY MAI PHAN: Hi, everyone. I'm here.

DR. DANIELS: Thank you. Camille Proctor. Susan Rivera.

DR. SUSAN RIVERA: Good morning. Present.

DR. DANIELS: Matthew Siegel

DR. MATTHEW SIEGEL: Here, thank you.

DR. DANIELS: Thank you. Laura Ivanova

Smith.

MS. IVANOVA SMITH: Here. And I'd like to go by Ivanova. Thank you.

DR. DANIELS: Thanks. Sorry. You're listed on the roster list here as Laura. That's why I just read it.

MS. SMITH: That’s my legal name, sorry.

DR. SUSAN DANIELS: Not a problem. Thanks. Hari Srinivasan. Helen Tager-Flusberg is not going to be present today, is away. Julie Taylor.

DR. JULIE TAYLOR: Present.

DR. SUSAN DANIELS: Thank you. And Paul Wang.

DR. PAUL WANG: Good morning, everyone. I'm present.

DR. SUSAN DANIELS: Good morning. How wonderful to see many of you virtually. And did I miss anybody? Is there anyone here representing an agency that I didn't call on or anyone else? Oh, JaLynn Prince, I don't know how I missed you. I just skipped over you on the list. Sorry.

MS. JALYNN PRINCE: I'm here.

DR. DANIELS: Well, you're here. Thank you so much. And thanks for pointing that out.

MS. CHRISTY KAVULIC: Hi. I think I missed my introduction. I'm Christy Kavulic from the Department of Education.

DR. DANIELS: Great to see you, Christy. Anybody else? All right. And we'll also keep track if people start popping in online. Oh, and Rob Ochsendorf, not a member of the committee but watching today. You want to say hi?

MR. ROB OCHSENDORF: Good morning, everybody. Rob Ochsendorf for the National Science Foundation. Happy to be here.

DR. DANIELS: Thank you. Anyone else? All right. So, then I think that completes our roll call. Next is the approval of the minutes. Unless -- do you have anything to say, Shelli?

DR. AVENEVOLI: I do not. Thank you.

DR. DANIELS: All right. You're on the

screen. So, I just want to make sure that you didn't have anything. So, then we'll go through the approval of the minutes. You all have the minutes from the April meeting in your packets, and it was sent out to you in advance. And this summarizes some of the proceedings of that meeting.

Does anyone have any concerns about the minutes or any corrections that you would like to have made? So, I'm not seeing anyone in the room. Or is there anyone virtually that has any comments about the minutes? Not seeing anyone, can I get a motion on the floor to accept the minutes?

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

DR. DANIELS: Thank you. Can we get a second?

MS. PRINCE: I second that.

DR. DANIELS: Thank you so much. All in favor, please raise your hand in Zoom or raise your hand in the room. Everyone in the room has raised their hand. How are we on

Zoom?

Okay. So, looks like we have a majority that are in favor of accepting the minutes. Anybody opposed to accepting the minutes? None in the room. Any on Zoom? Oh, it's a little hard to tell because of the -- maybe the hands are still raised from the previous thing.

And is there anyone -- and you can also speak up if you want to abstain from voting. Well, it looks like, from all appearances here, that we have a unanimous vote to accept the minutes. So, we'll accept them as written. If you do have any last-minute corrections or changes, just please let the office know. And we'll get those posted immediately after the meeting. So, thank you so much.

And I think at this point, I will continue then with the National Autism Coordinator Update, unless anyone has any questions? All right. So, then we will move forward with that.

So, I have a few updates for you today from the White House, some legislative updates, federal committee updates, federal department and agency highlights, which just add on to what people might want to share in round robin, and some additional updates.

-- Sorry about that. The remote suddenly decided it wasn't going to move. Okay. Thank you. Ready for the next slide.

So, first, an update from the White House. In support of President Biden's Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers, HHS selected 20 states to participate in two separate technical assistance programs that together will help participating states better recruit, train, and retain direct care workers -- which we know is a really important issue in this community -- and provide home and community-based services for older adults and people with disabilities. And we provided the link there for the press release. Next.

Okay. Oh, that actually worked. Okay. So, next, the Biden-Harris Administration unveiled a final rule that will protect and improve how millions of eligible people apply for, renew, and maintain health care coverage thru Medicaid, the Children's Health Insurance Program, and the Basic Health Program. We provided the press release here.

Also, with this update, the White House, Office of Science and Technology Policy has a working group for the National Science and Technology Council. And this working group is called the Disability Data Interagency Working Group.

I'm a member of this working group, and several of my federal colleagues are members of this working group that is working to coordinate activities to strengthen the federal government's use of disability data to advance equity for people with disabilities. And the membership crosses multiple departments and agencies.

And this working group is going to be

working toward creating a Federal Evidence Agenda on Disability Equity by the fall of 2024, so in just a few short months.

And they recently held a series of virtual listening sessions with individuals and organizations from the disability community. And individuals representing autism and IDD were included in that.

And there are also some interviews with federal subject matter experts that are underway. And the working group, importantly, has published a request for information called "Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity" to collect public input on the use of disability data, how we can ensure that federal disability data is inclusive of all different kinds of disabilities, how to make the data accessible, and many other related issues.

And this RFI was released on May 30th, and it's closing on July 15th, so just in another week. I would highly encourage members of our committee and people in the public who are interested in disability data, to look at this RFI and provide responses. Because it's really important we get representation of autism, IDD, other neurodiversity-related issues in this RFI, so that the committee can use that information to formulate its recommendations around disability data collections in the future.

So, the link is provided there. There's a Federal Register notice. And if anyone has trouble finding it, you can also just email me, and I'll be happy to share the RFI with you.

For legislative updates, I'd like to share just a brief update about the CARES Act and what's happening. So, the key provisions are reauthorization of the IACC through September 2029, and currently, improvements to ensure appropriate channeling of resources toward the most impactful forms of research, language to include individuals across the full spectrum and full lifespan, and individuals within the autism community having an opportunity to engage in research and -- the research process and other activities.

So, in February, a bill was introduced in the House, and that was co-sponsored by Representatives Chris Smith and Henry Cuellar. On the 14th of February, there was a House Committee on Energy and Commerce Subcommittee on Health hearing about this bill.

In May, there was another hearing to consider a markup of 23 bills that included the Autism CARES Act of 2024. And on June 12th, the House Committee on Energy and Commerce voted 42 to zero to report the bill to the full house. And so, that's where that sits at the moment. And the Senate also has their version.

And so -- sorry, I'm advancing. So, anyway, this is underway. We are hopeful that it will be reauthorized by September 30th. But our office will create a web page to keep track of all the different events, as we did in past years, for the reauthorization. So, be looking for that page. We'll send out an email to notify people that it's up, and we'll continue posting updates there.

I also just wanted to point out that there was a piece of legislation that is going to be receiving some action today that's relevant to the autism community. So, there is an amendment in a bill for agriculture that it would prevent FDA from banning devices that have been ordered for an individual by a court, which would include electric shock devices.

And the Appropriations Committee is expected to markup and vote on the bill today. So, I'm sure that advocacy organizations that are tracking this will be keeping people posted on it, but just wanted you to be aware of that activity.

So, for federal committee updates, I'm going to mention a few updates from different committees. So, the Interagency Committee on Disability Research just released a couple of important documents.

So, there is a white paper on the Federal Statutory Definitions of Disability, which has been updated now to reflect the latest in disability definitions. You may be interested in checking that out. And we will post it on the IACC website somewhere. We will get that available there as well.

The ICDR also released the Surveying the Landscape of Disability Data and Statistics toolkit that has information about disability data collections. The ICDR has held a few different Lunch and Learn webinars, and their latest was a series of presentations by representatives of federal agencies that provide funding for disability and rehab research.

And they also held their annual stakeholder meeting recently. And these are recorded. And you can find them on the ICDR website. The RAISE Family Caregiving

Advisory Council, we'll be hearing from today. But they had a joint meeting recently with the advisory council to support grandparents raising grandchildren, on June 13th. And we will hear updates on that later.

The National Council on Disability recently held a meeting on June 27th. And we provided the link for that in that meeting there. The Disability Advisory Committee met on May 16th and included a dialogue on digital accessibility. And you can watch the recording at the link provided.

The Coordinating Council on Access and Mobility had an update that the Federal Transit Administration announced that 17 projects in 15 states will receive funding to improve public transportation for people with disabilities, older adults, and individuals with low incomes. And so, we provided some information on the link there about that.

The Federal Partners in Transition is continuing to work on their strategic plan that is about youth with disabilities. And their general assembly meeting was held on May 16th, featuring a presentation on AI and disability employment. And they're planning their next meetings for September.

The Children's Interagency Coordinating Council is holding an event to explore issues and opportunities related to benefit access and utilization for children and their families that are experiencing poverty. So, you may be interested in that. And we've provided the registration link.

And again, I try to give you these updates about these other committees because they're doing really important work that intersects with our work. We definitely do not want to duplicate effort. But we also want to be aware of what's happening in these other federal agency committees -- federal advisory committees.

So, a couple of updates on federal departments and agencies. The U.S. Department of Health and Human Services marks the one-year anniversary of President Biden's Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers, which goes along with our theme today. And we have a link to the statements.

The Administration for Community Living announced nearly $2 million to support state implementation of the national strategy to support family caregivers, which I'm sure we'll be hearing more about today as well.

The U.S. Department of Justice's Civil Rights Division and HHS's Administration for Community Living and Office for Civil Rights held an event to celebrate the 25th anniversary of the Olmstead decision. And so, you can see the recording there on that link, and ACL did a blog post on it.

And the HHS Office for Civil Rights also finalized a rule strengthening protections against disability discrimination under Section 504 of the Rehab Act. And there's a press release for that.

I also wanted to highlight that NIMH has a new webinar series coming up that you might be interested in. It's called the Disability, Equity, and Mental Health Research Webinar Series. And the first two webinars have been scheduled.

The first one is on August 8th, featuring Nev Jones, on transforming mental health disability research through lived experience leadership and co-production.

And the second one is Dielle Lundberg and Jessica Chen, featuring the framework for understanding structural ableism in health care. And there will be additional webinars as well. So, keep an eye open for that. And we'll be putting that up on the events section of our website as well.

I wanted to share an update on a nongovernmental activity that I participated in recently. This June, the 17th session of the Conference of States Parties to the U.N. Convention on the Rights of Persons with Disabilities took place in New York. And this was a meeting of over 150 nations to talk about disability rights around the world.

And the overarching themes for this year were rethinking disability inclusion in preparation for the Summit of the Future. And some additional themes were disability employment, technology, innovation, including a lot about AI, and the persons with disabilities and how they're included in response to humanitarian emergencies.

And I had the privilege of serving on the U.S. delegation to the UN for this meeting, along with officials from the U.S. Department of State, USAID, ACL, CDC, and the U.S. Access Board. And I tried to be available to provide assistance with regard to autism, neurodiversity, and IDD.

And I also wanted to point out that IACC member, Dena Gassner, spoke on employment and family support at a side event that was sponsored by the government of Malta. And it was wonderful to see that this year, there were three separate side events that were focused on autism.

So, there was one that was an Australian event featuring their national strategy. And they had very high-level government officials from Australia attend the meeting to talk about their coordination around autism. And they have not only a national strategy for autism, but they have one for disability that they're trying to coordinate. And they're putting a number of different programs in place to try to support people on the autism spectrum, which was really exciting.

And there was a South African virtual event featuring autistic voices in Africa. And there was a collaborative event that was sponsored by Ireland, New Zealand, Hungary, and the WHO on supporting autistic people in society. And they talked a lot about self-advocacy.

And personally, I felt this was really important that autism was getting this level of visibility at the U.N. And hopefully, that will continue. So, keep your eyes open for that next summer. It takes place in June.

And I think this is my final update. I wanted to point out that there is a new "Neurodiversity @ Work Playbook: Federal Edition" that was developed by the University of Washington aimed at helping federal agencies establish neurodiversity employment programs and create a more inducive workplace.

And so, federal partners, you'll want to check that out. And if you're trying to support neurodiversity employment in your agency, that will be an important guiding document to be helpful to them.

And everything that I've talked about is in the document that you've all received, it’s posted on the web. And it's just more in paragraph format. So, are there any questions about this update that I've provided? All right. Well, thank you. Oh, yes, Yetta?

MS. MYRICK: So, just one thought I'm

thinking about, one of the first updates you provided with the RFI is open for five days. That was your information to me. And I wonder if there's a way for us to -- for your office to share out with the committee a little bit earlier, like when things are -- like if it's going to be close to the time that we have the meeting and it's due.

Just because I would love to provide a comment. But, like, given my schedule, I don't know if I'm going to be able to do it in five days.

So, I think it's important for us to have this information just a little bit earlier or if there is a way -- so, that's one option. Another option is if there is a way to be linked in, for those of us who are not federal members, to know which listservs to be on -- not that we need more e-mail -- but for option to, like, know when these things are coming down the pike, I think it would be helpful.

DR. DANIELS: Yes. We actually are

thinking about doing maybe a monthly -- or I don't know what the timeframe would be. Update e-mail, I know that people get overwhelmed with e-mails, and we don't want to flood you with e-mails. But there are times when there are things like this coming up. I also -- I did post it on my LinkedIn. But I know not everybody reads all the social media all the time. Oh, and we did tweet it. But yes --

MS. MYRICK: I'm not trying to give you all more work, but it's simply for the record.

DR. DANIELS: No, not at all.

MS. MYRICK: But I think, as we think about, how do we make these things more accessible to the larger community -- and we want diverse, you know, comments coming in -- I think giving more time and space for that will be helpful.

DR. DANIELS: Absolutely. So, we could, maybe for the next iteration of the IACC, look at having -- I don't know if it'd be a weekly, bi-weekly, or monthly e-mail that summarizes some of these things. But if you're looking for the information in a quick way, you can also visit my LinkedIn. I did a post about it.

But -- and we will be happy to send it to you directly as well. But it would be great to have comments from the autism community included there. Any other comments or questions?

All right. So, then we will move on to round robin. And so, we have a few minutes for people to share any updates from your agencies or your organizations or just your own personal work in the autism field, if you have anything to share? Is there anyone that would like to share? I'm just looking around the room. I'm looking at JaLynn.

MS. PRINCE: There's a very interesting project that has been started by the Huntsmans in Utah. And it's called Stop the Stigma Together. And it's about mental health care. And they had their second summit about three weeks ago. And I've had the opportunity of participating for two times with them, as they're launching this across the country.

And one of the things that we're very interested in is representing the autistic population and also caregivers. Because autism is not a mental health condition. But there are people on the spectrum who will have mental health challenges. And that is not being addressed fully yet. And people are still wrapping their minds around it.

And also, the importance of caregivers having good support and feeling that they can reach out without stigma. Because if you don't have healthy caregivers, you don't have healthy individuals. And so, it's an interesting situation.

And if anybody has any questions about it, it is open to others across the nation, the American Ad Council and so forth, is part of it as well, is going to be an important movement for America in the whole, but also for our population.

DR. DANIELS: Thank you. I saw a hand over here. Ivanova?

MS. SMITH: Yes. I have two updates. The first one is from the University of Washington LEND. This fall, there will be the 10-year anniversary of the Self-Advocate Discipline. And I started that discipline -- I had been in the first LEND trainee back in 2014. And so, we're going to be celebrating our 10-year anniversary. And so, I just want to share that.

And also, in Washington, we've made a bill that's called "Nothing About Us Without Us" that makes it so that people with direct lived experience get to have a say on workforces, task forces, and committees that directly impact them. And so, it's called Nothing About Us Without Us. I just wanted to share that as a celebratory thing. Thank you.

DR. DANIELS: Thank you. And I will go to the web here. We see that Paul Wang has his hand raised. And then Tom, you'll be next. So, Paul.

DR. WANG: Thank you, Susan. I just want to highlight the bullets that we have updates from the Simons Foundation in the meeting materials. First of all, we make available quite a number of research resources to facilitate research related to autism. And information for that can be found at sfari.org, S-F-A-R-I.org.

Secondly, we have an annual granting program that used to be called Bridge to Independence. Now it's called Fellows to Faculty. It is for senior postdoctoral researchers to transition into their first independent faculty positions.

And this is specifically targeted to candidates who have backgrounds and experiences that are underrepresented in science, whether they -- that is a minority, racial, or ethnic group or individuals who have autism themselves or, for example, military veterans as well.

Finally, I just want to share that the Simons Foundation is expanding its Autism in the Workplace initiative, having launched a grant program that gives funding to nonprofit employers to support autistic individuals in the workplace. Thank you.

DR. DANIELS: Thank you, Paul. Was the audience able to hear any of that? I don't think so.

DR. AVENEVOLI: Online? I heard it online.

DR. DANIELS: You heard it online?

DR. AVENEVOLI: I did. Yeah.

DR. ALICE CARTER: I could also hear It. I had to turn up my volume.

DR. WANG: I'd just point people to the bullets that are --

DR. DANIELS: I think -- I'm sorry to ask if you could repeat it, and maybe turn up your volume a little bit. Because our audience in the room wasn't able to hear. I could hear because I'm a little close to the speakers.

DR. WANG: Right. I'll try to speak more loudly also. Just pointing out the bullets that we have in the round robin updates meeting materials from the Simons Foundation. First of all, there are a number of research resources that we make available to researchers, whether they're from academia or industry or other spheres, through an application process. Please see sfari.org for information about that.

Secondly, we have an award program, which is now called the Fellows to Faculty award, for senior postdocs who are transitioning to an independent faculty position. This is targeted specifically to candidates who have backgrounds and experiences that are underrepresented in science, whether that -- they are from a minority, racial, or ethnic group, or they are individuals with autism or, for example, military Veterans who are underrepresented in science.

And finally, we at the Simons Foundation have a new Autism in the Workplace Initiative Grant Program. This is for nonprofit employers to build the infrastructure and training that are needed to support autistic individuals in their workplace. Thank you.

DR. DANIELS: Thank you so much. And we also do have the information in the packet for the round robin. So, if you want to just read it, you can go to the packet. All right. And then Tom Frazier.

DR. FRAZIER: Thanks, Susan. I wanted to just mention a couple of things relevant to Autism Speaks’ work. And obviously, there's things in the packet, I won't reiterate those, but please do read those.

But I just want to highlight a couple of things from Autism CARES to supplement what Susan said earlier. So, there's language in the bill to create a new Autism Intervention Research Network for communication needs. There's also language in the bill around aging as a focus for future research.

And the Government Accountability

Office, there's language in there to require them to issue a study and report on increasing the number of developmental and behavioral pediatricians.

The other updates for us are around our advocacy efforts for the Autism Family Caregivers Act. Obviously, that's relevant to today's meeting. The bipartisan legislation creates a new pilot program at HRSA to fund local caregiver skills training sites. It would be 25 sites in 15 states. And the bill currently has 34 cosponsors.

Oh, by the way, Autism CARES has 44 bipartisan cosponsors on that bill now. And then lastly for me, the Office of Caregiver Health, so Autism Speaks just recently joined a coalition with the Rosalynn Carter Institute and several other organizations -- many other organizations. I think it's 167 stakeholders that signed the letter that would call for the creation of a new Federal Office of Caregiver Health within HHS.

And the mission would be advancing

health and wellbeing of family caregivers across the nation. And I do just want to emphasize, we are looking for folks that would be interested in potentially being a site for Autism Speaks caregiver skills training, parent training, and information center.

And if you could contact Autism Speaks, the link is in the updates, the round robin updates. Our MSSNG resource also has been updated with now more than 13,000 individuals with genomic data and lots of clinical data as well for researchers.

And then lastly, just the WHO-UNICEF report, the 2023 Global Report on Children and Developmental Disabilities has been released. And they're holding a webinar on July 30th, 8:30 to 10:00. If people are interested, they're going to use that webinar to disseminate the report. Thanks.

DR. DANIELS: Thank you so much. Anyone else want to share for round robin? Bryan.

DR. BLOOMER: Yes. Thank you. Yeah.

So, I'm Bryan Bloomer. And I work in the Office of the Administrator and the Office of Children's Health Protection. And our Director of the Office of Civil Rights has undergone a multi-year initiative to create a safe and welcoming environment for persons with disabilities.

And as part of that effort, he's been working hard to baseline the number of employees who are currently working at the agency with disabilities as that has to be self-reported in our management tracking systems.

And I think, the last two years, he has been fairly successful at the end of this multi-year effort and has established, what I believe is a reasonable baseline in both employee counseling support services as well as ongoing training for the senior executive and political leadership at the agency.

So, I don't know if that had been reported out previously. But we have significant movement at the agency, in my opinion. And I just wanted to make sure everybody was aware of that and can see Juan-Carlos potentially as a resource. He's happy to help anybody else who may be undertaking a similar initiative. Thank you.

DR. DANIELS: Thank you for that update, Bryan. And Yetta.

MS. MYRICK: So, one more thing from me. I think many of you know I serve as the CDC's Act Early ambassador to the District of Columbia. And I wanted to share that -- and I don't think this is in the announcement about Learn the Signs, Act Early that's in the packet. But see, the Learn the Signs, Act Early program is 20 years old this year. So, I want to give a shout out about that.

Also, through my work, especially being a parent of a now adult -- autistic adult, is thinking about how to bridge gaps between the Learn the Signs, Act Early materials and autism.

And so, hot off the press, I actually need to send this to the CDC folks, created a document called "Using the CDC's Learn the Signs, Act Early Materials Post-Autism Diagnosis or Educational Classification" to help families think about what they can -- what goals they might be thinking about for their child using the Learn the Signs, Act Early materials.

So, one very good example is, you know, if a parent is interested in building social and emotional skills, they can talk to their psychologist or a special education teacher. Or for obviously, language and communication, they can talk to the speech and language pathologist. But after looking at the Learn the Signs milestones and saying, "Okay. My child might not be doing this right now. But I want my child to -- to be able to support them in doing -- getting to this milestone and having that conversation."

Because I think it's really important early on to ensure that families have the resources that they need to have these conversations with providers. So, just wanted to share that out.

DR. DANIELS: Thank you, Yetta. And Scott Robertson has an update.

DR. ROBERTSON: Yeah. Thanks. And sorry for not having -- provide this previously in the updated -- the update document. Just a few short things from us at the Department of Labor ends.

We have previously announced the theme of Access to Good Jobs for All as the theme for National Disability Employment Awareness Month coming up in October. We recently had webinars on cognitive disabilities and neurodiversity and mental health for the Job Accommodation Network, and EARN, which is our technical assistance and policy development center.

For employers, also recently had a webinar on The Mental Wellbeing of Gen Z Workers. And additionally, we have recently announced the awarding of cooperative agreements to help youth and young adults with disabilities address obstacles to employment.

And the announcement emphasized especially that $10.5 million has been awarded to fund the first year of these four-year, five-year cooperative agreements, aimed at developing strategies to assist youth and young adults with disabilities, particularly in underserved communities in successfully transitioning in the workforce.

So, those awards have been granted to the Connecticut Department of Labor, the Kansas Department of Commerce, Minnesota Department of Employment and Economic Development, and the New York Department of Labor. Thanks.

DR. DANIELS: Thank you, Scott. Any other updates? I think that we are completed with the updates. So, next we will move on to the FIWA presentations. And we'll have a break at 11:35.

But for this FIWA presentation, at the January IACC meeting, we had a series of presentations by members of the FIWA, the

Federal Interagency Workgroup on Autism, to share updates from their agencies about relevant programs and initiatives and activities related to autism and disabilities.

And we didn't have time to have all of the FIWA members present at the January meeting. So, we're going to have an additional set of members of the FIWA share their updates here. And to give you background on the FIWA again, the Federal Interagency Workgroup on Autism is a group -- an all-federal voluntary group of federal officials that meets on a regular basis to work on federal coordination around autism.

And I'm the chair of that committee. And we meet in between IACC meetings to work on the implementation of the strategic plan and also to work collaboratively on other projects such as Reports to Congress that were required for us to complete and any other requirements in the CARES Act.

And so, that's always going on in the

background. And they also hear updates about the IACC from me at those meetings. And the FIWA has a little bit broader membership than the IACC. So, there are a few agencies and departments that are not on the IACC that also attend FIWA meetings.

And it's a wonderful group of people. And this presentation will give you the opportunity to hear from several of those members. And I'm also pleased to say that we have new members to the FIWA from the HHS Office of the Assistant Secretary of Preparedness and Response or ASPR, and also from the Federal Emergency Management Agency within the Department of Homeland Security. And we'll be hearing from them today.

So, our speakers today for the FIWA presentations are Ms. Lauren Ramos, from HRSA, the Health Resources and Services Administration, Dr. Nicole Williams, from the Department of Defense, both of whom are on the IACC, Dr. Allyson Dean, also on the IACC, from the Administration for Children and Families; Barbara Roland, IACC member from the Indian Health Service and also on FIWA.

And then we'll be hearing from Dr. Maxine Kellman from ASPR, the Office of the Assistant Secretary for Preparedness and Response; and Dr. Sherman Gillums, Jr, from the Federal Emergency Management Agency.

So, each speaker will have five minutes to speak. And I'd ask each of you to please give us a little bit of an introduction to yourselves as you begin your presentations. And after the last speaker, we'll have some time for the committee to do some Q&A with you. So, we'll begin with Lauren Ramos.

MS. RAMOS: Excellent. Thank you. Will you advance my slides for me? Can't hear me? All right. Just want to check that you'll advance the slides. All right. Awesome.

Well, good morning. I'm Lauren Ramos from the Health Resources and Services Administration or HRSA, as we're known. I'm the director of our division of Maternal and

Child Health Workforce Development and serve as the lead for our autism investments.

In case you're not familiar with HRSA, HRSA provides equitable health care for the nation's highest need communities. Next slide please.

Our autism investments focus on three areas; training health care and other professionals to screen, refer, and provide services for children and youth with autism or other developmental disabilities.

We also promote evidence-based interventions through our research program; and lastly, ensure the implementation of best practices focused on transition for youth. Next slide, please.

I'll briefly go through each of those programmatic areas starting with our training programs. HRSA supports two training programs. The first is the Leadership Education in Neurodevelopmental and Other Related Disabilities or LEND Program, which is much easier to say.

The LEND program provides interdisciplinary training for health care and other providers and professionals that address the needs of children and youth with autism, developmental disabilities, and really promote the health of those with disabilities.

There are 60 LEND programs across the country. And so, we have a national reach. On the map, on the slide, you can see those states that are in the darker blue have at least one LEND program. Those in light blue have a partnership with an existing LEND program. And I just want to acknowledge that we have several IACC members that are connected to LENDs. You already heard that today.

We have project directors, faculty, and former trainees. We thank you. I'm going to acknowledge you. The LEND programs provide a fellowship program for those that are really interested in autism and the health of people with disabilities.

So, people go to the LEND program from their graduate or postgraduate training program and get really intensive academic, clinical, and leadership and community-based opportunities to really understand what it's like to have a disability and then to be able to screen, refer, and provide services as appropriate to those with autism and developmental disabilities.

The hallmark of LEND is its interdisciplinary nature. We reached over 25 disciplines. Those include medicine, nursing, psychology, social work, physical therapy, audiology, occupational therapy, and more. And a really important and unique feature of LEND is that we include in meaningful ways families of people with disabilities and self-advocates in our program.

Each year, LEND programs reach about 18,000 trainees and over 380,000 with continuing education. Next slide, please.

Our second training program is the

Developmental Behavioral Pediatrics Program or DBP. DBP programs really work to increase access to evaluation and services for children with developmental and behavioral concerns.

We support 13 programs, and each of those programs support the three-year fellowship for pediatricians that are interested in specializing in DBP. They also provide significant training and continuing education to other providers to give them some grounding in DBP issues.

In our last competition, we expanded the program to include a broader focus on some intensive training for pediatricians in DBP issues, really thinking about access to diagnostic services, decreasing waitlists, and really thinking about spreading DBP knowledge. Those programs reach over 1,900 trainees each year and another 38,000 practicing professionals through continuing education.

HRSA also supports an Interdisciplinary

Technical Assistance Center that is housed at the Association of University Centers on Disabilities that support the LEND and DBP networks. Next slide.

I'm going to shift and talk a little bit about our autism research portfolio now. We support research in three types of programs; the Autism Research Networks, Autism Single Investigator Innovation Programs, and Investigator Initiated Programs. You can see kind of what that looks like on this slide.

But essentially, we have four autism research networks, one focused on physical health aspects of autism, one on behavioral health, one on healthy weight for children and youth with autism and developmental disabilities, and one on DBP issues.

The research networks provide kind of a multicenter scientific collaboration for research into that topic area as well as development and dissemination of guidelines.

The single investigator innovation programs, of which we have two, focus on more emerging or understudied issues. We support one on longitudinal data analysis, kind of really looking at early origins of autism and life course aspects of autism. And a second that's focused on transition.

And lastly, our smallest piece of our research portfolio is the investigator-initiated programs. Those allow individuals to submit applications to study something, to replicate an intervention or a service, to test something with an underserved population, or to do some secondary data analysis.

All of our research work aligns to the IACC strategic plan. And we really try to work to advance the plan as well. Next slide.

Our last area is what we call the Best Practices Program. We have recently redesigned and completed that program this year to have a specific focus on Transition for Youth with Autism and/or Epilepsy. And we're really thinking about those youth with the highest support needs.

And so, these are new programs that will support states or other applicants to be able to develop frameworks, to really think about, what is successful transition from child to adult serving systems? So, thinking about the range of transition services, health care, employment, education, all of the things that we need for quality of life for youth and a significant focus on family support and caregiving support.

This program will also support a national TA Center to really be able to replicate and spread those best practices. We'll be awarding that first round of grants in the coming weeks. So, stay tuned for more information there. Next slide.

Before I close, I just wanted to highlight the Supporting Access for Everyone or SAFE initiative. HRSA supported this initiative through the leadership of our Developmental Behavioral Pediatrics Research Network, to develop a consensus statement that was really driven by public input and a range of health professionals, individuals, and self-advocates to think about, what is the standard of practice for health care to support youth with neurodevelopmental disabilities?

It was recently published in Pediatrics. And if you go to the safedbp.org website, you can access the consensus statement, a plain language summary, and an executive summary.

We ask for your help to promote it in settings that are appropriate for you to really spread equitable care and access for health care for youth with neurodevelopmental disabilities. And Yetta was also part of that panel as well.

You can follow HRSA on social media. You could go to our website, find more about our autism programs. And I'm happy to serve as a resource for you at any time. Thank you.

DR. DANIELS: Thank you so much for that update. Next, we'll hear from Dr. Nicole

Williams.

DR. WILLIAMS: Hi, everybody. I'm Nicole Williams. I am the program manager for the Department of Defense's Autism Research Program within the Congressionally Directed Medical Research Programs or CDMRP. Being in the DoD, we love our acronyms and our very lengthy terms.

For those of you who are not familiar with the CDMRP, we're a funding organization. Currently, we're over a $1 billion enterprise for FY24, which includes funding 35 different diseases and disorders, everything from breast cancer, prostate cancer, obviously autism research, epilepsy, and those more military focus, such as spinal cord injury, and Alzheimer's, TBI, PH, things of that sorts.

So, I just have a couple of slides. I'm going to give an overview of the ARP, a synopsis of how we started, and where we are, and then an update on our FY24 program. So, next slide.

So, the ARP's vision is to improve the lives of individuals with ASD now and in their future. And towards that, our mission is to promote innovative research that advances the understanding of ASD and leads to improved outcomes for service members, their families, and the American public.

You can see here from the chart at the bottom that the program first started in 2007 with a $7.5 million dollar appropriation. And we have continually received funding since that point. The one thing that'll jump out at you is that in FY20, we actually saw a doubling of our appropriation to $15 million. And that's where we've been for the past five cycles.

So, in total, the programs received just under 165 million, which is translated to 220 awards. And I'm happy to say that all of our FY23 projects have been funded. The 15 of those are on our website that you can see here at the bottom with a QR code. The abstracts are there, funding information, as well as the investigators and their institutions, if you wanted to take a look.

So, several years ago, we actually developed a strategic plan to better vocalize what the program was most interested in, where we felt our niche was in the broader scope of autism research. So, we developed our strategic plan which comprises of four strategic goals, which I have here on the right-hand side.

So, the program is interested in funding those treatments and interventions for autism projects that will help address the needs of autistic individuals as they move into adulthood, of projects that will support those caring for the autism community, and then the more basic mechanistic studies to help us understand the causes, mechanisms, and signs for ASD.

And again, those four strategic goals are really centered around our vision statement. What I show here on the sub bullets under these four categories are what we call our areas of interest, so the specific types of research we're looking for each year.

This is not an all-encompassing list. Each funding solicitation notes those specific areas of interest, but I just wanted to give everybody a feel for the types of areas we are most interested in. And next slide.

So, moving on to our 20 -- FY24 program, I just wanted to call attention to our funding opportunities, and some of our new areas of interest for this year. So, you can see here from the infographic, this program has worked really diligently on funding research across the continuum.

So, everything from those very initial concepts, those innovative, non-incremental research ideas with no preliminary data through our Discovery Award, to those bit more mature early ideas through our Idea Award or Idea Development Award, and then full-fledged clinical trials.

So, looking at those projects that have the potential for rapid implementation for the treatment and/or management of autism.

Also, over the past several years, we've really put more of a focus on recruiting and retaining those early career investigators, to give them the opportunity for funding to make sure they stay within the research field.

And we do that really in two ways. With our Clinical Trial Award, we offer an early career investigator option where we partner those early career investigators with an experienced investigator to give them the training and mentorship to become successful clinical trial researchers as they mature through their career.

We also offer a Career Development Award that's focused on those early career independent investigators, as well as trying to bring in perhaps those established investigators from another research field that want to dive into autism research.

So, one thing -- a couple of things I wanted to point out here for our areas of interest for FY24, there are four new ones we've included this year, looking at those projects that have the community support and participatory research interventions, studies that address factors impacting quality of life for current and former military families, projects centered around gender identity and sexual health, and then finally, projects looking to uncover new advances using a strength-based model.

Over the past couple of years, we really are trying to get the voices of the autism community to be involved with the research that's being conducted. So, across all of our funding mechanisms, we encourage researchers to involve autistic individuals, family members, and our caregivers in their research projects or teams.

Just one thing I wanted to point out that -- just an ancillary note -- that over the past couple of years, particularly with the Career Development Award, we have been seeing an increase in the number of autistic researchers submitting to the program. So, that's, you know, very exciting and really good news to get their voices heard.

The last thing I wanted to point out as far as timelines, currently our Discovery Award -- again, those are the initial concepts, no preliminary data, small dollar amount, you know, two-year period of performance. The letter of intent for those are due here in a couple of weeks, 24 July, and then full applications will be due mid-August.

As far as our other three award mechanisms that I mentioned, the Idea Development, Clinical Trial, and the Career Development Award, we actually had a pre-proposal submission, and that deadline has passed. But those who were invited to submit those full applications, those are due in the middle of August as well.

So, I just wanted to put a plug in, if

anybody's interested in taking a look at the Discovery Award, it is still open. So, I encourage everybody to take a look if you're interested. And that is actually my last slide.

DR. DANIELS: Thank you very much. Next, we'll be hearing from Dr. Allyson Dean, from the Administration for Community and Family -- for Children and Families.

DR. ALLYSON DEAN: Hi. Dr. Allyson Dean. I am the Inclusion and Disability Services specialist for the Office of Head Start. The Office of Head Start sits within the Administration for Children and Families, whose mission really is to support the economic and social well-being of children, families, and individuals.

So, there are many programs and initiatives within ACF that touch the lives of individuals with autism and their family. But today, I'm going to spotlight work near and dear to my heart, which is Early Childhood Education Initiative. Next slide, please.

So, within the Spotlight, I would say that our early childhood initiatives really fall into two big buckets. The first is supporting early screening, assessment, and detection of disabilities, autism, learning differences, et cetera, with the intent really to that through early detection, we can make a difference in outcomes for children and families.

We do that by partnering with other governmental agencies, including the CDC, OSEP, and other organizations committed to the same mission. And we do that by promoting their materials to families and really to our workforce.

One of the things we rely on is -- within CDC is the Birth to Five: Watch Me Thrive training, which our early care and education providers take, through many venues that we promote. Within direct service delivery, we -- within ACF, we deliver direct service to children with autism by including them in our Head Start programs, our Child Care programs, our public Pre-K programs.

And we do all of that in partnership with our IDEA partners, who deliver Part B and Part C services locally. We also work directly with the Department of Ed to promote and publish a joint policy statement this year on inclusion to really promote local partnerships to support children with disabilities, children with autism, to receive the early intervention and early childhood special education services that they are eligible for, within least restrictive environments, where they can play and learn and develop alongside their typically developing peers.

The population of children with disabilities in our early childhood education settings last year was about 13 percent. And within that 6,800, I believe, children had a diagnosis of autism. Autism is our fastest growing diagnosis within our early childhood education settings. Next slide, please.

Some of the ways that we support the adults within our work scope are, as I already said, the CDC as a -- particularly the Milestone Tracker -- as a resource for families, but also childcare providers, Head Start teachers.

We also developed this year a mobile app called the Inclusion Lab, which is a mobile application for early childhood teachers who can -- who are working with children with disabilities, who can really work through a teach-assess-adjust cycle, in terms of making sure that children have the supports they need, the tailored and intentional supports that allow them to be successful to fully participate in their early childhood learning settings.

We also have the Head Start Center for Inclusion, which is an online website that includes many resources tailored specifically to autism spectrum disorder. These include fact sheets, training modules, as well as actual practical supports for teachers, like classroom visual aids and other things that can really help children be successful in those group learning settings. Next slide, please.

We also do work, I would say, primarily through public pre-K and our Child Care Development Block Fund Initiatives with states. We issue policy and guidance to states. We also provide funding for approximately, I think, last year, 1.4 million children to be served through Child Care programs in state.

And within those state systems, we use many levers through that funding opportunity to support inclusion of children with disabilities, including children with autism in programs, including increased reimbursement rates for programs, and other incentives that help programs really create inclusive spaces for children, and provide care for children while families go to work or attend training or education programs.

This year in particular, we issued

policy guidance on early childhood behavioral and mental health supports, which really gives states guidance about how they can use their funding to increase access to behavioral and mental health supports, not only for children and families -- families and children with disabilities, but also for caregivers.

And in addition to behavioral health supports in terms of helping classroom teachers understand how to manage behavior for children with disabilities in group settings, whether that's related to their disability or not, those supports are promoted, and also mental health for staff, family and adult well-being.

So, those are some of the initiatives most closely aligned to supports for individuals with autism. And thanks for letting me share today.

DR. DANIELS: Thank you very much. Next, we'll be hearing from Ms. Barbara Roland from the Indian Health Service.

MS. ROLAND: Good morning. And thank you for allowing us to be a part of this program today. We support autism services and are very proud of the things that we do. Next slide, please.

The Indian Health Service provides clinical assessment services in support to American Indian/Alaska Natives regarding autism. These services often include other diagnoses such as depression, anxiety, and suicide among others.

Our patients may be referred to outside providers, and the cost may be covered by purchased and referred care when available. This is dependent on the Federal Tribal Urban Organization.

The provider consultation clinic allows federal, tribal, and urban providers to seek expert assistance in clinical guidance from health care professionals who specialize in ASD, FASD, and neurodevelopmental disorders.

And so, you can access the indianhealthservice.gov, Indian Children's

Program on our website. This consultation service is designed to support health care staff working in federal, tribal, and urban facilities and their treatment of American Indian/Alaska Native youth, ages 1 through 23, primary care providers, behavioral health providers, and other health care staff.

Consultations can help clarify diagnoses, provide behavioral health intervention, recommendations, and recommendations for support and resources. The Telehealth Behavioral Health Center of Excellence provides support to providers, family members, and the public by offering webinars annually. Next slide, please.

The IHS partners with the Interagency Autism Coordinating Committee, a federal advisory committee that coordinates all efforts within the Department of Health and Human Services concerning autism spectrum disorder, which you all know, the IACC and its federal public members to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

The IACC mission -- which I'm sure you all know as well -- provides advice to the Secretary of Health and Human Services regarding federal activities related to autism spectrum disorder; also, to facilitate the exchange of information on and coordination of ASD activities among the member agencies and organizations; and to increase public understanding of these agencies activities for which policies and research by providing public forum.

The mission of IHS Telebehavioral Health Center of Excellence Indian Children's Program is to equip healthcare providers working in IHS, tribal, and urban Indian Health System with training and education needed to provide excellent care for AI/AN youth with autism spectrum disorder, fetal alcohol spectrum disorder, and other neurodevelopmental disorders. Next slide, please.

IHS provides autism-related webinars to

TBHCE. There's a list of topics that have been provided this year. Unfortunately, all of the webinars have been presented. However, there is a place that you can go to, the IHS Telebehavioral Health website that's on the screen, and you can look at the archived presentations back for many, many years. Next slide, please.

Thank you. And we will wait on questions until the whole panel discusses them. So, that's it for IHS. Thank you very much.

DR. DANIELS: Thank you. Next, we're going to hear from Dr. Maxine Kellman from the Administration for Strategic Preparedness and Response.

DR. MAXINE KELLMAN: Hello, everyone. I am Dr. Maxine Kellman. And I'm a senior public health analyst and a designated federal officer for the National Advisory Committee on Seniors and Disasters. I am in the Administration for Strategic Preparedness and Response.

We recently went from a staff div to an OpDiv. So, that's our new name. But we still go by ASPR. Today, I'll give a brief overview of ASPR's advisory committees on older adults and people with disabilities. Next slide, please.

Now, ASPR's mission, in a nutshell, is to save lives and protect the nation from health security threats. Next slide, please.

For today's agenda, we'll go through legislation, regulations, and membership for the National Advisory Committee on Seniors and Disasters or NACSD, going forward, and the National Advisory Committee on Individuals with Disabilities and Disasters, NACIDD, going forward; and also give an overview of the recommendations. Next slide, please.

As for the legislation and regulations, these committees fall under the authorities of the Pandemic and All-Hazards Preparedness and Advancing Innovations Act, or PAHPAIA, that was created in 2019, and also Federal

Advisory Committee Act, or FACA.

For the committee purpose, the NACSD advises and provides recommendations to both the HSS Secretary and the ASPR as it relates to unique needs of older adults. Whereas NACIDD focuses on people with disabilities. And both are important for preparation for response and recovery during disasters.

Both fall under the General Services Administration, and requirements are set via FACA. Next slide, please.

In terms of membership, both committees have seven non-federal voting members. They serve a three-year term and provide recommendations to the Secretary and ASPR. Both committees also have 10 ex-officio members from various agencies, including the VA and ACL.

For the senior committees, at least two health professionals with expertise in gerontology and geriatric disaster planning are required. For the individual disabilities committee, at least two health professionals with experience in disability and accessibility care disasters, as well as to people who actually are with disability and also have disaster management expertise. Next slide, please.

For the NACSD and NACIDD recommendations, the committees offer recommendations to assist the Secretary in best serving older adults and people with disabilities before, during, and after disaster events. Recommendations focus on community readiness, infrastructure, and behavioral health. Next slide, please.

For the NACSD, the first set of recommendations completed in May 2023 included improving the dissemination of emergency preparedness and mitigation information by making it more accessible and user-friendly, and also the establishment of disaster care centers for older adults. Next slide, please.

The NACSD completed another set of recommendations in 2023 of September, advising that HHS should seek funding through the Older Americans Act Title VII for an Office of State Long-Term Care Ombudsman Program. This program will develop an emergency preparedness training curriculum, provide support through grants, as well as encourage regularly scheduled preparation meetings and drills related to long-term care advocacy. Next slide, please.

Here are additional recommendations related to long-term care. Give you a second to just quickly view. Next slide, please. And here are additional recommendations. But we definitely encourage you to visit our NACSD.gov webpage to review the recommendations in detail. Next slide, please.

As for the NACIDD, the recommendations included the timely development and distribution of videos, press releases, press conferences, and all other communications in American sign language and regional or locally used sign languages appropriate for the populations affected by a public health emergency, as well as just-in-time training for all public health emergency responders.

And as stated before, you can see more details of the recommendations for the NACIDD at its website, the NACIDD.gov public website. Next slide, please.

And any questions, we have a resource mailbox. For the NACSD, it's NACSD@hhs.gov. And the NACIDD, it is NACIDD@hss.gov. Thank you.

DR. DANIELS: Thank you so much. And our last presentation in this group of FIWA presentations will be by Dr. Sherman Gillums from FEMA.

DR. SHERMAN GILLUMS: Good morning, everyone. I just want to make sure you all can hear me.

DR. DANIELS: Yes, we can hear you.

DR. GILLUMS: Thumbs up. Thank you. Well, hi, my name is Sherman Gillums. I am the FEMA disability coordinator. I'm also the director of the Office of Disability

Integration and Coordination. These two titles embody a two-pronged approach to disability integration that we've been making at the agency since 2005, which we’ve been working to train -- [unintelligible].

DR. DANIELS: Sherman, you're breaking up a little bit. I don't know if there's anything you can do to make an adjustment. It's fine for you to turn off your video if you think that'll make things come through a little bit better. I believe he might be logging back in. There you are.

DR. GILLUMS: [unintelligible]

DR. DANIELS: Yes, we're connected, but your connection is a little bit shaky. It is cutting in and out a bit. If you might be able to move a little bit to get better reception.

DR. GILLUMS: Sure. I'll turn my video off, and maybe that helps. How's that?

DR. DANIELS: I think I can hear you better. Go ahead.

DR. GILLUMS: Okay. I'll continue and

let me know if you hear me. Okay. As I was saying, the [inaudible].

DR. DANIELS: We can't hear you now. Yes, technology sometimes doesn't cooperate.

DR. GILLUMS: Apologies. I'm actually off-site. We're bringing the deployment to Texas, but I'm [unintelligible] the presentation here.

DR. DANIELS: And thank you for your services.

DR. GILLUMS: Am I back?

DR. DANIELS: Can you try dialing into Zoom? So, as Dr. Gillums said, he's deployed right now in Texas, assisting with the disaster. And we really appreciate him taking a moment to try to update our committee. But we're having a few technical problems.

In the meantime, I see there's a question from Paul Wang until we get Dr. Gillums back. Go ahead, Paul.

DR. WANG: Thank you. Just two quick follow-ups to Lauren Raskin Ramos' presentation from HRSA. First, I want to self-identify as a LEND alum, along with many other people on the committee. I'm very proud to be able to say that. The interdisciplinary nature of LEND training is really, really important and has important impacts, I think.

Secondly, I just want to say the SAFE Initiative that she highlighted, I think is very important. And it was actually not only Yetta, but also Morenike and Matt Siegel on the committee who participated in that effort. I'd like to suggest that if this committee convenes again, whoever the representatives are on the committee, I think would be a great thing to highlight in more detail.

DR. DANIELS: Great suggestion and [unintelligible] opportunity. Sherman, are you back with us?

DR. GILLUMS: I am. Can you hear me?

DR. DANIELS: Yes.

DR. GILLUMS: My apologies. I'll try to

speed us up to get back on track here.

DR. DANIELS: No problem.

DR. GILLUMS: I was saying that the -- yes, the two-pronged approach was to have a person who was going to be close enough to the administrator to make sure that we account for the needs of people with disabilities during the preparedness phase, the planning phase of emergency management.

But the director part is really -- and it wasn't contemplated in the law, but this became the embodiment of what we actually do in the field, which will probably be of greater interest to this interagency coordinating committee. Next slide, please.

And you should see a slide that says guiding policies and mission tenets. When I assumed the helm back in August of 2022, two years ago, almost to the month, the first point of note was that we have a strategic plan that was crafted and implemented in 2022 to 2026 that heavily considered stakeholder feedback.

There was a lot of feedback about what -- where the gaps were, where needs weren't being met, and we're talking about before, during, and after disasters. A lot of times, people see FEMA as a response entity. But we also do a lot of planning before and during the disaster to ensure that we mitigate risks as disasters are unfolding.

And that's pretty important when you think about many of the ways that families who have a person with autism or an individual is impacted, not just in daily life, but during moments of crisis, where a lot of confusion sets in for a lot of people.

And then again, I, as a disability coordinator, my role is established under the post-Katrina Emergency Management Reform Act after many people with disabilities and who are older died in that disaster, I think about 80 percent.

So, the chances of dying in a disaster were much higher, not only during Hurricane Katrina, but in subsequent disasters. And so, this was the answer to that problem. And then of course, my office was established later on.

But Executive Order 13985 really gave us a direction, a mandate to not just look at equity as a mission essential, but how do we measure it and how do we actually give embodiment to what it means to be equitable in disaster response.

And the next slide gives us -- will provide a framework for how we did that during my time here. And on the next slide, it should say 14 points of inequity in a disaster cycle.

I spent the first maybe year and a half, not just going to disasters, but talking to survivors and stakeholders about where the common threads were, where the thread was through disasters that are highly variable.

A lot of variables distinguish one disaster from another, but what were the things that kept happening over and over and over again to people with disabilities, or how were they impacted during, what we call, their survivor journey?

And I came up with these 14 points where if we could do a better job of anticipating that this is where the problems will surface, then we can do a better job of assessing the risk and using data that tells us how many people are in a given area, what types of disabilities they have.

All those things factor against the ways in which inequity tends to come to the surface in disasters. And the first one is really probably the easiest to fix, but hardest to implement because it relies on states and counties and localities, prior to disasters, including people with disabilities in the planning process.

I spent a great deal of time last year working with NACDD and other of the DD councils at the state level talking through ways in which they become part of the disaster planning process. And if they're not invited, how do they find a seat at the table, whether it's through imposition or just talking to the right people. But they have to have a seat at the table to talk through these issues that are going to come up during disasters.

And again, we're seeing that right now in Texas and other places where we had a tornado outbreak throughout the Midwest and the West, where people are impacted. And they often have a say on what their needs are prior to those moments when a lot of things are going into chaos.

And if you follow the points of inequity, none of these should be surprises. You know, how do the families receive alerts and warnings? Is it directed to those families? Are we considering caregivers in that process? Evacuation, and transportation, sheltering?

And I'll talk a little bit about some of the practical ways that I've encountered these problems, but sheltering, transportation, establishing how we communicate with people in ways that they can tell us what they need.

So, all these ways are ways my team begins the planning process, either previous to landfall, if it's a hurricane, or if there is a no-notice disaster. When it happens, we immediately begin to look at these 14 areas of inequity.

And this is where, when I talk to DD councils and other entities that do the work that this interagency council focuses on, this is where we try to educate folks on how to look at this in a way that allows them to be proactive and self-sufficient in many ways when we contemplate how best to do these activities. Next slide, please.

It always helps when I talk about what we do to really get into the human dimensions of disasters. And in this case, we're talking about autism. That photo shows me at Sanibel Island after the hurricane, Hurricane Ian, which was one of the costliest in history, hit that area and killed quite a few people.

And I'm always looking for evidence of, you know, a family of, you know, who was impacted, and who are the faces that often become removed and anonymized by disasters when they're lumped in with a survivor group? But these are real consequences.

And I cite three that stuck with me during Hurricane Ian. The first was a call I received from a mom who had two sons who had autism or have autism, where they were sheltered in her car because she didn't want to be in that congregate shelter situation where people might misunderstand, you know, any behaviors or any ways that her sons might react to being put in that situation and then being adults, you know, at the same time.

So, I cite that because that was one instance where we show how families have to oftentimes go beyond simply adapting as survivors, but also adapt to social attitudes, even in the midst of a disaster. And we seek to stop that or disrupt that by getting ahead of these behaviors before disasters happen.

Another story was a six-year-old boy who drowned. His brother also drowned in an attempt to save him after he wandered off during or in the aftermath of Hurricane Ian. I tell that story because, one, it educates first responders on the need to understand autism as -- and some of the commonalities include an attraction to water and the tendency to wander off.

And we have to think about that when we put families in shelters and settings where we expect them to be safe in the traditional sense, but we also have to think about areas where there might be bodies of water or where we might need to enable families to prevent wandering in a situation where there are a lot of people housed in one area.

And then the last one was an inspirational story. This was a seven-year-old boy whose mom talked about the way he put on a mask, the Bendy and the Ink Machine character. He put on the mask during the hurricane. And because of that, he was able to take himself and remove himself from the danger and uncertainty by feeling like the character, the Bendy character.

And I thought that was interesting. Because, again, it helps us better understand ways in which we can support families. In this case, that was unique to that family, but knowing and understanding that there are ways we can help kids get through the uncertainty of disasters is helpful for us as first responders.

And so, I just wanted to point those out because we're always having to remind people that these are not statistics or data points. These are human beings. There are ways we need to support them. And then the last slide.

The last slide shows the actual efforts we'd undertaken. There was a collaboration between the Disability Integration Workforce in FEMA and the autism community in -- this was in Guam, where they were able to collaborate on messaging and making sure that families had the messaging and the instruction on how to get support even as power outages were happening. These were a spate of radio messages.

We also released IS-368.A: Including People with Disabilities in Disaster Operations. This is free-of-charge training that anyone can take. You simply have to have an email address and register on the FEMA EMI website to take this training.

And we could provide you with a link to that. Or you can Google the title there, and it'll pop up. But that's a way for us to create a common language around how we assist people with disabilities and disasters.

And then, you know, I'm going to be speaking at the NACDD conference this year in D.C. I spoke last year at the conference, but a lot of this is around how we brainstorm or co-create ways that we come up with solutions to helping families who have a loved one with autism, helping caregivers who provide care for them, cope with the uncertainty that disasters often impose upon them.

But these are the active ways, the proactive ways that we seek to be a part of the conversation without overtaking the conversation. And what I mean by that is we have to enable families and stakeholders and advocates to lead those conversations.

And my office has been good about making sure that we uphold co-creation of solution making and generate solutions as a component of how we support the autism community.

I'll stop there. I realize I've taken a lot of time with the tech difficulties. But if there are any questions, I'll be happy to answer them.

DR. DANIELS: Thank you so much, Dr. Gillums. That was a very informative presentation, as were all of the presentations today.

Dr. Gillums, I also want to say

congratulations again on receiving the 2024 Presidential Lifetime Achievement Award from President Biden for your service. And we look forward to having more participation from ASPR and FEMA in the future IACC. And I'm sure we'll be doing a session on emergency preparedness and response in the future and perhaps exploring that in the strategic plan. Thank you each for --

DR. GILLUMS: Thank you so much.

DR. DANIELS: You're welcome. Thank you each for sharing your recent initiatives and programs. As you all heard, many of these initiatives and programs directly relate to issues that we've covered in our strategic plan, including the caregiving topic we're going to be talking about today. So, we're excited to see the evolution of each of these programs and appreciate your participation on the IACC, which has been helpful in all of this coordination.

So, we have a couple of minutes for some questions if you have any. And then I'll try to transition us to our break, so that we can all take a break. Yetta?

MS. MYRICK: Dr. Gillums, if you're still on -- and before I jump into the question, thank you all for your presentations. I think it's so important for us to understand what's happening across all these agencies.

Dr. Gillums, if you're still on, I wanted to know more about the work that you did with the parents and caregivers in Guam and how that came about, and how can this be happening across the nation?

DR. GILLUMS: Thank you. I want to make sure you can hear me. Can you hear me okay?

MS. MYRICK: Yes, I can.

DR. GILLUMS: I'll tell you; it came about pretty organically. What happened during the Maui disaster -- and the good thing about these -- there's nothing great about them, but the good thing about pre-notice or pre-landfall disasters is we have a lot of time to plan. And because I've been engaging NACDD that summer, it was already top of mind for me. And I began to ask the question early about, what advocates are active on the ground? And Autism Speaks came up.

And so, I directed my staff, who was in Honolulu at the time, waiting for the hurricane to pass, to immediately begin to connect with those folks through the Red Cross, because they were already there, and figure out during the power outages, specifically, what can we do to make sure that those families are given directions, not just on where the shelters are, but what to expect at the shelters.

And so, we undertook a radio campaign. We figured the radio was the most reliable means of getting it out. Because internet communication wasn't going to be reliable. But we also didn't want to simply co-create or create messaging and impose that. We wanted to have some subject matter expertise weigh in on the best way, not just because of the unique needs of people with autism, but also because there were language concerns. There were other language and cultural concerns, so we wanted to get that right.

So, there was an organic conversation on what that looks like specifically for families with autism, because the advocates were active there. And because they were active, we found them to be a communication channel that we could exploit for the good of survivors who presented challenges that were unique to autism. So, the availability of people who are willing to do that work on the other side made it easy.

DR. DANIELS: Thank you so much.

DR. GILLUMS: Did I answer your question?

MS. MYRICK: Yes, thank you.

DR. DANIELS: And we have a question from Dena Gassner and then Jenny Mai Phan. And then we'll wrap up.

MS. GASSNER: Hi, everybody. Thank you so much for being here. I have a small concern, and I will be frank with you. I'm dissertating. So, I'm popping in and out.

And if I miss something, I'm open to that feedback. I hear a lot of conversations about families who have kids with autism. I didn't hear nearly enough about supports and engagement and co-creation with autistic adults.

You know, IACC is composed of a variety of roles and positionalities here. That includes a lot of people who are autistic. So, to be more explicit, in early childhood, I didn't hear anything about the additional level of support that is needed for a parent who's autistic, parenting their autistic child. Many of whom at the early childhood intervention level, don't even know that they themselves are on the spectrum. So, that creates a whole can of worms. I lived it.

I also heard very comparable things from FEMA about supporting autistic families instead of -- or in addition to needing to support autistic adults who may be going through crises. And I'd also like to know more about how all the agencies are doing co-creation in these policies and procedures with autistic people.

So, I'm trying not to be too detailed, but I'm trying also to get a broad view of how are autistic people actually contributing to these policies, procedures, and protocols?

DR. DANIELS: Thank you. And we can have a few brief comments from FIWA members if you'd like to say anything about that. Of course, we asked for these to be very brief presentations. And so, people weren't able to go in depth into all their programs. But if you have any brief comments, we welcome hearing from FIWA members.

DR. WILLIAMS: I mean, I can just speak for ourselves across all of our programs. Advocates are a part of not only our peer review process, which, Dena, I think you were a part of many years ago, but also our programmatic review process. We have a self-advocate on our panel currently. So, she's able to give a lot of insights that, you know, wasn't necessarily there just a few years back. So, we definitely lean on the autistic adult community to provide their lived experiences.

MS. GASSNER: Thanks.

DR. DANIELS: Thank you. And you also mentioned the participation of autistic researchers that has increased recently, which is great. Allyson Dean had a comment.

MS. DEAN: Yeah. I just wanted to respond in terms of the early childhood comment. Again, five minutes, I picked what I thought was most salient. But we have just recently launched an entire website to support adults and family members with disabilities.

And the focus of that site really is cognitive disability, learning differences, autism spectrum disorder. So, that would be probably where most of our resources would be. We also, of course, partner heavily with the Parent Training Information Center to support families with disabilities.

DR. DANIELS: Thank you, Allyson. And

maybe we can get that information from you and add them to the round robin document after the meeting.

MS. DEAN: Sure. Absolutely.

DR. DANIELS: All right.

DR. GILLUMS: I can weigh in with a quick comment. A lot of my work has really been internally focused on how we educate first responders on aspects of the work that they do where they may interact with someone.

I just completed an external affairs academy video in collaboration with NACDD, where we talked through how we recognize the signs of autism, where somebody may not be able to talk about that, or if they see it from afar, in ways that they can better understand and how they help.

So, it's really about educating the workforce and making sure that we understand it well enough to do a better job. And we also did a podcast with the former CEO of NACDD, Robin Troutman, where we talked about the intersection of autism and disasters and developmental disabilities broadly and disasters. So, we're creating content that hopefully will find its way into the right hands and minds.

DR. DANIELS: Thank you. And next, we'll hear from Jenny Mai Phan.

DR. PHAN: Hi, everyone. This is Jenny speaking. Dr. Gillums, I'm very thankful for what you do. I was a FEMA assistance recipient during Hurricane Katrina because I grew up in New Orleans. And so, I absolutely see the importance of the work that you do for the disability community.

And I'm wondering, because we are seeing increases of tornadoes and hurricanes happening earlier and earlier each year, and that there are families, as Dr. Gillums raised a few cases during his presentation, that have very unique situations that they're navigating and need further supports and assistance, that the IACC could perhaps maybe develop a working group with FEMA to address the concerns that could be approaching and grow in the future.

I have seen things improve in terms of FEMA support for families with disabilities, but I think there's going to probably be increasing demands. And Dr. Gillums maybe you could speak to this. With all the mobilization you're doing right now in 2024, are you seeing these increases happen and that there are higher demands of support requests from these families, from autism families?

DR. GILLUMS: That data point hasn't borne itself out in my work. It's more these isolated cases. I rely on stakeholders, community stakeholders to bring that to me though.

We never know where disasters are going to happen. And if it happens in a place where there's a significant representation of families or individuals who live with autism, then it's easy because they're already aggregated.

But in parts of Texas right now where

tornadoes were battering the area, and now we have a hurricane that may do more damage, it's hard. Because I need the advocates to surface. And a lot of this was ideally established before disasters.

One of the things I talk about is the need to have accountability at the state level. You know, who's overseeing disability coordination on the state side? So, I can begin that conversation quickly. That's often the gap.

Maybe that's where the interagency committee can help me socialize the idea of having every state have a person that's either my counterpart or somebody who's responsible to the executive leadership in the state.

And also, where does this show up in the state's disaster plan? I'd love to come up with model emergency management policies that contemplate the needs of those with lived experience with autism. And we can attach those to any state. The needs are not that much different. It's the context that differs. But I do have ideas on how we can scale. And I'd love to have that conversation at any point.

DR. DANIELS: Thank you. And thank you again for giving us this opportunity to share some of the work among FIWA members. And hopefully, you'll feel confident that the FIWA will constantly be meeting even when the IACC is out of session and continuing to coordinate on behalf of autistic families, individuals, and working with the community.

Thank you so much. And we'll take a break now and reconvene at 12:05 p.m. And I'll just try to keep the next session on my part a little shorter so that you can have this break. Thank you so much.

[Short Break]

So, I'll get started. I think people will be walking into the room here. We're going to get started on committee business. And so, Shelli and I will be collaborating on this to bring you all our updates.

So, in the overview, we're going to be talking about IACC accomplishments, as this is the last meeting and we want to recognize all that the IACC has managed to do in the past few years -- also our closeout planning for the committee, including completion of pending reports, and the 2024 IACC Summary of Advances discussion.

So, I'm going to start by saying thank you to IACC members and alternates who have served between 2021 to 2024. If you can believe this, there have been 80 different individuals who have served in various capacities with the IACC as members or alternates, and we got them all on this slide together.

And it's a wonderful diverse group, many different perspectives and points of view, many different federal agencies and departments represented. And it was the largest and most diverse group to date. And we're really very grateful to all of you. And Shelli, you may also want to say something about this.

DR. AVENEVOLI: Yeah. I just want to acknowledge the amount of time and effort that so many individuals have contributed to this committee. And I think this is a great opportunity to not just thank people, but for all of us to reflect and feel good about the things we've accomplished over the last few years. Thanks, Susan.

DR. DANIELS: Thank you. Yes, thank you for your service to the community, to the Secretary of Health and Human Services, and to all the federal agencies for providing your input on a regular basis in the committee. And to members of the public who regularly attend our meetings, provide public comments, respond to our RFIs, give us comments on our documents, we really appreciate all of your input and have continued to strive to reflect the community's input in our documents. So, thank you so much.

I also want to point out some specific

accomplishments. We've had 11 full committee meetings since starting up in 2020-'21. And we also have had one working group meeting focused on the strategic plan and several different important autism-relevant topics discussed, including housing, communication, mental health, employment, needs across the entire spectrum, aging, Social Security, prevalence and epidemiology, racial and ethnic disparities and equity, justice and law enforcement issues, international activities, wandering, COVID-19 impacts, supportive services, and today, we're going to be talking about family caregiving. So, we've covered a lot of ground, and the IACC strategic plan reflects these and more topics.

We also, as a committee, have completed six different reports, including a brand-new strategic plan, three issues of the Summary of Advances in Autism Research, and two portfolio analysis reports. And we currently have a strategic plan update on co-occurring conditions that's pending, an addition of the Summary of Advances that's pending, and a portfolio analysis that's pending and another issue of the Summary of Advances as well that we'll be trying to put out.

So, thank you for all of your hard work and contributions to these different reports, to every person on the committee and to the public for responding to RFIs to help inform some of these documents.

So, to give you an update on the Autism CARES Act, it's going to be sunsetting on September 30th, 2024. But -- and that will end the authorization for this committee. However, we also know that the Congress is working very hard on reauthorizing the CARES Act. And when that reauthorization hopefully goes through, then the IACC will be continuing its work, and we will be seeding a new committee.

So, the draft legislation to reauthorize the IACC has been introduced in Congress, and we provided the bill there. And the Senate is working on their bill. And HHS will begin the process to solicit nominations for new public members once we have received that reauthorization, and ONAC will work with the Office of the Secretary to put out a solicitation that'll go in the Federal register. And we'll send out emails, put it on X. We'll put it on our website, so you will hear about it.

And members of the committee currently, public members who have only served one term would be eligible for renomination. We also will welcome nominations from across the entire autism community. So, be looking for that most likely sometime in October or November.

And we just welcome as many people putting in nominations as would like to serve. It's a really valued experience being able to serve and provide your input to this committee in that way. And we've appreciated everyone here and look forward to the new committee in the future.

Alice Carter has a question.

DR. CARTER: I have a comment. I just want to thank you, Susan, for your leadership and for making serving on this committee really a pleasure. I had been present only during the timeframe you're talking about. And I just really want to thank you for wonderful leadership, and leadership makes a huge difference.

DR. DANIELS: Thank you so much, Alice. And I have to thank the ONAC team and our contractor, Rose Li and Associates, and the NIH Center for Information Technology that also have been really supportive in trying to make these meetings go smoothly. And we've all learned together on increasing accessibility.

I think we've actually really made some important steps in increasing the accessibility of our meetings. And we appreciate all the feedback and continue to try to improve and incorporate your suggestions. So, we will be continuing to do that and welcome feedback. But thank you so much for that. Dena.

MS. GASSNER: I just wanted to speak specifically to the accommodations. You know, we have more individuals identifying as disabled on the committee than ever before. And we -- you know, accommodating that many ways of communicating, I know has not been an easy lift. But I just want to champion the support staff, the contractors, and you, Susan, for listening with an open mind and expeditiously trying to address any voids in terms of accommodation and support that have made attending IACC as both a member and a committee member and as public members, so much more accessible than it's ever been before. So, I just wanted to give you kudos for that. All of you, thank you.

DR. DANIELS: Thank you so much. And thank you each for your input on that. We'll continue to try to make it more accessible over time. Sam.

MS. CRANE: I also wanted to give kudos.

And as one of the people who will probably be cycling off because I'm now approaching the end of my second term, I just wanted to say how far the IACC has come since I started. You know, we started with three members who are autistic. Now, it's close to a third.

I wish that we could have had more in-person meetings before I cycled off. Because it's so great to see how -- you know, like there are several other autistic people in the room. And it's a really fun dynamic that, I think, is way better than when we were trying to do this by Zoom only and -- now that it's hybrid. But I really hope that this continues.

I hope that, you know, this new IACC, with so many new voices, so many different people, as public members, can be maintained in the next cycle. And I look forward to joining you all over there.

DR. DANIELS: Thank you, Sam. And we hope that you will come back to meetings. Thank you both to Julie Taylor and Sam Crane for two terms of service on the IACC. So, you've all been with us since the Autism CARES Act of 2014. And it's been a long time, and we all have grown through this period. And we really appreciate all of your many contributions to the committee and look forward to continuing to evolve together.

Any other comments before we move forward? Oh, Ivanova.

MS. SMITH: This is Ivanova. I'm just very honored to have been allowed to be on the IACC. And I'm also very thankful for all of the accommodations and support that the IACC has given me. It was kind of scary, trying to get on to the IACC.

And I really appreciate that everybody really supported me with the onboarding process and supporting me with all those like logistical paperwork things that are really hard for me as a person with intellectual disabilities. So, I really appreciate all that support. And I've been really enjoying being on the IACC. So, thank you.

DR. DANIELS: Thank you so much, Ivanova. Well, we have really enjoyed working together. And I look forward to us all keeping in touch and to the new iteration of the committee in the future. So, we'll keep you posted on new developments in that regard.

So, the plans going forward from now are that, if we do get the reauthorization, our plan would be on -- at the time of September 30th, if we have a reauthorization in place, that we would extend member terms for 180 days, only to complete old business. So, we will not hold new full committee meetings and take up new issues. But we have a few projects to finish.

And so, we will work to complete the 2023 IACC Summary of Advances, which actually is almost complete now. And we'll talk about that in a few minutes. We also will complete this co-occurring conditions update of the strategic plan. And we don't want to give that to the next committee because the previous committee gave that to us.

And thank you, Julie Taylor, for your leadership with that. And we are determined to get this done. And so, we'll talk about that in a few minutes as well, and the 2024 IACC Summary of Advances. So, those will be our goals. And we'll accomplish some of this by --

After this meeting, if we need additional short Zoom meetings to talk with the committee, we may convene those. And we'll tell you a little more about that. But you will be hearing about those term extensions from the office when that comes up, once there's a reauthorization in place.

And our post-2024 or post-July 2024 activities will consist of, we'll be sending you emails, maybe asking you to respond to surveys, and setting up some smaller Zoom meetings, just to take in input so that we can complete projects.

And next, I'll share with you the 2023 IACC Summary of Advances update. So, ONAC has prepared the draft report, and IACC members will receive the draft report for a preview and comment very soon. So, we'll be sending that out for you. And then we'll prepare the final report once we've received any feedback from you and hopefully publish this summer.

One issue has come up with this. One of the articles that the committee selected, the author got in touch with us and actually told us that there were two articles that they put forward that were back-to-back published articles -- they're both named there -- that are part of a package that was important. And they said that they would like to see both articles acknowledged. And so, I wanted to ask you if you are comfortable with acknowledging both in the same advance.

And we have had precedent to do this before, where, say there were companion papers. And so, these are companion papers in the same issue of JAMA. So, I don't -- if anyone has any questions about that, more than that, what we want to ask you is if you have any concerns about us just adjusting that summary to acknowledge both papers together.

MS. MYRICK: So, just to clarify, the second article was not nominated, or we didn't, like vote the second article down.

DR. DANIELS: So, what happened actually at a previous meeting, those -- both of the articles were nominated. And at the time, I don't think we were completely realizing these were in a back-to-back publication.

And so, Dr. Gordon asked, "Can we just choose one of them?" And we did. And we chose one of them. But then now, the author has said, "Well, it's a little awkward for us to maybe acknowledge one without the other because actually, they were both in a part of an FDA package for looking at that intervention."

So, they said that it would make more sense for us to try to acknowledge both at the same time. And so, that's some new information we got that we didn't have at the time.

MS. MYRICK: Quick follow-up.

DR. DANIELS: Sure.

MS. MYRICK: This does not knock another article off --

DR. DANIELS: No.

MS. MYRICK: -- so to speak. They will be together.

DR. DANIELS: They would just be together and the same.

MS. MYRICK: Got it. Okay.

DR. DANIELS: So, it won't change anything in terms of that there's still 20 different articles that you all voted on. And you'll see when we send that out. And so, I just wanted to make sure the committee is okay with this. So, I'd ask you -- and we have -- do we have a poll set up? Or we -- yeah. So, we have a little poll set up. And maybe, Oni, can you explain how that poll works?

DR. CELESTIN: Yes. So, those of you --

sorry. Those of you who are on Zoom, you can use the poll. If you're in the room, you can just raise your hands, and we'll have people that are counting for and against. So, would you like me to do it? Okay. So, if you have no concerns with adding both papers to the publication, please raise your hands or vote in Zoom.

No concerns. Keep your hands up, please, so we can make sure we get everybody. And we have Walter in the back. I just want to make sure you guys see him. Thanks. All right. Does anybody have concerns about including both articles? Dr. Rivera? Oh, okay. Any abstaining from voting in the room? Dr. Johnson.

Okay. And online, we have 14 who said they have no concerns and would like to acknowledge both. No one online say they have concerns, and we have one abstaining from voting. Yeah, we haven't.

DR. DANIELS: So, it looks like the majority has -- said that they would be comfortable with having both acknowledged. If anyone who is dissenting wants to share any comments, you're welcome to do that. I'm happy to have you air any concerns that you'd want the committee to know about.

DR. RIVERA: I'm -- first of all, I'm fine with it both being acknowledged. It's not the hill I'm going to die on. But I do think that it's not completely clear to me that these are companion pieces. I think they are separate articles. We looked at them both. We voted on one. So, that's my only dissent. But I'm very happy to go with the majority opinion here.

DR. DANIELS: Okay. Anything else that needs to be shared in the room? Okay, then we'll -- oh, Sam.

MS. CRANE: I was just going to say like, could we put it in a way that reflects that they're back-to-back companion pieces so that it's more clear to readers?

DR. DANIELS: Yes, we have -- so, we have a version of the draft where we've tried to weave it in, and we say that they're companion articles. So -- all right. So, we will -- oh, Julie.

DR. TAYLOR: Not that I'm making any suggestions about you have to reword things that you've already done, but I wonder if it would make sense to sort of keep it the way that we voted and then make a note at the bottom that just says this is a companion -- I don't know. I mean, I'm sort of -- we did vote on one as opposed to the other. And I'm sure that they would like them acknowledged kind of as a package.

I'm wondering if we could sort of keep the suggestion or the sort of the description of the one that we had voted as an advance and then acknowledge the other one, sort of, at the -- or just have it acknowledged in some way, so people would see that they go together. But if it does -- as you put the description together, if it really does feel like they do really clearly go together, then maybe that doesn't make sense.

DR. DANIELS: That makes sense. Would you all feel comfortable with us just looking at it? It's hard to do it in the room because I'm not looking at it right now. I'm just looking at and seeing what actually makes sense in the context.

But that's an alternate suggestion. We could just acknowledge the other one as a footnote. And we could add it back to the nomination list. It was removed from the nomination list, but we could put it back on the list if it's not overtly, like put in the advance.

DR. AVENEVOLI: Susan, you have two comments online from -- one is from Alice Carter.

DR. DANIELS: Sure. Alice. Thank you, Shelli. Alice, go ahead.

DR. CARTER: Thank you. I just wondered, if we have a list of 20, I wonder if they could both go under one number?

DR. DANIELS: That's what the plan would be.

DR. CARTER: Yeah. So, I think in that case, it's clear like these are companion papers. And it will also probably be obvious from the citations that they're companion papers.

DR. DANIELS: So, how we have it if we were going to do this and how we've done it in the past when we have this situation of companion papers, is we'll list both citations, have one paragraph that mentions both papers and talks about how they relate. And then that's it. And it's one of the 20, but two papers are acknowledged in one of them.

And was it Paul that had -- Alison, do you have a comment?

DR. MARVIN: Yeah. Hi. Alison Marvin from Social Security. So, I think the main concern here is that was a -- there was a forced kick out of one of the papers. So, there's potentially both papers could have made it into the top 20. So, that was my concern, that that we eliminated one deliberately.

But I do like the option of you reviewing them again. And if they are truly companion pieces, you know, to call them you know, number 10 A and B, which is fine, or whether the other option was just simply to have the one which was selected and then say, "Please also see this companion piece." So, either of those would work, depending on what -- you know, what you feel when you've reviewed both of the pieces to see how they fit together.

DR. DANIELS: Thank you. And, Paul, do you have any comments, given that you were part of that discussion with Dr. Gordon?

DR. WANG: Thanks for asking. I don't have a strong opinion here on which way to go. It's very helpful to know that there was a precedent. I don't know exactly what that precedent was. And maybe it makes sense to follow most closely along the lines of what the precedent was.

But I also like the idea of like, just

keeping the one that we voted on and then mentioning the other one in a footnote as a companion paper. I think that also makes sense. So, I'm open to these various possibilities.

DR. DANIELS: Right. It sounds like the committee may be open to either option, depending on which one makes more sense. But I think it'll take a little bit of review for us to figure that out. Once that's resolved, then we'll be sending it out to you for review. Because I think the document is basically ready. So, with that, I think we will close out this discussion.

And next we're going to talk about the 2024 IACC Strategic Plan update, which was our report on co-occurring conditions, both physical and mental health conditions and their impacts on health outcomes.

And right now, ONAC is completing a draft of this report using information that we gathered through the previous working group that worked on this, as well as our very robust RFI that had over 1200 responses from the community, and discussions we've had here in the IACC and a couple of workshops that we held. And so, this is all being woven together into a draft. And I'll share with you the outline of how that draft looks.

So, our plan, given that we're not having another full committee meeting, would be that when we send it, we're going to be sending it to the IACC for review. At that time, we'll post it on a web page that is devoted to this report and also include information about all the other activities related to this report that we've done so far, so that the public can also access the information at the same time. And I'll go through the process that we have planned.

So, ONAC is going to revise the draft report based on IACC member feedback that we'll be collecting through a survey document that we'll be sending you. And then we'll distribute a second draft to you in the fall of 2024.

And our plan would be to have a brief, one to maximum two hours virtual meeting that will be scheduled for fall of 2024 to discuss the revised draft with the goal of maybe taking some final comments that we could include in approving the report.

However, if you have so many comments that we can't approve the report, we can always just have another short meeting later. So, we will kind of try to be flexible around that. But our goal would be hopefully getting it approved this fall. And once we have all of the feedback, we'll finalize the report and try to publish it within 2024 if possible. We don't want to pass it on to the next committee.

So, to go over some of the contents of the outline of the report, right now we have an introduction that goes over the epidemiology of co-occurring conditions, health disparities, recent IACC activities and interests that relate to co-occurring conditions, and community perceptions of research and services needs that are taken from the RFI analysis.

Chapter 1 is on co-occurring physical health conditions covering conditions such as epilepsy, GI issues and disorders, sleep issues and disorders, sensory and motor challenges, Ehlers-Danlos syndrome and dysautonomia, and health in older adults and aging-related health conditions.

And for Chapter 2, which is on co-occurring mental health conditions, it includes anxiety disorders, attention-deficit and hyperactivity disorder, depression, obsessive-compulsive disorder, self-injurious behavior, aggressive behavior and emotional dysregulation, suicidality, and additional mental health conditions such as bipolar, feeding disorders, gender dysphoria, pathological demand avoidance, schizophrenia, substance use disorder, Tourette syndrome and other tic disorders, and trauma and adverse childhood experiences, which is a wider scope of issues that we heard about through our

RFI. So, we've expanded it from the previous working group.

Also, Chapter 3, which would be on co-occurring intellectual, communication, and other developmental disabilities and will include intellectual disability, communication challenges, and related developmental disabilities such as fragile X, Rhett, Phelan-McDermid, tuberous sclerosis, and Down syndrome.

And Chapter 4, which would be about healthcare service provision, that will cover accessibility, patient-provider interactions, considerations for individuals with high support needs, reducing disparities, and the impact of COVID-19.

So, this is just a very quick summary of what -- how it's been organized to try to cover the issues that we've talked about here in this committee through our workshops and the RFI. And our goal was to give a nice summary without making it super lengthy. Because if it's a 500-page report, nobody will read it or only the most dedicated will take the time to read that whole report.

So, we're trying to be -- trying to cover the issues while also making it somewhat brief and trying to make it as accessible as possible. So, we're trying to balance that. And yes, and I see there are a couple of questions. So, the plan would be for committee members to receive all these chapters for review, along with a survey to facilitate collection of your feedback and then for us to make revisions. So, we expect to be making some revisions. It's not going to be perfect on this first draft. But that's the plan.

So, Dena, do you have a comment?

MS. GASSNER: I'm sorry. Can you go back to the very first slide?

DR. DANIELS: This one?

MS. GASSNER: One more.

DR. DANIELS: Intro?

MS. GASSNER: Yeah. Okay. I just wanted to -- I don't know. I think I can make my comments later. I just wanted to capture one of the -- the health disparities area there, in terms of, you know, communication, we saw it in the earlier comments. And we tend to think of this as being a binary of verbal and nonverbal. And I just -- I can't articulate more firmly how the array of communication challenges autistic people face become part of this healthcare disparity issue.

If you have some language, people expect you to not have any communication impairment. If you have intermittent communication capacities, people don't understand that. And, you know, simply having to pick up the phone to call to make an appointment can become an astronomical challenge. So, I just hope we're being very explicit in that arena around communication impairment.

DR. DANIELS: We appreciate those comments. And you'll have a chance on the survey to let us know if what we've written has not captured certain aspects, and we can try to fill in the gaps.

MS. GASSNER: Thank you so much.

DR. DANIELS: Thank you. And I see that Matt Siegel has a question. Then we'll go to Julie.

DR. SIEGEL: Thanks, Susan. Can you go back for a second, a couple of slides, to the list of mental health conditions?

DR. DANIELS: Wait. Okay. Let me go. That's forward.

DR. SIEGEL: Sorry, forward. Yes. Okay. So, I just wanted to say that it sticks out to me that pathological demand avoidance is unlike almost all of the other named conditions. There is not an official condition recognized in the -- in current diagnostic lexicons, DSM-5 or ICD-11. And so -- as far as I know.

And so, I question -- while there may have been feedback about it, I question it being on this list. And not looking to have a long discussion here, but just noting that I think that needs further review. Because it sticks out as different from the rest of the list.

DR. DANIELS: Thank you. And we definitely will take feedback through the survey. You know, one option -- and I recognize what your concerns are there -- is to just acknowledge it in the section that talks about the RFI. We did hear from a lot of people about it. So, we could acknowledge it there and not have a section in this section about that. But we'll share with you what we have and welcome your feedback and can make adjustments. Sam.

MS. CRANE: I want to second what Dr. Siegel said. I'm really grateful that he pointed it out because I had glossed right over it. But it is also sort of a controversial category. Oh, it's a controversial category of -- within the autistic community. And I think there's real things that people are talking about there, but the framework as demand avoidance versus other ways to frame it, it's definitely under active debate.

I think that sort of acknowledging it as something that people brought up and flagging it is something that needs more discussion, like more investigation to better flesh out what this is and isn't and whether or not it's a valid framework is totally warranted.

DR. DANIELS: Thank you for that feedback. Any other comments? Did we have -- oh, Julie.

DR. TAYLOR: Will there be any plans to go back to the original working group members from the last cycle, get their feedback on the draft as well?

DR. DANIELS: We can do that. We haven't -- we didn't work that into the plan going forward, but we could send it back out. I'd like to see the IACC maybe respond to it first and try to refine it. But is that something the IACC would like us to do, to try to go back to the previous working group if -- for those who might be available to help us out?

DR. TAYLOR: And you know, because it was in the last cycle, so we had two one-day, one two-day, right, where they were separate two-day workshops. One was on physical health. And we brought in international experts to sort of talk to us about it.

And then there was a two-day workshop on mental health. That was that. And that was a long time ago now. So, it may or may not be, you know -- appropriate is not the right word. We may or may not decide that we want to do that. But it's something that we could think about.

DR. DANIELS: And our plan, of course, was to acknowledge that working group for their contributions to this and both committees for their contributions. So, do people have a sense of whether you'd like for us to add a step of having that working group try to review this? Is there a strong sentiment that you want us to add that step?

MS. GASSNER: I don't think it would hurt anything. This is Dena.

DR. TAYLOR: And I do think there were

people from the group that came to the workshops that were wondering kind of what had come of that.

DR. DANIELS: Right, right.

DR. TAYLOR: So, we can share it back with them, of course.

DR. DANIELS: Of course, yes, we can share it back with them. So, we can look at the process and see if we want to add a step in there to have them provide some additional input. Things have also evolved since that time. So, there may be some additional updates. We tried to look through the literature for some recent updates to try to supplement what we already had. Any other comments from the committee?

MS CRANE: I just wanted to say I also think it makes sense to try and just take it back for a short review.

DR. DANIELS: With the previous working group?

MS. CRANE: Yeah.

DR. DANIELS: Okay. Thank you. All

right. We'll see if we can work a step in there to do that, too. But I think we'll get the committee's feedback first, so that we can try to make it the best draft we can get before we do that.

DR. TAYLOR: And I think we could also give them targeted instructions to not sort of like start over from. But I think we can sort of focus it around making sure that the updates in their content area in terms of sort of the advances in the literature or knowledge, since the time of the workshop, sort of reflects their understanding of the updates in that area. And then we can get more targeted feedback from them, as opposed to leaving it wide open for, you know, changes or edits.

DR. DANIELS: Exactly. And understanding that each section can't be an entire review of the entire field. Because otherwise, it would be maybe a thousand-page document, which we don't really want to have.

MS. MYRICK: Yeah, I was going to say I

like that idea. And I think the only other word I'm going to throw out is timeline, right? Like, look at your timeline and see, if we were trying to get this done within a certain amount of time, is there time to do that? I hope that there is. But I think it's also going to depend on the feedback that you get back from us as well. So, a lot of moving parts, but I'm not opposed.

DR. DANIELS: Wonderful. Thank you. So, this is good feedback. We'll take this all into consideration. So, you'll be hearing from us. And like we said, we will share the different drafts on the web. We'll create a page for it so that the public can also keep up with it even though we won't be having full committee meetings.

All right. So then, ready to move on to the next item. So, next we're going to talk about the 2024 IACC Summary of Advances and IACC members will discuss nominations received to date at today's meeting. And just a couple of reminders before I turn this over to Shelli.

IACC members can continue to nominate articles through the end of 2024. So, you can send them to us on a rolling basis. We will continue to send you our reminders asking you for nominations.

And IACC members will receive a ballot to vote for the top 20 advances in January 2025, which would be within the extension period. Of course, assuming that the CARES Act is reauthorized. And we also wanted to ask you if IACC members may wish to have a brief virtual meeting in January 2025 to have an opportunity to discuss the nominations before voting.

DR. DANIELS: Okay. So, I just wanted to ask you. Are you interested in having a brief virtual meeting in 2025 to talk about the nominations?

MS. MYRICK: Yes. Let's vote.

DR. DANIELS: Yes, go ahead. And you can raise your hands on Zoom, too, if you're in favor of having a virtual meeting to talk about nominations.

DR. CELESTIN: There's a poll.

DR. DANIELS: Oh, is there a poll? Sorry. If RLA can put up the poll. It looks like the majority in the room are interested. And I'm seeing hands raised on Zoom as well. I think that it looks like we're pretty safe in saying that the majority is interested in having a Zoom meeting to talk about that. So, we can do that.

And Shelli, I'm hearing a recommendation, given that we're overtime, that we could defer discussion of the 2024 nominations that have been received, or we could try to have a brief discussion. What would the committee like to do?

So, we had -- what, 27, 28 nominations -- 28 nominations that came in? Would you like to discuss that now briefly? Or would you like to defer until we meet in, potentially, January? Or we could even have another Zoom meeting.

DR. RIVERA: I guess I would -- oh.

DR. DANIELS: Please.

DR. RIVERA: I guess I would suggest that if we're going to meet that would -- and we would have a more robust list at that time, we could consolidate that discussion.

DR. DANIELS: Okay. Does everyone feel comfortable with that idea deferring and -- we'll just continue to take in nominations over the time period. So, please, do send us nominations.

We want coverage of all seven areas of the strategic plan plus the two additional areas we've added. So, please add items from your -- within your expertise and/or other items of interest that you run across in your work. So then with that, we're not discussing that.

Okay. So, I think that we will be able to move then to our lunch so that you are on time for lunch. And then we will reconvene after that.

[Lunch Break]

DR. AVENEVOLI: Okay. Great. So, it's

my job to welcome you back from lunch. Hope you all had a nice bit of a break. And we're happy to now turn to the oral comment session -- section of our meeting today, the public comment section. And we'll start with oral comments. And first on the list is Jackie Kancir.

MS. JACKIE KANCIR: Hi. Thank you for the time to speak on behalf of NCSA on the critical issue of caregiving from the high-support lens. Our reality is living in a persistent state of crisis. We face intense behaviors that require entire family the [unintelligible] needs to be [unintelligible] left totally to parents due to HCBS waivers that overpromised and never delivered.

Our founder, Feda Almaliti, perished in a fire she could have escaped. She was found with her arms wrapped around her son. With severe autism, he could not be convinced to flee. The recent movements in caregiver support are encouraging. Most are targeted at seniors requiring on average care less than five years.

The caregivers I represent may serve this role for five decades or more, in constant survival mode. Some say you can't pour from an empty cup, but they do. They must fill the role of an entire biopsychosocial multidisciplinary team for decades on end, yet they stand utterly alone over piles of denials. And then they're shunned from sharing their authentic realities.

NCSA recommends IACC authorize a report on autism caregiver burden across the lifespan and develop a strategic plan outlining solutions to secure the wellbeing of family caregivers, including distinct analysis for the profound autism population, explore caregiver physical and mental health, financial stability, educational and vocational opportunity opportunities, and food and housing security.

We also urge IACC to secure seats for parents with experience in this unique world, where very low adaptive functioning collides with intense and often dangerous behaviors, a world no one should be left to navigate alone.

In Feda Almalitis' last interview shortly before the fire, she said, I quote, "I didn't want parents to suffer like I did. I just didn't want one more mom or dad to go through what I went through." NCSA carries her wish with us [unintelligible]. Thank you.

DR. AVENEVOLI: Thank you. Thank you very much, Jackie, for sharing. And next up is Amanda Lopez from Sam's Sibs Stick Together.

MS. AMANDA LOPEZ: Good afternoon. My name is Amanda Lopez. I'm a speech language pathologist working at the ELS for Autism Foundation in Jupiter, Florida, and I'm a panelist on Sam's Sibs Stick Together.

I want to thank Alycia Halladay for providing my information to the committee, thereby allowing me to speak with you all today about the needs of siblings like myself.

My earliest memories after my brother Georgie's diagnosis were seeing how intensely my parents advocated for his needs. Younger me knew when my parents no longer could, supporting and advocating for Georgie would be my role. It's a lot for a child to think about, but it's not uncommon for siblings like me.

The Sam's Sibs Stick Together room, in honor of Samantha Els, began as a virtual sibling support group developed essentially overnight at the start of the COVID-19 pandemic. Dr. Kimberly Rivieccio and Dr. Erin Brooker Lozott saw the need to support siblings especially while we were all home together.

The group began, and Dr. Rivieccio created a space for school-aged siblings to meet and talk about their shared experiences. She welcomed adult participants to join and share their experiences. I was one of them.

Thinking back, I had never met another child my age with an autistic sibling and let alone an autistic sibling like my brother. And it was so special to see in this welcoming, thoughtful space. These kids had the opportunity to speak freely, ask questions, and listen to each other, share experiences only they could relate to.

Shortly after, in collaboration with Alycia Halladay and the Autism Science Foundation, a webinar series moderated by Samantha Els was launched. Adult siblings were invited to join in discussions about the sibling experience.

And the series began with panelists talking about their life as a sibling, and it grew to include reviews of research surrounding the sibling relationship, transition planning, and I found that as I've grown up as a sibling, my needs have expanded.

I'm now considering future planning as something that needs to be done rather than talked about. I'm considering the plans that I have for my brother along with caring for aging parents, and I need support in a different way than I did.

Currently, I'm facilitating an adult sibling support group with the guidance of Dr. Rivieccio. And in our first meeting, we developed goals. I want to share some with you all.

One, share in the common joys and concerns that are unique to the sibling relationship, provide a safe space to share and support one another, and to learn more. Learn how to take on that caregiver role and how to prepare for the future. Final goal speaks to one of the subjects of today's meeting, family caregiving.

Many siblings are aware at an age younger than you may think that one day they will be the primary caregiver of their sibling. And it's difficult to find resources and support that give quality information about how we get to that point.

So, Els for Autism, in close partnership with the Autism Science Foundation, have created an inclusive website, Sam's Sibs Stick Together. And it offers resources on stress management, transition information, and it houses quality up-to-date research about the sibling experience.

All webinars since its launch are recorded and available. And we really want to maximize our efforts to provide support to siblings in a space where they can access quality information and join in on these crucial conversations.

I want to welcome any adult sibling that would like to join the support group I'm currently facilitating. You're welcome to -- anytime. Registration is rolling. And you can find the registration link on the home screen of samssibssticktogether.com. I'm thrilled to see the world recognize the unique needs and strengths of siblings and the support we need. Thank you.

DR. AVENEVOLI: Thank you, Amanda, for

joining us. So, I'll turn it over to Oni for the written comments.

DR. CELESTIN: Good afternoon, everyone. We received 58 written public comments on the following topics. We received 47 comments, I'm sorry, on the experiences of family caregivers and the needs of autistic individuals with high-support needs. And the names of those commenters are listed on the slide.

We received six comments on the topic of research and service needs, resources, and policy implications, one comment on the topic of inclusion of autistic perspectives in research, two comments on the role of the IACC and the federal government, and two comments on the topic of potential causes of autism. The full packet of public comments is available on our website at the link listed on the slide.

DR. AVENEVOLI: Thank you, Oni. So, now, we want to open it up to all of you if there are comments or responses to anything that you've heard today. Dena, I see your hand up. Susan, you'll have to help with who's in the room.

MS. GASSNER: Hi. Thank you so much. I did want to mention -- and I'm sorry again, I'm multitasking. But the second speaker, if you're unaware of it, The Arc U.S. also has a National Sibling Council. And I see an opportunity for great collaboration there. So, I just wanted to mention that.

And then I did want to reiterate something that continues to be a miscommunication, misunderstanding, but there are several members of the current IACC who have direct parenting experience of caring for people who have high-support needs. I'm afraid people are getting the idea that there's insufficient representation for people with high-support needs.

But several of our members are going to be speaking this afternoon. And they also represent the needs of high-support-demand persons. So, I just want to make sure the public is aware that we do have considerable representation of an array of autism needs represented by direct caregiving experience on the committee.

Lastly, I did want to say that, as I reviewed the public comments, I just want to emphasize as we go forward, that we remember the unique caregiving needs of other autistic parents. So much of this is being communicated as though it's a binary, as though it's parents who are non-disabled parenting disabled kids.

And I'm here to say, as one of those parents that, you know, the communication barriers we face, the administrative burden we face navigating systems, the demand for social engagement in IEP meetings, as an example, is not unlike the burden that other parents carry, in terms of navigating systems.

But we're doing it with an 80-pound backpack on. We're doing it with a lot more cognitive effort. So, I just hope going forward that we can continue to prioritize the additional needs of parenting while disabled. Thanks.

DR. AVENEVOLI: Thank you, Dena. Other comments or questions?

DR. DANIELS: We have a comment in the room, Sam Crane.

MS. CRANE: This is probably not going to be my only comment. Okay. This is -- this might not be my only comment, because I want us to sort of get into other topics too.

But before we sort of move on to -- you know, while we're talking about the topics that Dena was mentioning, I wanted to really highlight one of the comments that I think got buried and is an issue that's very important to me, which is the lack of availability of legal representation to people who don't speak but are in community settings.

And the protection and advocacy system does have the ability to serve people who don't speak who are experiencing abuse and neglect in institutional settings. But now that we, you know, are seeing more and more people in the community -- which is a really good thing -- it's really important that the protection and advocacy system be given the ability to visit community-based settings and the mandate to visit community-based settings for situations where someone is nonspeaking, not able to communicate verbally, and might not otherwise be able to contact the P&As.

I know that it's -- it makes perfect sense to me that the P&As should, in general, be, you know, responding to the needs of people -- you know, with the person with a disability as a direct client and making sure that the person with a disability expresses an interest in having help.

But that's not usually a requirement for visiting, monitoring for abuse and neglect in institutional settings, which is something that the P&A's have the mandate to do. And I think I -- it is important that we highlight that they need to be empowered to do that in group homes and community-based settings too.

DR. AVENEVOLI: Thank you, Sam.

DR. DANIELS: More comments from the committee in the room and then Shelli is also looking on Zoom. Ivanova.

MS. SMITH: I'd like to thank Sam's Sibs for the comments on -- I think siblings are really important. I just have a question for -- if they're still around -- is, what are some ways that you help siblings, both the disabled sibling and non-disabled sibling, keep that healthy sibling relationship and not let caregiving become something that makes the sibling relationship torn?

Like you know, how do you help with, you know -- how do you help siblings support each other, they'll see each other as siblings, and help with that power dynamic that can happen and can cause a rip in sibling and family relationships? Thank you.

DR. DANIELS: If Amanda is still around, you can feel free to respond. I think that she may have logged off. Julie has her hand up in the room.

DR. TAYLOR: Scott, you've had -- have you had your hand up for a little while? I'll let you go first if you'd like.

DR. ROBERTSON: You go first.

DR. TAYLOR: Oh. All I want to do is just amplify one of the comments here that I think we've talked about a lot in this committee, so it's not going to be any surprise to anybody here in this room. But I just wanted to talk about the crisis in shortage of direct support professionals for people with all disabilities but also for people who are autistic -- for autistic people.

And the turnover that we see in our families among direct support professionals, people who are able to get direct support professionals into their homes, the turnover and how that really can really negatively impact the lives of autistic people and that, you know, the pay -- low pay that a lot of these people are experiencing is a real reason for that.

And so, we've talked about this before. And I'm sure we'll talk about it again. But it came up in a couple of the comments. So, I just wanted to take the opportunity to really amplify that and say that that continues to be a crisis and that autistic people are going to have a hard time living their full lives in the community and really reaching their potential if we don't have people who are not family members, to be able to support them in doing that.

So, I don't know if this is something that our committee can continue to really be thinking about in the next iteration of the IACC. But it's such an important topic. And it really limits quality of life for a lot of people to not have access to high quality or consistent direct support professionals.

MS. GASSNER: And can I just piggyback on that, Julie, and to say, we're looking at a tremendous number of people who get pulled out of the workforce, primarily mothers, but a lot of caregivers, because we don't have access to good, consistent day service services and direct support personnel.

DR. DANIELS: Thank you. Scott.

DR. ROBERTSON: Yeah. I just wanted to say I concur with those thoughts as far as community-based supports, enhancing in that area, which is also interrelated to -- as a social determinants of health -- to greater health and wellbeing and to independent living and employment too, for our end of things, is that folks who have better community-based supports have greater quality of life and more able to have employment access that fits their interests, needs, and talents and skills and have career development that works well.

And I also want to concur with Sam's comment as far as on the communication end of things. That's something I've been trying to emphasize is access to alternative augmentative communication systems devices across many different life areas, as far as employment and other areas that allow folks to have full access and opportunity. And I think that's not always emphasized as much.

And sometimes it's because folks who may have differences in communication or maybe nonspeaking or just have a variety of different communication means, may not always be fully represented in the room, in scientific studies, in papers, reports, et cetera.

And so, I think it's up to all of us to emphasize that as sort of the diversity and complexity in terms of autism lived experience.

And just briefly, I wanted to, you know, also appreciate the comments that were in the public written comments about employment access, including Kerry Berger. And then there was a comment from ASAN, including mentioning -- I don't know if this is a shameless plug, but our old project that ODEP on the regarding Research Support Services for Employment of Young Adults on the Autism

Spectrum.

So, we appreciate the community recognizing that. And we're striving to do more as we can. So, we appreciate -- you know, all the input we can get from constituents is always valuable for us in exploring how we can improve better access to employment, high quality of life. Thanks.

DR. DANIELS: Are you seeing anything on Zoom, Shelli?

DR. AVENEVOLI: I am not.

DR. DANIELS: Okay. Here in the room, JaLynn.

MS. PRINCE: For those out there, this is JaLynn Prince. I've had a very complicated situation with caregiving through our family. And to do a consolidated version of this, my mom turned 80 one week after our youngest child was born.

So, we had an 80-year span plus two teenagers, a husband, and myself, all in one household. And my mom who had turned 80 just at the time that Madison was born, lived with us until she was 94.

So, there were so many different types of demands and so many things that I've seen both with siblings and our children's associates and friends that also have siblings on the spectrum, that I think sometimes it's expected that the sibling would step forward and be the caregiver.

And in many situations, that is admirable. It is the right thing. But sometimes we need to understand what the other family members have given up not because of their choice.

My husband and I decided to have another child. Our children didn't decide that. But their lives were impacted. It may sound superficial in a way, but birthday parties were impacted, holidays were impacted, vacations were limited. Things were changed because of the person with the highest needs. And we did so lovingly and caringly, but there has been a sacrifice that is often made by siblings.

And when they move forward, and they have their own children, if they're taking care of their uncle, how can they necessarily take care of their children? Because those are their children, and they deserve a future too.

So, the idea of what you were mentioning about having additional trained and capable caregivers in line -- because if there's a single sibling, and something happens to them, what happens?

So, it's a complex story. And it goes on in many different ways that we don't see when we see the front door of our neighbors who are living with autism, what the complications are, what the implications are, and it can go on for generations.

And we do want to hope the best and provide the best for our loved ones who are autistic. That's not the question. But there's a lot of other lives associated with it. Thank you.

DR. DANIELS: And we also had Yetta in

the room with a comment.

MS. MYRICK: So, as always, I'd like to thank those who provided oral comments and written comments to IACC. I think it's so very important for you all to share your individual stories and experiences. It really helps to inform the work that we are doing.

A lot of comments in here. I mean, you saw the numbers of folks who have shared their experience about family caregiving, many of which, when you read the stories -- and I implore folks who might not be IACC members, to take time to read through these comments and find the threads and figure out, how, in your own communities, you can be advocating, right?

Yes, work needs to be done. We have these conversations. Every time we meet, things are moving. But it takes time, right? And so, the way things move is by us telling our stories and by us advocating.

And I just think it's so very important

for people to be acknowledged for, you know, what they're doing as autistic individuals, to advocate and to work every day, to be functional parts of society, to be accepted in society.

Because the reality is the world is not built for them. And I say that as someone who is the mother -- and you'll hear me speak later -- of a 20-year-old who was diagnosed with autism, ADHD, and intellectual disability, right? I don't have his experience, but I'm helping him to navigate. And it's challenging when people just don't understand.

Yes, we have come a long way. But there is so much more work to be done. And I've said that before, I'm going to continue to say that, right? But each of us, right, each individual, all of us, coming together and sharing our stories and doing this work is going to make a difference.

So, I just wanted to uplift and thank everyone for sharing their stories. Because it is making a difference. I know, when you're in your day to day, it maybe seems impossible, but I want to acknowledge you and thank you.

DR. DANIELS: Any other comments in the room? Doesn't seem like anything on Zoom. So, we'll do Tom and then Ivanova.

DR. FRAZIER: I can go very quick. To the support professional crisis issue, I think -- oh, sorry -- the support professional crisis issue, I think a role IACC can play is to guide us to -- I don't think we have sufficient research to understand what are the characteristics of individuals that do maintain employment in those settings?

What keeps them employed? How do we best orient them? How do we make sure that those individuals feel comfortable working with the family and the other caregivers in that role? Because that's a really collaborative process that I've experienced, obviously, personally, but also professionally.

And I think there's a lot for us to understand there from a research perspective, but then also, there's a ton of services, support stuff that needs to happen in order to improve that crisis. Because it is really a crisis.

DR. DANIELS: Thank you. Then Ivanova.

MS. SMITH: I want to give understanding and solidarity to people who are in crisis and families who are struggling. I think that we really need to advocate for better services in the community for people to get support outside of their family as well so that people start connecting with people in the community outside of family and gain those natural friendships and supports in the community.

It could be an employer. It could be a business owner. It could be a coach. It could be the teacher, the art class next door. But, you know, trying to support caregivers and helping young adults with disabilities gain those outside connections, I think that we need to advocate for more funding for that.

And we need better supports for that adult transition. Because a lot of families have been told that, "Oh, they'll never become adults." And that's not true. We become adults, and our caregivers and our families need to be supported in helping us with that transition.

I wouldn't have been able to transition without my parents' support and believing in me and allowing me to do adult things. And so, we really need to come around these caregivers and help them get support for that transition.

And so, they don't have to worry when they're older, that there is a place for their sons and daughters, that they are supported and loved and seen as a full human being and not just put it in an institution.

So, I really just want to stand by those caregivers and help them with that and get the funding and research they need to be able to get that support in the community so that we develop those friendships in the community. Thank you.

DR. DANIELS: Thank you. Jenny Mai Phan.

DR. PHAN: So, the additional point that I want to add is, I've heard someone here say siblings being trained in guardianship. There are parents who aren't even trained in that process. And I'm speaking specifically about families of color that I've spoken with, who knew nothing about guardianship as their children transition into adulthood.

So, I think that is a very critical, maybe underrepresented, or oversight in these conversations. And I think it's very important to also include parents of color who don't understand the guardianship process.

DR. DANIELS: Thank you. Sam.

MS. CRANE: I would also add that they need to be trained in alternatives to guardianship. And also, I think we need to be talking about the role of person-centered supports -- person-directed supports and services here, which are programs where people can choose their own caregivers, train their own caregivers.

It is an absolutely critical component -- one of many components in trying to address the caregiver shortage. Because it means that we can start paying, for example, family members to provide services, friends to provide services.

You can recruit people who aren't already direct support professionals, train them in the specific things that they need to do with -- through that person, and then get them in -- and helping provide care.

A lot of person-directed support and services programs aren't available to the people with the highest needs. So, in D.C., for example -- Yetta knows -- it's only in the waiver program that has a pretty limited cap on annual spending.

So, if you need 24/7 or even closer to

24/7 care, even full time, just 40 hours a week, you can't do participant-directed support and services. And we need to be advocating for expansion of those programs.

DR. DANIELS: Thank you. And Yetta.

MS. MYRICK: Just want to cosign what Sam said. Yeah, folks just do not have the education on how these systems work. And it's a challenge for a lot of people, right? I find this -- and I think I've said this before in other meetings -- I find this with the clinicians, right?

They don't -- like they are trained to -- and all due respect -- and I think I've said it this way before -- with all due respect to the clinicians, to the researchers. You guys know what you're doing when it comes to being a specialist in your area.

However, in the community, the families know. The autistic self-advocates, right, they know what's happening in the community on the ground. And that's why it's really critical for us to be partnering together to figure out, okay, what works, what doesn't work. And again, there's the added layer, when you know one autistic individual, you know one autistic individual.

So, then that's a whole other thing. Because how do you create programming for the individual, but it needs to be done if we really truly want the individual to be a part of society and to be included, right?

And that's going to look different. And that's going to look different for each person. Just like everyone in this room, regardless of whether we're autistic or not, is different and are moving in the world the way we choose to move in the world, right?

And so, I think when we look at it from that lens, that makes a huge difference. But I could talk all day, which we'll talk later about, caregiving and like this cliff that happens when folks are transitioning to adulthood. It is a mess. Even when you are linked in, you still don't know what's happening and what you're doing.

DR. DANIELS: And we'll give the last comment to Scott, so that we can close out this session. So --

DR. AVENEVOLI: There's one online too, Susan. Dena's online.

DR. DANIELS: Oh, there's one online.

DR. AVENEVOLI: Yeah.

DR. DANIELS: Okay. We'll have two then.

DR. AVENEVOLI: Thanks.

DR. DANIELS: Scott then Dena. Okay. Then we can move on to Dena, and then that'll be the last one.

MS. GASSNER: I just wanted to add a P.S. to that. I have a 35-year-old son. I'm an adult autistic. I've navigated every system from early intervention, all the way through to post-secondary instruction for him and I, Social Security, the food stamps office, housing.

And I'm here to say to you that the greatest cost to parents is the burden of having to figure out the hidden curriculum behind these agency protocols.

It is totally inhumane for parents and siblings to have to learn how to master these systems and parent a child who has needs after school. We absolutely have to create an entirely new workforce of systems navigators who are not aligned with the agencies directly.

When we approach agencies for support, they're looking for a way to deny us benefits. It's almost like a predatory relationship that these people experience. We need impartial, unbiased, direct support navigators who have mastery over these systems so that that burden is removed from the families.

That doesn't mean we don't want to voice. That doesn't mean we want to don't want to know all our options. But it's just inhumane to continue to demand that we have expert mastery of each developmental system that we have to go through.

We have got to create a workforce to

address this. Sorry, I just get really impassioned about this. Because I think it's just too much for families.

MS. CRANE: That does exist in some states, like Quality Trust in D.C. does provide that kind of service, and it should definitely be expanded.

MS. GASSNER: Absolutely. Thank you.

DR. DANIELS: Thank you so much. And Shelli, do you have any final comments?

DR. AVENEVOLI: I do not other than I think all of this conversation is a great segue into our final session for today. There's clearly a lot of interest in exploring the issues around family caregiving more broadly. And so, we're pleased to introduce this afternoon's session that's focused precisely on this.

We all know individuals on the autism spectrum need varying levels of support to ensure their needs are met. We've heard that from all of you today.

Caregivers are responsible for many

tasks, from coordinating with teachers, doctors, service providers, to ensuring smooth transitions through life stages, to providing 24/7 care in some cases, all of the things you all have been mentioning throughout the day and particularly with these last comments.

We recognize the family caregivers sacrifice their own wants and needs in order to ensure those of their loved ones -- the needs of their loved ones are met. And we also recognize that this often results in physical or mental health issues, employment, or financial challenges within these families as well.

So, we wanted to spend this afternoon acknowledging these challenges and the work that you do on behalf of your loved ones. And we plan this session specifically to highlight the resources available for family caregivers and to bring attention – to the additional needs that you've all been talking about in your communities.

So, I will turn it over to Susan now to introduce our first speakers.

DR. DANIELS: Thank you, Shelli. So, we put together this afternoon session to provide an opportunity to the IACC to hear about the work of our sister federal committees that are managed by the Administration for Community Living, that address issues related to family caregiving. And as we know, this is an important topic in autism. But we also want to coordinate and not duplicate efforts with other committees that are working in the space.

In the IACC, we touch on these issues with the specificity of autism. And there is also a committee, the RAISE Family Caregiving Advisory Council, that's assigned a broader mission related to family caregiving for individuals with disabilities and older adults. And we will hear about that today.

And we hope that the information shared will be conveyed to the RAISE Family Caregiving Advisory Council so that they can know more about some of the specific needs that the autism community is sharing.

And we'll make certain to share the public comments packet with ACL so that you can pass it along to your committee, and they can read through the comments from families of individuals on the autism spectrum and from autistic individuals. And that, in the future, we hope that our committees can further collaborate and coordinate on this really important issue and create synergy.

And with that, I'd like to introduce our first speakers for the session. So, we'll be starting with some presentations. And first, we'll be hearing from the Administration for Community Living, Dr. Jennifer Johnson, an IACC member who's the deputy commissioner of the Administration on Disabilities.

And Mr. Jonathan Westin is an Aging Services Program specialist in the Office of Supportive and Caregiver Services. And they're going to talk about ACL activities that support family caregivers.

So, I'll hand it over to you, Jennifer and Jonathan. Thank you for being here.

DR. JOHNSON: Well, thank you for having us and including us today. A very important topic, as was evidenced in this discussion that we just had about the importance of supporting family caregivers. I just wanted to start by providing a little bit of information about the Administration for Community Living, or ACL for short, in case some of you aren't familiar with us.

We are a part of the U.S. Department of Health and Human Services. And we were created about 12 years ago, with a mission to ensure that all people, regardless of age, disability, or level of support need can live and fully participate in their communities.

So, what we do is we really bridge the common interest of people with disabilities and older adults, to make sure that they have the supports they need to live in the community. And so, that's a very high level, you know, umbrella, where we have intersecting interests of both older adults and people with disabilities in terms of their interest to live in the community.

But from there, you know, obviously, some of the issues, while there are some commonalities, we do deal with issues specific to both the disability population and older adults.

But with that mission, we do fund a large number of community-based disability and aging organizations in local communities across all the U.S. states and our territories. We also invest in research and education and innovation that advances community living opportunities for older adults and people with disabilities.

So, now, in terms of the topic of caregiving, including family caregiving, it's long been a priority for ACL because so -- for so long, so many families have really filled in major gaps when it comes to providing support to older adults and people with disabilities for them to be -- to stay in the community, especially if they're at risk for institutionalization.

So, it's been not only an important priority for us for many, many, many years, it's also been an important priority for this administration, as Susan mentioned earlier, in the President's executive order that really recognizes the significant role families play in caring for their family members who need it.

And that's really because of family caregivers, as again was evidence of the discussion today, really provide an overwhelming majority of long-term care in the United States and are further supported by direct support professionals. But as mentioned, we certainly are facing an increasing crisis with the need for direct care professionals.

We estimate that there are 53 million or more family caregivers that are supporting their loved ones to stay in the community. And we know, again, that the shortage of direct care workers is really placing more responsibilities on families to do that caregiving.

Of this number, we estimate that 2.7 million grandparents are serving as caregivers to their grandchildren. And there is an unknown number of other relative caregivers that are supporting their family members.

When we look at people with intellectual and developmental disabilities, data shows that at least 60 percent of those that are receiving publicly funded services and supports, mainly Medicaid, are living with their families.

And we can only assume that number is the same or even more for families and individuals that are not receiving publicly funded services and supports.

And what this data reflects really is that family members oftentimes can't just be a parent, a sister, a brother, and uncle, grandparent, any, you know, family kind of --

family member. Because they have to also be the personal care attendant.

They have to be the driver. They have to be the social worker to navigate those systems and figure out those forms. They have to be the nurse practitioner. You can just name the list of things that family members take on as a responsibility.

When we look at the cost of it, just the financial cost of it, we estimate that caregivers are supplying over $600 billion dollars in unpaid care and experience almost $500 billion per year in lost income.

So, those are significant, staggering numbers in terms of the financial costs. And like I said, the situation is made that much more difficult by the shortage of direct care professionals.

And it's only going to get worse than it already is. Because the demographics suggest we will need over 1 million more direct support professionals by 2030. So, this problem isn't going away at all.

And because families were -- caregivers were really feeling unseen and unsupported, a group of family caregivers effectively advocated for legislation that led to Congress passing in 2018, legislation that directed HHS to develop a National Family Caregiver Strategy.

And you'll hear more about this from my colleague, Jonathan. But before I turn it over, I did want to highlight some of the other work we have in ACL that we have invested in to support families.

Within ACL, I'm with the Administration on Disabilities. And one of the programs that we administer is the Developmental Disabilities Assistance and Bill of Rights Act, which has long recognized the important role of families and families who have always been important in the DD Act.

And as a result, we have, over the years, many years, invested in family support projects. And that's been projects over decades of investment.

And also, our programs that are funded under the Act, the State Councils on Developmental Disabilities, our University Centers for Excellence in Developmental Disabilities, and the Protection and Advocacy systems, all are doing work in various ways to support families or to change policies in the state to better support families.

We've also funded national projects that have helped to build stronger and family support systems in a number of states, including those that are using the Charting the LifeCourse tools that were developed through a project that we funded that numerous states and local communities are now using to support families.

We're currently investing in a project called the Bridging the Aging and Disabilities Networks, which is addressing the needs of an estimated over 1 million families in the U.S. who both have adults with IDD but also are being cared for by aging caregivers.

And we estimate that two-thirds of these families don't have advanced care plans, making it, you know, a unique situation in need for aging families and a critical issue.

And that's because not only do families with a family member -- aging family member with IDD have to access multiple systems, but aging parents who are providing that support will require their own support as they age.

And so, it's very important that we start to think more about how we're creating more coordinated services for both older adults with and without -- well, older adults as they age into disability and then older adults with intellectual and developmental disabilities.

So, the center has a community of practice where they are supporting 17 states and really building the capacity both across and within the state's aging and disability networks to better support individuals with IDD as they age and their family caregivers as they age, to improve the planning to address their individual needs, goals, and preferences across the lifespan.

I also wanted to briefly mention a few other activities within ACL. We support the President's Committee for People with Intellectual Disabilities -- which is also a federal advisory committee. And they're currently working on their report to the President.

And the report that they're working on is focused broadly on how high-quality home and community-based services can best support individuals with intellectual disabilities to live well in the community.

And while the report doesn't have a specific focus on family caregiving, many of the topics and the recommendations, if implemented, would have a positive impact on families, as was discussed in the previous discussion.

Susan also mentioned the 20 states that are receiving support to address the direct care worker recruitment and retention issues that we've talked about. And that work is actually being done through our Direct Care Workforce Center that we are funding.

And they are the ones that are working with the 20 states that are working to address that growing crisis in the lack of direct care workers, in addition to other activities that they're doing, including a website that has resources on the direct care workforce.

I also wanted to briefly mention the -- a project that we are funding, called the Center for Youth Voice, Youth Choice. And this is addressing some of the comments that were made about alternatives to guardianship and the importance of having resources around alternatives to guardianship.

And so, this center is aimed at youth to address the school-to-guardianship -- I'm sorry, yeah, the school-to-guardianship pipeline for many youths, so that they can be more informed about alternatives to guardianship as they become a legal adult.

And while the focus of the center is on youth and one of the great highlights of this project is the development of youth ambassadors, we currently have 41 ambassadors that are being developed as peer leaders on alternatives to guardianship.

And I'm pleased to say that the group is very, very diverse. If I showed a picture right now, you would see the diversity of that -- of those youth ambassadors.

But the resource center also has resources for families, so they can support their youth and understand alternatives to guardianship as well, as they transition into adulthood.

The last program I wanted to highlight as a resource is the Lifespan Respite Care program that we have administered since 2009. I think, again, all the comments kind of alluded to the importance of respite care for family caregivers.

Because it's an essential component of home and community-based services as it -- as a contributor to healthier families and the health and wellbeing of caregivers and also the care recipients.

So, under this program, ACL has awarded competitive grants to eligible agencies in 38 states and the District of Columbia. And the grants are designed to create coordinated state systems of accessible community-based respite care services.

So, not only are they providing that as a resource, they're also focused on elevating the caliber and the availability of respite services through the expansion and enrichment of respite services within states and also enhance the dissemination and coordination of those services.

We're also working to facilitate ease of access to the respite care programs and identifying and addressing any existing service gaps in the states and the District of Columbia and then enhancing the overall quality of present respite services that are being provided.

So, these respite programs support family caregivers of children and adults across all age groups, disabilities, and also chronic conditions. And the respite care can be both planned and emergency based and extended to individuals needing assistance to temporarily relieve family caregivers.

As part of this work, ACL has funded the ARCH National Respite Network and Resource Center to provide TA to the LifeSpan Respite Program grantees in the field since 2009.

So, as I close up my part, I just wanted to quickly touch upon the topic of data, which was mentioned by one of our public commenters on the importance of having data on support for families and family caregivers.

And while we've made progress on having some of that data, we really do need to have more data and data on a regular basis on the family experience. And we need this on all families, regardless of whether they are supported by the state or not, if they're receiving publicly funded support or not. We need it on all individuals who are providing support for their loved ones.

So, now I would like to turn it over to my colleague, Jonathan Westin, who is relatively new to our agency, but already making a great impact in terms of the work that we are doing.

As was mentioned, he's an Aging Services Program specialist in our Office of Supportive and Caregiver Services in the Administration on Aging. And so, I'll turn it over to you then, Jonathan. I'll give you the mic.

MR. JONATHAN WESTIN: Jennifer, thank you very much. I also just wanted to take a note and thank you for your incredible leadership regarding our agency on disability and the work that they have done through the years. You could not ask for a more committed staffer on disability than Jennifer. So, thank you.

DR. DANIELS: Can you bring the mic

closer, please?

MR. WESTIN: I certainly can. That might be the first time anyone ever accused me of not being able to hear me, given this voice. But can everyone hear me now? Are we good? Excellent. Thank you very much. Really appreciate this opportunity to present to you all. If we can advance the slide, that would be great. Thank you.

So, "how do we create a world where caregiving is central to who we are as opposed to something that diverts us or is a sideline of our real lives?" This was a question posed by Carol Zernial, who is the RAISE Council co-chair. We're going to get into the RAISE Council in a moment. Next slide, please.

So, the RAISE, which as Jennifer mentioned was an act that was passed in 2018, stands for Recognize, Assist, Include, Support, and Engage Family Caregivers. This was passed, again, in 2018. And it also includes a national strategy to support family caregivers, which I'm going to be delving into in a moment.

So, there are three key components -- next slide, please -- to the RAISE Act. There's the Family Caregiving Advisory Council. That's the RAISE Council. There is the Initial Report to Congress. And there is the National Family Caregiving Strategy.

The Initial Report is currently in what they call HHS clearance right now. And that will be, we hope -- as long as it does go through clearance smoothly -- transacted to Congress sometime this fall. Next slide, please.

We pride ourselves at ACL, Administration on Aging -- which is part of ACL since the merger -- on maximizing public engagement at every step along the way. So, for starters, ACL, back in 2019, had a request for information or an RFI.

We got 1,613 responses. 75 percent of these responses were from family caregivers. There was a whole trove of caregiving focus groups that occurred.

They engaged about 80 individuals. We prided ourselves -- to ensure that all populations were represented including teens. Because teens are -- may comprise the majority of what we call our caregiving youth. And they are a population that we not only care about but are watching every step of the way.

We also engaged and created a bunch of Stakeholder Listening Sessions. And we had six sessions that focused on the operationalize -- putting into operation -- there's a tongue twister for me -- focusing on the recommendations.

So, it was how we operationalize these and how we make them, I would say, the most pragmatic that they can be for the family caregiving population.

Over the past -- well, over a period of a year, between December 2020 and December 2021, we had several interviews and listening sessions, 17 key informant interviews, 22 listening sessions, and we also solicited the advice and guidance of 145 stakeholder organizations vested in family caregiving approaches.

And these included state entities, counties, employers, both large employers and small ones, the healthcare and the long-term services and supports providers, as well as faith-based organizations. Next slide, please.

We ensure that there would be one strategy and four components of that one strategy. These were -- these components were comprised of the 2022 National Strategy to Support Family Caregivers, which is an overview and description of the strategy goals and the intended outcomes.

Secondly, we issued a document called First Principles, which was entailed to be cross-cutting considerations for family caregivers, to ensure that they had the support that was needed. These were four key principles that had to be reflected in all efforts to improve support for the family caregiver.

Federal actions -- I'm actually, frankly -- not to insert my opinion here, but I guess will do so -- most proud of this program, nearly 350 actions that 15 federal agencies took into account in the near term to begin implementation of that strategy.

I am in the process of speaking to virtually all of these, we call them federal agency members, to see what they've accomplished, what they're having challenges accomplishing, what's on tap for future accomplishments, and most, I think, fascinating, what they have learned from what they've accomplished, like peeling back an onion, and how that perhaps alters their view of future actions moving forward.

So, this is always meant to be, for the agencies, a work in progress. And it is, as I mentioned, like peeling back an onion. We don't know enough about family caregivers. We don't know enough about their struggles.

And this is having some very targeted consequences for what we are doing moving forward because this is a growth area.

Actions for states, communities, and others, there are about 150 actions that we are also monitoring, by states, by counties, even by large metropolitan areas, on what family caregiving entails for their residents and how we could make a meaningful impact moving forward. Next slide, please. Thank you.

So, let me -- let's picture two buckets here about what the strategy is and what it's not. So, the strategy represents a vision and a roadmap for change, a baseline for action and progress, a framework for all caregiving situations and experiences, as well as the fact that it must be intended for use by many stakeholder groups.

We did not want to make this some esoteric document that would be very difficult to implement. We wanted to make it crisp, clear, and above all else, actionable for the family caregivers and for the populations that feed into the family caregiver themselves.

The strategy is not a timeline or a how-to document. We didn't feel that this was our role, given the charge that we had due to the passage of the RAISE Act back in 2018. It is not a list of requirements or musts.

We felt that, again, there needs to be some flexibility at the state and locality level. And we also wanted to, if you will, not lean in but lean back just a bit to gather the feedback that we felt was necessary from four constituencies, those constituencies that I mentioned earlier in my remarks.

It is also not supposed to be -- not intended, as you can imagine, exhaustive of all possibilities. This had to be something that, yes, we would provide direction and instruction to. That had to be something that came from the ground up, from the trenches up. That, to us, was very important. It's really something, as I mentioned, that is an evolutionary work in progress. Next slide, please.

This slide really encompasses, I feel, the philosophy of how we interpreted the RAISE Act. It's a whole of society approach. So, here are some of the different groups that we see up here that represent some of the cross-cutting sections that are engaged and involved on a daily, sometimes hourly basis, with a family caregiver and their families, these consistent of states, tribes, county governments, and the community.

This would really -- this is first for a reason. And this really encompasses the majority of folks here that are engaged and have family caregiving.

Community-based providers of long-term services and supports, many of whom have seen unprecedented closures of institutional providers, which has had a chilling effect on demand and increased strain on the home and community-based provider and has called into question some of the scant resources that were available already, and how they have become more rare that we must -- we're forced to look at, given these changes and trends, post-COVID.

Child welfare agencies, kinship support systems, we actually delved into on a related committee called Supporting Grandparents Raising Grandchildren, a lot of slang terms, kin care, but that kinship and what that means and how we can also support those grandparents raising grandchildren through that. My colleague, Lori Stalbaum, heads that committee.

Healthcare systems of course, I would say that the healthcare system, as you all know in this room, has taken on increasing importance right now, given the advent of accountable care organizations, given mergers and acquisitions, and what they mean to care, particularly in this health information technology environment that we live in.

I mentioned the communities of faith-based organizations are vital in this arena. Philanthropy, another component of -- foundational component, and research, academic institutions and research, for us, hold a major place.

And we're going to go over just in a moment, the National Caregiving Support collaborative, which I'm pleased to staff as well, and discuss the importance of research. Because we need to build that bench out.

Advocates, family caregivers, care recipients, virtually anyone who has been touched by the process of family caregiving, which we all know is virtually anyone, people in your family, yourself, people in your community that you might be close to. Next slide, please.

So, let's talk about that national strategy as a driver for change. Next slide, please. Running through these slides, but I've got a lot of content here I've got to race through before somebody --

DR. DANIELS: Yes. And Jonathan, if you

can sort of give us the high-level messages for each of these, that would be really great. So, we can try to --

MR. WESTIN: I certainly will, yeah.

DR. DANIELS: -- keep on time here.

MR. WESTIN: You got it. My apologies for that.

DR. DANIELS: No problem at all.

MR. WESTIN: So, the National Caregiver Support Collaborative, let me focus on that as the MO of this slide here. We have five grantees, one goal apiece, as well as technical assistance coordination that we do and pride ourselves on.

These grantee goals include research. They also include family caregiver adult -- well, family caregiver coordination and support for adult caregivers, as well as education and outreach, as well as coordination of care. And lastly, financial security, that's a big one. Next slide, please.

So, we hope that the strategy will be a

unifying structure for working together. That is, for us, a major impetus. We know that it has already served as a framework for community planning. It has also spearheaded some employer engagement as we get underway. Next slide, please.

We are very pleased to have as a partner in this, the John A. Hartford Foundation, which has in turn, funded the National Academy for State and Health Policy or NASHP. And this encompasses a lot of the work that we do to have these extra resources and to really further understand state family caregiving policy. Next slide, please.

So, as we look ahead -- and almost done here, Susan -- as we look ahead, we look at the Joint RAISE/SGRG Council Report, which is again in motion. We hope to have it to Congress in the fall, after clearances.

Federal agencies that we will begin meeting with on a far more regular basis, these federal agency members of the RAISE and SGRG, to better coordinate with them and to make sure that not only are they meeting the goals that have been assigned to them, that they've identified, but also moving forward, how those goals have evolved into new goals moving forward.

So, this will be the subcommittees that we have, will be not only gathering information ideas that will update the national strategy, but they'll review research and data and begin crafting ideas for non-federal sector updates to the Strategy in 2025.

And I'll end with a quote from our administrator -- acting administrator. "We now have an unprecedented opportunity to achieve and go far beyond the goals Congress established in the RAISE Family Caregivers Act."

We do hope that you all are a part of this. And we're very grateful for the opportunity at AOA, within ACL, to be presenting before you all today. Thank you very much. Susan, thank you for your time.

DR. DANIELS: Thank you. And we're so happy to hear about the important work that this sister committee is doing and hope that members of our audience and committee members will feel free to tune in for their meetings, especially during the interim between IACCs. So, now you know who to talk to if you have questions about that. Thank you. And I'll turn it over to Shelli.

DR. AVENEVOLI: Thanks, Susan. So, I'm happy to introduce our next speaker. Our next speaker is Dr. Christina Marsack-Topolewski. And she is an associate professor in the School of Social Work at Eastern Michigan University.

And she will be speaking about her research studying caregiver burden among family members of autistic individuals. Thanks for joining us.

DR. CHRISTINA MARSACK-TOPOLEWSKI: Thank you so much. If it's possible, if I can unmute or show my screen, I am here. But it looks like I just -- there's a tech -- oh, there we go. Thanks so much.

Well, thanks for the opportunity to be here. I'm Christine Marsack-Topolewski. I work for Eastern Michigan University. And my background is in special education. And then my master's and PhD are both in social work, where I also -- I studied disability, but I also did -- focused on aging.

And so, I've worked in the public schools for about 20 years now, now in a part time capacity. And I say that just to give some context to my background and why I do this work.

And as I was working in the public schools, mainly working with adolescents transitioning to adulthood, working with a lot of individuals with various abilities, including autistic adolescents, really seeing kind of the different scenarios they were grappling with.

And so, at that time, I've really kind of focused and have since then focused on really kind of understanding the experiences of parental caregivers of autistic individuals as well as populations with other neurodevelopmental disabilities. So, I say that just to give some context.

I still do work in the public schools, although I am full-time at the University in the School of Social Work. But I -- it's allowed me to really stay really grounded into some of the different things going on.

I'll just start with kind of a caveat. We know -- and I know this has been alluded to throughout kind of today's meeting. When we know one person with autism, we know one person with autism. And so, autism spectrum disorder really is a spectrum or a continuum.

And so, I say that just to give respect certainly to the various situations and the various perspectives and the various people who are impacted, both as family caregivers and both as autistic adults with autism.

And then secondly, I'll be using the term adult with autism and autistic adults interchangeably. In my work over the last 20 years, I found that people have different preferences with this language. So, I just want to kind of share that and give voice to that and be certainly respectful to the different variations in terms of the language that's used.

I shared a little bit about myself. My bio is there as well. But in terms of just kind of the overview, today, I'm going to be talking about three main themes. These are grounded in the research that I've done individually, as well as collectively with some other research teams across the country. But certainly, national outcomes, really the work I've done really focused on the experiences of family caregivers of autistic adults.

I'm going to be talking first and foremost about the need for tailored accessible services; second, about support with service navigation -- and I wrote down -- I think it's Mrs. Dena Gessner really said this so well, when she articulated just some of the challenges with really, families navigating services and the time and the hidden curriculum, I think is the terminology she used.

And then third, I'll talk about the final theme, just the need to plan for the future. I kind of smiled when I saw that Dr. Jennifer Johnson brought up advanced care planning. My colleague, Dr. Jackie McGinley, out of New York and I have some work published on advanced care planning and looking at some different ways to even nestle this within person-centered planning.

We know that professionals, providers, family caregivers, adults with disabilities are taxed. They're doing a lot to even navigate the existing service, you know, continuum of what's available.

And so, putting anything more on anybody, I think, is just too much. And so, really, how do we start to think innovatively of how do we deliver services more efficaciously, but in a way that can really be done from a pragmatic standpoint, given the bandwidth and the capacity and certainly the shortages we're seeing across the country as it pertains to both paid and unpaid caregiving.

I just want to also mention, I'll be talking a lot about formal social support networks. A lot of my research does also look at informal social support networks. And when I say formal, I'm referring to paid networks, so things that might have either K12 funding or government funding or funding from healthcare providers or private pay.

Informal social support networks, if I do use that term, it will simply refer to our unpaid networks, so any support that one might receive from a family member, a friend, you know, those kinds of -- neighbors throughout, you know, one's community, those pieces.

And so, I just want to give voice -- there is a lot of support grounded in many researchers' work as well as my own -- the value of informal social support networks. While these are families, friends, communities, I do think our paid networks can have a really powerful opportunity to help families leverage informal social support networks.

And there is a lot of support to really look at the efficacy behind that as well as benefits for both autistic adults as well as family caregivers, in terms of augmenting quality of life, family quality of life, and those aspects.

So, the first thing that I mentioned is just this need for tailored accessible services. What we're seeing and what I've seen for the last 20 years, working in the public schools, as well now in a part-time capacity, through a special education system, is that there's a services cliff.

And we know this. It's been long documented. We know that when we start to look at disability services, we really start to look at services tailored for individuals with autism.

And also, when we start to think about services that might be really kind of the go-to areas for individuals as they age across the lifespan with a disability, so some of these perhaps aging services, there is a service cliff, and services really are not tailored for autistic adults.

You know, this one-size-fits-all approach, I think a lot of times we're seeing this, unfortunately. And we know that the services that are hence being delivered are often not relevant, are the services families are calling about, are the services families and autistic adults are oftentimes very frustrated about as well.

Families are often talking about inappropriate groupings. So, perhaps their adult child with autism might be accessing services that another population that's really not totally relevant, is also accessing those same services.

And hence, oftentimes, our providers,

you know, are really taxed with trying to understand a whole series of different backgrounds and experiences and disabilities and strengths and needs. And that's sometimes not realistic.

And then often, this mismatch occurs between the current needs and what services and supports do exist. And so, that, we're kind of continuing to see.

There's some great researchers out in Europe -- and I've included their names down there and some work that was published in 2023 -- that they really talk about this mismatch in current needs and services.

We know that juvenile services are not a solution for adulthood. Oftentimes, we see this a lot with healthcare is -- where somebody might even try to remain within a pediatric healthcare kind of setting, if you will, seeing a pediatrician for longer because a pediatrician is well-versed and understands, oftentimes.

And I've worked even clinically with

clients who have said, "You know, I am a disabled adult. And people forget that even though my condition is a juvenile onset condition, that condition can pervade into adulthood."

And so, as basic as it might see seem, those are oftentimes things that people are grappling with, that makes their everyday life really challenging and certainly ties back to some of the challenges with not only accessing equitable, relevant, and coordinated services, but also with just people even understanding them and that whole service navigation piece.

And so, I want to just underscore just for a brief minute -- because this is something that continues to come up in both the work that I do firsthand with disabled populations and their family caregivers, but also in the work that I've done in talking to families across the country who have loved ones with, you know, different disabilities including adults -- adult children with autism, is just this need for health, you know, services as well as mental health services to really be tailored.

And sometimes, at those more critical times, we're seeing different times, kind of across the life trajectory where certain health services or mental health services -- and/or I should say -- really become really critical and really needed and very timely.

And so, I just want to kind of -- wanted to make a nod to that because probably no different from some of the things that you're seeing or some of the things that families are sharing that those services are really cumbersome and really laborious.

One of the things that stuck out with me, a few years back, I spoke with a woman who happened to be a physician, very, very well versed with medical systems. And she said, as she was advocating for her son to receive mental health services, her son, an adult with autism -- young adult with autism, said, "It took me being an adult woman with lipstick to advocate for the services that my son needed."

And those words still stick with me of just how laborious, how cumbersome, how challenging, even for people that would be very well versed with certain systems.

Too, again, going back to Mrs. Dena Gassner's words, you know, look at that hidden curriculum. How do we start to navigate this hidden curriculum of these systems that really are uncoordinated? And I don't think I need to go on about the waitlist. I think we're all familiar.

So, in some of the work I did, I took some different medical frameworks, and I collapsed them and created broad themes of my own as we start to think about what it looks to navigate services, not only health and medical -- health medical/mental health services, but as well as any services for autistic adults and their family caregivers.

And so, I talked about things like accommodation, acceptability, availability, and affordability. I do have a table that's referenced in one of the links below that I published with one of my colleagues, Dr. Arlene Weisz.

But in essence, how are the available options organized? This continues to be problematic. This continues to be uncoordinated. How acceptable do people feel that these are -- I continue to have conversations with young adults with autism who often say, "Hey, Dr. T, I'm never going to access these services. These are not relevant to me." And I appreciate that.

And so, how do we start to think about having services that both family caregivers and autistic adults do find acceptable and do find something worthy of their time to even invest in terms of a phone call to look into?

In terms of availability, there's all sorts of availability issues that, you know, we've published in some of the articles that myself and my colleagues have written. But waitlists, geographic reach, even accessible in terms of -- as we start to think about --

Our fourth theme here is affordability. Oftentimes some of the services really are not affordable. And a lot of the families who are supporting in any way -- pragmatically, tangentially, financially -- in any way as loved ones and autistic adults, have really invested a lot of time and money and energy. And so, there's only so much, right, in terms of finances that we can be offered.

All right. So, there we go. So, I just also want to mention this bidirectional relationship. Anything we can do to support a family caregiver, I hope and believe that in many ways, we're going to see the fruits, you know, and the benefits for other family members, including autistic adults. And anything we can do to support adults with autism, right? Family caregivers are oftentimes much more supported, and there's a better balancing of needs.

The second theme, just as we start to

think about support with navigation, I'm going to talk briefly. I am -- I’m a big fan of family support navigator programs when they're done right, when people have the right training, when they're accessible, and when they're really tailored to the needs of that individual.

My colleagues and I received a grant, and we had a two-year program. And we created a family support navigator model here in the state of Michigan, which is the state I reside in. And this was done during COVID. So, there's that, we can say, in terms of just some new things that might have popped up and some new services and supports and kind of inner workings that might need to be worked through, you know, due to kind of the time, if you will.

But we know that navigating services is problematic. It's very time consuming. There's a lot of different service areas. In a lot of the work I do, I refer to it as boutique shopping. And so, when I am, you know, lecturing overseas and things like this, all the Europeans often know what a boutique is. They love boutiques. They have the best boutique there.

And so, I have started using this term as that. We are unfortunately in this country really forcing our family caregivers and our disabled populations to boutique shop, right? We have to go here for health. We have to go here for mental health. We have to go to another place for any form of employment supports then the housing supports. I mean, by the time you get there, you're just so tired.

And so, this concept of boutique shopping, anything we can do to mitigate the opportunity that this would be a reality for family caregivers and autistic adults would be really, really, really helpful.

And then finally, just this thought of, you know, whenever possible and to whatever extent it actually makes sense and can be effective, is just looking how do we offer coordinated systems and coordinated services so that somebody does not have to go to all of these other places.

So, I have just a little bit of information here about the family support navigation program where we had peers, so family caregivers, who had disabled adult children who were familiar geographically. And I think that was a big key.

And those caregivers were trained not only on services for disabled populations, but also in the aging services. Because oftentimes, as we move kind of across the lifespan, some of these other services will become very relevant.

And so, as we start to think about, you know, our eye on the future, really kind of thinking about, how do we start to advance both our services for populations with IDDs, our intellectual developmental disabilities, but also, for those of -- who are aging. And how do we start to almost cross train those professionals and providers, so they're really aware, when necessary, of the two areas.

One of my favorite researchers is Dr. Tamar Heller. And one of the things she'll talk about is how -- if you've ever heard her speak, she's out of Chicago -- but how we often see aging as not relevant to people with lifelong disabilities.

And I think that's a real issue as we start to think about our services, and we start to even think about what's even offered within, you know, the area agencies on aging and things like this. So, I just kind of want to make a nod to that as well, that that can be really important and really effective.

The other thing, just as we start to think about peer navigation supports, many of our family caregivers are not solely caring for one loved one. So, as their children age into adulthood, emerging adulthood, whatever we want to call it, those individuals, those family caregivers may assume other caregiving roles. And so, I have a trajectory of research published on compound caregiving.

And I want to mention because many of our caregivers are juggling the provision of care for multiple loved ones. And those multiple loved ones will oftentimes have very different needs. And so, I think that really should often be given voice as we start to think about and contextualize the experiences of family caregivers of autistic adults.

And finally, our third theme, just this need to look to the future. And so, as we start to look even at where the funding is allocated, as we start to think about across the lifespan for individuals, you know, family caregivers as well as autistic adults, you know, I think we need to kind of push the needle a little bit. We need to continue to do this and look to the future.

And I love when Dr. Jennifer Johnson mentioned advanced care planning. Because I think that there's a lot of opportunity within advanced care planning. As I mentioned, my colleague, Dr. Jackie McGinley, and I did a national overview, kind of looking at what's going on across the country by state, looking at policy analysis of person-centered plans, and looking to see if those plans are embodying the elements and the dimensions of advanced care planning.

And we're seeing it kind of sparsely done in different ways kind of across the country. And one of the recommendations from some of those published pieces is simply many autistic adults will have person-centered plans, not all.

But for those who are, you know, receiving Medicaid, this is a requirement. And there's a requirement that those person-centered plans be revisited in, you know, a specific designated time period. And hence, we could be looking at advanced care planning in very respectful ways. And it can be embodied within the person-centered planning.

And so, as we start to think back to this theme 3, this need to plan for the future, this is for both family caregivers and autistic adults. And I think sometimes when families feel that they have a better plan -- I know for myself and probably for all the people that I know, when we have better plans, things just go smoothly even if things go a little bit off the plan.

And so, our families will and do have changing and evolving needs. And those needs will change for both the family caregiver as well as adults with autism. And so, I think we really need to have our pulse -- a pulse on that to not only be thinking about the here and now, but also proactively looking towards -- toward the future with what can we do in terms of our planning for those that will require some form -- and I say some form because that can look very, very different -- but some form of caregiving support, being able to offer that as well.

So, I'm going to wrap up here. I do have some themes here from an article that we -- that my colleague, Dr. Jillian Graves, and I published just on the need for support and some of the barriers that families are experiencing that would really make it difficult to move forward in future planning.

All right. And so, in terms of just professional implications -- then I'll talk very briefly about policy implications -- but, you know, caregiving certainly can vary in length, duration, intensity.

But there's certainly a need to continue to think about, how do we support the practical needs of life? And certainly, the service navigation piece is part of that when we start to think about the pragmatics.

And then just, you know, continuing to recognize the needs and the ability for caregivers to be able to balance their own needs as well as the needs of their loved ones in their own family context.

So, our programs, services, supports, and policies really should aim to develop system structures pathways that make more accessible, inclusive, and equitable opportunities for both autistic adults and their family caregivers.

And so, just as a recap, I've included those three themes that I talked about. But first, you know, that need for tailored accessible services.

So, if we go back to that coordination of services, we don't want people to be boutique shopping, if you will, and having to do that. And that gets hard and that gets laborious. And it's -- we can go into kind of the nightmare of that.

But two, support individuals with formalized service navigation. And then three, this need to kind of look toward the future and plan for the future as our family caregivers -- their needs will change, and their loved ones' needs will change as well.

So, certainly, funding needs programmatic structure and service needs. And really this pipeline of providers and training needs also comes into play.

So, I just want to thank you for the opportunity to be here. I have some information about myself, if that's ever of help. And my references at the back. But thank you for that opportunity to be here.

DR. DANIELS: Thank you so much, Dr. Marsack-Topolewski. And we do have materials for each of the speakers online on our website in case anyone wants to check those out.

And next, I'll introduce our next speaker, Dr. Elizabeth Morgan, who's going to be talking about her work with African American family caregivers. And she's currently in the College of Education at California State University in Sacramento. And she will be soon transitioning to a new position as associate professor at Morgan State University. So, welcome, Dr. Morgan.

DR. ELIZABETH MORGAN: Thank you very much. I'm going to try to put my timer on and as well as read some of my notes because I am an educator. So, my profession tends to be quite loquacious. So, I'm going to try to make sure that we stay in our timeline.

First of all, thank you so much. I am extremely honored for being invited to be able to speak to you today to talk about something that I'm very passionate about and something that -- the shared passion that we have on the topic of advocacy and research in autism.

And I'm going to speak specifically on the topics of the intersection of race and disability in the context of supporting Black families who have Black children on the autism spectrum.

So, you gave -- you got a little bit of background about me. I also should add that I have been a program coordinator and also a family LEND director for our UC Davis LEND and at the UC Davis MIND Institute and our Center for Excellence and Developmental Disability since 2014 and also been a part of the AUCD Network very -- around that same time.

But out of all of those positions, I would say the most important one has to do with my position as mother. And I am a proud mother of a child on the autism spectrum. Next slide, please.

I really think that my positionality in particular, is very important when we're talking about this topic. My background as a teacher and also a K-8 administrator really sets the tone for the way that I present and the work that I do.

And it was -- as a teacher and an administrator, is when I first really experienced the challenges that parents and school administrators had when it came to navigating school systems for their children who had learning differences and social difficulties.

And then in 2010, when my own son was diagnosed to be on the autism spectrum at two and a half years old, I would say this flame became a wildfire. And I really became -- it brought me to where I am today. Okay.

So, now let's really talk about the stark realities that Black families have in advocating for their children on the autism spectrum. So, there are cultural and social stigmas that are cast on this journey adding layers of complexity to an already challenging path.

Access to resources and supports becomes a battleground where systemic inequalities often leave families without the tools they need to thrive. And navigating systems, be it education, healthcare, or community services, can feel like an uphill battle against entrenched bias and barriers.

So, we have lots of research on the disparities for Black families and specifically Black families of children who have developmental differences. But I was far more interested in the assets. And so, I'm going to talk to you a little bit more about that today.

So, the work that I will focus on today really focuses -- really centers the research that I've done, three projects in particular that I'll highlight.

The first paper which was published in the Journal of Pediatrics, which was a community collaborative work that I did with two advocates within the field, really focuses on how the intersectionality of race and disability play in our service delivery systems and goes deeper into the historical imprint that Black activists and civil rights leaders have played in the disability rights movement.

This next paper, which actually was published in the British Journal of Sociology of Education, focuses on and highlights the families, the actual mothers. I interviewed Black mothers to understand more about their experience of navigating service systems, specifically school systems, to be able to think about their assets and learn more about the assets that they have in their advocacy journey.

So, the bottom line to this particular study is that these Black mothers were able to navigate for their children. And it really -- that context was key. And so, that when schools and -- were family centered and they engaged in family-centered practices, they were able to use their strategies -- their advocacy strategies and their assets to be able to support their children. And so, that's a key part of this.

And I think in particular, it was mentioned, this hidden curriculum. Absolutely, there is a hidden curriculum. But I would say that the -- for some it's opaque. It's a little cloudy to see. It's really hard to navigate.

You have to be able to know some people, pull upon resources. And for some, it's invisible, and it almost is erased where you have to do superhuman feats in order to be able to understand these really complex systems.

So, just to give you a little bit more grounding and to give you some context to the type of assets that I was looking for in this particular project, I pulled upon some theoretical frameworks to help give me some -- to really situate it. And the -- these include cultural capital and community capital.

So, because I'm a teacher at heart, I'm going to give you a few visual illustrations just to make it plain. So, when we're thinking about cultural capital, we think about cultural capital as societal assets that groups of people hold, such as their education and their pedigree. This is the classic definition of cultural capital that sociologists have used for years.

And so, cultural capital will look something like this, right? You are born with a group of assets. Maybe you're the piggy on top, for instance. You have resources. You have things that you were born in. The transmission of status and power has been passed down. And of course, the piggy banks can vary.

Or you are someone that is born with none, right? And so, you're like this broke piggy bank. It's really simple. You either have it, or you're not -- or you don't when it comes to that basic definition.

Well, like I said, I was far more interested in assets-based work. So, I also pulled upon this community cultural wealth framework that really looks at the assets that communities of color in particular have that are transmitted and translatable into resources and supports for communities of color. These are capital that are often unacknowledged and are unrecognized in communities of color and are active in internal resources for vehicles for mobility.

So, an example for this would be this piggy. Sorry, I'm trying to go back. Oh, it won't. Oh, there you go. This piggy who's fortified, right, is enabled to navigate hostile environments entrenched with systemic, institutional, and societal oppressions.

All right. Now, here we go. So, I won't go too far into the details but just to give you some understanding. The specific capitals that we're -- I was looking for in the interviews with the mothers included some of these theorists.

And so, this particular theory is the Community Cultural Wealth Model. And there are six capitals. I'm going to highlight two of them because these were the most salient in the research.

So, resistance capital refers to the skills and that -- and acknowledges fostered through oppositional behavior and challenges and inequity. And navigational capital refers to the skills of maneuvering through systems that are built -- in institutions that are built with you not in mind.

So, we know for schools, in particular for Black families or Black people, that schools were not built for us in mind. Brown v. Board is a reason why we are included in these institutions. So, this is an example of those things.

So, I also pulled upon some other

theorists to be able to give us some context. So, just to highlight Ming-Cheng Lo's work from UC Davis, she's done some work specifically looking at motherhood capital. Because like I said, I looked at Black mothers -- single Black mothers.

And Ming-Cheng's Lo's work specifically looked at 25 low-income, monolingual, Mexican immigrant mothers and how they were able to use their advocacy to be able to navigate medical systems to be able to support their children.

And then Dr. Prudence Carter's work that looked at Black cultural capital. And this is the knowledge and possession of cultural capital or non-dominant cultural capital that exists in various spheres and the ability to fluidly go in between these things.

So, for instance, if you've ever heard of the term code switching. So, it's the idea of being able to understand values, norms, and practices that are -- belong to different groups and be able to fluidly go in between those things. So, I was looking at those things in the context of the interviews for the mothers and their experiences.

And this is just a few -- a little bit of demographics from my collaborators. So, for the five that I was able to interview, by the time I got saturation, I was able to see that there were some patterns that were coming about. And I'll talk to you a little bit about those.

So, just for -- most of the mothers were on average about 47 years old, and most children were about 10 years old by the time that I interviewed them. All of them, when it came to their child's placement in schooling, all of their children were in one of the most restrictive environments, right?

So, these children were all in disability-specific classrooms. Only one of the mothers was able to advocate for their child for a non-disability classroom, not until his junior high -- until he was in junior high.

And I should give you context. These parents were never offered least restrictive environment. They were never offered an opportunity for inclusion. And so, it wasn't until they had knowledge that this was something that was in their rights -- within their child's rights, they were able to try to advocate for this. And some were successful.

So, I'm -- like I said, I'll highlight just two particular capitals that I think are really important and just pulled out. And I want you to hear the voices of the parents. So, this came from Evelyn, and this was a resistance capital, an example.

"And I tell you this. This is what came through the years standing up to people in a room that don't look like you. It requires you to use the knowledge you have. It requires you to use the understanding you have. It requires you to realize that you got this, and you know what's best for your child."

So, these are, you know, specifically the two pieces that we're going to highlight. And then I'm going to tell you how they manifest themselves.

So, navigational capital is the next one. Josephine says, "And I think it was harder because I've seen -- I haven't seen a lot of single Black women out there. It required me to remove myself out of the grief state and realize that I have to find out, I have to figure out what's going to benefit my child."

So, now let me just quickly segue into research into practice, so translating this to specifically focus on a research-based model that has been developed in California, but also has been replicated in Wisconsin. And this is the Sankofa Family Resource model.

This is a framework that we actually have developed since 2015 and has been implemented at the UC Davis MIND Institute since 2015. And now, we have a framework that we are able to -- we're in the process of being able to distribute and make available to families and institutions and organizations in early fall.

So, it's specifically designed for and by Black families and providers and also, Black families and providers -- autistic Black families and providers that are -- to be able to give us insight to how to be able to support Black families who are navigating these systems.

So, this is a paper that you can read to understand a little bit more of the background to this particular support group and framework and model. And this was a paper that was written by all -- by Black mothers and providers and as well as UCEDD directors that are involved in Sankofa, so both in California and Wisconsin. And they're all directly connected to our group.

So, this is a -- these are a few excerpts from the paper. And this actually gives you -- these are two of the mothers who are leaders in Sankofa and one from Benita Shaw. She states, "Sankofa is a space for Black families of children with various disabilities to come and meet with other families, get mentored, learn skills, and be vulnerable with people they can trust."

And then Ida Winters, who's in Wisconsin stated, "I was fortunate enough to be connected to Sankofa, attending one meeting, and it changed my life." So, Sankofa in a nutshell is a group that meets monthly, now virtually.

And the whole purpose is to be able to support and provide culturally-relevant and sensitive resources and trainings and spaces for families who have Black children with developmental disabilities. And we really strive to be cultural brokers and cultural supporters of our community and as well as erase stigma associated with disability within our community.

So, I'm going to give you a few testimonies from our Sankofa members. And this is Valorie Crawford, one of our mothers. I'll give you just 10 seconds to read it. And just to really highlight the last part of her sentence, "I have become a strong advocate for my child." Right?

That's the goal, right? To have this opportunity for a parent and a caregiver to have a space to learn their own advocacy style, learn their own way of being able to navigate this system, and have that confidence to be able to do so.

I -- next, I'm going to give you a video from one of our Sankofa members, Diane Milner. And she's going to talk specifically about how she describes a need for groups like Sankofa and why Black -- for Black families. And so, let's listen a little bit to Diane and give a little more context.

[video presentation starts]

MS. DIANE MILNER: So, I wanted to talk a little bit about the intersection between race and disability and specifically, African Americans. What I found is that a lot of

African Americans are eager to get information and support from each other, including myself. But a lot of times, we're not privy to the sources of information. So, we have to help each other provide that.

So, for instance, I've already participated in probably three or four other general parent support groups that include all races. And the information that I've learned has been phenomenal. But when I talk to other -- many other parents of African Americans, a lot of times they don't know about these groups. They don't know about the information. And they are so grateful and eager to learn about it.

So, it's really a -- I think a lack of information and coordination, and we need to improve that. And that's why Sankofa is so important. One of the examples I think of the intersectionality of race and disability is involves my daughter.

So, my daughter is 32 years old. And over the years, we didn't really know that some of the symptoms she exhibited could indicate that she has autism. So, she was not diagnosed with autism until this year. So, she was 32 years old.

And I've read in the literature that a lot of African American children are diagnosed with -- on the autism spectrum very late. So, I don't know if it's deliberate, if it's just neglect. It's probably a combination of both or ignorance. But because I did not know that, I didn't know what to look for. I wish I had talked to more people. I wish I had had a group when Ashley was a lot younger, so that I would become more familiar with what to look for.

And I think it's important for us to let -- spread the word to other African Americans that they need to be looking for these and -- signs and asking questions. Because a lot of times, professionals, educators, probably not intentionally but sometimes probably out of neglect, don't always diagnose our children at the same level that they diagnose other people.

So, again, Sankofa has been extremely helpful to me. Spreading information in the Black community is so important, and I highly recommend it.

[video presentation ends]

So, Diane is one of many stories that we have of powerful Sankofa family advocates. And this, she needs to be able to celebrate, and we celebrate our families all the time. But celebration really is not enough. We must amplify the voices in the disability advocacy movement, ensuring that BIPOC communities' perspectives shape the policies and practices that we use.

Building supportive networks and communities become -- becomes essential as we recognize that collective action is the catalyst for meaningful change. The core of our collective mission must lie in the commitment to promoting inclusivity and equity and dismantling systemic barriers that perpetuate injustice.

So, as we draw near to the conclusion of our journey together, let's reflect on the path that we've traversed and the dream of the role that lies ahead. I urge each one of you for a call to action to start and stand in solidarity with the Black communities to advocate fiercely for equity and justice and to champion inclusivity in every facet of society.

The disparities that we see in diagnosis and access are red flags for the effects of systemic racism, sexism, ableism, -- and more and the intersectionality of oppressed -- in oppressed groups.

Thus, to create change we must take a long hard look in the mirror and think about how our institutions and personal attitudes have fostered and perpetuated these inequitable systems that exist today.

We must look for change to current policies and practices at all levels -- which I hear you are doing these things, I'm excited to say -- and really look at how to be able to access care so that it is not a feat but a given right for every person that is in need.

So, I thank you very much for your engagement and your dedication for change. And this is how you can be able to reach me if you're interested. And together, yes, we can redefine what it means to belong. Thank you.

DR. DANIELS: Thank you so much, Dr. Morgan. Appreciate that presentation. We'll take about 10 minutes for discussion. I know we're slightly behind schedule, but we'll try to make up the time that way. So, Shelli and I can take some questions. Julie?

DR. TAYLOR: I just had a quick comment. So, in a couple of the different presentations -- by the way, all the presentations were excellent. So, thank you everybody for coming here and telling us about the work that you're doing and what's going on in your different groups or agencies.

Something that came up a couple of times in these presentations and in the comments was this idea of the hidden curriculum of adult services and how hard that is to navigate. So, I just wanted to let you all know about a new resource that is going to be available through our Vanderbilt UCEDD very soon within the next couple months.

We've developed a 12-week program that teaches about the adult service system. Each week goes through a different piece of the adult service system with the real focus on how all the different pieces fit together and how do you think about which services and supports as a family caregiver are going to be the best fit for your son or daughter.

So, we've been working on this for a while. We're just wrapping up a large, randomized controlled trial where we've tested out this curriculum in three different states, in Wisconsin and Tennessee and in Illinois. And it seems to be helpful.

Family caregivers are reporting that

they know more. Oh, in fact, they don't report this, we test them. We actually give them a multiple-choice test. And they know much more about adult services after taking the program.

And we've even seen some evidence that it actually improves service access relative to families who are given all the information in a binder, but they don't have anybody to walk through it with them.

So, we are packaging it right now, putting things together, making sure it'll be as easily accessible as possible. But I just wanted to mention that since this has come up a couple of times, our attempt is to take this hidden curriculum and try to make it more transparent, try to make it clear.

It's not easy. The material is not easy and it's a lot. But we at least want people to know what the ranges of options are out there for them and then help connect them to the people that can help them take the next step.

DR. DANIELS: Thank you so much. Please do send that information to us too. We'll put it in our newsletter when it comes out. I think it would be relevant to a lot of people. Thank you so much. And I agree, the presentations were excellent. Again, thank you. Anyone?

DR. AVENEVOLI: Dena is -- has her hand up online.

DR. DANIELS: Go ahead.

MS. GASSNER: Yes. So, I second all of those. Kudos for great presentations. I did just want to bring up a personal experience of mine. Many years ago, in a state that will remain unnamed, I was in the throes of overmedication from a misdiagnosis. And I approached an entity that says that they help parents with disabilities.

But my expression of being overwhelmed was so dramatic that every agency I approached for support turned me down. And I would argue that that is the parent who most needs these kinds of wraparound services.

And while many parents, including these high-needs parents, can benefit from a training program like Julie's to know their rights and their privileges, that doesn't necessarily always equate to them being able to attend a meeting where there's a power dynamic in play.

I had -- as a social worker, I coached my parents, I got them ready, I sent them to the meeting, they signed away their rights because they were so overwhelmed with being told they had to do something. So, I just hope, as we're creating all of these options, that we do recognize that maybe 10 percent of the parents are going to have sustained needs, not a one-time problem-solving issue.

I also wanted to convey that while I believe in supported decision-making, my public high school had children turning 18 sign away their IEPs if they weren't under guardianship. And to due process that at age 18 would have consumed the balance of the child's educational experience. It would just not have worked.

And in a prior school setting, my son was pushed off of diploma-seeking track in a unilateral decision. But again, he was already 18. And I knew that if I due processed it, he would still not be able to graduate.

And he wasn't a high-behavioral needs student. He was a high-academic needs student. And they didn't want to assign a one-on-one staff member to an individual who just needed help with learning disabilities, which was what the global problem was.

So, I just want to give those as caution -- cautionary tales that, you know, there can be circumstances where parents need more than just the support of a class, which is very good at helping us know our rights but may not be translatable. They may need a shadow person, someone with them to open those things up.

And then second to that, you know, we need to be able to get parents' rights back more quickly than the protocol of a due process when a school is clearly taking advantage of a vulnerable parent or a vulnerable student. So, I just wanted to share that. Thank you.

DR. AVENEVOLI: Bryan is online as well, Susan.

DR. DANIELS: Great. Go ahead.

DR. BLOOMER: Yeah. Thank you very much for those presentations. I wanted to dig into a little bit about what was spoken about earlier with the augmented social support networks and see if maybe the speaker could expand a little bit as to whether or not they had some direct experience with how to establish and expand those social support networks. Or if there was, you know, some examples that we could look at and evaluate in terms of that as a policy approach.

DR. DANIELS: So, would any of our speakers like to address that.

DR. JOHNSON: I'm not sure if the speaker who talked about that is still online. But

I'm happy to share what I know which may be not as much as her. But I know -- and I think it's been mentioned under the Individuals with Disabilities Education Act. There is the Parent and Training Information Centers, which is a family-to-family, peer support model that are funded in every state and territory.

And I don't know if Christie is still online and could speak a little bit to those Parent and Training Information Centers. Under the mental health program, there are family-to-family programs as well, which do -- oh, I see Christina's on. So, maybe she can speak more about that.

But I also just wanted to mention that one -- many, many years ago, probably about 15, 16, 17 years ago, we did fund Family Support 360s under that same idea of what she -- Christina was talking about in terms of helping families get to family navigators, peers that have been through that experience to help them navigate through, and sort of what Dena was talking about as well, sort of that ongoing support of peer-to-peers or peers that can support their peers in navigating systems, dealing with issues.

I think there are a lot of supports out there like that. It's -- the challenge is finding those. But we hear about that a lot. A lot of people just aren't aware of the resources that are out there. But I'll turn it over to Christina.

DR. MARSACK-TOPOLEWSKI: Hi. Can you -- would you mind clarifying your question just so -- I just want to make sure I go in the right direction. I'm a talker, so I can go all sorts of ways. Were -- you were asking about the Family Support Navigator programs or --

DR. BLOOMER: Oh, no. I was actually more -- I was looking for an expansion of your comment about augmented social support networks. And it was in that --

DR. MARSACK-TOPOLEWSKI: Informal social -- okay. At first, I was like, is he asking about AACs? Yes, informal social support networks. I've published a series of papers on -- I was really interested in support -- social support. How does it impact quality of life, caregiver burden, those aspects. Yeah, great question.

What we're finding is formal social supports can be great when they're offered, when they're available, when they're accessible, when people can afford them, those kinds of things, or when there's a payer for them. But the informal social support networks can be really helpful.

And a lot of my work focuses on aging family caregivers. So, many of those support networks, right, people have gone to siblings. They've got family caregivers have gone to siblings. They've gone to in-laws. They've gone to neighbors over decades.

And so, what oftentimes they're talking about is that they've really maxed out their informal social support networks. Those networks are -- they're tired. They're maybe not understanding autism and adulthood, those kinds of things.

But anything that we can do perhaps more in a formalized manner can be really helpful because there's only -- and I'd like to imagine this world that we can just totally revamp all the services -- and I'm hoping that it does go that way -- but if we can revamp formal social supports simultaneous to ways to allow individuals to access informal social support networks, so those unpaid networks.

You know, because I have -- you guys can't see me, I'm pregnant with my third baby. But my informal social support networks have been super helpful, right? Being able to, like, call my neighbor down the street when I need, like, somebody just to come over for five minutes, so I could do X, Y, and Z. Or, you know, my parents being able to help me juggle my work schedule and these kind of different work times that I'm working.

And so, if we think about that in the context of family caregiving across the lifespan, so people who are really enduring caregivers and then who might be doing other formalized informal caregiving as well within their homes to a spouse and so forth, anything we can do formally and professionally to augment those.

Some of the work I've done very informally through my work in the schools is I work certainly with individuals with autism, but other populations as well. And we're seeing a lot of early onset schizophrenia, sometimes what we would consider prodromal schizophrenia.

And people are, like -- I mean, this is really traumatic. This is really hard for these families. And so -- and I'm not drawing commonalities to autism, but I'm giving the example of connecting people with maybe certainly formal networks and certainly those kinds of aspects, but somebody else who might be able to understand. And so, a lot can be done even through -- I'm seeing a lot done through Facebook groups.

Last year, I developed a training for an organization out in California that will go to family caregivers of adults with autism and other neurodevelopmental disabilities. But even talking about these aspects in there in this training I developed.

So, I guess in some -- like, if I were working as a social worker, I could work to kind of help people augment what they already have. Some of the funding that I've received from my own research has been through Michigan Health Endowment Fund here in Michigan.

And it's really interesting, as we start to think about these broader networks and kind of this ecological system, if you will, where different supports can come from. So, if I continually to -- call you and say, "Hey, you know, Dr. Bloomer, I need help, I need help, I need help," you're going to probably stop, you know, picking up my call as frequently or as enthusiastically.

But if I go to you, if you come to me and then there's this whole other network where we can all kind of help each other out. And then we augment and have formal networks as well that are navigate -- you know, that people can actually navigate with some ease and understand.

And I think one of the hard things with those formal networks is, like, again, we expect the families to be experts. A lot of the families will come in. And when I'm consulting on cases now, they'll tell me everything. Like, I'm like, "Oh, my gosh, you just did my whole job because you've spent decades studying it."

And so, anything we can do to kind of take the onus off them, both in kind of those formal realms as well as the informal realms. And some of the things that I'm envisioning and that I've seen that are -- that's really helpful is, like, connecting people with the right supports, like helping people think about, like, who -- well, who is in your network?

And as we age -- you know, we're all aging, right? As we all age and many of us, as some form of family caregiver, our networks are going to change. Because people will naturally have different capacities and bandwidths.

Some people might have more because their kids are going to grow up, and they're -- it's easier to call. And so, helping to think about -- so, some of the really cool things I've seen is kind of, like, thinking about helping families look at the ecological context, if you will.

Well, who are these players, and where can we go to, as we start to think about caregiving? And I think what a lot of the families and certainly the data that I've run, is when we have informal networks, quality of life is so much higher.

And so, like, we're getting -- families are saying, "Oh, we're getting -- when done right, we're getting a lot from these formal networks, but we still need these other things. I still need to be able to run up to the grocery store for 20 minutes and grab my eggs. But when I bring, right, my two younger children and my perhaps adults, you know, whoever, it gets more difficult."

So, I don't know if that answers -- but just one, connecting people, helping people see and contextualize and visualize who is in their informal social support network and then really being mindful not to tax those informal social support networks as well.

DR. BLOOMER: I think that's a really good discussion kind of our sort of more formal on-ramp into these kinds of things. But I thought Dr. Morgan also probably had some very interesting insight into this through the Sankofa effort.

Because you have to develop, I think -- and I'd be interested in a discussion about this -- sort of culturally aware and appropriate on-ramps for those communities.

You know, for example, a community that may mistrust government, for example, you know, has a very hard time entering onto that on-ramp, you know?

And so, it seems like the informal network may be key for offering them support and services. So, I was just wondering if maybe there was a larger conversation that might grow out of what you just brought up that I thought was very good. So, just --

DR. DANIELS: Yeah. I'd suggest maybe we take that conversation offline as we're falling behind on our schedule, and we want to move forward. So, if it's okay, Scott, I'm going to just close the session here, so we can all take a break.

[Short Break]

So, we're looking forward to this next panel that we're going to be having on lived experience related to family caregiving. And we're so pleased to have this panel put together that will have representation from parents of individuals on the autism spectrum, siblings, and grandparents.

So, our speakers today are Joe Joyce, a parent of a young adult autistic son and a board member of the Autism Society and also, the Autism Science Foundation.

We also will have Ms. Vontril McLemore, who is going to be on the virtual with us. And she's a grandparent to an autistic young adult. We'll also have Ms. Yetta Myrick, who is a member of our committee and a parent of an autistic young man and an IACC member.

Fourth, we have Ms. Lindsey Nebeker, who's also a member of our committee. And she's the sibling to an autistic adult with high support needs and also a member of the committee.

And finally, we have Ms. Nancy Richey. And she's the mother of an autistic adult and a member of the RAISE Family Caregiving Advisory Council that we heard about earlier today.

So, I look forward to having this conversation with all of you. I may skip a question if we are getting short on time. I'll try to keep us moving along. But I will start with my first question, and I'll just direct it to each one of you.

And I -- maybe I'll just go in the order that I can see here. And is Ms. McLemore online? Oh, there you are. Hello. Welcome. So, please, can each of you please briefly introduce yourself and tell us about your journey as a caregiver? So, we'll start with Lindsey.

MS. LINDSEY NEBEKER: Okay. Okay. I want to make sure. Does that -- can everyone hear? Okay. Just want to make sure. It's my mic -- so, hi, everyone. So, I am -- just a second. Let me just -- so, I am Lindsey Nebeker. I am an independent consultant from the Washington, D.C. area.

I'm focusing on creative services, research, project collaboration, and providing educational training for clinicians and healthcare professionals.

Many of you already know that I am

autistic. But you might not know that I also have an autistic sibling -- my only sibling. His name is James. And he's a couple years younger than me. We do share a few similarities.

James and I were both born in Japan in the early 1980s. We each received our initial diagnosis of autism when we were around age two. We both were evaluated at UCLA. And we were both assessed by Dr. BJ Freeman, who was a fairly renowned specialist in the field at the time.

We both started by attending special education classes, including a brief enrollment at Higashi Gakuen. Gakuen is the Japanese for school. It's a school named -- some of you may recognize because it also has an expanded campus in the Boston area.

Eventually, I transitioned to an international English-speaking school in a fully inclusive classroom. But however, because there were no schools in Tokyo that were really taking in students with high-support needs, my mom, along with a small group of parents, formed a committee to create a small, nonprofit, English-speaking school dedicated to children adolescents with developmental disabilities.

Our family eventually moved to the United States when he was about nine, and I was about 11. There are also a lot of unique differences between me and James. My brother has substantial high-support needs, and he requires 24/7 care. He is non-speaking and does not use a communication device. So, we primarily attune ourselves to his behaviors, gestures, and vocalizations to help us understand his unique methods of communicating.

He has lived in a community-based residential housing program since the age of 16. And he was able to continue attending a public school for students with disabilities until the age of 22. A little while after we settled into the U.S., James was placed on a waiting list for government funding and waivers. It took several years before he finally got on the list.

And then he -- let's see. Another very distinct difference is that he was born a true redhead. And I must admit that I'm extremely envious of his red hair. James turned 40 earlier this year. And he currently lives in the western U.S. over 2,000 miles away from me. I'm continuing to learn an invaluable lesson about the humanistic nature of caring for one another, something many of us, including myself, can sometimes forget.

As an autistic individual, I can develop a tendency to be self-centered, sometimes feeling like the world revolves around me. Growing up with distinct differences has made me more open-minded to the diversity of communities, cultures, and beliefs in our world.

Through the initial four years of my life being non-speaking, I have developed a full conviction that those who do not speak understand more than we assume.

I often contemplate, how can I honestly convey real life experiences, including the impact on my brother, while also portraying him in a compassionate light? Both aspects are important.

We have to acknowledge the realities we face and their effects on us and our loved ones, while ensuring that our storytelling is respectful and humanizing our loved ones. This extends to any issue, whether that be addiction, financial hardships, relationship struggles, job loss, loneliness, chronic illness, or navigating life transitions.

DR. DANIELS: Thank you, Lindsey. And Yetta?

MS. MYRICK: Hello, everyone. Thanks for giving me a moment to speak and to be on this panel today. I have a hat rack of roles. I've graduated from having many hats. My most important role, of course, is as the mother of a soon to be 20-year-old -- 21-year-old -- he's 20 now -- in September.

I don't say his name, but I will say A or will say, "He," to denote when I'm speaking about him. But he was diagnosed with autism, ADHD, and an intellectual disability.

Many of you know that I'm president and founder of an organization locally here called D.C. Autism Parents. It's a 501(c)(3) non-profit organization that I founded way back in 2008. You all know I'm a public member of IACC. I'm also the CDC's Act Early ambassador to D.C. and a community member on the D.C.'s Developmental Disability Council.

I'm not here to give you my resume. But I share this with you so that you can understand that where I am right now is not who I was when my son was initially diagnosed. I had no idea what I was doing in the early days. I did not know where to start.

Many of the stories that we have heard through public comment, through us sharing a conversation today really is a reflection of where I was in the very beginning. And sad to say, that's where many families still are right now today.

Prior to my son's diagnosis, he was diagnosed with an expressive receptive speech delay at two and a half years old. To give you a little bit of flavor of how we got to the autism diagnosis, I had enough sense, and I really think it was either divine intervention or me just really being intuitive about what I needed to do.

Because no one was guiding me through the process at this point. Really was me watching him and trying my best to be in tune with him and figure out what his needs were.

And so, when he was not speaking, I was like, "Okay. Let me find someone that can help me work with him." And so, I got connected with a speech and language pathologist.

The challenge was, we are in D.C. proper. The speech and language pathologist was over the line in Montgomery County, which is where we are situated right now. She did not know how to navigate D.C. services. So, she was like, "Yetta, why don't you talk to A's doctor about autism? I think your son might be autistic." And I said, "Okay."

So, we went for a well-child visit. And I was speaking to the nurse, and I said, "Hey, A is going to see a speech and language pathologist because his speech delay." And I, again, had good sense enough to know, we got a report. She did an evaluation. I took it to the doctor. The nurse, as well meaning as she was, she said to me, "Mom, you can't just let anyone diagnose your child." And that delayed me.

So, fast forward, and we think about the work that I'm doing at the CDC's Act Early ambassador, that one moment changed my life. It delayed me in getting my son diagnosed. It wasn't until the childcare center that he was in was actually changing over who was running the program where they actually identified him and got me linked into, at that point, was called the CARE center, which, who the heck knew what the CARE center was?

I now know it was a center of assessment and referral and evaluation. I mean, but who knew that? The information just was not readily available, right? And so, we went through the process, got him evaluated. We got connected with an amazing psychologist at the Center for Autism at Children's National Hospital, which is locally here.

And she saw me. She understood, and she's a White woman. And I say this is an African American woman. I truly was blessed. I don't necessarily have all the horror stories. There are some. But not all the horror stories that I sometimes hear as it relates to Black and African American families.

And I'm truly blessed. And sometimes, I think that it has to do with the fact that I was situated in the District of Columbia where there are a lot more people of color, if you will, right? And so, she saw me. She saw me come in with the PECS. We had the picture exchange communication system to help them.

And she says, "Yetta, you're the only mom that I see coming into these -- you're coming into an evaluation with this -- with the PECS system. And you're like actually really trying to use it." And so, over time, right, when we got -- she's -- she will say this to this day.

And I want to give her a shout out -- Laura Anthony. She's now at the University of Colorado doing work. And I've done work with her through the years when she was here locally. But she was like, "I see you, and I want to help you. And this is what you need to do." And I did -- I took all the steps. I took time to research and learn and figure out what worked for him.

My son is an artist. I figured that out early. I was like, "Okay. How do I get someone that can help me with his art?"

Because I knew, in the back of my mind, that what he was doing right now, his love of art, would maybe translate to something as he became an adult, right? I read about horses and how horses, you know, help children with autism.

And so, we started going to pony rides every week. I was paying whatever the cost was. And we would go and pay for pony rides, right? And now, he is a full-fledged equestrian. We go. We show up every week. We go. And he can tack that horse and take that horse out and ride.

Now, this is not to say that I have not made sacrifices. We live at home with my parents. We live in a multi-generational home. And I'm not at all embarrassed to say that. We have to make sacrifices and do what we need to do.

I want to give a shout out to my mother, to my father, to my brother, to my grandmother -- God rest her soul -- who, when he was little, took care of him, supported me, right? And I recognize there are so many families out here who do not have that support. And I think that is the reason why I can be here today and talk to you and share about my experience. And we've been so blessed to tap into a lot of services.

I wasn't always able to pay for art. I had to make choices. Can I pay for physical therapy? Can we pay for it? Okay. We took a break for a number of years, right? You make choices. And -- but fortunately enough, I was able to make those choices because I decided to stay at home. And my family was willing to have me. Let's just be real.

But we're truly blessed. I think that my life is all the better because of my son. And I have learned so many things. And I'm still learning. And I think that's the piece, right? And I say this to all the families and individuals. We just have to keep fighting the good fight and working and advocating. That's what's going to make the difference.

DR. DANIELS: Thank you, Yetta.

MS. NANCY RICHEY: Hi. My name is Nancy Richey. And I started so many times, looking at all of your notes this past week to write down my answers. And finally, I just said, "I can't. I just can't write them all down." So, they're just going to come as they come out of my head. My son -- we have one child. And it's Dan. And he's 30 years old. And he lives with us.

I can give you a little bit of the -- you know, the beginning of this journey story. And I share this, not for any kind of pity. But prior to having Dan, my husband and I experienced five pregnancy losses. So, the only reason I say that is because when that happens and then you finally have a full-term delivery, you're like, "Finally." You know, the life we've anticipated is beginning. And so -- and yet, I'd say the same thing as you, that I'm a better person because of him.

My husband and I say all the time that

Dan just really taught us what matters. He really taught us what's important. And I am very, very blessed to be in a marriage with truly my best friend and a partner and an incredible father. And I don't quite know how a single mom or a single dad could do this on your own.

My hat is off to someone who's doing it alone. Because we'll see a situation with Dan where, you know, he's starting to have a meltdown, and he's really mad at me usually. Because I'm supposed to know every thought in his head. And Tom will just say, "I got this. You know, you take a break. Go do what you need to do to recover from this." So, we're a very, very tight little family of three. Dan -- let's see.

I was thinking that some of the most difficult times were in the whole school years, you know, just really hoping and praying that each school year, his team, his teachers, and support people would be like partners with us. And there were many years where that wasn't the case, hence we changed school districts.

But by the time he got to high school, it was just amazing. He just had an incredible teacher, an incredible team. And being that he could stay in school until he was 21, he had this incredible group for like five years. So, that was great.

In terms of waiting, Dan was diagnosed when he was about four, but we had about an eight-month waiting period when we knew something was going on that he needed to be evaluated. He was on three different lists for an evaluation. And all three of them were eight months long. So, that was a very long and difficult and scary stretch.

I think something that we've echoed through this afternoon, just listening, is that, for me and for us, the greatest thing in the beginning was the Autism Society. Our local chapter -- hi, Kim. Our local chapter of the ASA in -- around Harrisburg, Pennsylvania. It was through those other parents that I learned, okay, who can give this kid a haircut? Who's the best dentist? You know, what are we going to do? What -- you know, how do I navigate this or that?

So, other parents were just the most amazing. In fact, I remember walking into the Autism Society meeting for the first time. And I walked in, and here were all these people kind of laughing and smiling and having a good time. And I remember thinking, "How can they be happy? This is serious." And then in no time, I realized, it -- you know, it was a group of comrades, a group of people who were sharing experiences.

And we really -- it was okay to be together and laugh and be together and, you know, really let your hair down and relax. So, that was very important. One thing I just was thinking about is, early on -- and if you remember what was going on in 1993 with autism, you know, there was a lot of controversy of what caused this.

Who -- you know, who do we need to see?

Who can fix this? Remember that? You know, like, was it vaccines? What was it? Is it in the air? You know, who knows what it was?

But I suddenly had an awakening one day where I thought, "What if Dan thinks he's not just perfect the way he is? What if he reads that, you know, we're trying to change him? What if he perceives that, you know, he needs to be fixed?"

And so, suddenly, at that turning point, we just took a different approach. Like, we're going to support him and love him and, you know, do all we can. But he is who he is. When he was in about the second or third grade, the school psychologist evaluated him for intellectual disability. So, he got that diagnose tacked on.

And my attitude at the time was, "You're just doing that, so you don't have to work as hard." No, he was right. He was right about that diagnosis but just those kinds of hurdles to get over and get past. To come present, Dan has a job. He works in a grocery store in the produce department with a job coach.

I'm very grateful that he has a Medicaid waiver in Pennsylvania that -- and we use the model called self-direction. So, I'm the common-law employer. We can hire our own people. And it is positively a godsend, at least at this point in life, to be able to do that. So, I'll pass it on to Joe.

MS. RICHEY: So, just a funny little thing. We had a pre-Zoom of the panelists. Was it last week, I think? And Joe started describing his family and where he lives. And he said, "I live in Harrisburg, Pennsylvania." And I went, "So do I." But we never met before.

MR. JOE JOYCE: Exactly.

[laughter]

DR. DANIELS: Are we back? Okay. So, we can proceed? Okay. Thank you so much. And we apologize to our audience on video cast. We were having technical difficulties. But we're just picking up with Joe Joyce and his comments.

MR. JOYCE: Great. Thank you, Dr. Daniels, and everyone on the IACC committee. It's a great honor to be able to speak with you today.

My wife, Elise, and I are the parents of a young adult, David, who is profoundly impacted by autism. He is completely nonverbal, and he has very severe self-injurious behaviors. We are very grateful to have the opportunity to share some of our experiences with all of you today.

And in fact, some of you may remember meeting David. I had the privilege of speaking once before in 2019 at an IACC meeting. And David accompanied me to the meeting and got the opportunity to meet many of the professionals on the IACC committee.

And I believe -- I could be wrong, but I believe he was the very first profoundly nonverbal self-advocate to speak at the IACC meeting. Actually, I did a lot of the speaking, but he -- nonverbal does not mean quiet.

And so, it's great to be back and to talk about some of the challenges that our family has faced. And as you have heard from others, the support system for families with -- that are impacted by profound autism is very much inadequate and insufficient to cover their needs.

David was diagnosed at a very young age with autism. And shortly thereafter, he developed the severe self-injurious behaviors, where, at that time, he actually -- you know, when the -- our team would keep data with clickers. And he would literally hit himself 8,000 times a day.

It was so severe that they would actually measure it by the minute. So, it was very much a heartbreaking experience for us as parents. David would not smile. He just didn't seem to have joy in his life. And it was extremely heartbreaking for us. In addition, every family's journey is very unique.

Ours is very unique, I have to say. Because in addition to David, we also have another son who has intellectual disability. Matt is 28 years old. And Matt has down syndrome.

So, raising two special needs children at the same time that are only two and a half years apart was greatly challenging, especially for my wife, Elise, who I'll talk about more in a few moments. But she was so dedicated to raising our boys that she is, you know, my hero.

David, as I said, would really be severely impacted by his self-injurious behaviors. And it was a very challenging time for us. In addition to David, we also have a neurotypical daughter, who now has two beautiful daughters of her own.

But, you know, as a young person being -- witnessing all the time someone hitting himself and doing all we can to keep him safe, was just very difficult for the whole family.

DR. DANIELS: Thank you. And online, we have Vontril McLemore. So, Vontril, would you like to go ahead and introduce yourself? I don't think she can unmute. Can you unmute yourself, or can our IT team help?

MS. VONTRIL MCLEMORE: Now.

DR. DANIELS: There we go.

MS. MCLEMORE: Can you hear me now?

DR. DANIELS: Yes.

MS. MCLEMORE: Hi. Hello. My name is Vontril McLemore. I'm 70 years young. I'm an advocate for my grandson, Trey. I'm a native Texan. I am also a caregiver to my husband of almost 50 years -- Alfonso. I am mom to Alex and Junior, two neurotypical, fantastic children; grandmother to Trey, who is autistic and has IDD, and Trinity, my granddaughter, Gavin, my grandson, who has dyslexia, and Langston.

Trey was vocal when he was born. Around 18 months to two years, something happened. And we don't know what it was, but we connected it to a fever that he contracted in his very young toddler years.

And after that fever and, you know, he recovered, we noticed that he had lost his ability to speak. But he could comprehend and follow directions. He could take orders, but he could not verbalize to you what you wanted him to do.

And my daughter and I were concerned about it. His parents were young. And they were told, and they thought that, you know, he would grow out of it. But my daughter and I were not of that opinion.

So, we had delved into autism at the time, around 2022, '23. Trey was born 2001 -- 2004, I'm sorry, getting tongue tied. But anyway, we were not of that opinion. So, I had a doctor look at him. And he was diagnosed at about 3 years old with autism and IDD.

And, Yetta, that doctor was also a White doctor. He's no longer with us in the natural. But Dr. Mandell was a lifesaver in that regard. Trey is handsome. He's kind.

He's compassionate. He's empathetic. He's giving. He makes a mean bed. He takes trash out. He loads the dishwasher. He helps me care for his granddad.

So, as much of a blessing as we've been to him, he has been for us. He's high functioning. He has aspirations and dreams. One of those dreams is to live in the -- one of the most affluent areas in our neck of the DFW metroplex, which is Dallas, Texas. It's called Plano, Texas.

He and I drive around every Sunday after church. And he daydreams about living in a house in this very affluent area, a million to $2 million. I don't have the heart to tell this young man, "Hey, this is not something within our economic strata to fulfill right now."

He works at Five Below. And he's been there since September. He was awarded the employee of the month after only two months. So, he was able to secure this job with the Texas Workforce Commission. And I know I've heard reports from some people about how the Texas Workforce Commission was not helpful to them.

Totally the contrary. They were a very big help for us, along with Quest Employment. They were the ones that took Trey out last summer, once a week, three to four job prospects a day.

And he finally decided that Five Below was a good fit. And as fate would have it, the manager for Five Below also had an autistic son. And the manager there and the line person as well had autistic loved ones.

So, had it not been for the Texas Workforce Commission and Quest Employment, we may not have even known if Alfonso -- or Trey was able to work -- to hold a gainful employment.

We've been his caregivers since 5/28/22, which coincidentally was the day he graduated from high school. He's been a component of our life ever since he was born; on long vacations, holidays, and that sort of thing but not being a permanent caregiver to him. That was -- there was a transition.

Being a Black man with neurodiversity, living at the intersection of class, race, and culture dynamics, there are many concerns for his safety as he navigates the present world. Not only is police brutality uppermost in our minds, but vigilante citizen on citizen crime is always a concern.

Driving a vehicle presents another dilemma since we think that Trey is able to drive. But as we know, driving is more than just making contact with a pedal and brake. It's also, as a Black parent and caregiver, the ability to make it home safely every night.

We feel he's capable of learning. But with autism and IDD, we are equally concerned. His reaction time is delayed. His comprehension is delayed. And even under the best of circumstances, we would have concerns about his driving.

So, our son, who is Trey's dad, who's

neurotypical, has had several negative interactions with law enforcement. Trey, with autism, the invisible condition, at first glance appears neurotypical, but has cognitive issues that aren't readily available to law enforcement.

They may misconstrue Trey's condition as "failure to comply, rudeness, or just plain arrogance." And that's another issue that we are quite concerned with. And on the lighter side of this, my grandson is a very handsome young man. He likes to dress up. He likes to get his hair cut and all the latest styles.

And now, the thing he wants to do with his hair is sponge. He wants his hair sponged so that he can get dreadlocks. Those of you who are of the Black culture may know something about that. But that's something he's looking forward to. And we are encouraging his creativity in every way that we can.

And finally, I'd like to say that a

social life is not out of the realm of possibility for our grandson. But here, again, there are no resources available where he can meet someone.

And my cousin has a son who's visually impaired. And we had this conversation a couple of weeks ago. She said, "Cuz, my son wants to meet somebody. He wants to date and see if he can date, you know, and do all the normal things. He's able to do that." And I told her, "Okay. We'll work on that."

So, if anybody knows of a dating site that a young man can go and be safe and possibly get to meet somebody online, I would appreciate that. So, I want to thank you all for this brave, safe space, and for the equity, diversity, and inclusion that I see here today. Thank you for having me.

DR. DANIELS: Thank you so much. And I'm going to skip to our third question because I think we've covered some of the challenges in our introductory question.

And I'd like to ask each of you to

comment on what kinds of resources or supports you feel are most needed for caregivers and things that you'd aspirationally like to see developed to help you in your caregiving roles or your future caregiving roles?

Are you okay to be the first, Lindsey, or would you like us to --

MS. NEBEKER: Yeah, I'm fine. But I'm wondering if I can actually skip three and do two instead.

DR. DANIELS: Sure. Go ahead. So, the second question was about challenges you've experienced as you cared for your loved ones. So, go ahead.

MS. NEBEKER: Yeah. So, I'll share that instead of three. And I'll let everyone else share three. So, as far as like just -- I'm going to just mention a few unique challenges.

So, I've met thousands of people in the autism community, both personally and professionally. I've encountered families with multiple autistic children, sibling pairs on the spectrum, and neurotypical siblings of people with high support needs.

However, I don't recall meeting anyone with a family story quite like mine, where two siblings have the same diagnosis but very different presentations. It's a unique position for me to be in. It's also, at times, a lonely position.

I often feel like I'm not fully accepted due to my unique duality of roles in deep personal experience with various aspects of autism. And I feel an intense pressure to make sure I am not saying the incorrect words or phrases.

And that is difficult because what is defined as correct or incorrect is subjective. Ensuring my brother's safety is one of my top concerns and priorities.

Non-speaking individuals who use untranslatable communication methods are particularly vulnerable. Even in high-quality residential placements, incidents can slip through the cracks.

A few years ago, James was sexually assaulted by a formal direct support staff worker. We only found out that when that employee, who had already left the agency, had confessed to a therapist. And as a mandated reporter, the therapist had to notify the authorities.

Without this chain of events, we would've had no idea. The detailed notes in his daily report showed no indication of any unusual behavior during the time in question. There was no evidence. And this leads into one more significant challenge that I would like to share.

I have an old family video of my brother's first birthday, which I rarely watch because it's too emotional. One day, I rewatched it, and I could not help but weep incessantly. Seeing that precious red-haired little boy laughing and smiling, sitting in his highchair while being presented with a small birthday cake.

As tears had rolled down my face, I spoke out loud in front of the TV screen, and I said, "I'm so sorry, James, I -- that we had to give you up. I am so sorry that I have not been able to be there for you." When a family member leaves for residential care, that guilt lingers indefinitely.

As a sibling, you never want to feel like you're abandoning your brother or sister. I wish I had that capability and resources to take care of my brother on my own, but I simply do not. Our resources and ability to care for him dwindled as he grew stronger. And his meltdowns and self-injurious episodes became more unpredictable.

I still wonder how and why our paths ended up in different places even when we started on the same path. We shared the same diagnosis, participated in the same early intervention programs, and briefly, attended the same special education classes.

I have accepted that I probably will not find an answer to that curiosity. And that's okay because my focus now has to be on his future. I have to keep reminding myself that I did my best, and that accepting outside support is okay.

James' quality of life is better now with the supports he has. And my parents' decisions were made out of love and a desire for his happiness. Now, I'm reflecting on my next steps to best support my brother after my parents pass, ensuring that he's protected from exploitation while honoring his autonomy.

DR. DANIELS: Thank you.

MS. MYRICK: So, in terms of what supports and resources are needed, my son is currently in a non-public and has been for a number of years, full disclosure. Because the local school system could not support him. And I have gone due process twice to get him into these placements.

He transitioned to a post-high school program last year, which was really challenging for him because he was the big man on campus, to be perfectly honest. He -- the running joke in the family is that my son literally was like the teacher assistant in his autism program. Like, that's how well he was doing with the supports that he had in his autism program.

And after the pandemic, I knew that it would be best for him to be in the post-high school program at his school because I know about the cliff that happens when you turn 21, 22, right? And I have real concerns about that.

And so, he transitioned. And my son, for the most part, is chill. But I know he was upset. Because he would come home, and he would say, "Post-high school is different." He will knock on the wall, literally. It's literally a knock. Or he will stomp one foot. And that's his protest.

Like, I recognize there are an array of behaviors across the spectrum that are happening. So, again, truly blessed that it was not worse. But, you know, we're looking now at, okay, is he becoming more anxious about this program? He just started school again on Monday. And he seems to be settled in because he is a routine guy. He likes his routine.

And so, he has to dress for success and wear, you know, the clothes that he needs to wear. And he knows what days that he is wearing which outfit to school, which is great. And we've really come a long way. But we had to be in a placement that's outside of the school system.

And so, when we think about the challenge and what is needed, we need school systems that have staff that are appropriately trained to support this whole spectrum, right? I recognize that sometimes, there -- I don't want to say there's no choice. But the choice is if I want my child to thrive, I need to fight for X, Y, Z, right? Every -- it's all individualized.

But I think about the parents who might not have the resources to even advocate to get an attorney to fight, right, to get their child to the appropriate placement. That's one thing.

Another thing that has come up and thinking about the work that I'm doing and speaking to parents, is having an Autism 101. What is autism? How does this look for my child? What is general information about autism that families can get when their child is first diagnosed?

Because families, basically, they get the report once they get in for an evaluation, if it's not two years. Like, it was eight months then. We're talking two, two and a half years now, right? And so -- you know, and this is all across the country.

So, programs like ECHO, which I've talked about, are all the more paramount in making sure that community providers are able to help to mitigate that and get these kids diagnosed. But access to services, resources, where people are not going broke, that is a real thing.

Also, again, getting back to this transition to adulthood, making sure that we are not falling off a cliff, that our children are not falling off a cliff when they become adults, and we have a clear understanding of what these systems look like.

So, I'm really excited, Julie, about what you're building, you know, the Vanderbilt. I have done a presentation on transition to support families locally in D.C. And to be honest, like, providers who listen to presentation like, "Yetta, like, I have not heard like this robust a presentation." And I use Charting the LifeCourse. That was noted, right?

So, there are things out here in the larger community. And we've talked about, how do we like, create some repository of information so that everyone can access, and we're not recreating the wheel, right? You've got to start from somewhere. Everybody cannot be starting from scratch.

Yes, we need to make sure that it's culturally competent, right? And it's reflective of the community that we're serving. But we still cannot be starting over and over again. And we've got to fix this because people are falling through the cracks.

DR. DANIELS: Thank you. And Nancy?

MS. RICHEY: So, we've -- I've heard the word falling off the cliff used a lot in terms of graduating from high school and into adulthood. And then there's another cliff. And that's when the parents age and have to decide what's next and who and where.

Vontril, I'm in the 70-year-old club with you. Okay? So, as that happens, I mean, we love Dan living with us. But we realized -- we're realizing now, we've got to get some advanced plans. We've got to get some things in place. And truly, it is like a cliff. I look over the edge and go, "Ooh, not today." And, you know -- and I back up. Then I back up.

So, that kind of guidance would be immensely helpful in terms of a very specific and intentional resource and support. I cannot emphasize enough in our experience that it was other families who were our best teachers -- our very best teachers.

And so, as many opportunities as there can be for families to connect with each other. I have young parents contacting me saying, "Help. You know, what do we do?" And it's very gratifying to walk through, you know, "Okay. Here's what -- here's where you are and what you need to be thinking about now, but you've got this. You're the expert on your own child. You're still the expert on this little guy."

The other thing I was thinking about in terms of services and supports that are missing or that could be helpful for caregivers, I didn't mention this before, but I was also the primary caregiver for our -- for my parents and my husband's mother, who lived with us for 13 years.

So, that kind of, you know, multi-generational situation as my mother-in-law, in particular's health failed. Some kind of a bridge support, you know, where they could have both had support at the same time, for example, you know, so something along those lines. But when you're juggling multiple caregiving roles like that, that's a time when extra support would be most helpful.

DR. DANIELS: And Joe?

MR. JOYCE: Thank you. I think the challenges that family caregivers face and the supports and resources are very much intertwined. As was said earlier, many family caregivers are also single parents. And as Nancy said, it's just mind boggling to think how someone could handle that as a single parent.

But even for couples, most couples that are acting in the form of family caregivers, it's a one-income family. You know, and that's what we faced in our household. Elise literally gave up her career in the art world to stay home and focus on the family.

So, I became the sole wage earner for the family. So, that put stress on all of us. You know, I felt like I had to deliver. And so, which meant I had to work even harder and travel even more.

And when I was out on the road, I was always worried about what -- you know, what is taking place at home. And often, when I would come home, I would see that, you know, Elise may be bruised from basically trying to intervene and keep David from hitting himself.

David was really not aggressive towards others. But when you get in the -- in between to try to keep him safe, often, you're the recipient of the behaviors. So, there's a lot of stress on families to be able to provide.

Also, Elise always tells me, half-jokingly -- I don't know about the half part -- that I can never retire. I have to keep working because I'm supporting not just us, but our kids for the rest of their lifetime.

So, I think some of the, you know, supports that are needed are -- in Pennsylvania, we call it TSS -- therapeutic support staff that work. But they have limited hours.

And, you know, one of the issues we faced was that we could not leave David alone overnight while he was sleeping. Because he would just wake up out of the blue in the middle of the night and start having self-injurious behaviors. And if we weren't right there to intervene, you know, the room could look like a war zone with -- war scene with, you know, blood and so on.

So, the -- these -- the supports that are needed for behavioral and support staff are just -- need to be continually looked at and improved. Another resource that is vital is transportation, especially, you know, with a family like ours where my wife was caring for one son with Down syndrome, one son with autism.

And the therapeutic support staff are not permitted to drive their clients. So, my wife was the chauffeur. And, you know, often, the two boys are very different. One would -- wanted to be in the library, and one wanted to be at the park. And how do you accommodate both?

So, there's a real need out there for transportation services for those with autism and other disabilities. And then finally, other resources that are needed, access to services. There's a very severe shortage, as you all know, of qualified professionals who really understand the unique needs of those with profound autism and all autistic individuals.

So, access to the service, to the qualified professionals, is extremely limited. My wife really worked as an unpaid professional because so often, they -- there was not -- the agency that provided our TSS service was understaffed. And, you know, they would rely on us as parents to provide the services.

So -- and finally, respite care. Family caregivers need a break. You know, they need the opportunity to get away for a day or two to avoid burnout. And the respite services that, even if they are available, are very limited. There's limits on how many nights per year you can use. So, you really have to plan it well in advance.

So, I think respite services is another resource and area of support that is sorely needed.

DR. DANIELS: Thank you. And Vontril.

MS. MCLEMORE: Okay. Where do I start? All right, the challenges. I heard one of the speakers earlier speak of boutique shopping. That's what I felt like when Trey moved in with us.

I was going over here to get a little bit of this, a little bit of that, a little bit of this, little bit of that. There was no comprehensive database or gathering of information that would show me what I needed.

So, we had no template.

And even though Trey had been in our lives as a child growing up, it's totally different. The supports he needs and the supports that we needed were drastically changed. For instance, the challenges of healthcare.

Now, we needed to find a doctor. And when he moved in, he was on one kind of Medicaid plan. And then when he became 20, then we had to transition. So, we had to get him a -- find a dentist. We were responsible for emotional support for him for counseling.

Because if you think about it, having lived with your parents and your siblings all of your life until you were 18 and a half years old, has got to be traumatic and devastating to make that transition.

Even though he decided that he wanted to live here with us, it had to leave emotional scars. So, we had to find the counseling. We had to be his recreational support.

As Yetta was saying about her son and

all of the skills and, you know, ideas that he has that he wants to get involved in, hobbies, well, Trey is the same way. Luckily, 2019, I connected with the Special Olympics. And they have programs that are almost free. I think we pay about $12 a year. And they only require you to renew the physical every two years. So, he swims. He bowls. He took boxing.

All of those things were on us. Because as human beings, we are emotional beings. We are physical beings, and we are spiritual beings. The financial resources, where are we going to get these resources to cover these things?

You know, did he have this benefit when he was with his parents? How does that transfer to us? Does that transfer to us? So, how do we fill in those holes so that he won't miss any benefits that he should have?

More collaborations, I think, are integral and critical on the state level, the community level, the federal level, and the non-profit level. I wish, again, that there were more databases, banks, information systems, that were intersectional to one another so that we wouldn't always be operating from a deficit.

Having to reinvent the wheel when we really didn't have to reinvent the wheel. We just weren't aware the wheel was already there.

And another thing that I -- that's very concerning to me -- and when I heard this years ago, I just almost blew a gasket -- that by third grade, penal institutions -- carceral systems are deciding how many prison cells they need to construct for our young people. Third grade. And they contemplate that on reading scores or lack thereof.

So, where are our advocates in school advocating for these kids, getting these kids diagnosed? Or some who are misdiagnosed as being incorrigible and difficult; instead, they may very well have learning differences and learning disabilities.

So, I would like to see more engagement with our public school systems the same way the penal and carceral systems are engaged with the school system.

Perhaps if we worked together hand in hand, we could thwart and maybe diminish the need for so many prison cells, when many of the occupants of the prison cells are disproportionately marginalized Brown and Black people who did not have the advantages that some of the other cultures had. So, that was -- that's always one that just makes me crazy.

Now, on the positive side, the resources that we were able to access -- I've got the book here. Ms. Yetta, here is your book, and you all see that. I came into the knowledge of this phenomenal woman and her team, community autism research ambassador program, Family Voices.

MS. MYRICK: Thanks for the shout out, Vontril. Thanks for the shout out.

MS. MCLEMORE: Family Voices.

MS. MYRICK: And shout out to Dr. Allysa Ware as well.

MS. MCLEMORE: Yes. Yes, the whole team, Dr. Allysa Ware and the others. That's -- that was one of my main resources. I have so much information in this book. I referred to it today when making my presentation.

And I found out about Family Voices and Yetta's organization through a Texas non-profit called Texas Parent to Parent. They were able to give me documents -- legal documents, able to advise me on the best avenues to go in order to take care of my grandson's special condition.

I was speaking to a friend last night on the phone. She has a granddaughter. And they have guardianship, the state of Texas. They were advised that they needed to complete guardianship papers.

And then after they completed the guardianship papers, she said, well, then they had to adopt the granddaughter. And I thought, "Oh, my goodness. I don't know anything about this."

But with the help of Texas Parent to Parent, we were able to do the correct legal information and forms that we needed so as not to do something that would further incapacitate or further demean or delay his progression.

Another agency was the Texas Workforce Commission. I've already told you about them. They were an invaluable asset. Quest Employment, Dallas, Texas, that was another job placement. Without them, we would not have Alfonso working today, which is where he is.

And we have a respite person that took him today for me so that I could prepare for this presentation that's so important to my heart. So, we take advantage of those. Let me see.

DR. DANIELS: Thank you so much.

MS. MCLEMORE: I'm going down my list [laughs].

DR. DANIELS: Thank you so much, Vontril.

MS. MCLEMORE: Yes.

DR. DANIELS: It's 5:00 p.m. So, we're going to have to wrap up. But we really appreciate those comments. We appreciate the comments of all of our panelists here. And you all fit a lot in into a couple of questions. So, I'll hand it over to Shelli and then we will be wrapping up shortly.

DR. SHELLI AVENEVOLI: Yeah. Let me just echo Susan's thanks. I really want to thank everyone for joining and participating today. I think we'll all agree this has been a really fantastic meeting and a really great way to round out this phase of the IACC. So, congratulations and thanks to all.

Special thanks to our speakers and all of you for sharing either your programs or your research efforts or your personal experiences. We really appreciate that. Thanks so much to our committee members for always making very astute comments, all of which serve to ensure that we continue to grow and to improve upon the work that we do together.

And finally, a very sincere thanks to Susan, Oni, and the entire ONAC and IACC organizing team for running the meeting, organizing us, getting all of the reports out, and just doing a fantastic job overall. It's been my pleasure to listen to all of you today. So, again, thank you so much. Back to you, Susan.

DR. DANIELS: Thank you so much. We really appreciate all of you. Thank you to all of our wonderful committee members for three great years of full committee meetings. And you know that your job isn't completely over because we will be in touch to finish up some projects. Thank you again. And we will be reaching out via email and posting different updates on our website. Thank you, everyone.

(The Committee adjourned.)