INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, OCTOBER 11, 2023

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

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AGENDA

PROCEEDINGS

DR. JOSHUA GORDON: Again, I want to express my welcome to everyone here in the room and to everyone online -- committee members, members of the public, others listening in. It's a real pleasure to open this meeting of the Interagency Autism Coordinating Committee.

My name is Joshua Gordon. I'm the director of the National Institute of Mental Health and chair of the IACC. To my left here is Dr. Susan Daniels, who is the director of the Office of the National Autism Coordinator and the National Autism Coordinator for the United States and the executive secretary of the IACC. I want to acknowledge that it's wonderful to see so many faces in the room and also to see so many faces on Zoom. If members of the committee would please -- who are on Zoom, would please turn their cameras on if they feel comfortable doing so, that would be helpful.

Members of the committee here in the

room should feel free, if they're on Zoom, to turn their cameras on. But the room cameras will also capture you as you speak.

I want to first say that we have some committee member updates. We have some -- I want to welcome two new members to the IACC that were recently appointed by the HHS secretary. First is Dr. Tom Frazier. Tom, would you like to say a few words to introduce yourself?

DR. THOMAS FRAZIER: Sure. Thanks, Josh. Hi, everyone. Tom Frazier, I'm a clinical psychologist, professor at John Carroll University in Cleveland. And my wife is a BCBA, and I have a 19-year-old son with autism and intellectual disability.

DR. GORDON: Thank you very much. We welcome you and look forward to your many contributions to this committee.

Our next new member is Dr. Camille Proctor, who I believe is joining us virtually. Ms. Proctor, would you like to introduce yourself? I can't find you. If you are speaking, we can't hear you, so you need to unmute. Okay. We'll come back to Ms. Proctor later.

Next, I want to welcome Dr. Jane Simoni, who's the director of the NIH Office of Behavioral and Social Sciences Research. Dr. Simoni is joining us to represent Dr. Larry Tabak, the director -- the acting director of the National Institutes of Health. Jane, would you like to say a few words to introduce yourself?

DR. JANE SIMONI: Yes, hello. It's a privilege to be here, and I'm very happy that it was the in-person meeting for my first meeting. I'm a clinical psychologist, just coming from academe -- my first year at the federal government. And I'm excited to be in this space. We're hearing from people both outside and inside the feds.

DR. GORDON: Thank you very much, Jane. I also want to thank Dr. Courtney Aklin for representing the NIH as the alternate for Dr. Tabak for the past two years. Dr. Aklin has stepped down as acting deputy director of NIH. We congratulate her as she's stepping into her new role as deputy director of the National Institute of Nursing Research here at NIH.

I also want to acknowledge that Ms. Skye Bass, who represented the Indian Health Service on this committee, has transitioned to a new position. Ms. Barbara Roland will represent the Indian Health Services until a permanent member is named. Barbara, would you like to say a few words to introduce yourself? All right. Looks like we don't have Ms. Roland yet. And so, we'll have her introduce herself at a later point.

Finally, as we've done in the past, I just want to acknowledge and congratulate committee members on some of the accomplishments that we have to share. Dr. Julie Taylor has been appointed as the co-director of the Vanderbilt Kennedy Center UCEDD, or University Center for Excellence in Developmental Disabilities Education, Research, and Service. Congratulations on this prestigious appointment, Julie. In addition, Mr. Craig Johnson is here in the room, recently completed his Masters of Education degree in special populations from the University of Houston. Congratulations to you on that achievement.

Finally, I want to congratulate -- I sort of spilled the beans a bit earlier in my introduction, but I want to congratulate Dr. Susan Daniels, our own executive secretary, who, as you know, was named National Autism Coordinator this past May. This is the first time we're meeting. And so, I want to take this moment to congratulate her. She had been serving as the acting National Autism Coordinator since July of 2021. It takes a long time sometimes to get things done in government, but we managed to get it done. Congratulations, Susan, on your appointment to this important new role.

Finally, in a moment of self-congratulation, or rather, congratulation for many people who work in this building and on the main campus of NIH, I want to share the exciting news that this is the National Institute of Mental Health's 75th anniversary year. We were founded in 1949 in the aftermath of World War II, with the recognition that mental illnesses were afflicting many, many Americans at that time, especially those who returned from war. We have a full year of events planned to celebrate the accomplishments, the achievements, and what remains to be done to help those with mental illnesses of all sorts. I want to commend you to visit our web page for this, nimh.nih.gov/75years -- that's the number 75, and the word years -- to find out more about the events we have planned.

Turning to today's agenda, we have some very informative and hopefully really engaging presentations on the agenda today. We're first going to hear from the Department of Labor to recognize October as National Disability Employment Awareness Month. We'll also hear an update from our newly appointed National Autism Coordinator and have a round-robin with committee members this morning, followed by the IACC committee business. This afternoon, we'll hear several presentations on the topic of mental health and autism. We will have presentations about mental health research, as well as mental health services that are available for individuals with autism who all too frequently suffer from comorbidities of a number of different kinds in the mental health space. We'll also hear from a panel of individuals sharing their lived and professional experiences with mental health in the context of autism.

Coincidentally, yesterday, October 10th, was World Mental Health Day. It was also my daughter's birthday, by the way. Happy birthday to my daughter yesterday. World Mental Health Day is designated by the World Health Organization. And we share their goal of improving knowledge, raising awareness, and driving actions that promote and protect everyone's mental health. So, I think it's suitable that today, in the afternoon, we will focus on the mental health of individuals with autism. So, that's my way of introducing the meeting. Again, welcome to everyone. I'm going to turn it over to Susan for opening remarks, roll call, et cetera. Susan?

DR. SUSAN DANIELS: All right. Well, thank you so much. It is really exciting to welcome you in person to this meeting. It's been a couple of years since the IACC has been able to meet in person. And this is the first time for this particular group to be meeting in person. And we also have people virtually on Zoom that are participating in the meeting. And welcome to our public audience. We are excited to be here and recognizing the important topic of mental health. And we’ll also be talking about National Disability Employment Awareness Month being addressed by the U.S. Department of Labor today. So, I am going to make a few housekeeping announcements. For people who are on Zoom, we encourage you to participate in the meeting. Please raise your hand in Zoom. We have people from our team watching the Zoom channel, and they will be letting us know when somebody wants to speak. We also welcome you to put in a message to ‘send comments here’ as the title. And I'll introduce some staff who are at the table with me. I have Dr. Oni Celestin to my left who will be helping me out with Zoom and also just keeping track of certain things in the meeting, and Steven Isaacson, who is going to read aloud any comments that are sent in the chat. Behind me also on both sides are the Office of National Autism Coordination staff, and they are behind the scenes helping to make sure this meeting goes smoothly, as well as our contractor, Rose Li & Associates, and the NIH team here. So, we welcome you. We will now go ahead, and I will take a roll call so that especially people who might be watching us through NIH VideoCast will know who's here. So, first, Joshua Gordon.

DR. GORDON: I'm here.

DR. DANIELS: Diana Bianchi -- or Alice Kau?

DR. ALICE KAU: Alice Kau is here.

DR. DANIELS: Thank you. Amanda Bryans for Administration for Children and Families? Mitchell Berger or Anita Everett?

MR. MITCHELL BERGER: Yes, Mitchell Berger, SAMHSA, present.

DR. DANIELS: For SAMHSA. Thank you. Tiffany Farchione?

DR. TIFFANY FARCHIONE: Tiffany Farchione, Food and Drug Administration.

DR. DANIELS: Thank you. Maria Fryer? And I think Maria is going to be joining us a little bit later. Elaine Hubal or Rebecca Dzubow? And I think Rebecca is going to be joining us a little bit later, from EPA. Jennifer Johnson?

DR. JENNIFER JOHNSON: Here.

DR. DANIELS: Oh, hi, Jennifer, from the Administration for Community Living. And

Kristina Hardy?

DR. KRISTINA HARDY: Hello, I'm here.

DR. DANIELS: From the National Institute of Neurological Disorders and Stroke of the NIH. Leah Lozier?

DR. LEAH LOZIER: Good morning. Leah Lozier from the Department of Housing and Urban Development or HUD.

DR. DANIELS: Thank you. Alison Marvin?

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

DR. DANIELS: Thank you. Matthew Miller or Scott Patterson, from the Veterans Administration? Kamila Mistry or Justin Mills from AHRQ? Stuart Shapira?

DR. STUART SHAPIRA: Yes, good morning. Stuart Shapira from Centers for Disease Control and Prevention.

DR. DANIELS: Welcome. Lauren Ramos?

MS. ROBYN SCHULHOF: Hi, this is Robyn Schulhof, sitting in for Lauren, from HRSA-MCHB.

DR. DANIELS: Thank you, Robin. Barbara

Roland from Indian Health Service?

MS. BARBARA ROLAND: Good morning. This is Barbara Roland. I'm the mental health branch chief for the Department of Behavioral Health at IHS. Thank you.

DR. GORDON: Welcome to the committee, Barbara. Glad to have you on board.

MS. ROLAND: Thank you.

DR. DANIELS: Thank you. Yes, welcome. Jodie Sumeracki or Melissa Harris from Centers for Medicare and Medicaid Services? Dr. Jane Simoni? Welcome, representing the NIH Office of Director. Judith Cooper?

DR. JUDITH COOPER: Good morning. I'm present, and representing our director of the National Institute on Deafness and Other Communication Disorders, Deb Tucci, who's away.

DR. DANIELS: Thank you. Larry Wexler?

DR. LARRY WEXLER: Here.

DR. DANIELS: And from the Department of Education, Nicole Williams?

DR. NICOLE WILLIAMS: Hi, all. This is

Nicole Williams with the Autism Research Program.

DR. DANIELS: At the Department of Defense. Taryn Mackenzie Williams or Scott Michael Robertson or Anupa Geevarghese?

MS. ANUPA GEEVARGHESE: Anupa Geevarghese is here.

DR. DANIELS: Thank you, thank you.

DR. SCOTT ROBERTSON: And for the rest of the meeting after Anupa's remarks, this is Scott Robertson. I'm also signed on from the Office of Disability Employment Policy.

DR. DANIELS: Wonderful. So, yes, U.S. Department of Labor, we're looking forward to hearing from you later. Richard Woychik or Cindy Lawler?

DR. CINDY LAWLER: This Cindy Lawler, alternate for Rick Woychik, National Institute of Environmental Health Sciences. Good morning, everyone.

DR. DANIELS: Good morning. Maria Mercedes Avila? Alice Carter?

DR. ALICE CARTER: Here.

DR. DANIELS: Thank you. Do you want to say where you're from for our audience?

DR. CARTER: University of Massachusetts Boston, Department of Psychology.

DR. DANIELS: Thank you. Sam Crane? Aisha Dickerson?

DR. AISHA DICKERSON: Aisha Dickerson here from Johns Hopkins Bloomberg School of Public Health, Department of Epidemiology.

DR. DANIELS: Thank you. And Thomas Frazier?

DR. FRAZIER: Here.

DR. DANIELS: Thank you. Dena Gassner?

MS. DENA GASSNER: Dena Gassner. On a personal point, I didn't make the round-robin to announce this, but my dissertation defense was accepted for my dissertation. So, I'm excited.

DR. GORDON: Congratulations to you. That's fantastic, Dena. Or should I say, Dr. Gassner.

DR. DANIELS: Yes, congratulations. Morénike Giwa Onaiwu? Alycia Halladay?

DR. ALYCIA HALLADAY: Hi, I'm Alycia Halladay [inaudible comments] --

DR. GORDON: Just a quick note on these, only a certain number of them can be on at once, so be sure to turn yours off when you let go.

DR. DANIELS: All right. Craig Johnson?

MR. CRAIG JOHNSON: Good morning. Craig Johnson from Champions Foundation for special needs individuals and families.

DR. DANIELS: Thank you. Yetta Myrick?

MS. YETTA MYRICK: Good morning, everyone. Yetta Myrick here from DC Autism Parents, and I'm also a parent.

DR. DANIELS: Thank you. Lindsey Nebeker?

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

DR. DANIELS: Thank you. Jenny Mai Phan?

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

DR. DANIELS: And do you want to say where you're from?

DR. PHAN: Hi, I'm a self-advocate mother of four children, and a researcher at Children's National Hospital.

DR. DANIELS: Thank you. JaLynn Prince?

MS. JALYNN PRINCE: JaLynn Prince from Madison House Autism Foundation, a parent, and heading work with the first -- foundation to look at all of the lifespan issues collectively, and trying still to help coordinate many of those things.

DR. DANIELS: Camille Proctor? Susan Rivera?

DR. SUSAN RIVERA: Good morning, everyone. Present, and I'm from the University of Maryland.

DR. DANIELS: Thank you. Matthew Siegel?

DR. MATTHEW SIEGEL: Good morning. Matthew Siegel, Tufts University, and Maine Medical Center.

DR. DANIELS: Ivanova Smith?

MS. IVANOVA SMITH: Hello, my name is Ivanova Smith. I live in Washington State, and I am a self-advocate public member.

DR. DANIELS: Thank you. Hari Srinivasan?

Hari is having some power issues at his house, and will hopefully be on in about a half hour as soon as he commutes into college.

DR. DANIELS: Perfect. Thank you. Helen Tager-Flusberg?

DR. HELEN TAGER-FLUSBERG: Hi. Good morning, everyone. I'm Helen Tager-Flusberg from Boston University.

DR. DANIELS: Thank you. And Julie Lounds Taylor, I believe, is not here, because she has a UCEDD meeting this morning, I believe. So -- but she will be catching up with us later. Paul Wang?

DR. PAUL WANG: Good morning. Paul Wang, public member from the Simons Foundation.

DR. DANIELS: Thank you. And did I miss anybody?

MR. STEVEN ISAACSON: Good morning. Morénike is online.

DR. DANIELS: Oh, Morénike, would you like to say hello?

DR. GORDON: Thanks for attending,

Morénike. I know that you like to communicate via the chat, so we'll look forward to having your contributions however you like to provide them.

DR. DANIELS: Wonderful. So, that completes our roll call. We again welcome you all. And as you're seated in the room, if there's anyone that's toward the end of the table and you see open seats that are empty -- I'm not sure if all those folks are coming -- feel free to swap and move in closer to this side of the table if you wish, or you can stay where you are. So, that concludes our roll call. I now am going to turn our attention to the minutes from the last meeting that we had in April 2023. You've all received a copy of the draft minutes. We posted them online in the meeting materials. And I wanted to see, at this moment, does anyone have any concerns about the minutes or anything that you thought needed to be corrected in the minutes? Not seeing any. Can I get a motion on the floor to accept the minutes as they're written?

MS. MYRICK: This is Yetta. I'll put a motion on the floor.

FEMALE SPEAKER: Second.

DR. DANIELS: And we got a second. All in favor of accepting the minutes? You can physically raise your hand if you'd like, and on Zoom, you can raise your hand on Zoom. All right. Anyone opposed to accepting the minutes or anyone abstaining from commenting on the minutes? All right. Well, the motion carries to accept the minutes, and we will get those posted right after the meeting. And since there are no changes, it's exactly the same as the draft minutes that are currently on the website. And I'd like to remind everyone that is joining us online or even here in the audience or at the table, all the materials for this meeting are online on the IACC website. You just navigate to the Meetings tab, go down to the meeting that's happening this date, and there's a whole long page with everything you need for this meeting and access to all the PDFs, all the information about our speakers, their bios, and all that. So, you can access that all online, and feel free to find that. So, with that, I'm going to turn it back over to Dr. Gordon.

DR. GORDON: All right. Thank you very much, Susan. Now, we're going to get right into the program. With no further ado, it's my pleasure to introduce Ms. Anupa Geevarghese, the chief of staff in the Office of Disability Employment Policy at the U.S. Department of Labor. Ms. Geevarghese will be sharing a few words with us in recognition of National Disability Employment Awareness Month. And I'm sorry, I mispronounced that. It's Geevarghese. Thank you very much for coming to us today and for giving us an update on employment awareness for disability and individuals with autism.

MS. GEEVARGHESE: Thank you so much. Good morning, everyone. My name is Anupa Geevarghese. I am a brown woman with black bangs, wearing a silver necklace and a blue dress. And behind me is actually the background for this year's NDEAM, which is a series of multicolored arrows and people with various disabilities smiling in boxes, and the words "Advancing Access and Equity." I am the chief of staff for the Office of Disability Employment Policy at the Department of Labor. I want to start my remarks by thanking Dr. Gordon and Dr. Daniels and members of the Interagency Autism Coordinating Committee for inviting me to speak today on behalf of Assistant Secretary Taryn Williams. For those of you who are not familiar, ODEP is the only non-regulatory federal agency that promotes policies and coordinates with employers at all levels of government to increase workplace success for people with disabilities. Our mission is to develop and influence policies and practices that increase the number, and, I must stress, the quality of employment opportunities for people with disabilities. And ODEP is working every day to improve access and opportunities and advance workforce inclusion for diverse people with disabilities through policy change, research, outreach, and technical assistance. Now, part of our work is to promote awareness of the importance and benefits of disability-inclusive workplaces. So, I am excited to promote National Disability Employment Awareness Month, or NDEAM. We have actively celebrated the inclusion of workers with disabilities in October since 1945, when Congress established a week-long celebration that year. This eventually gave rise to our month-long celebration of National Disability Employment Awareness Month in 1988. This year's NDEAM theme of advancing access and equity builds on our theme commemorating the 50th anniversary of the Rehabilitation Act of 1973, which theme was advancing access and equity, then, now, and next. The Rehab Act was the first piece of legislation that guaranteed access and equity for people with disabilities. This year's NDEAM theme also matches the IACC's emphasis on support for diversity, equity, inclusion, and accessibility in your recently released Strategic Plan. I am so proud of the historic commitment the Biden-Harris administration has towards improving accessibility for job seekers and workers, including people with disabilities. When President Biden issued Executive Order 14035 on Diversity, Equity, Inclusion, and Accessibility in the Federal Workplace, it was the first time that broader DEI efforts for the federal workforce emphasized disabilities by adding the A for accessibility. And we have prioritized our commitment to DEIA through our engagement to ensure the administration's historic funding of Investing in America creates and sustains good jobs for workers with disabilities, including neurodiverse workers. We recognize that people who are neurodivergent, including people on the autism spectrum, face major work barriers, and they may find it challenging to attain and maintain jobs and pursue careers that can fit their strengths, talents, skills, and interests. Many autistic people unfortunately remain underemployed or unemployed, and they cannot access needed work accommodations and supports for job and career success. ODEP's Employer Assistance and Resource Network on Disability Inclusion, or EARN, for short, works to address these issues, and has worked as our policy development and technical assistance center for employers. For instance, EARN's website offers a guide to neurodiversity in the workplace for employers. This guide highlights our organizational employee benefits for neurodiversity at work and approaches and practices for management, mentoring, and peer training. It also describes hiring and recruitment programs for neurodiversity at work in the federal government and private sector. Another TA center, the Job Accommodation Network, or JAN, supports workers and job seekers with disabilities, employers, and service providers. Specialists at JAN provide free confidential and expert guidance on work accommodations. JAN's website at askjan.org features an A-to-Z guide on work accommodations. And this guide includes a dedicated page on neurodiversity, as well as specific disabilities, such as autism, intellectual disabilities, and mental health conditions. In April, JAN hosted a webinar on accommodations solutions for neurodivergent workers in its training series, and this webinar is archived online. ODEP's project on Research Support Services for Employment of Young Adults on the Autism Spectrum, or REYAAS, also continues to investigate key issues to improve access to jobs and careers, and address barriers impacting young adults on the autism spectrum. In April, the REYAAS project released a report on the use of federally and state-funded vocational rehabilitation services by autistic young adults. Additionally, the REYAAS website contains reports from prior listening sessions and literature reviews on programs, models, and strategies, and evidence of effectiveness. ODEP's activities to help support mental health and empowerment of people with mental health conditions also play a crucial role in our overall engagement to foster neurodiversity at work. And we are delighted that IACC is hosting sessions on mental health research and perspectives on mental health needs of autistic people this afternoon. In May, the Department of Labor launched a webpage with resources to help cultivate mental-health-friendly workplaces at dol.gov/mentalhealth. One of the resources highlighted is EARN's Workplace Mental Health Toolkit for employers, which you can find also at EARN's website, askearn.org. This toolkit shares resources and information to support the mental health and wellbeing of all workers, including people with disabilities. It describes strategies for creating a mental-health-friendly workplace and a supportive work culture, such as providing assistance to employees and ensuring access to needed work accommodations and supports. Furthermore, ODEP's project on Advancing State Policy Integration for Recovery and Employment or ASPIRE also advances employment access for people with mental health conditions. This October, I encourage you to help promote inclusive access to employment and career pathways for people with disabilities by hosting NDEAM events. And remember, NDEAM is not just October; it can be every single day. So, please visit ODEP's webpage for NDEAM information at dol.gov/agencies/odep/initiatives/ndeam, or Google ODEP-NDEAM. To download the NDEAM poster in English and Spanish, you can also watch a great video commemorating NDEAM and find NDEAM resources. Thank you, all, for supporting inclusive employment and careers for people with disabilities, including autistic people, to help improve economic wellbeing and quality of life. Thank you so much.

DR. DANIELS: Thank you so much for your remarks. We really appreciate it. And we in the Office of National Autism Coordination and the IACC are -- we also have a webpage that is devoted to NDEAM resources. And you can find that on the IACC website. We've also joined the celebration of NDEAM, and really appreciate the important work the Department of Labor is doing. I know that on our website today, we do have some of those resources listed. And if there were any additional ones that were mentioned today, we can add those on. But thank you so much for being with us today. And I heard that Matthew Miller is now on for the Veterans Administration.

MS. SAM CRANE: And this is Sam Crane as a public member. I'm also now on.

DR. DANIELS: Thank you. Anybody else that has joined late and missed the roll call? Want to say hello? All right, then. Well, thank you so much.

We'll move on now to the National Autism Coordinator Update, and I have a few updates to share with you. This is just repeating that now, the National Autism Coordinator has been appointed, and there's some information on this slide for maybe people that are not able to join us for the meeting. There we go. So, I'm going to give you an overview of some different updates, including updates from the White House, federal committees, federal departments and agencies, and non-governmental agencies and organizations. So, for the White House, President Biden issued several proclamations since our last meeting and statements, and I wanted to point you to those. And we have links in the slide set for those who want to access them.

First was the proclamation for National Disability Employment Awareness Month that just came out. There was also a statement from the President about the 50th anniversary of the Rehabilitation Act, and they had a wonderful event up at the White House for that, and the proclamation on the Anniversary of the Americans with Disabilities Act this summer in July. President Biden also announced his intent to nominate cancer researcher and surgical oncologist, Dr. Monica Bertagnolli as the Director of the National Institutes of Health. And we've linked to the announcement there, and we hope that in a future meeting, Dr. Bertagnolli might be able to join the IACC and say a few words. So, I'll give you a few federal committee updates.

So, first, the Interagency Committee on Disability Research, which is managed by the Administration for Community Living, had several different recent activities including webinars on disability cultural competence in healthcare, how did COVID-19 recession impact people with disabilities across America or in rural America, emergency preparedness and the impact of climate change on people with disabilities, disparities in healthcare in Medicare advantage associated with dual eligibility, participatory action research with people with disabilities, and there was also a stakeholder meeting in June. And there's more information on the website, and there's a summary now available for the February 2023 State-of-the-Science on Disability Statistics. Also an update from the RAISE Family Caregiving Advisory Council -- they met in July 2023 and had a joint kickoff meeting for the new council that's been appointed, and met jointly with the Advisory Council to Support Grandparents Raising Grandchildren. And they focused on public comments and implementation of the national strategies to support family caregivers. The National Council on Disability, which is a federal agency devoted to disability issues, had a recent NCD council meeting -- or they have an upcoming one in November 2023 that's going to be focused on housing and transportation. They also had a quarterly business meeting, an ADA anniversary event that is recorded, if you want to watch that, and a new report on the impacts of extreme weather events on people with disabilities. And that is posted on the IACC website in case anyone wants to access it. We have a section on disability reports as well as a section on specific autism reports on the website. The Federal Partners in Transition, which is a voluntary all-federal working group that's managed by U.S. Department of Labor focuses on transition-age youth issues for people with disabilities. Their recent activities include a steering committee meeting, a general meeting, and they're continuing to work on a Strategic Plan that would address issues for youth with disabilities. The Interdepartmental Serious Mental Illness Coordinating Committee managed by the Substance Abuse and Mental Health Services Administration had a -- they have a meeting upcoming on October 18th. And we've provided the information here if anyone wants to access that meeting. The Disability Advisory Committee of the Federal

Communications Commission had a September 2023 committee meeting, and we provided a link to the video and agenda. And the topics that they covered were disability rights, AI accessibility (artificial intelligence accessibility), and audio descriptions. The President's Committee for People with Intellectual Disabilities managed by the Administration for Community Living had a meeting in May 2023 focused on the needs associated with aspects of home and community-based services, including the shortage of direct support professionals and the needs for employment and community living services. And you can access the recording on the link that's on this slide. And all these slides will be posted after the meeting so people can access them. The National Advisory Committee on Individuals with Disabilities and Disasters that's managed by the Department of Health and Human Services' Administration for Strategic Preparedness and Response had a meeting in September 2023. It was a joint public meeting with the National Advisory Committee on Seniors and Disaster to discuss respective reports. And the recommendations from both those committees are available on the links provided there. The Coordinating Council on Access and Mobility -- and this is managed by the Federal Transit Administration in the U.S. Department of Transportation -- their recent activities included an October 2022 council meeting, and they approved a new Strategic Plan. And that, I believe, is posted on our website as well. If it's not, then we will post it shortly, and it will be available for you. And in November 2022, they have an upcoming webinar to talk about the Strategic Plan, if you want to learn about its content. The Interagency Task Force on Trauma-Informed Care that's managed by SAMHSA, Substance Abuse and Mental Health Services Administration, and that talks about families impacted by substance use disorders and other forms of trauma. They had a report that was published in November 2021, the National Strategy for Trauma-Informed Care Operating Plan, which we haven't mentioned in the committee before, but wanted you to be aware of that -- related to our discussion for this afternoon. And then I will move into some federal agency updates. And so, with the committees -- the purpose of sharing all of that with you is, as a federal advisory committee, we don't want to be duplicative with any other federal committee. And as you can tell, there are lots and lots of federal committees, and many that do work related to disabilities. And so, it's important for you to be aware of that. And we want to be coordinating and complimenting the efforts of other agencies' federal advisory committees. Sorry, I'm having a little bit of trouble advancing slides.

So, an important announcement that has taken place at NIH is that NIH designated people with disabilities as a population with health disparities. And this was a very important decision that was made in September 2023 by the National Institutes of Health and the National Institute of Minority Health and Health Disparities. And this means that people with disabilities have been designated as a population with health disparities. That will enable research on these issues. And there's a press release that's linked here. And also, the NIH issued a notice of funding opportunity, calling for research applications that are focused on the intersecting impact of disability, race and ethnicity, and socioeconomic status on health care access and health outcomes. Next slide. So, in addition, the NIH issued a request for information -- or this is like a request for public comments -- on a proposed update to the NIH mission statement. And the deadline for those comments is November 24th. I'd encourage the committee to look at that, and anyone who's in this listening audience who is interested in the NIH mission statement. And the following change is proposed -- they want to change it to seek fundamental - oh, sorry, the old one is "To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to -- enhance health, lengthen life, and reduce illness and disability." And they're suggesting a change to, "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people." And the acting director of NIH, Dr. Larry Tabak, posted a blog about this, and we have a link to the blog there. But I'd encourage anyone who's interested to check out that request for information and submit your comments.

In addition, the I/DD Counts National Summit Report highlights health data as an equity issue, and -- in November 2022. The ACL initiative organized a national summit on this, and there's a report now that you can read about the outcomes from that. In addition, HHS issued a new proposed rule to strengthen prohibitions against discrimination on the basis of a disability in health care and human services programs. And this was an announcement of the Biden-Harris administration. And it is a part of the 50th anniversary of the Rehabilitation Act. And the Office of Civil Rights announced a proposed rule that will prevent discrimination on the basis of disability in any HHS-funded health care and human services programs. So, we've linked to the release there for that item. In addition, the Centers for Medicare and Medicaid Services have taken action to protect health care coverage for children and families, and were successfully able to encourage states to make sure that individuals who may have been inadvertently dis-enrolled for Medicaid or the Children's Health Insurance Program -- to ensure that they're reinstated. And to date, nearly half a million children and families from 30 states are going to be regaining their coverage. So, the press release is linked there. Next slide.

The U.S. Department of Justice also has advanced a proposed rule to strengthen web and mobile app access for people with disabilities. And there is a federal register notice on this proposed rule, and it's inviting public comment. Oh, sorry, it just ended, October 3rd, the public comments for that. But that rule is in process. Next slide. And next slide.

To talk about some non-governmental activities, this past June, there was a recent conference, the 16th session of the Conference of States Parties to the Convention on the Rights for Persons with Disabilities at the United Nations in New York. And I was able to be a part of this event that was sponsored by the Autism Alliance of Canada. And it was an autism-focused event called, "Challenges, Best-Practices, and a Way Forward: Looking at National Autism Strategies through the lens of the CRPD." And they had representatives of a number of countries that shared what they are doing to develop national autism strategies for their populations, and how those align with the CRPD and protection of human rights for people with disabilities. And I was able to speak on the IACC's Strategic Plan. And ours is the first Strategic Plan in the world for autism. It's been around since 2009. And so, I was able to share what our new Strategic Plan was shaping up to be. And there were several other countries that are aiming to get a Strategic Plan put together, including Canada, which had recent legislation to create a national strategy. And Australia is working on theirs, and the UK has one. Yetta?

MS. MYRICK: Real quick question, Susan. Did they provide any feedback when you presented on our Strategic Plan? Like, were any thoughts shared?

DR. DANIELS: It was a panel. I only had a few minutes to present, so it wasn't very long. And unfortunately, the recording didn't turn out. So, it's not something that can be watched again. But it was a great presentation. And perhaps we would be able to put something together to do another form of this type of presentation, because it was really informative, hearing from a number of countries, and really looking at how our plan actually does hit most of the main points of the CRPD, even though we didn't exactly design it on purpose that way. But in our country, we have a whole network of disability rights legislation that are also our foundation in the U.S. But it was interesting to see how this compared with the strategies of other countries. And of course, here in the U.S., we want to be supportive of every country that is trying to put together a strategy for autism. And our office will certainly be a part of discussions with others that want assistance or have questions about that. But excited that we have a new national Strategic Plan that is out on the street now. So, this was an exciting event.

And also, I wanted to mention the INSAR meeting that took place in May, since we haven't met in a while. That was in Stockholm, Sweden. It was a wonderful meeting with autism researchers from around the world. And there were some keynote presentations that are listed there. And several people around this table were there. We may not have seen each other here at the IACC, but we saw each other in Stockholm. And I'd encourage you to check out anything on the INSAR website about updates from that meeting. The next one is in Melbourne, Australia, next May. There was also the recent conference on the Stanford Neurodiversity Summit 2023 that happened last week. And the topics included employment, mental health, higher education, K-12 education, and human rights. And this is always an outstanding conference with people from around the entire neurodiversity community. And I know there were people around the table who spoke, and I was able to speak at this meeting. And it was just a wonderful meeting, and I'd encourage you to check out online the recording if you weren't able to attend. Also upcoming is the OCALI online conference, which is also a large conference with a lot of wonderful presentations on neurodiversity-related issues and autism-related issues. And I'll be sharing some of our work on the Strategic Plan at this conference to help disseminate that. The next slide.

A report on healthcare experiences during the COVID-19 pandemic -- that is a new national autism indicators report. I encourage you to look at that, released by the researchers at the A.J. Drexel Autism Institute's Policy and Analytics Center. Next slide. So, that concludes the update. Does anyone have any questions about anything I've mentioned? So, I just wanted to give you that overview, because there are just so many exciting activities happening across the autism community. And it's hard to keep up with everything, so I wanted to give you an overview of some of the highlights since the last meeting. And so, we have moved round-robin up to this section of the meeting to give you a chance now after just hearing those updates to share your updates. So, I'll turn it over to Josh.

DR. GORDON: Hi. Let me just reiterate, if there's any questions for Susan, we'll just pause for a moment, allow people either online or in presence to raise them. Thank you, Susan, for the thorough update. I mentioned earlier, we have one item that we wanted to share from the National Institute of Mental Health. I'll take the chair's prerogative to present that first. And then I believe we have some others as well, people who want to, to make sure they have the chance. Sam, you raised your hand. Is that to provide an update or to ask a question of Susan?

MS. CRANE: Just an update.

DR. GORDON: Okay. We'll get you right

next, okay?

MS. CRANE: Okay.

DR. GORDON: So, if I could have the slides that have been prepared. I mentioned earlier that this is the 75th anniversary of the National Institute of Mental Health. So, I just want to provide a little bit more detail for those following along regarding some of the events that you can attend and other items that you can look forward to. Next slide. Starting last month, we began a year-long celebration of 75 years of transforming the understanding and treatment of mental illnesses. To mark this milestone, we planned a variety of activities including symposia, sessions at scientific meetings, lectures, and also media that share stories, discoveries, and inspiration. We have a number of podcasts that we will be releasing throughout the year, video messages, stories about science that has been accomplished, as well as stories about science that needs to be focused on for the future. Again, we have a website that details all this information, nimh.nih.gov/75years. You can subscribe to the NIMH email updates on our website or follow us on social media to stay up to date as we add new items throughout the year. Next slide. I think that's it.

And with that, we will go into the round-robin. We'll go ahead and start with Sam Crane. And if anyone in the room is not on Zoom and wants to raise your hand if you have an item, I will note it down, and we'll put you in order. Go ahead, Sam.

MS. CRANE: So, the main thing that I wanted to share from Quality Trust is that we have just been awarded continuation of our grant from the Office of Violence Against Women to develop best practices to support people with intellectual and developmental disabilities, both men and women, who have survived sexual violence. And hopefully, that can include appropriate education to recognize both healthy sexual relationships and inappropriate, or, you know, either abusive, non-consensual, or exploitative relationships. So, we're really excited about that, and we'll be soon releasing the report from the first round of that grant soon. So, keep an eye out.

DR. GORDON: Thank you, Sam. Next, I'm going to turn in the room here to Paul.

DR. WANG: Thank you Josh. I just wanted to follow up on an item from our last meeting in April, and as reflected in our minutes. We received public comments about a proposal related to the training of pediatricians. There had been a proposal from the ACGME accreditation council on graduate medical education to eliminate the requirement that the pediatric faculty include a board-certified developmental behavioral pediatrician and to eliminate the requirement for "adequate exposure" to typical development longitudinally, and to the development of children with special health care needs. There were public comments, there was, I think, also strong advocacy from the members of this committee that those changes would really be detrimental to the care of children with autism. And in fact, the committee issued a statement to the ACGME about that, and reflected on the fact that our Strategic Plan also touches on this issue and the importance of -- and then of course, this recent NIH announcement that it is recognizing individuals with disabilities as being affected by health care disparities. So, a partial win -- the ACGME retracted the deletion. So, they will still require having a developmental behavioral pediatrician on the faculty for pediatric residencies, but they are, in fact, deleting that requirement for "adequate exposure" to typical longitudinal development in children with special health care needs. Honestly, I think pediatricians in training have never quite gotten fully adequate exposure. Pediatricians continue to learn a lot in the early years after their residencies have concluded, and they will continue to do so, I hope. But the advocacy of this committee was certainly an important part of the change of the ACGME plans.

DR. GORDON: Thank you, Paul, and thanks to the entire committee for pushing on this. I think it was at the last meeting. And thanks to Susan and her staff for following through over the next several days to put out a statement on our behalf. Yetta, I'm going to move to you. Thank you. Larry, I see you.

MS. MYRICK. Thank you. And I agree with what you're saying, Paul, about pediatricians. I know that from my own experience that I've had to basically support my son's pediatrician through the years in helping him to support other families, because they don't have that knowledge. And I'm just really excited that we were able to push that through. So, I just wanted to say that. On another note, I'm really excited to share that through work with Dr. Allysa Ware at Family Voices, we recently published a white paper and an executive summary about the work that we have done that was funded through Patient-Centered Outcomes Research Institute, Eugene Washington Award. And the title of this work is a patient-centered autism research agenda to engage the African American community. So, over the last two years, we have really worked to engage over 200 stakeholders, researchers, self-advocates, family members, providers, community providers all across the country, and they really helped us to shape what this research agenda is. And we're really, really excited about it. So, just to give you an outline of what is included, there are three key strategies for researchers to ensure their research is culturally responsive and relevant to the African American community. It provides equal opportunities for African Americans to participate, and considers how research results will be shared back with the community in ways that are accessible and actionable. So, again, I want to share my appreciation to be a part of that work and co-working that work for the last few years, and hope that you all will take the time to review it and read it and adopt some of these things in your work, if you're not already doing so. So, thank you for giving me the table.

DR. GORDON: Thank you, Yetta. That's fantastic, and I look forward to being able to share that with our NIMH researchers broadly. Scott Robertson, we're going to move next to you.

DR. ROBERTSON: Yeah. Thanks, Dr. Gordon. Sorry that I -- I should have sent these in a written form. So, after the meeting, I'll make sure to get the links for these. I just have a few brief updates for National Disability Employment Awareness Month. I just want to reiterate that we have a website for that at ODEP, and we have a blog post from Anupa, who spoke earlier, with remarks on NDEAM. For National Hispanic Heritage Month, we have a blog post from my colleagues at ODEP on "Data Spotlight: Employment of

Hispanics with Disabilities in Skilled Trades Professions." So, National Hispanic Heritage Month is going on right now. It ends, I believe, on the 15th. Our Research Support Services for Employment of Young Adults on the Autism Spectrum project, as was mentioned, has a report that was released on vocational rehabilitation services. I'll make sure the links for that is in the brief updates. And also, National Apprenticeship Week is happening next month. So, our Partnership on Inclusive Apprenticeship, whose website is inclusiveapprenticeship.org, is going to be emphasizing that month, and how apprenticeships support inclusive career pathways for people with disabilities, including neurodivergent people such as autistic people. Thanks.

DR. GORDON: Thank you, Scott. Alison.

DR. MARVIN: Good morning. I'm just going to briefly summarize SSA highlights from the round-robin document, which includes all the relevant links. First, our multi-year

Supported Employment Demonstration project has concluded. Findings show significantly higher employment rates for those who receive the intervention. The reports and public use files are now available. Second, congratulations to the six applicants who have been selected for the five-year Retirement and Disability Research Consortium cooperative agreement awards. This is a 12-million-per-year award. $12 million per year is split between the partner centers. Third, we have information about Social Security services for the Hispanic community, including links to our Spanish language website, and our many publications in Spanish. Fourth, we're looking for your comments regarding our proposal to revise the time period that we consider when determining whether an individual's past work is relevant for purposes of making disability determinations and decisions from 15 years to 5 years. To ensure your comments are considered, we must receive them by no later than November 28th. And lastly, Social Security's National Disability Forum on youth transitioning to adulthood and preparing for an age 18 redetermination will be held next Wednesday, October 18th, from 1:00 to 3:00 Eastern via Microsoft Teams. Please register by next Monday, October 16th. Thank you so much.

DR. GORDON: Thank you, Alison. Mitch, I saw your hand up. I don't know if it's still up.

MR. BERGER: Yeah, I put the comment I sent to just the send comments now. In addition to the -- you mentioned the Interdepartmental Mental Health Committee.

DR. GORDON: Sorry, Mitch. It's a little hard to hear from -- hear you. Can you get a little closer to your microphone?

MR. BERGER: Yes. We had mentioned in the round-robin the interdepartmental mental health committee upcoming meeting. There's also now an upcoming -- the date for the next Interdepartmental Substance Use Disorders

Coordinating Committee will be December 6. So, I put the link -- I sent the link to the send comments now. We can put that in the minutes for those that are interested in that topic.

DR. GORDON: Thank you. Larry?

DR. WEXLER: Thank you, Dr. Gordon. I work in the Office of Special Education Programs at the Department of Education, and I administer all of the discretionary grants under the Individuals with Disabilities Education Act, as well as all of the data for the up to 7 million children with disabilities, birth to 21. I just wanted to update you that we just made $35 million in personnel preparation grants towards the end of the fiscal year. On any given day, our funds support about 6,000 scholars. We spend about $100 million a year on personnel preparation. These grants were for master's level grants, bachelor-level grants for teachers of generally special education or early intervention teachers, the production of related services personnel, OT, PT, speech, school psychologists, counselors, social workers. We had a separate program for minority institutions that focused on HBCUs, minority-serving institutions, and tribal colleges and universities. We also made a large group of doctoral training grants. Our funds support about 40 to 50 percent of the doctorates that are awarded every year. So, my message is, there's a lot of free money out there right now for scholars. And if you have family, friends, or colleagues who are looking towards degrees in the disability field, it's usually very highly supported with federal funds. And I can tell you they're the finest programs in the country. So, thank you. And you can contact me at larry.wexler@ed.gov. And I'd be happy to hook you up to whomever you're interested in. Thanks.

DR. GORDON: Thanks, Larry. Exciting programs. Stuart.

DR. SHAPIRA: Yes, good morning again.

Stuart Shapira from the CDC, and I have a very brief public service announcement from the CDC. Everyone is likely aware that we are coming up on respiratory virus season, which will include flu and COVID and RSV, without a doubt. And all of these can cause rather serious infections, particularly in the very young and the elderly, in people with chronic health conditions, and in people with disabilities. So, vaccination is the best protection from these illnesses. So, all are encouraged by the CDC to get vaccinated in order to protect oneself and one's family from vaccine-preventable serious infection by these viruses. Thank you.

DR. GORDON: Thank you, Stuart. Any other requests? Alycia.

DR. HALLADAY: Hi. I just wanted to make a couple updates from the Autism Science Foundation. So, one is kind of a continuation of an initiative started at INSAR, which Susan mentioned. We are continuing a special interest group or a group of scientists and stakeholders and advocates around severe, intense, and dangerous behaviors -- so, these are behaviors that can range from things like aggression to self-injury -- are different, or kind of under the rubric of repetitive and restricted behaviors, but are qualitatively different. So, if anyone is interested in joining that, they can email me. My email is somewhere on the IACC webpage, I think. And the other thing is, I don't know how many people know that we are partnering with the Els for Autism Foundation on an initiative specifically for siblings. So, I know that siblings sometimes are kind of the unsung heroes of the autism community. And they all feel -- or most of them, I've found, feel that they are kind of isolated and alone. So, we've created something a little bit different than, say, Sibshops, but it's more of an online networking. And then also, they -- we have scientific speakers that talk about research and are informed by what siblings think should be researched. So --

oh, and before I forget, we have pre- and postdoctoral fellowships. They are due in early December. So, please look on our website and apply.

DR. GORDON: Thank you very much. We are right on time. Go ahead, Jen. And JaLynn, I’m going to ask you to be very brief so that we don’t run late. Jennifer and JaLynn, sorry. Both.

MS. PRINCE: JaLynn Prince with Madison House Autism Foundation. And Susan, your comments at the summit were absolutely remarkable, and you shed a lot of light on the IACC. Thank you. And I do want to mention to Stuart, I've lived with the developer of vaccines for children and the treatment for RSV for over 40 years. Yes, it's serious, and I'm glad you're putting that wording out there. It is very, very important. We are currently working on a pilot program in the state of Utah, which is yielding some very, very interesting results. We have publications on our first findings, knowing where we need to go broader and deeper. We have housing report out of the -- out of Salt Lake, which should translate to many of the other municipalities of similar populations. But the research that we are doing, collecting data, because there's so little on adulthood, we're trying to get information that we can empower legislators, lawmakers, on all levels about the facts in the lives of adults with autism, the experience that their families are having, and where the needs actually are, rather than some of us sitting around a table guessing at what some of those needs may be. It's been a very interesting thing, and we're going to be making all of these things available to the nation, and if there are municipalities or states who want to do things. We're finding a great empowerment. The governor of the state has endorsed everything that we are doing. And we are finding great power in educating thought leaders, including legislators on the state level, national level. And also locally, we're dealing with mayors and county council individuals, and informing parents about some of the things that they could facilitate within their communities and making certain that they're talking to one another. So, it's a rather unique situation to do that, along with some very heavy information along the way. But it is looking at the issues of adults with autism and other neurodiversities. We are working very hard with our specialty in housing, because the rate of homelessness is estimated to be upwards of 20 percent and more, if you include neurodiversities of the homeless population. We're working on not only addressing the current situation, but trying to prevent homelessness in the future. And it's going to take into consideration many things and the expertise of many of you around the table. And I would like to talk to anyone who is interested in this. And we're working with urban, suburban, rural, and Native American communities to gather data.

Thank you.

DR. GORDON: Jennifer?

DR. JOHNSON: I just wanted to provide a few updates from the Administration for Community Living. And to Stuart's point about vaccinations, our grantees continue work to assist people in getting vaccinated, not only for COVID, but other viruses that oftentimes happen in the fall. So, as part of that effort, we recently launched an enhanced website for the Disability Information and Access Line, where any member of the public can go on the site to search for their state or local ACL program, disability program. So, that is a new resource that's available to members of the public. The Administration on Disabilities and ACL also awarded several projects at the end of September that I wanted to highlight. One very large project that we are getting started on is called the National Center for Disability Grassroots Advocacy. And this project is designed to get information and resources into the hands of people with disabilities so that they are better informed to be able to then better advocate for themselves. We will have specific areas of focus, but some of the areas of focus will be on the HCBS Settings Rule and issues related to housing, but also other areas of advocacy in terms of health and safety in the community, as well as the direct care workforce. The project will be designed in a way to also connect these grassroots advocates to state entities, as well as national entities, as well as other grassroots advocates at the local level. We've also awarded a project that will be looking at peer-to-peer support models for augmentative and alternative communication to increase the use of augmentative and alternative communication for those who are potential users, but may not be using it, because there might be either gatekeepers that are preventing them from using it, or they just don't have enough exposure to it. And working with peers might help with that exposure and help with the adoption of using AAC. And then lastly, we awarded a contract to provide both logistical and planning support for our I/DD counts initiative, which is to get better health surveillance and prevalence data on the I/DD population. There's an element of this that we're funding with our partners from CDC to look at establishing a center for excellence on data on the I/DD population. So, I'm glad that we're able to continue that work with that additional support.

DR. GORDON: Thank you very much. We're going to now take a break.

DR. DANIELS: Yes. And I also just wanted to point out that we have a written document with round-robin updates that were submitted by all of our members. And so, for anyone who's watching this meeting online or anyone who is here at the table, you can also read through those updates, and we provided links. And after the meeting, we often update that document based on what was shared at the table too. So, just go back to that as a resource. And if there's something that you heard here and you didn't catch it, you can always write to our office as well to get the information. So, yes, we'll go on break. Thank you.

(Short Break)

DR. DANIELS: Okay. We're ready to get started with IACC committee business. Next slide. So, an overview of what we're going to be talking about today are the IACC Strategic Plan, the Summary of Advances, and planning for future projects. Next slide. So, first, I'm very happy to announce that the new 2021 to 2023 IACC Strategic Plan has been released. And you may have received the email or seen announcements on social media. But this was just released recently. And as a reminder just of the past activities, the IACC have voted to approve the IACC Strategic Plan in January at the full committee meeting that took place at that time. And now, this IACC Strategic Plan is posted on our website, along with an easy-read version. The regular Strategic Plan is over 200 pages, and the easy-read is 16 pages. So, it's condensed substantially. And these are on our website. You can access them there in PDF. And the plan contains 24 recommendations for activities to improve the health, wellbeing, and outcomes for autistic people with diverse needs across all communities. And it is the most comprehensive Strategic Plan to date. So, congratulations to the committee for ensuring that we covered new areas that had not been covered in previous Strategic Plans. And we, of course, appreciate the new departments that have joined our committee since we started up in 2021, who also added additional details about areas that we need to cover. And we're just very excited to have this plan released to the public. And I will be continuing to do presentations across the community about the Strategic Plan to help people get in touch with it. And we welcome you to share this information as well. And I know I've provided social media graphics to the committee. If you'd like to share it, or if you are going to be speaking somewhere and you want to mention the Strategic Plan and you need some support from our office, just let us know. But thank you so much to members of the committee, to members of the public who shared your input to make this Strategic Plan cover the many diverse needs of the community. So, we're excited to announce that it's out. So, next slide.

And this is just for anybody who might be reading the slide set later, just mentioning that the new Strategic Plan still covers the seven original areas that the old Strategic Plan covered, including screening and diagnosis, biology, genetic and environmental factors, interventions, services and supports, lifespan issues, and infrastructure and prevalence, but also adds a new section on equity and disparities, an expanded section on sex and gender, and a new section on the impacts of COVID-19 on the community. Next slide. And this slide just shares some of the very important themes that are in this new Strategic Plan, including greater acceptance and inclusion of autistic individuals across the community, increased accessibility of services and research for autistic individuals and their families, solutions for people across the entire spectrum, including those with the highest support needs, solutions for people across the entire lifespan, including adults and older adults, solutions to improve physical and mental health for autistic individuals, intersection of social determinants of health and the services system, and the goal to increase equity and reduce disparities. And so, those are some of the main themes. Next slide.

So, this is just an overview of the easy-read version that's available. So, thank you so much for your work on this. Next slide. So, the next item I'm going to turn to -- unless there are any questions or comments about the Strategic Plan.

DR. GORDON: I would just like to make one comment, that, you know, I really appreciate the input from members of this committee who insisted on us developing that easy-read version of the Strategic Plan. I think that's a major contribution that you all have made, so that the members really -- as far across the spectrum of autism as possible of the community -- can understand and see what we are recommending, what all the various organizations that contributed to it are doing. It's really wonderful to be able to have that document. Yetta, you also want to make a comment or a question?

MS. MYRICK: Yes, if I can just add -- so, not this version, because it just came out -- of the easy-read document, but the version before. When Alicia and I were working on our project and have breakout sessions, we used the easy-read documents with the families and self-advocates when we were having conversations. So, I want you to know that it is being used in a lot of different ways. And I'm sure other members will share out with you, but I just wanted to highlight that. I forgot to share there earlier.

DR. DANIELS: Thank you so much for sharing that with us. And we also really welcome feedback on the easy-read version, because this was our first time doing an easy-read of such a big document. And we're open to learning what will be most accessible for people. So, if you're reading the easy-read and you have comments or feedback for us to make the next time we do it better, let us know. Dena?

MS. DENA GASSNER: Yeah, I just want to, first of all, congratulate your crew on putting together such a phenomenal document. I want to thank Josh for putting up with us persisting. I think I'm grateful that you see the value of it. And I did want to suggest one thing. In a PCORI project we're working on, we also use easy-read. But we've also started embedding someone's face in the process, and they talk you through what's in the easy-read. They basically read it to you. So, for many autistic people or people with other kinds of learning challenges, being able to see someone's lips at the same time as you can see the printed document is so helpful. It's baby steps in improvement, but, you know, I'm really happy with what we've done. But that would be one little tweak we might be able to do to make it even more accessible.

DR. DANIELS: That's fantastic. I would love to hear more about that. And perhaps we could put members of the committee to work if you'd like to each read a chapter in some sort of video version. So, we're open to working on that with you.

MS. GASSNER: My helium hand is up.

DR. DANIELS: Excellent. Any other comments about the Strategic Plan? Ivanova.

DR. GORDON: We have some comments online, actually.

DR. DANIELS: Oh, great.

DR. GORDON: Scott.

DR. ROBERTSON: Yeah, I just wanted to say, thank you for having that easy-read version and the supporting accessibility for folks. It is really good best practice, and it's been done increasingly in research in a lot of -- a number of the autism journals have encouraged lay summaries or easy-read versions of technical articles so -- and you see it also in promising practices for supports and services. So, I think it's phenomenal that we have that for the IACC Strategic Plan. And I will probably be seeking to see if I can maybe get permission to maybe be part of reading one of the chapters or whatever out loud. I think that that would also be very helpful for accessibility. So, thank you for the staff at NIH, the ONAC staff, for putting together that easy-read version. And your work on supporting together the Strategic Plan, it's wonderful.

DR. GORDON: Thank you. I think we have a next -- next comment is from Morénike.

MR. ISAACSON: Yes, good morning. Morénike says, "We appreciate the inclusion of a layperson version. I'd like to state that it's not true easy-read, because it's somewhat more high-level than what would be ideal. But it's certainly more of a layperson version." They go on to say, "Incorporating more imagery would be an additional idea to consider, as well as having less content per page, and a larger font. Tremendous appreciation for helping with this."

DR. DANIELS: Thank you so much for those comments. And what I may do after this meeting is reach out by email -- and any members who are interested in giving us some more concentrated feedback on the easy-read, we can just take that into consideration for our next projects to make sure that we continue to optimize.

DR. GORDON: Ivanova?

MS. SMITH: I just want to thank the

committee for the effort on making the materials more accessible for people with intellectual disabilities, because a lot of times, intellectual disability is not thought about with accommodations. And so, I'm really excited that we're talking about that, and that the Strategic Plan is working on recognizing that. And it just makes me really happy, and the plan that represents that community that, like, that there's a lot of effort to make things more accessible. I hope that we have even more accessibility in the future. And I'm just really excited about this, so thank you.

DR. GORDON: Thank you, everyone. Back to you, Susan.

DR. DANIELS: Great. I wanted to mention something that I neglected to say earlier in my remarks about the Stanford Neurodiversity Summit -- that I wanted to thank members of the committee who joined me for a really nice breakout session we had after my talk. We had an hour to share with the community the perspectives of IACC members. So, we had some neurodivergent members from our committee, including Dena Gassner, Morénike Giwa Onaiwu, Lindsey Nebeker, Jenny Mai Phan, and Ivanova Smith, who shared their perspectives of what it's like to be on the committee and what kind of impact this committee has on the community. So, that was really nice, and we look forward to perhaps other opportunities where we'll be sharing about the work of the committee and giving opportunities to the committee members to be involved in presentations. So, thank you to you all for participating in that. And Craig Johnson mentioned that he had an update for round-robin that we didn't get to. And so, I want to give him an opportunity to say what he wanted to say.

MR. JOHNSON: Well, everybody knows obviously what's happening in Ukraine and the war in Ukraine. And so, I've been able to -- we've been able to -- our foundation's been able to partner with Mykola Kuleba who has --

he served on two cabinets, presidential cabinets, and there are a lot of families with special needs in war-torn areas that they are having to rescue and bring them out of combat zones, and they create help centers. And these help centers allow them to be able to have a place to live for at least a year, food to eat -- but also, the big need they have, obviously, is services. They need services. It's a huge crisis situation. So, Champions Foundation has been able to -- we just dedicated the first special needs developmental center in Bucha. And there are 13 more that we're going to put special needs developmental centers in where these families, these kids that are being rescued can get services and help. So, really cool that we're able to go and do that and be a part.

DR. DANIELS: Thank you so much for sharing that wonderful work in the Ukraine. So, next, I'm going to move to the next order of business, which is our projects that we have ongoing. So, I wanted to give you a status update on the 2022 IACC Summary of Advances. You all voted on this, so I just -- I have a slide here checking off the different actions that have happened on the 2022 advances, including that you've all nominated articles. We discussed them in committee. We voted on the top 20 articles back in February to March. And now, the article summaries and draft publication are in the works. And we are expecting publication pretty soon, but it didn't quite make it for this committee meeting. So, be expecting that you'll hear about the publication shortly. So, we are going to give the IACC members a brief preview of the draft before it is released to the public, but we expect it to be happening soon. So, I wanted you just to have an update on that. So, next, we will -- there we go. So, I also wanted to talk about what we're going to be doing in the final year of the current IACC. It's gone by pretty fast, but the authorization for this committee ends on September 30, 2024. And we wanted to talk with you about what remaining business we want to complete before that time. And so, there are a few things. One is the 2023 IACC Summary of Advances. And we continue to invite you all to share your nominations for the 2023 advances, and thank you to those of you who provided some nominations this round. And we'll be talking about that shortly. But that is a project we'll want to complete, so we'll be having you vote on that probably in January 2024 so that we can get the publication out hopefully around spring of 2024. And that would likely be the last one we would publish before the committee goes out of session, unless we briefly extend some committee service to finish the 2024 version. Also, we will begin collecting nominations for the 2024 Summary of Advances as we get into January. So, you can expect, basically throughout your entire term, you're going to be submitting items for the Summary of Advances. We also are required by Congress to do an annual update of the Strategic Plan. And as you know, we just released a Strategic Plan. And you probably noticed we called it 2021 to 2023, because it really does take that long for us to get all the input from across the community and put together a plan. And it would be difficult to do all of that in a single year and then do it again every single year. So, we really focused our efforts, and we came up with a nice comprehensive plan. And what was done with the last committee is they did something similar. They put out a comprehensive Strategic Plan. And then the following year, they had a briefer update that was provided. And I'll share a little bit with you about that possibility. But we are required to put out some type of an IACC Strategic Plan update in 2024. So, keep that in mind. And in addition, we talked with you earlier in January 2023 about the fact that we had a report on co-occurring physical and mental health conditions and their impacts on health outcomes for individuals on the autism spectrum. And this report is partially completed and was started by the previous committee, and you agreed to work on completion of this report during your term. And so, our office has been behind the scenes, trying to get that project tee’d up as we're finishing out other reports. And of course, the Strategic Plan is now done. And ONAC is going to be working with the working group chair, Dr. Julie Taylor, on updating the draft, and we'll share it with the IACC for your review. Next slide. So, we wanted to talk to you about what are some of our options for completing the 2024 IACC Strategic Plan update. So, we came up with a couple of different options and want to share those with you and then get your feedback.

So, option one would be to finish our 2024 IACC Strategic Plan update. We could do an update sort of like what the last committee did, and in this briefer update, just focus on summarizing IACC activities that are related to the themes of the recently released Strategic Plan. And the 2018 to 2019 IACC Strategic Plan is like that. It has sections that talk about discussions we've had in committee on various topics that are in the Strategic Plan, and agency activities that relate to -- or organizational activities that relate to what's in the Strategic Plan. So, it's sort of a briefer summary document, but it doesn't introduce any new recommendations. Option two, which is another possibility, is that we could take the 2024 IACC Strategic Plan update and focus it on co-occurring conditions and merge the content from that existing partially written co-occurring conditions report with that new update and sort of do a highlight on co-occurring conditions and make that our Strategic Plan update. So, those are two of our options. Next slide.

And I don't know if everyone here is logged into Zoom. Do we have everyone who's in the room logged into Zoom? So, I think what we can do for people who are not logged into Zoom, we can look for hand votes. But we have arranged to have some options for you to vote so we can get your feedback on what you'd like to do as a next step. So, I wanted to know whether you would prefer -- oh, okay. A question from Morénike.

MR. ISAACSON: Yes, there's a comment and a question. Morénike says, "I remain concerned that we essentially lost a year due to political issues. We did not meet or convene tasks, and as such, have not had a true three-year term. This, in my opinion," they say, "is especially problematic, given that a number of public members hail from underrepresented groups. The question is, is there any recourse that would enable us to be extended to address the situation?"

DR. DANIELS: So, to answer that question about the term for people that are on the committee, so as you know, the committee is authorized by legislation, and that legislation has a sunset date. However, I know that in the advocacy community, many people are working on that reauthorization to hopefully happen before that sunset date. So, the existence of the different programs in the legislation will continue. But with the terms of the members of the committee, they will end on September 30, 2024. However, the majority of the committee members that we have now have only served one term. And the current legislation allows for two terms for public member. Federal members, you know, just continue to serve whoever is nominated to serve for their agency. But for most of the public members on our committee, you've only been serving for your first term. And so, you would be eligible for renomination. And so, that would enable you to continue if you'd like to potentially be on the committee for longer. But it will be an open call for nominations to the entire public, and the secretary will select from among all the many nominees. Dena?

MS. GASSNER: I don't have a dog in the

fight regarding which one of these plans we choose, but one thing I would really like us to focus on -- especially in light of our speakers today, I think it'll be informing this -- is I'd love for us to add an element related to lifelong trauma. Whether it's the big-T trauma of -- you know, forgive me, but sexual trauma or abuse, or the small, more persistent traumas of micro aggression and a lack of services. I think when I look at the mental health issues of the autism population and their family members, a lot of the mental health issues that we've experienced are specifically related to systemic trauma or personal trauma, or, you know, misinformation. To illustrate, my son was pulled into a room with two teachers and told not to go home and tell mom what was happening at school. And if we go to that part of the country, as soon as the plane lands on the ground, he's convinced that teacher is going to be waiting for him somewhere. And what expands his trauma is that he has a strong visual processing system. So, when he thinks of trauma, he visualized it as if it's in real time, like he's in a movie replay again. You know, I just -- that's tiny, tiny example, but it's affected him his entire adult life. So, I think that when we're looking at the Strategic Plan addressing -- at least commenting and observing on the experiences of trauma in the community would be a great addition.

DR. DANIELS: Thank you for those comments. Yes, and with the co-occurring conditions reports that is partially written, there is an opportunity to provide more information on trauma. And we are going to have a presentation this afternoon that can help inform that. So, thank you for sharing that. Another question, Larry?

DR. WEXLER: Thank you. In the previous sort of ramp-up to the previous Strategic Plan, I think we had extensive discussions about lifespan and getting beyond kids and much more into adults, which I think we have successfully done. I would -- and I don't know if this is under option two or under other, but I would advocate for an increased emphasis on people with severe autism that -- we've heard from the community that that's a group that tends to be ignored by this -- not ignored, but certainly not highlighted by this committee. And that's what I would advocate for, at least as an element of this.

DR. DANIELS: Thank you. And that certainly can be a part of either one of these options. And with co-occurring conditions, whether that's a standalone report or made into part of the Strategic Plan updates, it already does include some high-support-needs issues, but we can certainly expand that. And my expectation is that when we share this back with the committee -- our team has already identified themes that come from our Strategic Plan that we may think that you might be interested in highlighting in the co-occurring conditions report, but we have a process that you'll see upcoming here for us to get your input so that we can expand that report. Any other comments or questions? So, I'd like to get your feedback on between these two options, which one you'd like, or if you have something else to propose. So, the first one is that we would do a Strategic Plan update that is its own document that's focused on committee activities across the board that relate to the Strategic Plan. And we would be preparing summaries of these activities in this report. And I can't see the rest of the slide, because of the poll. Can you move the poll over? Does that move? Oh, no. Oh, okay.

DR. DANIELS: Great. So, option two would be to take the strategic -- oh, in option one, so we would have a separate Strategic Plan update and a separate co-occurring conditions report. So, they would be two different reports that we would finish in the next year. Option two is to take these two things and merge them into one and call it all a Strategic Plan update, but have a highlighted emphasis on co-occurring conditions and health outcomes. So, I wanted you to go ahead and vote on Zoom, or if you need to do it by hand if you don't have Zoom, to let me know which of these two options would you prefer. Basically, do you want us to work on two reports or one report? I think that either one is feasible.

MS. SIMON: [inaudible comments]

DR. DANIELS: Slow down?

MS. SIMON: No, no, no. You've just given us two choices, but we don't know which one to raise our hand [inaudible comments]

DR. DANIELS: Right. So, why don't I let Dr. Celestin do this?

DR. ONI CELESTIN: Sure. So, option one would be a Strategic Plan update focused solely on committee activities and a separate report focused on co-occurring conditions.

DR. GORDON: All right. So, if you voted already online, don't vote here.

DR. CELESTIN: Correct.

DR. GORDON: Right. But if you have not voted online because you're not online, go ahead and raise your hand for one, two, or three.

DR. CELESTIN: Okay. So, votes option one?

DR. GORDON: For now, just vote online. We'll figure that out for you later.

DR. DANIELS: She can't get online.

DR. GORDON: Oh, sorry, just do it in person. Sorry.

DR. CELESTIN: So, for option one, Dr. Cooper, Dr. Wexler. Anybody else? Okay. So, option two is a Strategic Plan update focused on co-occurring conditions. So, merging the two documents together. So, we've got Dr. Tager-Flusberg, Dr. Shapira, JaLynn Prince, Dena Gassner, Dr. Simoni, Jenny Mai Phan, and Matt Siegel.

DR. GORDON: I think Sam Crane and Morénike.

DR. CELESTIN: Online?

DR. GORDON: Unless they're making

comments.

MR. ISAACSON: Morénike says, "Voting for the combined, option two."

DR. CELESTIN: Okay. Option two. And Sam Crane, did you have a comment?

DR. GORDON: Would anyone like to vote for option three, which would be other, or abstain?

DR. DANIELS: Yes. And option three, we didn't put on the table three reports. But we don't have a topic for any more reports.

DR. GORDON: Okay.

DR. DANIELS: So, it's sounding like option two is the choice -- so, for us to merge the Strategic Plan update process with the co-occurring conditions report that's partially written already. So, thank you so much for sharing that with us. So, that's what we'll be working on. We're going to be looking at the draft we have with Julie Taylor and starting to fill in where we think some possible gaps are based on the work we've already done with the Strategic Plan.

And we will be gathering input from the committee by one of these SurveyMonkey surveys to get you to provide us with some written feedback, or if you prefer to talk with us, you can always -- we can arrange a call and hear your feedback. Can we go to the next slide? So, thank you for making that decision. We will move forward to that. And anticipating either one of the options, we also would like you to let us know if you would like us to do a request for information or a -- basically a call for public comments on the topic of co-occurring conditions so we can get some fresh input from the community about this issue. And if you'd like us to do that, our office will put that out on the street and collect information from members of the community to share what they think are the most important issues -- in related to co-occurring mental and physical health conditions. JaLynn? You just need to get it close --

MS. PRINCE: There we go. I'm seeing a

lot of buzz across the country with two things -- with neuordivergence, and also with ADHD. Can we bring some of those things into this? Because some of the water are somewhat murky. There haven't been great definitions or looking at things or discussions that I have heard that aren't necessarily online types of things. Can we incorporate some --

DR. DANIELS: Yeah. So, ADHD is already a topic within this draft report we have. But there -- I know there's been a lot of research that's happened since 2019 that's new. So, we would want to update everything to the latest in research. So -- but that is an area that we have in the current draft.

MS. PRINCE: Can we also talk about perhaps diagnosis in adults? Because I'm seeing a lot of that happening as well, and how is that being handled. Is there a uniformity? What --

DR. GORDON: JaLynn, I don't think that's a really important issue, which this group dealt with in the last iteration. I don't think that that conforms to the issues around comorbidities or co-occurring conditions, which would be the point of the report, unless you're talking about diagnosis of comorbid or co-occurring conditions in adults in particular.

MS. PRINCE: And they could be, because it seems like some people had a diagnosis for one thing and find something else along with it. I think it goes along with it. Thank you.

DR. DANIELS: Yes, thanks for sharing that. And you might want to reiterate any kinds of comments in the survey that we'll put out to the committee. So, can I see hands and -- on Zoom?

DR. GORDON: There's a comment from Scott.

DR. DANIELS: Oh, Scott?

DR. ROBERTSON: Yeah. Thank you, Dr. Daniels.

DR. ROBERTSON: I just also wanted to make a suggestion. I don't know if you have space potentially for this too. But could it also potentially consider merging in maybe a brief report from that other work group that was on housing issues and homelessness? That also was something left over from the prior iteration of the committee that hadn't been addressed yet that we had had that work group, and there was no final report out there on the housing issues and homelessness. And I think that's a really major key focus. And it would be helpful at least for that to maybe briefly integrated into the update.

DR. DANIELS: I would say that housing is a really different issue than co-occurring health conditions.

DR. ROBERTSON: Okay.

DR. DANIELS: And so, it -- we didn't vote to do two separate updates. If we had a separate Strategic Plan update that was general, we probably could cover that. But I would say that we would want to stay on physical and mental health, and there's a lot of ground to cover there. But we did put out a summary from the Housing Working Group. And in the future, the committee could always come back to that in more depth if needed.

MS. GASSNER: I think even under co-occurring conditions, when we talk about the implications of the trauma of poverty and being unhoused, there are ways to get elements of it in there without it being its own thing. And maybe in the next Strategic Plan, we can look at that.

DR. DANIELS: So -- yes. So, it included your feedback -- or you just turn it on mute. It's okay. I was having problems earlier too. This is our first hybrid meeting, so we're testing out things. So, just include all of that on your forms. And while we're working with Dr. Taylor to make the initial updates, we will see what seems to fit in the flow of the theme of this report. So, I wanted to get your feedback on whether you'd like us to issue an RFI to get community input on this topic. So, can I see hands for how many would be in favor of us doing an RFI to get input from the public?

DR. SIEGEL: Susan, before -- could I just ask, before we vote on that or you take hands for that, can you remind us what -- I believe we ran a process prior and did receive some form of input prior to the --

DR. DANIELS: We did.

DR. SIEGEL: -- report that was created. Could you just remind us, if you're able, of that process? Because it might then inform whether we want to get more input now or not.

DR. DANIELS: Yes. So, the input from the previous RFI is already in the draft that we've got. So, the purpose of doing a second RFI would just to get anything that might be updated. Has anything changed since 2019 in terms of people's experiences in the community, or more awareness about any of these topics related to physical and mental health -- and especially in light of the pandemic, which was not something that it happened by 2019. So, if we think there's anything new from the community that could be shared, we would collect it, analyze it, and make sure that it makes it into the Strategic Plan. But the previous input that we collected already is -- I mean, sorry, not the Strategic Plan, this report. But we did incorporate feedback from the previous RFI in the report already.

DR. ALYCIA HALLADAY: Quick question, what would be the timeline on that? So, you issue an RFI, and then how long. And then how -- you know, just the general timeline.

DR. DANIELS: So, we usually would probably keep it open I would say around eight weeks, six to eight weeks. So, I would say -- I would veer toward eight weeks to give plenty of time for us to publicize it, make sure people have heard about it, and to collect that. And so, our goal would be to get that input back to you hopefully in January, so that you can see what -- we would give you an analysis of what came back and share the raw comments with you as well. And we usually do post those up on the website. Yetta?

MS. MYRICK: And similarly, for what you did for the Strategic Plan, in drafting some language, would your team be willing to do that for this, that way we know it's open, and we can share out through our networks? I think that will be helpful.

DR. DANIELS: Yes, we can even create the social media graphics and stuff so you can put it out on your LinkedIn or whatever you would want to try to get more input.

MS. MYRICK: That would be amazing. Thank you.

DR. DANIELS: So, we can work on that if you're interested in doing an RFI. More questions? Morénike?

MR. ISAACSON: There's nothing in the chat.

DR. DANIELS: And Sam Crane?

MS. CRANE: One of the things that I would just sort of add about when you mentioned COVID is that we know based on a few preliminary studies that people -- that autistic people are more likely to have certain kinds of connective tissue disorders. And those connective tissue disorders are also linked to conditions like postural orthostatic tachycardia syndrome, chronic fatigue, immune activation, that are seen also among people experiencing long COVID. So, I think it would be helpful to see if there is a felt sense in the community that autistic people are at high risk for long COVID or other negative long-term outcomes from COVID and other infections.

DR. DANIELS: Thank you, Sam. We certainly -- in doing an RFI, we normally have one or more questions that we put into the RFI. So, we could have one that's targeted toward COVID and any input that might be related to that. And we have not collected that in a targeted way before. Any other comments? Dena?

MS. GASSNER: I'm just wondering -- and forgive me if this is not the space or an appropriate place for this. But when we look at co-occurring trauma, I'm wondering if we need to make any kind of contribution in regard to primary and secondary war-related trauma as it's affecting people with intellectual and developmental conditions. I just can't imagine what's happening to people who were institutionalized in Ukraine or -- and then so many of my friends who have direct connections to Israel and Palestine are going through so much secondary trauma. And then I'm hearing -- and I don't know if this is going to happen -- that they're going to start posting just horrific things on Instagram and other places that the public will have access to, which could also lead to a different kind of trauma. So, I apologize if it's not appropriate for placement, or if it doesn't fit here, but that's just been on my mind for a while.

DR. DANIELS: So, a topic like that, if we have it on the list of items to weave in to the Strategic Plan, we would be looking at the literature to see if there's new research that's been published on this, and also looking to community input that we're receiving. And so, that's how we get some of the updates. Another item that our team noticed in looking back at something that was written in 2019 is the committee has made a very strong shift in terms of equity, diversity, inclusion, and accessibility. So, we would imagine that you might want to have a little bit more of an equity lens on this report than was created in the previous version of it. So, that's something that we're -- we've already sort of noticed that -- with this committee's emphasis on equity that we may want to reframe or add more on equity across all communities to this report to make it more complete. So, any other questions before we just get your temperature read on whether or not we should do an RFI? Okay. Not seeing any. So, can I get some hands raised for how many of you in the room or online would be interested in having us do an RFI to gather public input on issues related to this update? All in favor? So, Dr.

Celestin, you want to help us with that? Oh, Katrina. Dr. Ferrara is helping us out. So, everyone who's in favor has their hands raised. Okay. You can let me know when you're -- you're good? So, anyone opposed to doing an RFI, does not want to receive community input at this time? No. And anyone abstaining? Okay. It looks like you have voted to have an RFI. So, we'll work on developing an RFI. Also taking into consideration some of the things you've said here that would gather broad public feedback for this so that we can make sure that our report is completely up to date with the latest issues that the community is facing and interested in. Thank you so much. Oh, okay. And I had mentioned that we would like to do a survey with the committee, but again, just to get your consent to do this, are you willing to fill out a survey, members of the committee, in order to share your feedback with us about what you want to see in this report? So, hands up for anyone who's in favor of receiving and responding to a survey. All right. Next, anyone opposed to receiving a survey and responding to it? Or anyone abstaining? Okay. So, it looks like you're all in favor of doing that. We really appreciate it, as it was a highly --

DR. DANIELS: Okay, perfect. So, it sounds like you're in favor of that. And it was a really effective way of us working on the Strategic Plan to get your input, and even some of your specific references or words that you had shared with us that helped us to update the plan. So -- all right. So, we have a decision on that. Next. So, we'll be working to continue this co-occurring conditions report and form it into the new Strategic Plan update for 2024. And we'll provide you with the status update in January, and you'll be hearing from us. You'll see some of the items coming out. And thanks for sharing that you do want social media graphics and other things, so you can help us publicize this across the entire community. And we will be working to complete all reports by September 30, 2024. With the opportunity, we are allowed to do a brief committee extension that is just to complete prior business. And so, if we need to, to get your input on a few things to finish up your work, we will also do that. But I will update you on that later. Thank you. So, given that we are a little bit behind schedule, we're going to ask of the committee if we can come back to the Summary of Advances nominations at another time at the January meeting, because we're behind schedule, and we want to make sure you have enough time for lunch. You have received those nominations in your packets. And if you have any feedback, we'd also welcome you to share written feedback if there's something that you really support that's on that list or something that you feel that maybe is not meeting the standard that we would want for a nomination for the Summary of Advances. But we can do a more extensive discussion of this in January to catch up. So, we will do that. And now, we will more to our next item of business, which is a spotlight on Sunflower Bakery, which is a local business that supports individuals with disabilities. And they are providing boxed lunches for certain members of the committee that may have ordered from them. But we wanted to highlight their organization and the work they're doing in our community for individuals with disabilities. So, I'd like to introduce John Katz. And John, would you like to go up to the podium?

MR. KATZ: Thank you, Dr. Daniels. It's really an honor and privilege to be able to showcase what some of our students are able to do, and really just really reimagining what people with learning differences -- specifically, autism -- can do in the workplace. Sunflower Bakery was created or founded 11 years ago. And it has taken every bit of 11 years to work through kind of where we are now, but we are on the verge of being one of the largest workforce development programs for, specifically, learning disabilities in Maryland. We have a 70 percent employment rate after completion of our program, which is pretty unheard of. And the way we do this is showcasing what our students can do, not what they can't do. We work with employers to let our students know not only that they're needed, but they can do the work right alongside if not better than most neurotypical young adults. We give our students a foundation in learning and growth, and we teach not only the hard skills associated with baking pastry, hospitality, and food service, but the soft skills which are quite honestly what everybody needs prior to going into work. We really are unique in that we take an approach that -- I went to culinary school. I would have loved to have the Sunflower experience versus my culinary school. It's a lot more hands-on, and it's a lot more what you need to know and building off foundations versus just conceptual theories. Again, we are honored, privileged -

- was the video already shown or -- so, I think we'd just let you watch the video and see kind of our work. That's okay? Perfect. I appreciate it, and I hope everybody who got a lunch enjoys it. And anybody who wants to find out more about us, please feel free to find out more. We're excited and ready to show off our bakery. But please enjoy.

VIDEO: The main purpose of our program is to get people ready to work. So, they're learning how to show up on time, how to be accountable, how to take responsibility for their production lists, also, how to communicate with their coworkers and their peers.

MS. TICK: Our graduates have worked tremendously hard to acquire the hard skills of pastry arts and hospitality, and the soft skills of employment readiness. These coupled together ensure a student's long-term sustained employment.

MS. GRANDA: It has been an incredible experience working with not only Sunflower, their administrators and directors, but also the students themselves.

MS. SCOTT-GEASON: People like me with disabilities, we feel important, because, like, there's a lot of people like me who can't work with the disability that I have. So, being able to, like, work in the kitchen and work with other chefs, we feel important, because I -- we feel like they care about us and our career and stuff.

MS. KRAFT: As a parent, I was involved from the beginning. I was able to go to meetings. I was able to understand what they're trying to build with Julia, and went through the process of basically making Julia a member of society, being able to hold a job and have those skills. And as a parent, there's nothing like seeing your child succeed in things that I never thought were possible for her.

[music playing]

DR. DANIELS: Thank you. And it looks like we have a question.

MR. JOHNSON: Yeah.

DR. DANIELS: Craig Johnson.

MR. JOHNSON: Hey, John, I just want to commend you on what you're doing. I'm seeing a rise in this and more businesses starting to do this. And we have a resource and job fair every year where we have Bitty and Beau’s, you might know that. They come in and they serve all the coffee. And it's a huge impact on parents seeing the possibilities. My son, last year, he got first job at Whataburger. And he just celebrated one year and got a raise and promotion. And I can't tell you for a dad and a mom what -- how huge that is in our lives. So, we commend you on the work you're doing. This is amazing work. Thank you.

MR. KATZ: Yeah. And I'd just like to thank you all for leading the charge and understanding and development and all that. I mean, we don't exist without organizations like this for paving the groundwork for us.

So, we appreciate you and everything that you guys do.

DR. DANIELS: Thank you. And we have a couple more questions or comments from the committee. So, Ivanova?

MS. SMITH: Hi. I'm Ivanova Smith. And my question is what work are you doing to help the people that you serve -- people you employ get in an advanced position, become managers in your company, and become -- like, be able to take on the leadership roles within your company as well? Is there any efforts in that?

MR. KATZ: So, we do -- we provide the training and the job services for young adults with learning differences. And then we work with various -- we have 60 different employee partners within the D.C. metropolitan area that we work with. And we ensure that they have equal opportunity for advancement and growth within those. Oftentimes, when we set up the jobs, it has a three-year tracking that we work with our students for three years to ensure growth promotion. And promotion and growth, I want everybody to think of -- It comes in a number of different ways. It's not just always in roles and responsibilities. But oftentimes, it's in fair and equitable pay and advantages, benefits, and hours worked. A lot of our students start at part-time and then end up transitioning to full-time. But we continuously track our students that we work for, for three years after the state funding ends. So, we do that all for free. We fundraise for that and we sell our products to cover that. But, you know, it's really getting them involved in their community because we have two little shops in Rockville. I'd love to have more. Hopefully, in the future we will. But it's not feasible for everybody to travel to Rockville to come to us. So, we work where they are. Our idea is to develop individualized employment plans for each of our students to find out what their goals are. And then we do a 30-minute commute, door-to-door to find them their job.

DR. DANIELS: Wonderful. And, JaLynn Prince.

MS. PRINCE: One person stated early on that when there is a product that is done by individuals with disabilities, that people will often purchase the first time for sympathy, maybe the second time to look good to their neighbors. But if you're going to have a sustainable business, you have to have quality. These folks are in our community. They have quality. They have provided things to so many different locations. And I've talked to parents who are so delighted to see the progress of their individuals. I've talked to a couple of individuals that have been with you. And this is the real deal, and they're doing a great job. Thank you.

MR. KATZ: I appreciate that. All of our organizational members, our instructors are trained chefs from industry, including myself. Right now, our biggest problem is we've turned down Whole Foods as a vendor. We've turned down Harris Teeter as a vendor. We've turned down Sodexo as a vendor, Sysco as a vendor, US Foods as a vendor. Because our goal is to train the students, not pump out a product over and over again. It's to give the students their experience and get them employed. So, I appreciate you saying that. And, you know, we do think we're the real deal. And if you haven't been to either our cafe or bakery, we encourage you. Our cafe is right across the street. And I believe that everybody in this meeting, as long as you say, IACC, you get a free cup of coffee today and 20 percent off any additional purchases. So, just go ahead and enjoy. And you're going to be taken care of by one of our students that is graduated and we're paying while we work to find them a job. So, I just appreciate the whole opportunity and really, just thank you all for your work ahead.

DR. DANIELS: Thank you. We have one other comment from the U.S. Department of Labor, Scott Robertson.

DR. ROBERTSON: Yeah. Thanks, Dr. Daniels. I just want to say thanks for this update on the important work that your organization is doing, John. And if there's anything we have as far as resource information, let me know, that might be helpful to you from what we have as far as resources for service providers and on the employer and then the job support. And so, maybe I can touch base with you after the meeting, if there's any resources from our technical assistance and policy development centers that may be able to help support your work. Thanks for the work of your organization.

MR. KATZ: Thank you. And we definitely appreciate that. And I hope that Dr. Daniels and her team can get us in contact.

DR. DANIELS: Absolutely. So, thank you so much, John and the entire Sunflower team for your work and for being here with us today.

DR. GORDON: All right. Thank you very much. The next segment of the meeting is the time we devote to hearing oral comments. And also, to hearing a summary of other written comments that have been submitted. Before we do the oral comments, I'll just remind everyone that you each received, in advance of the meeting the assemblage of the public comments made and submitted in advance from many, many different members. We'll hear a summary of that after the presentation of oral comments from people. We have two individuals who have asked to give oral comments to this committee. They will each be allotted three minutes to give those comments. And there are additional written comments as well from both of those individuals if you'd like to look at them again, now, here at the meeting. The first public commenter is Nicole Corrado. I hope

I'm saying that correctly. And I believe she's appearing virtually.

DR. DANIELS: And, Nicole, can you let us know if you're there? I know that she had technical difficulties and maybe relocating or trying to call in on the phone line. So, Nicole, are you there?

DR. GORDON: If you are on the phone, you could unmute yourself with Star, six.

DR. DANIELS: And if not, we may need to come back to her later in the session.

DR. GORDON: Then I'll ask the second oral commenter please to come to the podium. I believe Ms. Cheryl Chafos is in the room. Thank you.

MS. CHERYL CHAFOS: Hi, thank you for listening to me today. My name is Cheryl Chafos. Public speaking is not my forte. And I am from New Jersey. So, forgive me if I go over my time allotted. I'll do my best. This is my son, Zachary. I just want to put a picture of him up here. I am not a PhD or an M.D. I'm a mom of four boys, one who had severe autism. He was diagnosed with autism, epilepsy, and he was intellectually disabled. My story is a sad and tragic story. He passed away in 2021 in August -- on August 24th under the care at Sheppard Pratt while seeking mental health help. We are a military family. My husband served 30 years of active duty in the Army, which came with many challenges, especially with a child with special needs. Zachary was born in Tuscany, in Italy -- beautiful Italy. He was a healthy baby. He was a healthy baby. He was a healthy baby. I'd had a healthy pregnancy. He was a happy baby. And when we moved back to the States, I started to notice he was not developing like his older brother. Upon taking him to his pediatrician in 2004, I was told I'm a nervous mother. I didn't need to worry. He's just the second boy. He will be fine. And I knew my son was not where he should be. So, I used my mother instinct and I went and got him diagnosed right down the street at the Naval Hospital. And he was diagnosed on the autism spectrum. And my husband deployed to Iraq about four weeks later. And he left for over a year. And I had to manage and try to understand this new journey of autism, as back then in 2004, we still were trying to understand autism. Jenny McCarthy was very vocal about autism back then. That's when the controversy started with vaccines. I am pro-science. I'm pro-vaccine. I have four -- like I said, I have four boys. Three of them, typical and healthy boys. And our journey was a very difficult one. As Zachary developed, we faced many challenges of therapy, schooling, healthcare. I was very lucky to go and meet down with a congressional panel twice about TRICARE fighting for therapy for Zachary and what military families have to go through. We have very significant challenges with military life, moving, deployments, education, therapy. And it's -- it was a journey I was very passionate about. When Zachary started continuing to grow and his challenges became very intense -- aggression, I realized we were failing him in giving him what he needed. And so, I continued to fight the schools and get him what I thought was what he needed to give him the best life. In 2019, my husband retired after 30 years. And we moved from Fort Meade, from our military community, not too far away in Maryland. And COVID hit a couple months later. And I was fighting for Zachary to stay at Kennedy Krieger High School. It was difficult, and his world fell apart. So, COVID was challenging for many families, not just mine. And we were lost. I reached out to every agency that would listen. And Zachary's behaviors became increasingly worse. So, in November of 2020, I was told by his psychiatrist, he needs to go to Sheppard Pratt. In order to get there, he had to go to the ER first. So, we admitted him to the ER in the middle of COVID, with doctors that are trained for emergencies. Not trained to handle mental health patients, not trained to handle autistic adults, not trained to handle violent autistic adults. And that's when our journey began. He was there for four weeks in the ER, in a windowless room without therapy, education, speech, and OT. Basic human needs that he should have been getting, sunlight, exercise, he was not getting. All along, I was fighting. I was fighting with every agency, asking them for help for a bed at Sheppard Pratt. There are, I believe still seven neurological behavioral beds at Sheppard Pratt for the entire region. So, all of these patients that were waiting to get mental health services that were desperately needed during COVID were not there -- were not getting to those beds. So, in November of 2020, he was in the ER for four weeks. I knew he was getting moved when I saw in MyChart that he was COVID tested and he was negative. So, they moved him to Sheppard Pratt. And I was hopeful and happy that he was finally going to get regulated and get some type of normalcy back. He was only home with us a couple months. He was only at Sheppard Pratt for about 10 days. They were able to, at the best that they could, stabilize him. And he was returned to us. And we continued with COVID. And he wasn't getting the schooling and Kennedy Krieger and the other services. He was just not living what he was living before COVID. So, again, in June of 2021, after reaching out to his therapists, his doctors, his school, DDA, all of the agencies that could help me said he needs to go back to Sheppard Pratt. Well, I was hopeful that this time, it would only be a couple of days. But he waited seven weeks in the ER again, waiting on a bed. And I knew, again, after seven weeks of this battle, should we keep him? Should we take him out? Do we need to start over? What should we do? I knew we had to leave him to get him the help that he needed. And that seven-week mark, I saw on MyChart again, that they COVID tested him and I knew that he would be moved. After 10 days at Sheppard Pratt, I received a phone call on the soccer field with my youngest son that

Zachary had passed away. And my whole world crumbled. I didn't know what to do. I was lost. We relied on the community and the mental health community to help us. And everyone failed us. We were failed across the board. And I don't want another family to have to go through what we went through. So, I'm here to tell you all that we are doing what I think we can for the autism community. But there needs to be more that has to be done for our young adults and children. Our families are really struggling. They're still -- I'm getting phone calls and messages constantly from other people saying, "We're living the same nightmare you are living." And there has to be something that we can do for real change so we can give people the real lives that they deserve. My son was healthy. Besides the epilepsy, his autopsy came back healthy. He had a healthy heart, lungs, everything was perfect for him. He should not have died. So, I want to say my son's story is tragic. He should not have died. And I really don't want another family to have to go through what we endured. Our children deserve to live life to their fullest potential. And any way that I can tell my story and help and figure out a way to give adults, this community, the best of life that they can live, I would like to help in any way.

DR. GORDON: Thank you, Ms. Chafos.

MS. CHAFOS: Thank you. I know I was probably over my time. I don't know if I'm -- if anyone has questions.

DR. GORDON: You should take a seat. We may discuss --

MS. CHAFOS: Okay. Thank you.

DR. GORDON: Before we open the discussion, I wanted to check again to see if Nicole Corrado was on and able to contribute her public comments orally. I'm so sorry. We seem to be having technical difficulties in ensuring her ability to testify here. I would like to recommend that everyone look at her comments if they haven't read them already in the written form. And we'll next have the summary of written comments and then we'll engage in discussion. Thank you.

DR. DANIELS: Thank you. So, can we get the next slide and then put the slides back up? So, for the summary of written comments, we received a number of comments. One hundred comments submitted on the topics that are listed on these slides. So, we had 37 comments that were regarding addressing the needs of autistic individuals with high support needs. And the names of all the commenters are listed below. And by the way, everyone has this in your packets. They're online. Anyone in our listening audience who wants to read the text of those comments, you can go to the public comments packet and read them. We also had 14 comments on research and services needs, resources, and policy implications. We had eight comments on research, services, and supports for autistic adults. Six comments on the inclusion of autistic perspectives in research. Next slide. We had three comments regarding employment. Four comments on mental health research, services, and treatment. Five comments on the role of the IACC and the federal government. Four comments on potential causes of autism. Next slide. Two comments on increasing autism acceptance and reducing stigma. Five comments on inclusion of underrepresented groups within the autism community. One comment on the educational needs and workforce training. One comment on communication and alternative and augmentative communication techniques. And one comment on parent and caregiver support needs. And I believe that's the end of the written comments. Is there one more slide? Oh, there is another. So, there are seven comments on concerns about medical practices. One comment on language regarding autism and one comment on the needs of the direct support professional workforce. So, those are the topics that we received public comments on. Thank you so much to everyone who wrote in. Our committee receives those comments in advance and is instructed to go ahead and read them. And so, I know people come prepared and have already read those comments. And we also make them transparent to the public so everyone can see them. So, I'll turn it back over to Dr. Gordon.

DR. GORDON: Well, thank you. I want to add my thanks to all the public commenters. And please, someone alert me if Ms. Corrado comes online so that we can give her an opportunity to provide her oral comments. But now, we're going to open this -- the -- open the floor up for discussion from committee members on any of the public comments that were made, oral or written. And I see already a hand up from Morénike. Please, go ahead and give us your thoughts, comments, questions.

DR. MORÉNIKE ONAIWU: Hello, everyone. I typically prefer to type my messages, but this one would've been a little difficult to do as it's long. So, thank you for allowing me to comment on this. I wanted to share that

I think it's really important, you know, as we discuss these comments, to just really put them in perspective. And so I reviewed them, you know, as I think the majority of us do each meeting -- prior to each meeting to get an understanding of what our community is sharing. And I noticed that there were like six overarching themes. And I wanted to kind of briefly discuss those. But I wanted to talk about -- I first -- the first thing that I wanted to bring up is that I think it needs to be emphasized that more than a third of the remarks that were -- the public comments that we received were specifically related to individuals and their families with very high support needs. Level three autism, or what some might say is profound autism, if they use that administrative term. Thirty-seven remarks alone related to that of a hundred comments. And that's a great -- a lot. And I just wanted to -- you know, to kind of highlight some of the things that were mentioned by the families over and over.

There were -- there was a lot of discussion about the barriers that they are facing. Many people shared just a sense of lack of representation or lack of visibility, not being represented, not being spoken for, or being seen. There was a great deal of discussion about caregiver overwhelm, lack of respite, concerns and fears with regard to aging. And then just inadequate supports in general. You know, not having a number of housing options. Day-hab programs that either won't accept them or suspend people or don't have adequate supervision. Staffing issues where you cannot have family members hired or you can't get a one-to-one, even if that's what you need. And all of these things result in suboptimal healthcare and a sense of isolation, both for the family and the individual. And it impacts safety. Many people mentioned things such as self-injurious behaviors and aggressions being exacerbated as a result of this. Their concerns about abuse risks and communication challenges. And, you know, some of the things that some people mentioned, there's no consistency. I just want dignity for my child. We are sleep deprived. My son gets black eyes. You know, people talked about polypharmacy and wandering and all the things that they've had to try to do. And so, I think that -- the reason I'm emphasizing this, I know, again, everyone has read this and I'll be brief -- more brief when I go through the other sections quickly. I wanted to mention this because I know sometimes, perception is not always reality. Like, for example, there has not been a single meeting -- IACC meeting, either since I've been a member or prior, where anyone has said, "We are trying to improve the supports for Cabo Verde, [inaudible comments], Yoruba, Benin people." You've never said that. But that's who my children are. It's my family. But I can read between the lines and I can determine from the context that you are addressing our needs. You are talking about us even if you don't specifically mention us. So, I do want to encourage -- I know families are busy and overwhelmed. Just because you're not hearing the terms that you're accustomed to hearing, please do not feel that your needs are not, you know, important or considered. But also, know that we are hearing you. We're hearing what you shared. What you shared is important. These things about wandering, death, property destruction, self-injury, these things are not acceptable. And it wouldn't matter if you were a third of the population or 1 percent of the population. It’s an unaddressed, you know, need. Quickly, I just want to go through the other areas people mentioned. And I -- again, I'll be faster. People talked about the unique and unaddressed challenges of various underrepresented groups. So, people with intellectual disability, non-speaking, refugee, people of color, foster children, the preschool-to-prison pipeline, and so forth. And the -- people talked about a lot about services, about the difficulty with systems navigation, and how people are having to manage these things. There isn't enough case management or adequate shared decision making and services. You know, service cutoffs where people can't get what they need. You know, not enough support for community living, segregation in schools, not adequate workforce, and rehabilitation programs. People also shared a lot about research needs, about wanting to include groups that have been excluded because of intellectual disability or non-speaking. Prioritizing autistic voices. Practical benefit, whether parents or autistic people. That was something we saw over and over. People said, "Things that help us now. Not things that are, you know, ethereal, you know, ideological things for the future. What can help us right now?" You know, what are alternatives to -- you know. And then people also shared about medical trauma, the -- you know, and wanting healthcare providers to be better equipped to deal -- to address their needs. Early identification and services across the lifespan. So, you all shared -- there's a lot here for us. And I just want to challenge myself and our -- my colleagues. We've talked a lot about the research angle of things in IACC meetings. I think we really do need to hone in deeply on these issues with services because a lot of the things that the families are sharing, I can relate too, being a mom myself. I can understand that some of these things are just not there. These services are just not there for us. And you do fear what's going to happen when you die. What's going to happen to your child. And so, I encourage -- I know we've talked about work groups and tasks that we can do. And so, I hope that this might be something that we might consider trying to, you know, address in a more, I guess, direct and impactful way. Thank you.

DR. GORDON: Thank you very much. Are there other comments or questions? Yes, Dena.

MS. GASSNER: Thank you very much, Morénike. I am going to try not to replicate anything she's already spoken to. But I did want to highlight Brittany Daniels on page 10 as she discussed the fact that we do not get access to therapeutic supports after we leave childhood. As someone with a hypermobility condition, I can tell you every time I leave physical therapy, I'm going to have a six-month decline. And then I'm going to go back to physical therapy. You know, the reality of it is if you have these kinds of co-occurring conditions or you have low muscle tone, you need ongoing, committed regular therapy. And so, I do hope we can talk, at some point, about policies to shift that. I did appreciate Amanda Tipkemper's comment regarding systems navigation. And Morénike brought that up. I do systems navigation. That's my work. My question is why do we need systems navigators? Why are the programs not accessible so that people can access them without having to hire professionals to tease these things out? I find it incredibly frustrating, delaying. There are severe consequences, as you brought up today, when we have those systemic delays. So, I think as a body, we could really start to discuss what kinds of delays people are enduring. Angie Vigliotti talked about restraint in public schools. I think that needs to end. But more importantly, what jumped out to me is how she had stated that at some point, she looked at her boss and says, "Maybe I just need to quit my job to take care of my kid." I think we need to be investigating that. How many people are not in the workforce because we have inadequate supports for these families. And then I appreciated all the comments around the underrepresentation of people assigned female at birth in the autism research. We continue to be the least progressing in terms of prevalence identification of any of the minority populations. And, of course, we experience all the intersectionalities, which magnify that marginalization even more. And then lastly, in light of our last meeting, or two meetings ago, I think, AJ Link from ASAN and their comprehensive comment on the needs for early and ongoing access to AAC for minimally speaking, non-speaking people. But I would also say I know many people who are very, very verbally competent in very relaxed, familiar settings. But when they're confronted with pressure to perform, it's a healthcare situation. Their language evaporates. And so, when we think about AAC, I think we need to talk about early access, but ongoing access for this community. Thank you for taking my comments.

DR. GORDON: Thank you, Dena. I do -- I've got -- we will get you down on the list. There's -- Jenny, I got your hand up. I just want to make -- first of all, I want to thank you and Morénike for summarizing many important comments that were made. It's wonderful to hear the details out. I want -- do want to make one thing, which the CDC data has shown. Over the last several years, we've made tremendous strides in narrowing the gap in diagnosis for members of underrepresented minority groups of all kinds, actually. So, I think that's one thing we -- and that's something that this committee talked about years and years ago. And that has really begun to turn around. There's still many other disparities remaining, but I appreciate you highlighting that, Dena, for us.

MS. GASSNER: I'm really ecstatic that we are finding people of color more frequently with better reporting and better outcomes. But when you look at how the numbers have increased with these 8-year-olds, what we're really seeing is evidence that 8-year-old girls are probably not going to be identified unless they are very expressive in their autism features.

DR. GORDON: Still a lot of research that we need on, as you point out, differences in the presentation and other aspects of autism in individuals assigned female at birth. I just want to -- we have Scott, Ivanova, and Jenny and Paul. Okay. Go ahead, Scott.

DR. ROBERTSON: Yeah. Thanks, Dr. Gordon. I first wanted to share my solidarity with Cheryl. And thanks, Cheryl, for sharing that personal narrative of the lived experience of herself and her family. And what had happened to her son as far as inadequate supports on that, as far as on mental health and in the service system. And I hope that comes up in too informing some of our discussions and -- later on this afternoon. And on the employment end, I just wanted to emphasize that I appreciate the comments that were shared in there about workplace-related barriers and challenges. And access to inclusive supports and services to attain and maintain employment and advancing careers and career pathways for autistic people. And especially, the impact of focuses like burnout that I think are really understudied in the research and need to be highlighted a lot more. Because this often hinders autistic people from being able to have full access to gainful employment that supports economic prosperity and a high quality of life. So, I'm glad this was highlighted by public commenters. And obviously, we take this to strong heart here at the U.S. Department of Labor. Thank you.

DR. GORDON: Thank you, Scott. Ivanova?

MS. SMITH: This is Ivanova. And I also want to stand in solidarity with Cheryl and her son. And I think that it's important in looking at what happened in that situation is not one size fits all with public health policy or any policy that affects services for people with autism, intellectual disability, or any other co-occurring conditions. We really need to make sure that when we're making public health policy, that we're honoring that not everyone can do the same thing. And that providers still need to be there for the people they serve. And isolating people hurts people. And so, I really hope that we reflect on that and make sure that when we're talking about services for people with disabilities and public health, that we're not demanding a one size fits all. But a policy that works for different people and has an understanding that we all need different things. And we all need different autonomies when it comes to public health. So, I just really want to echo that. And I'm really sad and sorry for what happened to Cheryl's son and others who have gone through that. I've actually lost several friends that are self-advocates who were also restricted and passed away during this time. And it's been very hard. So, hearing your story, it really encouraged me. So, thank you.

DR. GORDON: Thank you, Ivanova. Jenny.

DR. JENNY MAI PHAN: Hi. This is Jenny Mai Phan. I echo what my colleagues have already stated about the public comments. I want to thank Cheryl for sharing her story. And it resonates in the sense where we're a military family too, and have had to experience gaps in supports and services being a military family among many other hats that we wear. So, thank you for sharing. And I want to actually bring up Angie Vigliotti's comment that she wrote in. Thank you so much for writing in. And please keep writing in if it's not getting enough attention. So, Angie brought up about autism waivers that many states have, which is under Medicaid. And as we all know, many of our kids who are autistic are trying -- at least their families are trying to get them on the autism waiver and are sitting on waiting lists, my family included. We were told that we will be on a nine-year waiting list. And my son is 13 years old. So, by the time he is able to get onto the waiver, he aged out. And I think we're not alone. There are many families that are like this. And I live in Maryland right now. I'm in Frederick County and my kids are in Frederick County public schools. So, Angie, please reach out. But we moved a lot. We moved from Louisiana to Iowa to Wisconsin, and then to Maryland. And every state had an autism waiver that we had to sign up for and get my kids on Medicaid. And every state had a different time on waiting list. Wisconsin was the fastest. We got in within three months into Medicaid. That was the quickest we've ever gotten onto Medicaid. But moving from Wisconsin to Maryland, now we're back on the waiting list and we're not able to access supports and services. So, to Amanda Tipkemper's comment about cross coordination of services and funding, I absolutely echo and agree that there needs to be better conversations and collaborations across agencies and providers wherever we are. But there are a lot of kids who cannot even get onto Medicaid to access these supports and services and are sitting on these waiting lists. What are they doing? What are they waiting for now? They're not getting any supports. And so, this is such a concern. It's still a concern in 2023. And I think that we need to have a bigger conversation about this as a committee. And I leave my comment there. Thank you.

DR. GORDON: Thank you, Jenny. I think time will permit us just two more comments. Paul and then Lindsey. Paul.

DR. WANG: Just extending on many of the comments that we've heard, starting with Mrs. Chafos and through Dena and Morénike and others. And as Jenny was just describing, there are enormous issues, both with the accessibility of the resources and supports that are needed, but frankly, with the capacity. There just aren't enough of those resources and supports that are needed. One small part of it that I want to draw attention to is the pediatric subspecialty workforce. And a very recent report, which was issued by the National Academies of Science, Engineering, and Medicine just last month, there aren't enough child psychiatrists, child neurologists, developmental behavioral pediatricians. And Mrs. Chafo's story just illustrates that very, very clearly. And the bottom line reason is that they're not fairly compensated. So, people don't go into those fields. Two particular recommendations in this National Academy report is, number one, Medicaid needs to be reimbursed at the same level as Medicare. People aren't aware that Medicaid payments are -- to physicians -- are a fraction of what Medicare payments are. This is not the fault of CMS, who we have representation from on this committee. Congress must appropriate those funds so that even-steven reimbursement for physician services can be made. So, that -- that's a very important part of it. And then also, the so-called relative value system, which is just so corrupted is called out in the National Academy Report. It must be thoroughly revised so that, again, these needed services are valued and, therefore, reimbursed in a fair manner.

DR. GORDON: Thank you, Paul. Lindsey?

MS. NEBEKER: Yes. So, I just want to thank Cheryl for sharing her testimony today and for sharing her son's story with us. I can appreciate how difficult it must have been to get up in front of everyone to speak. I think my colleagues and I agree. It's a heartbreaking and it's a sobering reminder that it's an issue we need to bring more to light. And as a sibling who has had to spend an entire lifetime advocating for a non-speaking autistic brother with high support needs to be connected to adequate health services, the story hits home to me. No one in our community should have to go through what Cheryl and her family has had to go through. It's important that we remember families like hers. And we remember other autistic self-advocates who are going through similar issues. When we continue our discussions on autism and mental health research and services, not only do we need to focus on expanding and improving mental health services tailored to the needs of the autism community. But we also need to focus on educating and expanding our outreach efforts in informing the public on what information, resources, and supports do currently exist for families and self-advocates. So, to reiterate her written remarks, we need to urge our medical communities to help address and fix this process so no other family or individual has to suffer such this. And that's all I have to say. Thank you.

DR. GORDON: Thank you, Lindsey. To close out the public comments, we are actually going to have read the oral comments from Nicole Corrado, who unfortunately continues to have challenges connecting with us. Susan?

DR. DANIELS: Yes. So, Dr. Oni Celestin from my office is going to share a summary of Nicole Corrado's comments.

DR. CELESTIN: Good afternoon, everyone. These comments are from Nicole Corrado. And they're on the subject of moving out as a young -- as an autistic adult. She says, "I, like many adults, have wanted to move out independently to my own home. As an autistic person, this was harder to do than the average person. I was on ODSP, which is a disability support program, unemployed, and living with my parents and siblings. I had lived in Toronto all my life, but found Toronto to be rather busy. I wanted to move somewhere else where I did not have any baggage from my past. Moving out to another city felt like the only way to move forward. It was very difficult to find anything affordable in Ontario, but I found affordable apartments in Beaconsfield, Quebec. It feels very different from where I used to live, which further distances myself from negative associations with my hometown. The first apartment I moved into in Beaconsfield did not work out due to some personal stresses. My parents later found a basement apartment in Beaconsfield on Facebook Marketplace in a residential neighborhood that was owned by a laid-back person who lives upstairs. Having less people involved in the rental process was key to success. Connecting with the right people allows me to access support when I need it. I live five minutes away from relatives who can support me. Being independent from my parents involves being interdependent with caring neighbors, some of whom are neurodivergent themselves. I walk everywhere. So, having everything close by is really convenient. For the most part, I find living on my own both exciting and rewarding. I enjoy getting to know my neighbors. And I've found an accepting church to attend. Meal planning is a bit of a challenge as I have trouble with money and often overspend at the farmer's market. But I find the outdoor farmer's market less overwhelming than conventional grocery stores. My parents still drive in from Toronto and bring me groceries and other essentials. Though I would like to get executive functioning support in shopping with one of my friends and neighbors from church. I still need to find a source of income as I'm no longer on ODSP, and I'm relying on my parents to pay the rent, groceries, toiletries, and other essentials. Finding a job and supplementing it with disability pay would take some of the burden off of my parents. I still have issues with keeping a good schedule since I don't have another person keeping me on task. Transitioning from wake to sleeping at night and from sleeping to waking in the morning is hard. I have been walking to a daily church service. It keeps a routine. It is social and reduces my anxiety. The daily exercise in the morning removes some of the stress that I experience from the transition to living alone. Creating a routine and developing good time management is something I am working on. I hope to continue to make connections with the community as I settle into my new living arrangement as an independent adult."

DR. GORDON: Thank you very much, Ms. Corrado. Hopefully, you're able to hear this at least through the video cast. Thank you, Oni, for reading those comments.

We're going to now transition to our next agenda item. We were to take a five-minute break. Perhaps we ought to in the interest of trying to stay a little bit closer to time, dispense with that break. We will take a break in the midst of the afternoon though.

So, I want to thank everyone for a really wonderful discussion. And just remark on behalf of the committee that clearly, committee members' remarks during that discussion make it very clear that the written comments, although they are not all read aloud as was Ms. Corrado's, are clearly poured over by members of this committee and taken quite seriously.

We're now going to move to the -- to a focus for the afternoon on autism mental health -- on mental health in autism. We're going to have at least two segments. Three. We're going to have three segments. The first segment will focus on mental health research. The second segment will focus on community perspectives and on mental health needs. And the third, on mental health services. Did I get that right, Susan? Yeah. Okay. Joining us for the first panel are Dr. Carla Mazefsky, the Nancy Minshew Endowed Chair in Autism Research and Professor of Psychiatry, Psychology, and Clinical and Translational Science at the University of Pittsburgh. Dr. Matthew Siegel, Professor of Psychiatry and Pediatrics at Tufts University School of Medicine and Vice President for medical affairs at Maine Behavioral Healthcare. And of course, a member of our committee. Dr. Christina McDonnell, Assistant Professor of Clinical Psychology at the University of Wyoming. And Dr. Kelly Beck, Assistant Professor of Psychiatry, also at the University of Pittsburgh. Thank you to the four of you for joining us today.

And I believe, Dr. Mazefsky, you're going to start us off. And I'm sorry if I'm butchering your name. Not good with names today, I'm afraid.

DR. CARLA MAZEFSKY: Okay. thank you so much for having me. Let's see. Does anyone know how I advance these slides? Is there a -

DR. GORDON: We're getting it to you.

DR. MAZEFSKY: Okay. I could try and do it from memory, but I'd rather not. But I'll start with thanking the IACC for highlighting this topic and inviting me here today. So, I thought I would start by getting us all on the same page about what we're talking about when we say mental health. So, I think, of course, we think of co-occurring psychiatric conditions. So, diagnosed disorders. But also, I think we want to think more broadly about mental health and include aspects of emotional and behavioral wellbeing. Some that you'll hear about today will be emotion dysregulation, self-injury, aggression, suicidality, and trauma. Okay. So, how common are psychiatric conditions in autism? And I really debated what I was going to say about this and just decided to go with, "More common than not," because the ranges out there are so wide. And unfortunately, we're still at a place where the research really reports very different rates based on using different measures. There's challenges in the differential diagnosis of psychiatric conditions in autism. And quite likely, the rates would vary if we looked closely within subgroups based on IQ or age range. So, I think instead, I'm going to highlight some general conclusions. We do know that anxiety, ADHD, depression, and OCD are incredibly common in autism. And also, there's a lot of research suggesting that psychosis and bipolar disorder are much more common in autism than non-autistic populations. And then there are several areas -- this is just some examples where we have such little research, it's almost impossible to say. And some of those would be substance abuse and eating disorders. So, thinking about why we care about mental health. This is just a snapshot of some things -- some statistics about adulthood in autism. So, thinking about the high rates of physical disability, loneliness, difficulties with competitive employment, living independently, which we just heard about, suicidal thoughts. And here's an IACC public comment that also touches on many of those same things. And basically, mental health is an opportunity to impact all of these things. Because mental health plays a role in some of these outcomes, and they, in turn impact mental health. So, we have an opportunity to really improve quality of life, safety, and decrease premature mortality by focusing on mental health. So, for a little bit of good news, I thought I would highlight the progress and momentum we've made in this area. I just did a quick update search looking at the search terms of autism and some just illustrative key terms related to mental health and some of the conditions in -- symptoms we're going to talk about today. And basically, you can see that attention to this topic is rapidly escalating. The progress is certainly not even across different topics in mental health, which I think is also worth taking a moment to take in. So, again, these are just illustrative. I just picked some to give some examples. And I wanted to make a few points. So, here, on the graph, what you see is these bars are total number of publications. Those in blue were published before 2018. So, 2017 and earlier. And in black are publications just in the last five years. So, you can see clearly that, especially in terms of emotion dysregulation, trauma, and suicide, the research has almost exclusively been in the past five years. And then also, I want to point out to other areas with very low publication rates, aggression and self-injury, you don't see the same sort of upward trajectory. It's pretty evenly split between those in the past five years and prior. So, clearly we are not there yet and there's much to do. So, we'll be hearing about that today.

One big area we need to focus on, we know that our research is not representative enough of the full spectrum of autism, including all IQ and speaking abilities, all racial, ethnic and gender identities. And importantly, the full lifespan as mental health is not something just for children, just for adults. The whole lifespan needs to be considered. And then also, I think we need to do a much better job considering all of the different ways in which we can understand mental health from biological research down to more community-engaged research. And then I just want to end the intro with the sentiment that we urgently need to think about how we're translating our research advances into practice much more rapidly than we're doing. And I think that follows nicely with a lot of the public comments today. I just thought I would use this quote as an example of an email I got from a parent. "My 27-year-old daughter suffers acutely from emotional dysregulation, manifesting through meltdowns, self-injurious behavior, and suicidality that no one seems to know how to treat. My daughter's been hospitalized many times and medicated heavily. We've looked extensively, but both the hospital-based and community-based DBT and CBT programs, which are standard, traditional therapy programs that have a wide evidence-based outside of autism. Have uniformly told us either that they don't accept patients with an ASD diagnosis, or that CBT or DBT cannot be used with autistic patients." And I have heard this similar sentiment so many times. And it is just heartbreaking and a really good example of what families are facing and autistic individuals who are seeking mental healthcare. So, clearly, we really need to do a much better job in translating to practice and doing it rapidly. So, with that -- And with this comment from one -- of a teen that participated in our clinical trial. "It's not always easy, but any mountain can be climbed." So, we have our challenge. And now

I'm going to shift to the next part of research talks, starting with me focusing on topics that have received relatively limited attention thus far. And then we'll have our community perspectives panel, and later, a focus on services and programs. So, now, I'm going to talk a little bit about our research in our program, which is called the REAACT Program for Regulation of Emotion in Autistic Children, Teens, and Adults. And our overall mission is to improve mental health and wellbeing for autistic people across the lifespan. I'm going to present research that's by our entire team. So, these are my disclosures. And I'm going to start by just anchoring us in what is emotion dysregulation, which is a big focus of our REAACT program. So, in brief, referring to difficulty changing or controlling the strength or length of an emotional response. And it's something that interferes with ability to meet personal goals. And I'm going to skip the quotes since I know we're a little behind on time. So, emotion dysregulation is very important because we know that it's associated with -- we found it to be associated with a range of psychiatric conditions and other aspects of mental health. So, some examples here are depression, anxiety, aggression, and suicidality, are all higher in those with high emotion dysregulation. You'll also see more psychiatric medications, hospitalizations, ER visits, and police contact with higher emotion dysregulation. So, in our journey to try and address emotion dysregulation, we started with finding a better way to measure emotion dysregulation that works for autistic people. So, we developed the emotion dysregulation inventory which measures two aspects of emotion dysregulation that you'll hear me talk about more today. So, the first is reactivity, which is the idea of negative emotional reactions that come on rapidly, might be very strong, and difficulty calming down. And dysphoria, which is more of a lack of positive emotion and general unease. So, we really started developing the EDI to have something that clinicians and researchers, educators, and also, some parents are using it themselves, to be able to really understand and track emotion dysregulation in a variety of contexts in clinical research and clinical care. So, we started with the EDI for ages 6 and above, five years ago. And I'm proud to say that we've made a lot of progress since and it's now being used in 45 countries worldwide. And what's exciting about that is that I know there's much more going on than just the research I'm going to present here. And we've also, since this year, four months ago, we published a young child version for 2 to 5-year-olds. And two days ago, we finished our self-report for 11 through adulthood. So, it's validated in both autistic and non-autistic populations, which I think is important for making ease of use in clinical care. It can be used across any verbal or intellectual ability. It's brief, has norms and clinical cutoffs, and is sensitive to change. So, I'm going to shift to some of what we've learned using the EDI. And first, is being able to document the rates of emotion dysregulation in autism. So, we had published this earlier about the 53 percent of ages 6 to 17 years old exceed clinical cutoffs for reactivity. And we've recently shown that this is present very early in childhood with rates of 58 percent. Importantly, these numbers are four times higher than non-autistic populations. With dysphoria, you also see high rates, two to three times more than autistic populations. And again, starting early. I didn't have time to put it in the slides, but I ran this yesterday. And in our self-report version, we see 50 percent exceed cutoffs for reactivity. That's ages 11 to 83. So, I still have to break that down to see teens versus adults. The other big message I want to highlight is, in our research, we found reactivity to be highly related to aggression and self-injurious behavior. I'm just going to give two examples. One is a study looking at young children where we found that reactivity was the strongest predictor of aggression. More so than autism diagnosis or traits. More so than ADHD symptoms. And when you account for reactivity, you no longer find an effect of speaking ability or intellectual disability. Also, looking at self-injurious behavior in real-time, with 500 hours of observation, we found that 50 -- like half of the time, emotion dysregulation is observable at the exact same time as self-injury is occurring, as well as you see it before and after. So, I think this is an important point because if you look at the non-medication treatment options, they tend to still be behavioral. And I think we're really missing a piece by not considering the role of emotion dysregulation in aggression and self-injury. And it's a chance to improve the effectiveness of our interventions. I also want to just acknowledge that it's not all emotion dysregulation, as can you -- you can also see that here. And we have a paper that I didn't include a slide because we're getting ready to submit it. But where we looked at different predictors for different types of SIB. And you -- self-injurious behavior. And you do see that some are related more to emotion dysregulation and some are related more to medical comorbidities. So, certainly, an area we need to continue to look more into. Most of that research I just summarized very rapidly is on children. And we also, are now focusing a lot of efforts on adulthood and understanding mental health outcomes in adulthood with our new NIMH Autism Center of Excellence. So, our ACE center has a very strong focus on suicide. And I'm putting a quote here. "I hated how everything was so hard for me that was easy for everyone else. And things that were easy for me were not valued. I was miserable and I no longer wanted to be on this earth." So, those sentiments, we are now seeing like very high rates of suicide now that it has been finally getting some research attention. So, in our center, we're focusing strongly on suicide in every project. But I just want to acknowledge, we're hoping to really understand the full spectrum of mental health in adulthood. So, we're looking at both -- or looking at those who have persistent or current suicidal thoughts and behaviors, including many past attempts. And how that might be different from someone who has fleeting suicidal thoughts, but no attempts. Or just historical suicidality that they've managed to get past and how that relates to other mental health outcomes. And then importantly, understanding also those who've managed to flourish and have high life satisfaction. So, I'm excited about this because most of the research on mental health and suicide in adults has been relatively cursory or using one method. So, we're really -- I think of it as our deep dive into understanding what's contributing to adult mental health. We're using neuroimaging, clinical interviewing, self-report, physiology, behavior. And we're considering pretty much everything under the sun, discrimination, other structural factors of life, like neighborhood, SES, as well as personal experiences and personal characteristics across domains. And then again, of course, we're starting with trying to improve our measurements. So, I think we need to go beyond understanding just when someone is at imminent risk for a suicide attempt and needs a safety intervention. To really make rapid progress in this area, we need to have a way to understand the range of suicidality. So, we've developed this measure called the Autism Suicidality Inventory, working with autistic adults, suicide researchers, mental health researchers, and those with personal suicide experience. We developed 300 items that cover pretty much everything that you could think of that might be related to suicidality, including what's connected in the non-autistic literature. And some other constructs that have come up in the autism literature, and ideas from personal experience and clinical experience. So, we are now getting ready to test our -- we refined those and are getting ready to test the best 148 items in a sample of 1,000 autistic adults. Which I think will really give us insights into what's most connected to suicidality and autism, and hopefully, a new measure to spur on research in this topic. In the meantime, we are looking at how we can improve emotion dysregulation and have had success in this area. We just finished a randomized control trial of our intervention called the Emotion Awareness and Skills Enhancement Program, which targets emotion regulation. We started -- we did a DOD-funded trial with 12 to 21 year olds with verbal IQ over 70. And we found two thirds were categorized as responders based on improvement in emotion dysregulation compared to one third in comparison therapy. And then we also developed a version that could be used in those who have lower IQs and may not be speaking. And I was very excited putting these slides together for the first time with these back-to-back, seeing that the response rate was actually identical. So, we are moving forward with this research and are excited about the potential of EASE. So, I'm going to end with where we're going. That was a very rapid snapshot of some of our current work. Led by Jessie Northrup, we're looking at early development of emotion regulation and the parent-child co-regulation. We have combined those two versions of EASE into one user-friendly manual. And are now launching a 10-site community trial funded by PCORI to really understand what works in the real world with community clinicians. Very excited down the road to pool all the ACE data together. And I'm sure that we're going to find some things that we thought would be related to mental health. But because we're having such broad strokes, I'm sure we'll identify new factors to consider in improving adult mental health outcomes. And led by Kelly Beck, we we’ll hear more about soon looking at minority stress in autistic adults, the interplay between sleep, sensory and emotion dysregulation, diving deeper into that self-injury and aggression research that I mentioned. And then finally, working towards identifying objective markers of distress and developing technology supports. So, hopefully, I did that rapidly enough. And I want to acknowledge the core REAACT team. These are the faculty and postdocs who did much of this work that I presented. Our ACE lead investigators and lead partners. And many other key collaborators and staff. And this is not a full list. So, thank you to everyone who has supported this work. And I will turn it over to Matt Siegel.

MS. GASSNER: Are we saving questions for the end?

DR. GORDON: Yes. There'll be a discussion period at the end of the panel.

DR. MATTHEW SIEGEL: Okay. Thank you. Thank you, Carla. And wonderful to be here both as a member and to get to present to this group. And I have 12 minutes. So, I'm going to move a pace and try to be as on time as Dr. Mazefsky. It was amazing to see that line of work. And I don't think I can overstate how important I think the work is that Dr. Mazefsky has been doing for now 15 years. Defining the field of emotion regulation, the measurement, and then developing interventions. And as you all know, it takes a long time to move from evidence of -- for an intervention into therapists in the community actually able to do it. And that's the -- I just encourage everyone to support her and that team in trying to make that translation and make it not take 20 years, which is what it usually does. With that said, I'm going to talk about self-injury and aggression. I see what you mean. Not easy to advance. Not just you. Okay. These are my disclosures. So, aggression and self-injury are quite common depending on the sample you're looking at. But I'll just give you a couple examples. So, aggression -- and when we say aggression, in this world, we are not talking about verbal aggression. Verbal aggression does not bring you to the attention of the services I'm talking about. We're talking about physical aggression. And so, as one example in the autism treatment network, it was a parent survey. So, these are clinically referred kids. This is not a community sample. But 53 percent of parents said, "Yes," to "Are they currently displaying physical aggression?" So, even in a clinically referred sample, that tells us that this is quite a common presenting problem in -- and these are outpatient autism treatment clinics in the autism treatment network. Another piece of information, self-injury, very different source. This was the CDC ADDM review of 8-

year-olds that comes out every two years and helps give us some of our best prevalence data. And in that review, which is a record review primarily, over a quarter were identified as having self-injurious behavior. That is a community sample, and that's pretty remarkable. So, the impact. I don't think I can add really anything to what we heard earlier today about the impact on individuals and families. But I will just note that we hear repeatedly, and has been shown in THE literature, that the impact -- many families will say that the impact of aggression is greater than any of the features of -- the core features of autism. They -- some families will say to me, "We can handle the autism. We can do great with that. It's just this aggression is what keeps us from going to the restaurant, going to the grocery store, being able to access therapies, being able to go to the dentist. That is the limiting factor. We can work with the rest of it." And so, I think that is remarkable. And so, that has been reflected in the literature. So, I think this area, aggression, self-injury, can be seen across the spectrum and is a particular concern for those with profound autism. Also, sometimes called severe autism or level three autism or autism with co-occurring intellectual disability and/or limited speaking ability. And so, as people here likely know, most recently, there was a report from the CDC that showed about 26.7 percent by their definition met this criteria of profound autism. When you look at that report, that was a very important report and very helpful. It is notable though that the definitions from the Lancet Commission really focused on adaptive functioning. The ability to be on your own in a home with or without adult support. The report from the CDC didn't really use adaptive functioning. It used IQ and communication, which are related concepts. But the point I bring -- the reason I'm bringing up this somewhat nuanced point is because I think the 26.7 is an underestimate because it was based only on IQ and communication. But I think many of us experience in autism that regardless of IQ or communication, adaptive functioning can be challenged or challenging. Also, in this report, it was shown that aggression is more likely in this profound autism group, which is something we knew. And SIB was significantly more likely. So, I think a takeaway I would like -- that I include in basically every talk I give regardless of topic is this concept. I'd love for people to take this away, which is aggression and self-injury are a final symptom or outcome. They are not a disorder. They are not a diagnosis. And the reason I put it that way, at least from a medical perspective, is it means you have to look underneath or in front of that, or however you want to phrase that, for what could be contributing or what is driving this aggression and self-injury. And so, not in any particular order, there are many factors to look at, including, are there co-occurring psychiatric disorders? Is the symptom, which some people call behavior, aggression or self-injury, what is the function of it? And how is it being reinforced in the environment? Or is it self-reinforcing? Is it related to communication challenges? Is it related to side effects of medications or other therapies? How does it relate to the sensory system? A question that is not often asked, but I think could be helpful, is how does it relate to a potential mismatch between the person's abilities and demands being placed on them? Demands too high or too low. Changes in the family, of course, medical illness or pain, which we worry about a great deal, particularly with our individuals who cannot communicate as easily. And emotion regulation, as Dr. Mazefsky said. If I can get our trainees -- our clinical trainees to think this way and think a little broader about what can be, you know, a very dramatic presentation in front of you, I feel like we're making some headway. So, what do we do about these problems -- about these challenges, aggression and self-injury? So, one way to answer that question is to show you kind of my take on what is the system of care? What options are available in the U.S.? And so, from sort of most intensive or acute to least intensive is this pyramid and going down. So, at the top, we have specialized psychiatric hospital units, extremely few in the U.S. About 18 by my last count, although that is a doubling since we last looked in 2011 when there were about nine. By reference, there's about 1,600 general inpatient psychiatry units in the U.S. So, it's a very small number, but at least there are some. And then there are other levels of care, which I won't go through all of these. And the distribution, the availability, of one or more of these levels of care varies enormously based on geography, urban versus rural, and many other factors. The bottom of the pyramid is the biggest because the fact is, most people get their care in -- from their primary care, if they get any care at all for these challenges, or their school. So, just focusing -- I've done a lot of work in the inpatient realm. So, I'm going to focus on that a little bit. So, a -- the first point to make about that top of the pyramid, the most intensive setting, is that even though there's so few units, kids with autism have very high rates of psychiatric hospitalization. So, one study by David Mandell, a former committee member, showed that 11 percent of kids, by the age they hit 21, have been psychiatrically hospitalized. That sounds like a small number, but that is a huge number because the corollary number in kids who don't have autism, who have private insurance is like 0.11 percent. So, this is much higher. Another way to say that is -- or get at that is, Lisa Croen did a study some years ago now where she found a 6/1 ratio of hospitalization for kids with autism versus not autism in a fairly large sample. This is psychiatric hospitalization. A point to make is that this group of people are being hospitalized, not necessarily for the same reasons that kids who don't have autism are being hospitalized, who are often presenting with suicidality, severe depression, severe anxiety, et cetera. This group is generally presenting with externalizing behaviors, aggression, self-injury, property destruction, et cetera. They may also present with depression or suicidality, et cetera. But this -- and what the study was is what was the chief complaint to the degree that it could be determined. And that's worth noting because typically, psychiatric -- inpatient psychiatric settings are not actually designed for externalizing behaviors. They were designed for internalizing problems like depression, anxiety, et cetera. So, you can't -- I think to get the best treatment, you can't use a typical setup. So, a quick look at -- we tried to see, well, can we produce some evidence for these specialized inpatient units? And so, this was a study of six inpatient units -- specialized inpatient units, kids with autism. And we looked at 350 of them. And this is a busy figure, but it essentially shows that they come in very high in terms of aggression, self-injury, and tantrums at admission. They leave with a significant drop. And then there is some regression at two-month follow up, but not a significant amount. And so, we're able to get some enduring effects of this psychiatric hospitalization in these specialty units. This is not being hospitalized in your local child and adolescent unit that you might access. Those outcomes are unknown. So, those units are -- can be helpful. And I've, obviously, focused on them. But I also -- we also did some work recognizing that there'll never be enough of those units. There won't even be close to enough, right? There's 18 now. There were nine a decade ago. That's not even one per state, obviously. And so, how else can we improve care in psychiatric hospitals for this population? So, quickly, we did a project with Bellevue Hospital in Manhattan, which is a public, low-resource, psychiatric hospital. And essentially, developed a care pathway for youth who have autism or intellectual disability. Did some very basic -- what I would call a pretty low intervention with this care pathway. And we got some very dramatic results where the length of stay in the hospital decreased significantly. And perhaps striking the use of physical holds or restraints went down almost 80 percent. So, pre-intervention versus post. So, I think that says there are ways to improve care in non-specialized settings potentially. So, as much as I told you about treatment, there are big gaps which everyone has spoken to in various ways today. So, just a summary of some of those common gaps. There's very uneven geographic distribution. You know, there's a -- we have a specialty unit in Portland, Maine, which has a population of 250,000 people. And New

York City does not have a specialty unit for youth with autism or developmental disability. Zero. So, they have some great providers who are doing their best, but they don't have a specialty unit, just as an example. Intermediate levels of care, from my view, are rare. Things like intensive outpatient, partial hospital, even specialized clinics that can work on these challenges are quite rare. And so, most people are seen in primary care or not at all. Something else to note is that there are many, many residential treatment centers in the U.S. People call them different things, group homes, PRTF, et cetera. I would just say they're places where people live and they're supposed to get treatment. And there are very few who have significant expertise for this population, and there's almost no data about them. And we are spending vast sums of money on residential treatments. I don't have a problem with residential treatment, but I have a problem with having no idea what the outcomes are. And so, I think that is an area that could use some more attention. And then finally, many places might have one piece of this continuum or levels of care. But very few have a continuum with multiple levels of care, which is actually what you need to really care for the population. So, we have a long way to go. So, briefly, and then I'll wrap up. Research gaps. In aggression and self-injury, there are many gaps. So, this is my take on some of the prominent ones. First of all, we really still don't have a good natural history studies on this. In other words, I can't say to a parent of a 12-year-old, "This is likely to get better as this child ages." Or, "It won't get better," or, "It will get worse." I don't have a study to help me, you know, give that kind of guidance for a parent. Certainly, the etiology needs a lot of work. So, you know, because we have the behavioral functional approach and a lot of work there, but we really need more novel approaches to aggression, self-injury. Really looking at biological mechanism and using objective measures, perhaps physiology. There's been some very early work in that, but it is early. And I think this is an area that got attention 20, 30 years ago. And really, not much has happened, as I think Dr. Mazefsky's publication chart showed. And I think is ripe, but it will require attention and funding. There is a need for good tools to diagnose psychiatric co-occurring disorders across the spectrum. There's certainly more work to do within applied behavior analysis and functions of behavior. And certainly, the relationship of emotion regulation to these things that we observe and see. Access is a huge issue, and we need more research on that. What exactly are the barriers to access? Is it reimbursement? Is it capacity of providers as Dr. Wang said? Is it other things? And which ones are modifiable? What can we do about this? Finally, further research gaps. In treatment, I think some particular gaps from my perspective are, we have big gaps in not having controlled group studies of ABA for aggression or self-injury. We have lots of single-subject designs, single-case studies. Those are scientifically valid. But frankly, insurers, policy makers, people who run hospitals, they don't understand them and they don't know what to make of them. They need to see group randomized trials or at least group comparative effectiveness trials. That's just the world we live in. We also need controlled group studies of treatment packages. You know, perhaps ABA plus functional communication training. Or ABA plus meds plus parent training. That's what happens in the real world if you're lucky enough to access it. But we don't have much. We have a little -- a few studies that have been funded by NIMH on meds plus parent training or AMED plus parent training, but not much beyond that. And a few other things. Finally, we need to include people with profound autism in our studies, particularly of treatment. And so, that's my final point, is we have, unfortunately -- so, we published this paper a few years ago. We have unfortunately seen a decreasing inclusion or participation of people with, I'll use the term profound autism, in, specifically, treatment studies. I think it may be in all studies, but certainly, in treatment studies. And as an example of showing that, this is a figure from that paper where you see the average IQ and communication ability, and even adaptive functioning, rising over time when we looked at 367 treatment studies. A very significant rise in these things. And so, the percentage of studies that include or even focus on people with profound autism has become smaller and smaller over time. So, I just want to acknowledge co-investigators and collaborators. The group is much larger. As well as our research team, who, of course, did the bulk of this work. And thank you.

DR. GORDON: Ivanova, I see your hand up, but we're going to hold off on questions until all of the panelists. But I'll mark you down. Thank you.

DR. CHRISTINA MCDONNELL: Great. So, hi, everyone. Thank you so much for the opportunity to share our work with you all about supporting autistic individuals with traumatic stress across the lifespan. So, this will be known to the room and it's come up a lot today, but we know that mental health and physical health and wellbeing all occur in context. And that one really important piece of the context for many are experiences of adversity, which can involve many different things. But today, I'll be talking about traumatic events, those that can lead to post-traumatic stress disorder, or PTSD, as well as kind of the broader network of effects of trauma that we call traumatic stress. And then I'll also be touching briefly on adverse childhood experiences more broadly for this kind of wider set of negative experiences that can also influence health. And so, despite all we know about the importance of adversity for mental health, as we've seen, very little research to date has examined adversity among autistic people. Or considered either how to prevent or support people after adversity has happened. So, I will briefly first share today some of our basic research trying to better understand the types of traumatic experiences autistic people face across the lifespan. And the goal of that is really to inform the second aim, which is to try to develop programs and supports that can be helpful for autistic people in reducing traumatic stress. And then I'll touch briefly on some of our future directions in this area. So, in terms of this first aim, just looking at the types of traumatic experiences we see, this first paper was using the South Carolina ADDM dataset. It was published a few years ago now in 2019. And this was conducted with colleagues at the Medical University of

South Carolina. And what we were able to do is link the information from the ADDM dataset with data from the South Carolina Department of Social Services in terms of reports of abuse or neglect to that center. And so, just for a very quick overview, what we see here is relative to the non-autistic comparison group. We see a significantly higher rate of any report of maltreatment in childhood for autistic youth. So, over one in five had experienced some type of reported maltreatment. And we see an even higher and significantly higher rate for autistic youth who also had intellectual disability. So, almost one in three here in this sample having some experience of reported maltreatment. We also looked at different types of abuse and neglect to try to inform future personalized prevention strategies. So, we see here the odds ratios. So, how much more likely autistic youth with and without intellectual disability were to experience each of these forms of abuse and neglect? So, there are some differences there which I think could help pinpoint areas of support for Child Protective Services and related offices. But some of the numbers are very strikingly high, as high as over three times more likely to experience some of these forms of maltreatment. So, because we know that reports to social services are not going to capture everyone, we've also looked at this in other ways and in other samples. So, this was a sample where we used caregiver report. So, caregivers reporting on the adversities that their autistic children had experienced relative to a non-autistic comparison sample. And I think this just really echoes a lot of what has been shared today. But in addition to experiences of abuse and neglect or maltreatment, we also see very high and significantly higher rates of all of the broader forms of adverse childhood experiences we talked about. We have also asked autistic adults about their experiences. So, what we see here is very similar. That autistic adults report a higher number of traumatic events, not only those that they experienced, but also those that they have witnessed or that they have learned happen to other people in their life. And they also report higher levels of all types of PTSD symptoms. So, I like to also acknowledge that I think this data is important to show to really emphasize the need for trauma-informed services. But I think it's also consistent with what many advocates have been saying for a long time. And I think it's also consistent with the growing body of research. As we've seen, this has fortunately taken off in the last five years, where many different research groups are finding this. We see these very high rates of trauma and PTSD. We also see higher rates of traumatic stress symptoms more broadly. And because, to date, we know there are such barriers to accessing mental healthcare, and there has been very little research done on trauma-focused therapies in particular; it's likely that untreated PTSD might be quite common for autistic people and can be one factor contributing to health disparities across the lifespan. So, we really feel that evaluating interventions in this space is one really important priority to address this problem. So, to share a little bit of what we have done in this area, I'll walk you through just some highlights of some of the program evaluation research we have been fortunate to start recently. So, the first is a small pilot feasibility study that was funded through the Organization for Autism Research to see whether trauma-focused cognitive behavioral therapy or TF-CBT is also helpful for autistic youth. So, TF-CBT has lots of evidence for non-autistic youth but has not -- there hasn't been as much data yet to see whether it's also helpful for autistic youth. So, we tested this with children between the ages of 10 and 17. And we ran this pilot study all over telehealth. So, we just finished up our pilot results.

And in this pilot sample of 17, we see significant pre- to post-reductions in youth PTSD symptoms. And this is both when we asked parents or caregivers to report on child's symptoms, and also when children reported on their own symptoms. And these were also maintained to the same effect size and same significance at one month post, suggesting that there's a lot of promise in this program for improving PTSD. But what was also very promising to us is that we saw improvements in that broader net of traumatic stress more broadly. So, we saw reductions in youth depression, youth anxiety. We saw improvements in emotion regulation consistent with some of the other work we've been talking about. We saw improvements in parenting and some resilience outcomes. So, a lot of promise to this intervention to evaluate in more detail, moving forward. And one of the things that we're doing now is trying to better understand how this program works so that we can optimize it, moving forward. And one of the ways that we're doing that is through the feedback we've gotten from both caregivers and youth themselves about the program. So, I won't go through this in detail. But here, a five would have been the highest level of satisfaction regarding this particular domain. So, overall, of course, we don't think this program will be for everyone. But we do think that this was a really promising finding so far, to warrant future study and larger trials of this program. We also just received pilot funding from the Wyoming INBRE Program, which is funded through NIGMS, to start a pilot feasibility evaluation of a narrative-based support program for autistic adults. So, this will be a similar kind of pre, post feasibility design. And we're interested in whether we see improvements in mental health, and also physical health outcomes, which we'll be assessing using Fitbit devices. So, we're excited to get started on this now. So, finishing briefly with some of our future directions in this area. So, I've spoken mostly today about, you know, traumatic experiences, stressful experiences. We're also doing some work to try to better understand what are the positive childhood experiences that autistic people value and that their families value. And how can we also promote those in interventions? We've also done some work looking at how caregiver trauma relates to individual trauma, trying to understand patterns of intergenerational stress and trauma over time. And then in this outer circle where many have spoken to, today, we're really committed to understanding and working within the systems of care in which autistic people should be able to access these services. So, in adults, one of the things that we've spent a lot of time on is healthcare services, and pregnancy services in particular. So, we've heard a lot in our work about the medical trauma that many autistic adults can experience, and the need to better understand those experiences to improve them. So, I've been really fortunate to partner with an advocate who's doing a lot of work in this space trying to develop resources for autistic people about pregnancy-related healthcare. So, that's one of the things that we're spending a lot of time on now. And we're hoping to continue this work, moving this research and these topics out into community settings with the autistic community. And so, I will stop there. But please reach out if you all have questions or interests. We're looking forward to continuing to better understand these programs, to make sure to disseminate them in meaningful ways, moving forward. And I'll briefly acknowledge the funders again, the Organization for Autism Research and Wyoming INBRE. I've also been really fortunate to partner with the Wyoming Institute for Disabilities and their Equality State Research Network, which is funded through PCORI. I also want to acknowledge all the graduate students on this work, who are each doing exciting work in this area as well. So, I think I will turn it over to Dr. Beck.

DR. KELLY BECK: Hello. Thank you to the IACC members and leaders for having me come and speak today. What great work that my three colleagues have presented so far. So, my talk today will be about Perspectives from Autistic People, Parent, and Clinicians on Mental Health Interventions and Areas of Need. There we go. So, the work I'm going to talk about today is some steps to take all the great work that you've heard, and how do we translate it into the community? So, the purpose of the study that we conducted was to understand intervention needs and barriers for autistic people in community mental healthcare. And some of the questions that we were interested in are, why are autistic people seeking mental healthcare? What contributes to emotion dysregulation in daily life, since we know that relates to mental health and suicidality and aggression? What mental health interventions are helpful? And what barriers prevent interventions from being helpful? So, this is a qualitative study, which is a useful design to hear stories from across the autism community. Then we can take these stories and find common themes across groups of people so we can inform future research designs and test it with larger samples. So, we talked to 55 individuals. You'll see here there were four different groups. We talked to autistic adults ranging from 21 to 68. We talked to autistic teenagers. We talked to caregivers and parents. 50 percent of the caregiver and parent group had children that were non-speaking or had severe self-injury and aggression. And we talked to 16 community mental health providers. So, our first theme that we looked at were, what were the reasons for seeking mental healthcare? These are the top three across all of those groups -- was emotion dysregulation, which we've heard about today many times, and how that relates to other behaviors, externalizing behaviors and suicidality. One interesting thing that, you know, we weren't expecting, going into this, was there was a large focus among the individuals in the study talking about how sensory needs and sensitivities contribute to emotion dysregulation and how they -- the need for that in mental healthcare. And then similar to the talk we just heard, is trauma and chronic invalidation was the top reason for seeking community care.

So, highlight some quotes and let the participants speak for themselves. This is from a 21-year-old autistic man. "I want people to know how cripplingly lonely I am. All I have known is gaslighting, lies, hatred, physical and psychological abuse. So, I just unfortunately do not have very high self-esteem or self-care." And this is from a community mental health therapist. "They're hurt so bad by people. It's like touching a stove a thousand times. At some point, you just quit touching the stove. You don't even want a stove because it's dangerous." So, in these interviews, we asked folks to tell a story. So, we asked them, "Tell us a story of a recent time you felt out of control of strong emotions." And in the adult group, nearly every single participant shared a story of a meltdown or emotion dysregulation that occurred on the way to, or in a healthcare setting. So, I think someone earlier had mentioned access. Accessing healthcare was so stressful to get there. And all the steps it took to get there, interacting with the different well-meaning healthcare providers, was not a smooth process and often resulted in pretty significant troubles. The teenagers most frequently experienced dysregulation in school. And I will say a strong runner-up to these settings were grocery stores, grocery stores and traveling. So, we looked at what contributed to those stories, what contributed to emotion dysregulation in these stories. And we found that inaccessible environments, living in a neurotypical world was one of the strongest predictors to emotion dysregulation in these stories. And a lot of that was sensory, but other things like unpredictability and things like that, which contributed to it. Discrimination was a very prominent theme with contributing to emotion dysregulation; not feeling safe, being chronically invalidated, feeling like you had no power in various settings. Masking autistic traits and symptoms was a strong contributor to dysregulation, as was having difficulty knowing emotion dysregulation was coming. So, not realizing they're having sensory overload or emotion dysregulation until it was too late because they're spending so much time hiding it. And then social misunderstandings with neurotypical peers and leading to social rejection. This was also -- these themes were prominent in the teen interviews as well. Although the three that I have highlighted on the slides here were more commonly endorsed by the teens; the sensory needs, the awareness, and social rejection. So, some quotes here, a 31-year-old woman, "I'm forced to keep it toned down because I'm at work and can't be seen. Forcing it down is actually worse." It's talking about masking. Here, a 45-year-old autistic female, "You're hurt, and people don't try to understand things from your perspective. It's like you're expected to understand things from their perspective, but there's no effort on the other person's part." And lastly, we have a quote here from a 17-year-old teenager talking about a social misunderstanding at school that impacted the entire rest of their year. "So, there was a bug on the playground that everyone was gathered looking at. I had no clue what was going on. So, I ran over, and I stepped on the bug. And for the rest of the year, I stayed inside." The consequences of dysregulation in these stories from our participants were quite severe. So, there are frequent unjust responses to emotion dysregulation in healthcare settings, in school settings, in community settings. Involuntary sedation. There were several participants who described loss of healthcare services, jobs, and friendships. Discipline at school. The need for safe people and plans, or places to go when experiencing dysregulation was very prominent. And here's a quote from a 42-year-old autistic female. "They're threatening to suspend me. How are you threatening to suspend me from a mental health treatment program? It makes no sense because I'm not well enough." Because she had a meltdown at the program. So, shifting to the interventions and barriers to mental health interventions, across the community mental health providers, we asked them what intervention approaches they're using. The wide majority of them described an eclectic approach. They described validation, working on parent-child relationships, social skills, mindfulness, sensory tools. And why I think this came up so often is because all of the providers mentioned, when they start seeing families, they see them for years and years and years and the need for long-term care. And then 25 percent mentioned behavioral approaches. The strongest theme across all the groups related to interventions was that mental health interventions that are existing are poor fit for autism. There was a question, do they even honor lived experiences of autism? If someone's being treated poorly and unjustly and being discriminated against, why are we trying to -- feeling like they're -- we're changing the individual? They're not generalizing to real life. And so, what came up for that was progress made in a therapy session wasn't working when they got home or when they got to school. And that they weren't designed for the diversity of autism and different communication abilities and other forms of diversity. So, this is a -- you know, I feel like we've heard this sentiment a few times today. A parent of an autistic adult mentioned, "And you asked me, 'What's good?

What's positive? What works?' Like I said, I can tell you what doesn't. You know, relinquish your child to the country, and they'll find them somewhere that's a good program. Are they out there? They tell me they are. I see them. I see money. I see lots of money. I see money for autism services and waivers. I see all these great places having all these kinds of fundraisers, and they send me all kinds of emails. Donate now. But my son has nothing." So, here's the theme about whether or not interventions are appropriate. This is a 45-year-old autistic female commenting on cognitive behavioral therapy. "My feelings are valid, and many situations cannot be reduced to faulty thinking patterns. If you're getting discriminated against, some emotions arise that are complicated." A parent of an autistic teenager, "He thinks that he's seeing providers because something's wrong with him." And a community therapist mentioning, "I wish there were more programs that weren't about, 'You can't regulate. I need to help you regulate,' or 'Your social skills aren't good. We need to get you social skills.' I feel like a lot of those are deficit-based." So, the difficulty, translating to real life. Communnity mental health providers share that their main tool to help generalizing progress is involving parents and caregivers in treatment. So, then we asked all the groups, "How do you feel about involving parents and caregivers in mental health treatment?" We found really wide discrepancy on preferences. So, all the providers mentioned needing the support of parents and caregivers in mental health treatment to generalize progress, to varying degrees of how much of a session they'd be involved. Only one teenager said they would prefer to have a parent or caregiver involved. 40 percent of adults were open to it, and the rest were not open to it. And then the caregivers and parents were split right down the middle in that the caregivers did mention more nuance to, like, be involved in parts of the session and also generalizing, to help generalize things at home. Insufficient service eligibility, a main thing was long-term mental healthcare across the whole lifespan is needed. That interventions that are being tested in research are 8 to 10 sessions long, and folks and families are seeking mental healthcare for years. And so, how also can we coordinate care with mental -- between health and mental healthcare teams? So, here's a quote from a parent of an autistic adult. "You can go to any kind of exhibit fair where they have all kinds of different services, and they'll say, 'Yes, we welcome people on the spectrum.' And if you happen to say, 'Even those with behaviors?' 'No, no. Sorry, no.' So, you don't welcome the spectrum." So, the top overall barriers and themes is that the current mental healthcare system is a poor fit for autistic people, citing long waitlist, interventions not fitting needs, providers mentioned not having enough training and support. And we already heard about this lack of translation or generalizing to real life. So, moving forward, you know, this is -- IACC's job is putting out recommendations. But some of the things that this project came up with are having quality services and also improving services eligibility for the diversity of autism. And in terms of mental health intervention research, that we might continue to think about honoring and addressing marginalization, invalidation, and trauma. Integrating sensory into mental health interventions and care. How can we design interventions where we're thinking about the community first, and developing it with community mental health providers so that they translate better to what's going on? And how can we think about what are some other tools for generalizing progress than just involving parents and caregivers? So, this project was not done alone. I have many amazing mentors and collaborators. And I partner with the community group on all of our work that we do at Pitt, and lots of staff and students that supported this work. Thank you.

DR. GORDON: Thank you very much to all the panelists. We're going to abbreviate the comment session. So, I'd ask all of the members of the committee who'd like to ask questions or make comments, to please keep it brief out of respect for the other members of the committee who might want to have a chance to ask questions. We're running quite a bit behind. Ivanova, please go ahead first. I know you have to leave.

MS. SMITH: Hi. This is Ivanova Smith. And my question to Matt Siegel. Is there any research in how lack of autonomy could contribute to challenging behaviors? And how to allow people who need higher support, more autonomy in their lives and see if that helps relieve that challenge? Thank you.

DR. MATTHEW SIEGEL: Thank you, Ivanova. I think that's an excellent question and a very powerful way to look at things. And I don't have the answer to that. In other words, I'm not familiar whether there is or is not research from that perspective, particularly looking at autonomy and how it interplays with these behaviors and whether -- or these aggression and self-injury, and whether it's a path to reduce them or is a predictor of them occurring. So, it's a really good question.

DR. GORDON: Sorry. I know we have Dena from before, Helen, Yetta, and Morénike. And then I'm going to have to cut it off because, otherwise, we won't have enough time to hear from our wonderful panelists this afternoon. Dena? And again, I'll ask all the members of the committee to be brief, as Ivanova demonstrated quite nicely. Go ahead.

MS. GASSNER: If you guys can keep up with me, I'll just ask my questions all in a row. So --

DR. GORDON: Can we just, out of respect for the others, ask one question, Dena?

MS. GASSNER: Oh, God. Are you going to make me do that? Okay. Just an observation, I saw many opportunities there to delineate by gender or gender nonbinary status. And if any researchers doing work around any of these subject matters could continue to delineate that information when it's available, I think it would help to inform our research tremendously going forward. Plug for Russell Lehmann, if you want to watch a lived experience recording. He's with The Arc U.S., on their board. And his YouTube videos describing just completely losing it in a mental health environment and having him just be disregarded, it's heart-wrenching. I would encourage you to find it.

DR. GORDON: Thank you, Dena. Appreciate your forbearance with my strictness here.

DR. GORDON: Helen?

DR. TAGER-FLUSBERG: So, thank you so much. This has been really fantastic. I sort of have two interrelated questions. One is, have we actually developed any new effective treatments for skill regression in the last 30 to 40 years, and particularly for those with profound autism? And second, I'd have thought these were conditions that would be really low-hanging fruit for biological research, particularly animal models related to autism and other neurodevelopmental disorders. And we know that so much money is going to biological research. But what proportion is actually, these days, focused on these critical conditions? And these are really interrelated. Because without animal models, we're not going to get to new effective biological treatments that I think people in the trenches know is what we desperately need.

DR. GORDON: Thanks Helen. Any of the panelists try to respond to the questions?

DR. SIEGEL: I could take the -- maybe try to take the first one a little bit. So, simplistically, I would say, no, we have not seen in the last 20 years or so. Since the trials for atypical antipsychotics in 2002, 2003 were published, and the really seminal ABA for aggression, self-injury were published, I don't think we've seen significant advances. We've seen some marginal ones. I think we have some very promising things, you know, such as emotion regulation intervention, the EASE intervention, particularly EASE-ID for those who have higher support needs. Very excited to -- as an example, we're looking to integrate that into our inpatient unit. But in terms of -- and that will be helpful. But in terms of significant steps and new approaches, I think it has not been a rich landscape. I don't mean to sound negative, but I really think that is the case. What I'm doing today, and my colleagues, is really -- we're trying to do it better. But it's not really different than it was 15 years ago when I started doing this. Carla, if you have anything.

DR. CARLA MAZEFSKY: I mean, I don't really have much to add other than I agree with you fully. And I did try to emphasize that a little in the intro. I don't think we've made much progress in those areas. And I do think we need to do a better job thinking holistically about the methods we're using, including, you know, new biological research, not just antipsychotics, but other ways to think about this.

DR. GORDON: Thank you. I'll just point out that NIMH after -- it was several years ago that we had a session that was devoted specifically to aggression and violence, and have a lot of testimony from parents and individuals living with it -- put out an updated notice on aggression research with this particularly in mind, and with the idea that it would be compelling to try to study it from the preclinical standpoint. Nothing new coming out of that yet, but we hope to see something in the future. We have Yetta. And then I was mistaken, it wasn't Morénike. It was Hari. And then, I'm sorry, Scott. We're not going to be able to take your question. So, maybe hold it toward the end of the day. Yetta?

MS. MYRICK: Thank you. Thanks for presenting. Really quickly, could you -- and you don't have to give us this information now. But I'm curious to know who all participated in your different studies? I didn't see that clearly laid out across presentation. And then as you talk about taking these plans to the community, how do you plan to engage a diverse population and network?

DR. MAZEFSKY: Yes. We left out some of the -- we left out some of the method's details just to give, like, the whole overview. So, I'm happy to, like, share more about our samples. I mean, we are trying very hard to get diverse samples. And I will say, I think it's an area of growth. And we're trying to build community partnerships, really target more diverse samples, more recruiting in areas that will foster diversity. I don't know. Kelly, you want to say anything else about that?

DR. BECK: I think -- yeah. So, we have a Autism Center of Excellence who are focused on dissemination, implementing in the community. And our approach is truly forming relationships with communities that maybe necessarily don't trust research to start. And so, we're partnering with leaders in the community in autism and not in autism, to reach those marginalized groups, so that we can translate some of this into those areas. So, I think that our approach has been partnering and building trust. But it's a huge focus that we're working on at least.

DR. GORDON: Thank you. And I believe we have a question from Hari?

MR. ISAACSON: Hi, there. We have two comments from Hari. The first one is from Dr. Mazefsky's talk. He says, "Thank you for that talk. The website of many CBT providers states not only serving high-functioning autistics, it would also appear that their thinking is the rest of the autism spectrum does not have mental health issues. It does not seem fair that the only option for this -- for the rest of the spectrum is use -- heavy use of psychotropic medication. What is troubling is what I've heard at a autism conference in Stanford a few years back. That such meds for behaviors don't work in the same way as autistics, as they do in the general population. Yet, he says such meds are the first course of action. Plus a lot of these meds come with long-term health side effects, like memory loss and increasing motor issues. For the general population, they have CBT for kids. Why can't they be adapted for autistics? We also need better pharmacological options." Hari says, regarding Dr. Siegel's talk, he says, "I agree that aggression is the biggest block to inclusion, even more than lack of communication or OCD or even self-injury." He says, "Bottom line, because no family is going to want their neurotypical kid around an autistic kid who has even a small chance of being aggressive; no gen ed teacher is going to want that autistic person in their classroom; or even support staff don't want to work with aggressive autistics, it becomes a downward spiral for the autistic person on many fronts. In and out hospitalization can't be the only solution. And basically, no one wants to be around that person, and even their own family is not able to manage them at some point due to sheer lack of support and burnout. So, the autistic person is sent away. All these compounds ACEs, adverse childhood experiences, and lifelong trauma and neglect." He says, "Often, the alternative to aggression towards others becomes SIB towards their self, due to sheer mental health and trauma, neither of which are good options."

DR. GORDON: Thank you very much, Hari, for those comments. Would anyone like to respond briefly from the panel? No? Thank you very much. I want to really thank the entire panel for stimulating research. It's wonderful to see some of these results come back and we'd love to see that implemented more. We are going to take a five-minute break. I can't ask you to go from 1:00 p.m. to 5:00 p.m. without a break. So, please come back at 3:07 p.m. precisely.

[Short Break]

For this next panel, I'm going to turn it over to Susan who's going to be introducing the panelists and leading the discussion.

DR. DANIELS: Great. Well, welcome back from your brief break. We are looking forward to this section of the meeting where we're going to hear community perspectives on mental health needs in autism. And I'll introduce our speakers. They include Dr. Xenia Borue, who's a psychiatrist at Full Spectrum Psychiatry, and the lead advisor for the Pittsburgh Autism Center of Excellence. We also have Lisa Morgan, who is the founder and co-chair of Autism and Suicide Prevention Workgroup. Kayla Rodriguez, who is the co-chair of the Executive Advisory Board of the Autistic Women and Nonbinary Network or AWN. Ian Neumaier, a student in Frederick Honors College at University of Pittsburgh. Dr. Morénike Giwa Onaiwu, who's a member of the IACC and the Equity, Justice, and Representation Executive Committee chair at the Autistic Women and Nonbinary Network, and a Humanities scholar at the Center for the Study of Women, Gender, and Sexuality at Rice University. We also have joining us today, Angie, the mother of a young adult son on the autism spectrum who's requested to keep the last name out for privacy purposes, but wants to share. So, we are going to talk with each of these panelists. So, I'm going to condense it a little bit for the sake of keeping on time, and ask you each on this first question to mention your connection to autism. So, whether you're an autistic person, a family member, or community professional, or if you identify in more than one of those categories. And then to let us know, why is mental health an important issue for autistic people? And what challenges have you either faced or observed in the autism community in addressing mental health needs? And so, we will start with Dr. Xenia Borue.

DR. XENIA BORUE: Let me unmute myself here. Can everyone hear me okay?

DR. GORDON: Yes, we can.

DR. BORUE: So, my connection with autism has been multifaceted. I started out doing research in autism during my training as a medical scientist. I then dedicated my clinical practice to serving autistic individuals. And I also, myself, am a late-diagnosed autistic adult. So, in terms of the challenges that I've observed, I think a lot of them have already been echoed in some of the presentations that you've seen today. Probably, the biggest one that I've seen clinically, as well as experienced personally, has been the lack of training that most mental health providers have with autism. And because of that lack of training, there is so much misunderstanding and miscommunication and misdiagnosis of individuals that are autistic, so much so that usually by the time somebody who's autistic gets to my practice, they had dozens of providers that have either missed them being on the spectrum, misdiagnosed it or something else, or just simply not known how to actually provide any kind of meaningful help for them. And so, I think that training individuals and training providers to better understand what autism is and what autism isn't, is a really crucial piece of the puzzle.

DR. DANIELS: Thank you. Next, to go to Lisa Morgan, who's in the room with us.

LISA MORGAN: Hi. I just want to thank Kelly and Carla for supporting me up here. And thanks for inviting me to speak today. I'm an autistic adult. I was diagnosed later in life at 48 years. And I have lived experience in suicide loss and attempt. I live with PTSD and anxiety. And during the

30th year of our marriage, my husband died by suicide. The challenges are -- have all been said today. So, it's really comforting. But we're a misunderstood, marginalized population of people who experience sorted belonging in this society because we're different. And I continually experience invalidation, stigma, and misconceptions as an autistic person, even in the graduate program that I'm attending, by the professors. Too many people in mainstream society do not see autistic people as autistic people. We're dying by suicide at a rate of up to seven times higher than the general public. And that's because of the unique risk factors of autistic people have, as well as all the other risk factors of the general population. Yet, the support and interventions that we receive are not designed for us. They're designed for non-autistic people and expected to help us. I'm going to use a metaphor during -- using some common beloved animals to show what I mean.

It would be like supporting a cat using interventions known to be best practices for dogs. A cat is not a dog. It's not a weird, different, quirky kind of dog. It's a cat. It's a different animal who understands and experiences the world in a very different way than a dog does. And they have different support needs. An autistic person is not a different, weird, quirky non-autistic person. We are different people, and we have different support needs. And I believe the challenges that face autistic people is the fact that availability does not mean accessibility. And what that means is, yeah, there's 988. There's a national crisis line that's available, but not accessible due to crisis center workers not understanding how to support autistic people without causing them unintentional harm. And unintentional harm is rooted in misconceptions, stigma, and preconceived notions that are reflected back onto autistic people through the way professionals behave towards us. Living with suicidal ideation myself that gets very strong at times, I reached out and called -- texted 988 in August this year. And the call ended with me being accused of causing conflict because I texted to clarify a question about something I didn't understand. And then I was hung up on.

DR. DANIELS: Thank you for sharing that powerful testimony. Next, we will hear from Kayla Rodriguez.

MS. KAYLA RODRIGUEZ: Hi, everyone. I'm glad to be here. First of all, like, I am a -- I describe myself as a Puerto Rican autistic lesbian adult with ADHD. And a visual description of me, I am a light-skinned woman -- Puerto Rican woman with a white headband, black hair, and black shirt with flowers on. And I'm in my room, basically. So, in terms of mental health, you know, I have several mental illnesses. I have OCD, PTSD, depression, anxiety, and binge-eating disorder. I also have chronic illness like type 1 diabetes, and other stuff, so that all affects my mental health. So, basically, you know, I'm part -- first of all, you know, I prefer identity-first language because autism is a part of who I am. And I'm part of an autism and suicide study to create a suicide program especially for autistic people, with Aspire. And I'm also part of the autistic LGBTQIA+ study about mental health in UCLA. And then the challenges I see with mental health in the autism community, first of all, I'd like to point out that autism is not a disease that people grow out of when they're adults. And autistic people do have joy in their lives, and their lives can be a happy one. However, the media often shows autistic people's lives as painful. And society makes autistic lives worse. Most of the problems autistic people have is because of our ableist society, not their autism. And I don't support any organization that support or fund ABA/PEERS and/or eugenics and/or try to cure, prevent, or treat autism, because all of these are harmful to the autistic community. As a matter of fact, ABA has caused autistic people to be suicidal, and autistic people are more likely to be suicidal. There needs to be funding to support autistic people throughout their lives, not just their childhood. And for myself, you know, the mental health providers I've experienced, I went through a very terrible therapist who is very homophobic to me. And I've also went through terrible psychiatrists. One of them was basically laying -- on her knees, telling my mom, "I'm not a miracle worker." And so, I've been suicidal since I was 11. That's when I wrote my first suicide note. And, you know, I just struggled, and I've been struggling since then. And, you know, lately, I was doing better. But then every once in a while, I get suicidal. But uncertainty in my job and personal changes in my life have made my mental health worse. And that is weird because not having a job can worsen my mental health because of lack of money, but having a job can worsen my mental health because of stress and lack of free time. So -- and my job is social media coordinator at Foundation for Divergent Minds. And they're going through some trouble right now, so I'm not working right now. And that's definitely been a harm for my mental health, but -- so, my suicidal ideation has been starting up again. But I was doing better for a while. So, thank you.

DR. DANIELS: Thank you. Ian Neumaier?

MR. IAN NEUMAIER: Hi. Thanks for having me. I'm also an autistic adult. I was diagnosed in adulthood. I sought out my diagnosis under my own volition after a lifetime spent avoiding it. So, I came to identify my diagnosis as, itself, being a sort of privilege. However, the context by which I came to be diagnosed, I think, was what allowed me to identify the diagnosis itself as extending to me a privilege. That is to say, all of my needs were essentially met. You know, my hierarchy of needs were solid. I had already come into contact with the disability justice community. I had somewhat situated myself in relation to others in that way. And, you know, being able then to interact with clinical mental health professionals, you know, I was able to take those messages and apply them in a way, you know, that just instantly led to a sort of windfall of opportunities and resources. And that didn't occur earlier in life when I had been compelled to interact with mental health professionals who offered their own diagnoses of different sorts of things, but weren't able to take into account my history. And I think that what Dr. Borue said is, you know, vitally important. You know, there needs to be training. There needs to be recognition. And, you know, if it isn't possible that one person, that one clinician has the level of expertise to sit across from a person and appropriately diagnose them, then maybe the model of a single practitioner is not the right one. Now, I don't think that's something easy to fix. But we ought not sort of shoestring ourselves into the structures that we've had. And, you know, how can we fix it? How can we fix it? Maybe it's set up incorrectly from the jump. I don't know. In terms of my experiences with mental health and autism, I think that the relationship of the two are compounding. One amplifies the effects of the other. When I speak, particularly with a background relating to several different types of trauma, the -- you know, the salience of the antecedents to trauma become much more impactful. They become more prolific. They become more exhausting. You know, they're -- we can see them everywhere. And, you know, how then does that fit in to my ability to manage and live as an autistic person? You know, there's like, you know, a constant sort of feedback loop that I think is challenging. A couple of concrete things, you know, when I look -- when I look out and I see that there are mental health initiatives, awareness initiatives, and they're using a spokesperson who's only willing to speak of another person's mental health or mental illness, who's not willing to say, "You know, I have a mental illness. I managed my mental health in X, Y, and Z way," you know, that's a problem, I think. And I think that's sort of, you know, an 'other-ization' of mental health, 'other-ization' of these sorts of issues from the people who are being put onto a platform, into layers of spokesperson to increase our awareness about it, which is downright dangerous. Well, I'll finish with that. And thanks for having me.

DR. DANIELS: Thank you. Morénike Giwa Onaiwu?

DR. MORÉNIKE GIWA ONAIWU: Yes. It's quite interesting because we're talking about mental health. And I could feel my mental health take a bit of a dive when you mentioned that we were going to have to kind of change up the way we had planned to do the panel. And that is because I have nearly a page of justifications as to why I am on this panel. Because, you know, I, like a lot of, you know, like a lot of autistic people, like a lot of people of color, like a lot of people assigned female at birth, suffer from impostor syndrome. And, you know, I was trying to pre-emptively mitigate accusations about why I shouldn't be on this panel. Because I'm on the IACC or I'm too mildly autistic or too high functioning to have any real understanding of mental health issues, you know, et cetera. But because I cannot do that, I'm just going to basically say that I am someone -- rather than kind of -- my bio is publicly available on the IACC page. And rather than share that, I just want to say that I'm a person who, you know, like a lot of people, has a lot of layers. And I think -- I guess my life has always been and still is now a sea of contradictions. I am a person who has collaborated with renowned global thought leaders. I've spoken as an invited guest expert at the White House and the

United Nations. But I'm the same exact person who's fled from a previous home in the middle of the night, barefoot in my pajamas, escaping my abuser. I'm the same exact person who has gone to bed hungry because I didn't have -- you know what I mean -- money for food or a place to live. I'm the same person who sobbed uncontrollably because my child was in a hospital bed fighting to survive, and was not able to speak to share what had happened or what was wrong. And I was being manipulated or -- I'm sorry -- patronized by the people there. And so, I think that like for me, like a lot of my peers, I have a range of various different diagnoses, some neurodevelopmental, some autoimmune, some psychiatric, et cetera. So, you know, I think like a lot of my peers, there's a lot of things that have been going on throughout life, you know, multiple types of trauma, and, you know, how that has impacted who we are and, you know, on top of being autistic, you know, for me. So, my first actual, you know, I guess, diagnosis which precedes autism, because autism didn't come until adulthood, was when I was 11 years old, I was diagnosed with major depression because I was extremely suicidal. I had a suicide journal that I kept from the age of 11 and 12. And so, this is something -- a number of different other things that I've struggled with throughout my life despite being "a success story," being gifted, being accomplished, being whatever. Those -- that doesn't erase, you know, any, you know, sexual or physical abuse that one might have encountered. It doesn't erase the anxiety, you know, or the, you know, severe sensory sensitivities that you might have. The social challenges that, you know -- co-occurring physical or health challenges that you have, like, you know, myself, I am a person with, you know, an early -- young onset form of dementia. So, I have that, you know, and autoimmune disease, rheumatoid arthritis, and alopecia, along with autism, ADHD, and other things. And I'm a parent. So, you have to kind of manage these things. You have to live your life. You have to find a way to cope and do all of the things, and yet still be there for the ones who depend upon you, who need you, who love you, and who -- for whom have their own challenges in a world where there's diagnostic overshadowing, and everything is autism, whether it's autism or not. In a world where, you know, things are already hostile and taxing -- things -- there's already so many microaggressions and things occurring; can you really tease out what is -- you know, can you have a really -- an understanding of -- if things are worsening in your life because you're always dealing with kind of like a base level of struggle? If you are in a place where there aren't the proper practices, if we're not using the models of medical -- you know, like a medical home or integrated care to be able to address things, and if you don't have specialists who can understand what's happening, and if people are dismissive of your concerns and/or that of your caregiver, parent, or whomever, and if people are relying on external factors to determine whether things are okay or not, when you may not display them in this -- in the way that is typical, then you essentially have the ingredients for a perfect storm.

DR. DANIELS: Thank you. I'll call on Angie.

ANGIE: Okay. Thank you. Yes, I'm Angie. I'm the mom of a young adult son who has an autism diagnosis. Just for context, I think it might be helpful to briefly explain, my son has moderate intellectual disability. He needs significant support for communication. And what I'm focusing on today, he, you know, unfortunately has a history of aggression, property destruction, and some self-injury. And it's really hard for me to talk about, but I think it's important that stories like his be told. I'm attempting to do it in as a respectful way as possible. So, I won't be using his name. When I think of mental health specific to the autism community, I would say, it's important for things like safety and inclusion. And with that in mind, let me explain some challenges that we've faced finding services, particularly with respect to supporting his aggression. In school, you know, we've met some wonderful people along the way. But unfortunately, we've also encountered situations, like when special education staff have used a uniform resource police officer in very public ways. We've generally just struggled to find the right school environment with several placement changes, each becoming increasingly more restrictive. They're not necessarily conducive to supporting my son's academic or work skills. He, currently, as a young adult, receives school services still. He gets two hours of school services a day, which I should know are good services. They're focused on functional communication and self-advocacy skills. But at this stage, it's disappointing that he's alone in his program, with no peer interaction and no community-based instruction. From a therapy standpoint, my son has been discharged three times from therapies like OT and speech, and not accepted for others, because they were not set up to handle his intense behavior. As an adult, he has access for things like respite and CLS, that we've never been able to staff. And there just doesn't seem to be any infrastructure in place to provide the staffing for that. We have used outpatient psychiatric assistance. And, you know, medication has been helpful, but not life-changing. Just kind of feels like a guessing game with serious side effects. And then from a crisis standpoint, you know, unfortunately, if I do find myself in an unsafe situation, the only options available in my community are to call the police, or to take my son to the emergency room. Neither of which I've used because they don't seem like effective options, and potential risk for a seriously more trauma. In another angle of crisis, there are situations like when I got a phone call that my daughter was in a bad accident and been taken to the hospital. And in that moment, I had no one to watch my son, and he needs to be watched. And I had no natural supports to help. And there's no type for emergency respite. Just create safety concern for our family. And it's that combination of safety concerns and lack of services from school and lived -- and the community, combined with our everyday need to do things, like earn a living and take care of other family members, that eventually led us to look for a group home. And after much looking, we eventually found one. And it's close to our home. The staff seem really, actually, deeply invested and very caring. They're better prepared than most group homes, but really, probably, minimally prepared to handle intense behavior. He's there during the week and home on weekends. And he's been there about six months. And unfortunately, we've already had discussions that indicate they're not sure if they can continue to support our son, while we're simultaneously receiving reports from our mental health authority that they're decreasing funding for his one-to-one support. And so, that's where we find ourselves right now.

DR. DANIELS: Thank you. I'll ask another question to all of the panelists. And if you can keep it somewhat brief, just so that we can hear from everybody. What key changes are needed to improve mental health in autistic people, and ensure that their services needs are met? So, I'll start with Xenia Borue.

DR. BORUE: So, I think probably one of the most crucial things is getting better recognition for the disability that autistic people have. So, even high-functioning autistic people can have periods where they are profoundly disabled by their symptoms in a way that's not consistent across time. And this gets misunderstood so frequently by people that are not familiar with autism because they think, "Hey, I taught this person a skill. They should be able to use this skill all of the time in all settings, regardless of whatever else is going on." And that's simply not the case for autistic people. Our functioning can vary dramatically, depending on whether we're well-rested, whether there are other sensory things interfering, whether there's other things going on in our lives, so much so that me, as a professional, you see me here today in a setting where I can communicate really effectively about my experiences and my understanding of things. But in a different setting, I can have a meltdown because of a vacuum cleaner. And that kind of disparity in functioning is something we don't see very often outside of autism. But within autism, it's the norm. And it can interfere substantially with daily functioning for a lot of autistic individuals in a way that doesn't get recognized well by our system. So, when I have autistic individuals try to get additional support, either try to get on the waiver or try to get government disability, they're not able to get it. Because the way that these things are determined doesn't recognize the type of intermittent disabilities that autistic people have. And then there's additional gatekeeping. So, for instance, to get onto the autism waiver, you need to have ADOS testing. Well, as an adult, accessing ADOS testing is incredibly difficult. And so, I've tried referring dozens of adults for autism waiver services, which they really need, and they can't get it. So, access to services is really crucial, and access depends on being able to have our disabilities be recognized. And so, that's probably the biggest change that I would like to see happen in addition to additional training, is having better recognition of disability related to autism.

DR. DANIELS: Thank you, Lisa Morgan?

MS. MORGAN: I think we need to improve accessibility -- I think we need to improve accessibility and reduce unintentional harm. And make the available mental health centers, crisis call and tech centers, first responders, and even clinicians, safe and accessible for autistic people by requiring anyone supporting autistic people to be credentialed by completing a training and subsequent evaluation developed by autistic people in collaboration with non-autistic allies. The only people who truly know what it's like to live with autism are autistic people. Policies, programs, and systems to improve mental health services of autistic people need to be designed, developed, and implemented by autistic people in collaboration with non-autistic allies. The solution to improved mental health in autistic people and ensure their service needs are being met. And even more importantly, they're not being unintentionally harmed, lies in the knowledge and expertise of autistic people. Again, autistic people -- again, that's because it was in the first one that I missed. Autistic people are dying by suicide at a rate of up to seven times higher than the general population, and yet on national suicide prevention websites. Autistic people are not included in the lists of vulnerable populations. The resources being developed by the work group that I founded and still co-chair in 2017, they're being used in Brazil. And the mainstream media in Brazil are supporting them and they're having a social impact. They see the value of having autism specific resources developed by autistic people in collaboration with non-autistic allies. The resources to support autistic people as autistic people are available, so, I would just really love it if we just use them. That's it.

DR. DANIELS: Thank you. Kayla Rodriguez?

MS. KAYLA RODRIGUEZ: Yeah. So, there's a few things, but I'll try to be as brief as I can. I think that first of all, that professionals need to be better trained to help autistic people during autistic burnout and mental health crisis. I also would like to see that doctors treat autistic people as humans. Because autistic people are human too even though, we go through the same things as other know everybody else does, just in different ways. And I just wish like doctors remember not just to focus on their autism, you know, and just focus on everything else they have, including mental health, which I believe is more -- it's just as important as physical health. It really is. Mental health should be taken more seriously and shouldn't be a taboo topic, and you know, I also believe that like special interests that autistic people have are good because they bring autistic people joy and shouldn't be taken away from them.

Autism can be a part of anyone in all intersections, so like trans people for example. Trans people can be autistic and people of color can be autistic. So, removing gender affirming care, and living in a racist society can worsen the mental health of autistic people in those intersections. Autistic people deal with trauma, and autistic people need resources specifically made for them to help deal with trauma. So, because, you know, like it's just because we deal with trauma a lot, living in a world that doesn't accommodate or accept us, so we need -- we need trauma resources made specifically for them. I specifically, or for us like, I struggle with trauma because of my PTSD, and I don't know how to deal with it. I don't know how autistic people are supposed to deal with it because there's no resources out there, and that's what I would love to see. Something like, how do -- how do autistic people deal with trauma like that? And other things I would like to see is like, don't take augmentative and alternative devices or AAC devices away from autistic people if they need them, because that will help them communicate. If they get them taken away from them, then it worsens their mental health. The last thing I want to see is there should be more funding in general for mental health. I remember three years ago, the last hospitalization I had, I've been through a few inpatients and hospitalizations for suicide attempts, and the last one I went to is a place called Summit Ridge in Lawrenceville, Georgia, and I promise you, please do not send anybody there because it was the worst place I've ever been to.

I thought I was never going to get out of there and I felt threatened. There was fighting. There was peeing on the chairs, and the floor, you know, it was just a really disgusting place. I think that if there was more funding for mental health in general and these mental health hospitals, then, you know, maybe Summit Ridge wouldn't be so, so, so bad. And maybe -- and I know there's more places like Summit Ridge, and I just -- I just feel like we need more mental health funding in general. So, places like Summit

Ridge can get better in treating people. And we --again, like I agree with everybody else was saying with that we need specific resources for autistic people to deal with suicide. So, yeah thank you.

DR. DANIELS: Thank you. Ian Neumaier?

MR. NEUMAIER: I really have not much to add, and I think she amplified everything that the previous speakers mentioned. Something that resonated with me though, was what Lisa said about the mandating training for first responders and you know, emergency, and medical professionals. I think that's crucially important. The absence of it results in an untold number of violent interactions between police and civilians, not to mention deaths, of course, and I think that that's vitally important.

DR. DANIELS: Thank you. Morénike.

DR. GIWA ONAIWU: Yes. I just wanted to share that I think that with mental health needs, one way that it needs to change is that it needs to be -- it needs to be practical and like solution based, you know, and address the situation that people are dealing with. Is it anxiety? Is it sensory? You know, are they sensory issues or what have you? Whatever is happening? I think it needs to be, you know, collaborative and family oriented. But we're not islands, and a lot of us have people who are connected to us, and so, the wellbeing of those around us and our family at large, you know, the model that they take in early childhood with the integrated family service you know, plan is one that should be considered across the lifespan. The mental health needs to be more intersectional so they can address issues, you know, in a way that's, you know, culturally competent that addresses the other parts of a person's life because we are not just one dimensional.

It needs to be non-punitive. People calling the police is not an option for a lot of people; I'm not calling the police on my child. I don't care how they're hitting me or whatever, because I, they, -- because I don't know what they may not make me, you know what I mean? One -- neither one of us might make it, and that's not going to happen neither, you know, and then there's also people who don't understand the nuances of disability. And so, you can have risk of, you know, child protective services, adult protective services of seeking to disrupt as opposed to support. It needs to be affordable and accessible so, you know, and flexible. And I think they need to be preventative. It should not be when a person's in severe crisis, when the things have, you know, have increased to the point where now there is constant aggression where there is constant, you know, unrest and you know, and so forth. That now you're seeking help where you have no choice, but the emergency room. You have no choice but, you know, the county medical, you know, like crisis team. You should be able to receive help before it gets to that point.

We really need to look at some of the

other models that they're using and other, you know like for example, for HIV and Wrap-Around care. And look at how they're addressing the holistically, you know, person across the lifespan and their families, and we need to do some of that. Thank you.

DR. DANIELS: Thank you, and Angie.

ANGIE: I think we need to first of all acknowledge, people like my son, are not able to get the services they need because our current system does not know how to safely support people with disruptive behavior like aggression. We need to recognize that for people like my son, aggression is related to his disability, and that the behavior should not be criminalized by using measures like police or excessive school suspensions. We need to dig deep to make sure we're meeting everyone's critical needs, such as sensory and communication and medical among others, and we need to rely on the autistic community to better understand how to meet those needs, and we need more research. Our family has worked so hard trying to accommodate all of my son's needs, and we have had some success finding ways to support his lower levels of agitation, yet what appears to be sudden and intense distress response of aggression with no obvious cause still persists. We need more research to understand what seems to be a physiological response for some people, and look, I understand this is hard work and we need to give proper support, training, and resources so, direct support workers and educators and therapists know how to safely and effectively help. So, I go back to my original thought, is we need to acknowledge the mental health needs of people like my son are not being met, and I wish I could be here telling you about all of my son's wonderful qualities because there's many, but since this is a mental health forum, I had to focus on his hardest moments. And the reality is that his opportunities in life are limited by his hardest moments, his progress and academics and communication, recreation and work-related skills are all hindered by our society's collective inability to meet his behavioral needs, and he's a really great guy and he needs help, and I can't overstate how important and dire the need is. Thank you.

DR DANIELS: Thank you so much to all of our panelists for sharing your personal and professional perspectives on mental health issues in autism. We'll now take a few questions from our committee. So, I see Dena Gassner has her hand up.

MS. GASSNER: Thank you and thank you to everyone. I think your comments and your sharing today were really, really informative and emotionally very demanding. I appreciate your efforts. I just wanted to say that I think the thing we're not talking about today is the lack of research around people who've survived. We, we really aren't looking at resilience factors in this community and how people get past these traumas, past this mental health crisis to reach some level of personal satisfaction, and I think until we decode how they do things to inform mental health services, we're limiting ourselves. I'd also like to discuss from my personal experience, the medical trauma that autistic people endure when they do in fact present with mental health issues, but the mental health issues are a manifestation of never identified autism. I myself presented with depression and anxiety that were actually a result of months of early childhood sleep deprivation from my kids. I didn't know I was autistic even though I had a child on the spectrum, and they diagnosed me with bipolar disorder, which cost me basically 10 years of my life, my whole thirties were either being over medicated or detoxing from medications. So, I think accurate diagnosis is so crucial when we're looking at a mental health issue. It frustrates me that in my field of social work, we are not training community-based mental health providers who are social workers, how to at least red flag the possibility so that a person can be evaluated before they're medically maltreated. So, those are my two talking points, but I really appreciate everybody's input and it was a heavy topic today, but so critically needed.

DR. DANIELS: Thank you. And I briefly saw Hari's hand up, but I think it went down, and then next, Scott Robertson.

DR. SCOTT ROBERTSON: Yeah. Thank you, Dr. Daniels, and thank you for this great session on the community perspectives on mental health. I -- it really resonated with me, and I agree with Dena's thoughts and, and a lot of this is very stressful to talk about and I think at times, but so important with the impact in terms of community living for, autism employment, obviously mental health is a great -- is a major impact in terms of whether folks are able to maintain employment and advance in their careers. And I'm also glad that you all brought up in terms of that we need to have adjustments to how we think about like assessments and testing and, and use of things like the ADOS et cetera. And I just wanted to add that, one additional factor, for instance, for things like the ADOS is they often don't pick up autistic adults who've adapted or compensated or maybe mask, et cetera.

I'm an example of that, where if I was in a study, I might not show up as autistic on the ADOS, even though I definitely have all the traits obviously, I've had autism my whole life. I just also wondered for the panel two, in terms of I don't know if this is a complex question to ask, but about sort of the role of technologies too, like accessible technology in helping address some of these challenges you experienced, and a lot of colleagues and other folks you work with have experienced. And I-- because I think that's some of the solution, I think for having improvements and advancements is having some innovation, and some of this is like emerging tech from a good standpoint of how it can be addressing mental health and wellbeing. And I know we touched upon that a little bit, but I just wondered if, if folks have any more thoughts on innovative technology, information technology, and tools including mobile technology that could be helpful for empowering mental health supports. Thanks.

DR. DANIELS: Any response to that from the group? So, Lisa.

MS. LISA MORGAN: Actually, I actually wanted to respond to Dena's comment about people who do stay. And I think a lot of it has to do with reasons for living. And you know, when it came down to it for me, I just couldn't possibly leave even though I really wanted to because of my kids, and then other autistic adults reasons for living. They -- they're based around senses of purpose because there's a lot of autistic adults who don't even have a sense of self. And so, if you can build reasons for living and just build a list, and it could be online, or could be just pen and paper, and have that reason for living list with them when they get into these crises to remind them in the time. Because there's a reduction of skills when they were in a crisis like that of why they want to live. That answer your question?

DR. DANIELS: Thank you. Anyone else on the panel want to respond? And I can't see, you can just speak up if you're online and you're on the panel and you want to respond because --

MR. IAN NEUMAIER: Can you hear me? This is Ian. I think that Scott asked a great question. You know, there's like, I think a great deal of opportunity ahead of us with the accessibility or the, you know the equity of things like generative AI however they might be misused of course, but if we're looking for progressive positive uses of them, you know, I can think in my own context, just, you know, decades ago having access to the internet, being able to study people's behavior, learn how to model it, essentially, sort of test things out. I can think of a generative type of system that

that might be developed particularly for the purposes of helping people prepare, anticipate you know, upcoming interactions and things like that. That's something I think, that's definitely within the grasp of technology that we have right now. In terms of more, you know, simplified stuff, in terms of the apps that are available. You know, be -- you know, had my enrollment in college been accompanied by some, some assistive technology consultation where there was offered to me a sort of a suite of technological applications, you know found to be particularly useful for autistic folks. Gee, that would've been great. You know, it might include things like speechify, which right now is like super expensive. And you know, the ability to have you know, multiple sources of information even if it's the same source, but in multiple formats, goodness, is that ever helpful? But I think it's a matter of, you know, coordinating, organizing these things so that they can be made available to students on demand. That's the challenge it seems and cost.

DR. DANIELS: Thank you. Hari has a comment.

MR. ISAACSON: Good afternoon. Hari sent a comment. He said that the only two solutions being offered right now for behaviors like aggression and SIB as they relate to mental health are either psychotropic medications or behavior therapy. He said the bottom line is that neither of them work. And so, we need to think beyond just circling tired solutions that don't work.

DR. DANIELS: Thank you. Any comments from the panel, Lisa?

MS. MORGAN: I think we're going to be honest about what's out there right now as far as the internet is, you can search for all kinds of ways to die. And then when you search for ways to live, autistic people are not included on those national suicide prevention websites. So, that's the way the reality is right now.

DR. DANIELS: Thank you. And Jenny, did you have a question? A comment?

DR. JENNY PHAN: Hi. Thank you so much for this discussion, and for everyone who shared their stories. My question is about autistic people who may struggle with self-reporting their mental health or emotional problems in order to seek the help that they're looking for, they may not know exactly what help they're seeking, but then they may also be struggling with, you know, like how to identify their problems. Anyone in the panel? Can you comment on that experience and, you know, any potential solutions to that? Thank you.

DR. DANIELS: Lisa.

MS. MORGAN: The autism and suicide prevention work group has resources out there that talk about just that. We have four resources available. We're working on the fifth one right now. They talk about the presentation of autistic people who are in a crisis, and they may look calm and fine, and everything's happening on the inside. And we have a proposed set of warning signs of suicide for autistic people where there's scenarios that cover pretty much every single thing that could happen with an autistic person in crisis and what to do about it and emerging research findings. And they're all available free, downloadable, free to use for everybody on www.autismcrisissupport.com.

DR. DANIELS: Thank you. And Morenike.

DR. GIWA ONAIWU: Yes. I was just going to add that I think that that's a situation that a lot of us face where you don't know what, -- how you feel exactly, or what is needed, and as Lisa mentioned, a lot of these tools, you know, don't really -- may not pick up the way that we think or, you know, or, you know, or the way that we feel. And so, I'm grateful that we have groups such as Aspire that are taking a number of existing tools and are working collaboratively with researchers with, you know non-autistic and autistic researchers with community individuals and other leaders to make versions to modify these tools, these screening you know, the assessments and so forth to make them more relevant to our population at least the adult population. I know I would love to see more work happening with other institutions doing the same. I know that there's, you know, some, you know, work with the mental health and IDD center and some, you know, global IDD work, the Korean General. And then there's the work that was mentioned earlier of the REAACT Center at Pitt. And there's, you know, at the A.J. Drexel Autism Institute, there is a policy center and, you know, a social dynamics of networks of, in that, you know, that those are all looking at kind of some of these other pieces of the things that -- because sometimes the -- it's the ones around us who can kind of pick up on these things or it might manifest itself in physiological you know, means.

DR. DANIELS: Thank you. And something that is related to Hari's comment and the one that was just made, I'm going to direct back to Matthew and Carla perhaps. What can we say about advances maybe being made with physiological sensors and wearables and things like that in terms of these behaviors?

DR. CARLA MAZEFSKY: Well, we are using that currently in our research, and Matt and I have collaborated also with looking at physiological measures related to aggression and self-injury. And we're looking at it now in our ACE center where one of our projects is wearing physiological sensors for two weeks, while also completing surveys, half the time randomly triggered by changes in physio, and half of the time are well -- half the time are triggered, half of the time are random. And I think it's just, it does show there is promise. I think there's a clear signal that you can identify some signs of distress and some markers of aggression and self-injury with these physiological signals. I think there's a lot more work to be done to get it specific and accurate enough, but there is certainly movement in that area. And a challenge will be, you know, doing it with measures of physiology that are cheaper and more widely available than those being used in the research setting.

DR. DANIELS: Anything to add? So, I think Hari had his hand up, and then that'll be the last question.

MR. ISAACSON: Hari has a comment in the form of a question. He asks, has anyone thought that SIB (self-injurious behaviors) could be a form of suicidal thoughts, especially in those that don't have the motor skills or body regulation to be able to actually attempt the act of suicide?

DR. DANIELS: So, back to our panelists. Any thoughts about that question?

DR. GIWA ONAIWU: This is Morenike. I think it's very interesting that that was mentioned because I've looked at some of the literature from the scoping reviews where they talk about lower suicidality in some of our, our peers who have higher support needs. And I'm thinking, how do you really know if you're using traditional mechanisms to do it? You know, if you're seeing higher rates of this, of some of these things non-suicidal, self-injurious behavior or property destruction, all these things, how do you know that some of this is not, you know, it's a form of communication. You know, I think about myself, you know, again; I am with the diagnosis that I have with the early onset dementia. I have days and times that you know, speech alludes me or were like basic functions of life. I cannot, you know, perform them. Or I can't think of -- or I can't -- I want to call one of my children to bring me a glass of water, but I can't recall their name, you know, or I want to type, but I have neuropathy. I know about how distressed I've felt in those moments, how frustrated, how angry and how, you know, like, so, you know, a lot of times people talk about anger can be you know, repressed sadness and it can lead to, and, you know, I don't doubt, I know for myself, you know, some of the self-injuries behavior that I've engaged in has certainly had that that slant to it, and I don't think I'm alone.

DR. DANIELS: Thank you. And Lisa,

MS. MORGAN: I have heard from a lot of autistic adults that self-injurious behavior can also be suicide prevention and that it can reduce overwhelming emotions that may cause them to die by suicide. And that suicide, that self-injurious behavior can reduce that emotion, those emotions to the point where they can start regulating and they can stay.

DR. DANIELS: Thank you so much. This has been a really enlightening discussion. We really appreciate our panelists and all the wonderful questions. I'm going to turn it back over now to Dr. Gordon.

DR. GORDON: I want to add my thanks to

these panelists both virtual and in attendance today, and I'm going to ask for the next set of panelists to come up. We're going to swap out the folks at the head of the table. While we do that, I'm going to invite our committee members who are in person to stand up and stretch your legs but ask you not to leave. We're going to take a moment's break so, if you need to use the restroom or, or get a glass of water, by all means, please do so. But we're going to try to go right into the next panel. So, if you don't have to, don't leave the room.

[Short Break]

DR. GORDON: Okay. So, we're going to go ahead and get started now with the final segment of the meeting. It's really my pleasure to continue this focus on the mental health needs of autistic people, and this final section of the afternoon focuses on addressing these needs through the mental health service system. We have three panelists today, two of whom are joining us virtually these are Dr. Stacy Nonnemacher and Dr. Debrah Pinals, I'll introduce them when their time to speak is here. And then we also have one joining us in person Jonah Cunningham. As Dr. Nonnemacher hopefully can unmute herself and get herself on video I'll introduce her. She's our first speaker. She's the director of Cross System Strategies at the National Association of State Directors of Developmental Disabilities Services. She will be speaking to us about the Link Center, a national resource center funded by the Administration for Community Living, of course, one of the member agencies of the IACC. Dr. Nonnemacher, welcome, and I see you already. Thank you.

DR. STACY NONNEMACHER: Hi there. Good afternoon, everyone. First, I would like to thank you for the invite to talk about what others before me have already highlighted as an important topic in this field. And I'm honored to be able to talk about the Link Center bridging IDD and mental health systems. A five-year grant awarded in September of 2022 funded through the Administration of Community Living. Next slide, please. So, why is this grant so important? And I feel like others before me have already pointed all of this out. But more recently, the field really is paying more attention to this topic. Identifying better ways to support people with co-occurring cognitive and mental health conditions; supports are predicated on an individualized integrated approach, which the panel before me so eloquently talked about. And to me, that means that someone should be able to access behavioral health, habilitative services, physical health support, all dependent upon what he or she needs.

And unfortunately, systems are not set up to support this, and supporters may not have the skills. So, what this slide here is saying is that, and what the previous panel, again, more eloquently highlighted, is, we know that we need to build capacity of the workforce and systems to support people's whose needs touch multiple systems. And we know that we need to have a continuum of community services that focuses on prevention and not just crisis for people. We know we need to address historically flawed policy that may exclude people from taking advantage of much needed services and supports, and to do that, systems need to collaborate and engage, looking for solutions and not just placements or one-dimensional answers. And most importantly, all this needs to be informed and guided by people with lived experiences. So, all of these pieces and elements are at the core of this grant, so let me just take a step back we'll go to the next slide. So, this grant was awarded to three main partners, NASMHPD, which is our sister organization, the National Association for State Mental Health Program Directors and (NADD) The National Association for Dual Diagnosis. To us, this is an important partnership. Independently our members have been seeking guidance and support and finding better ways in states to support people with co-occurring cognitive and mental health support needs and recognizing the power in partnerships to tackle this need, we convened a round table discussion where promising practices were identified. Practices like opportunities to transcend structural stove pipes or misaligned incentives for providers, clinical capacity building, particularly for the DSP workforce development, service design innovation opportunities within states. How do we do things differently and ensuring a lens on cultural and linguistically appropriate approaches to ensure meaningful access across systems and to the point made earlier, not just what's available, but is it accessible.

So, these really were the motivation for the partnership with this grant, and we've also capitalized on the partnership of these three entities for other efforts that seek to address this need outside of the grant. So, for example, we have embarked on a two-year national clinical and system capacity building effort that's offered to member states. This effort focuses on creating trauma-informed restorative supports that include mental health treatment and other initiatives like translating evidence-based mental health treatments like CBT and DBT for people who have cognitive limitations but may benefit from these treatments. So, I'm hardened to hear today everybody talking about things like the need for capacity building, the need for trauma-informed approaches, the need to adapt mental health treatments for people with IDD and mental health needs. Next slide, please. In addition to NADD and NASMHPD, there are six other partners that to us really bolster our focus on diversity, equity, and inclusion, and also our quality arm of this work. So, we also have Green Mountain Self-Advocates, Autistic Self-Advocacy Network, National Association of State Head Injury Administrators, Communication First, National Center for Start Services, the Sonoran Center, and Ohio State University's Nisonger Center. Next slide, please. So, the Link Center is focused on three primary goals. The first is really looking at systems change, looking at where we can make improvements in policies, service design, and service coordination. And the second is looking at building capacity, particularly for the direct workforce. So, the direct support professionals, clinical professionals and giving them the tools and supports that they need to support people who have co-occurring diagnoses. And last but not least, we're feeling as if we tackle those two goals, both system change and building capacity. This will open up access to people and not just as Lisa aptly put it again, not available service, but accessible services. Next slide, please.

So, in order to reach these goals while also maintaining diversity, equity, inclusion and quality throughout, there are several grant activities including engaging expert contributors ongoing. What we found out rather quickly in being awarded this grant is we're not the only ones thinking about this, and as all of you illustrated that today as well. We also will be hosting quarterly topical shared learning groups or learning communities where we'll bring people together to talk about specific topics that we feel are relevant in this field -- in this work. And also sharing what we're thinking about through the grants, getting feedback from these communities but also using these communities who have experience and expertise to help us inform some of the other grant activities, sharing resources, information and training. And then the main output of this grant is the identification and vetting of existing resources, information, and training to add to a national repository or the Link Center website.

Prior to coming to NASDDDS, I spent 16

years of my life in Pennsylvania as a clinical director of DD services in the Office of Developmental Programs. And it was there that I spent a lot of time helping people navigate the systems and helping people understand why people were showing up the way that they showed up and to have something like a national repository, a place where all resources, information, and training is housed, would have been an amazing gift for somebody like me who was working in the field, who was trying to figure these things out, and also trying to find where the -- where those tools were to help me figure that out. So, that particular, the Link Center website we're really looking at a wide audience. We're making this available and accessible for individuals and families, and other supporters like direct support professionals and other clinical professionals.

We're really hoping that through curating these resources, we'll be able to provide a better understanding of what things are out there and should be elevated. And to also encourage the translation of research to practice and identify where the gaps are, that we could potentially be addressing through grant resources or through some of our other activities like engaging with those expert contributors or holding those shared learning groups. So, we have a continuous evaluation loop for all of our efforts, and that's led by the Nisonger Center at OSU. But above all, the most important component to the Link Center is really the role of our steering committee. Our steering committee is made up of a group of 12 incredibly passionate people who represent diverse lived experience and who have been tasked to guide and direct the work of this grant. And they already have, have really shown up, and we've learned so much from them.

Additionally, to some of the earlier comments, we're working with SAMHSA through this grant to increase awareness of 988 crisis services in the DD community, and it's a two-handed class. So, we're also working with SAMHSA to increase the skills of lifeline workers and crisis centers to better respond to and direct people to appropriate services and supports. So, while ambitious, the work through this grant is critical to our field, as others before me have highlighted, and we know that a great deal of time, energy, and resources in states are allocated to finding better ways to support people with co-occurring needs. And we believe that the more we can structure our systems, the more that we can build capacity, the better we are able to get people what they need, when they need it. Last slide please. So, this is where you can reach us at thelinkcenter@nasddds.org, and this is letting you know that our website will be coming soon so keep your eye out for that. And just another acknowledgement to our funders, the administration community living for their vision and their leadership in, again, what we hope will be such an amazing asset to the field. Again, thank you for having me today.

DR. GORDON: Thank you, Dr. Nonnemacher. Next on the panel we have Dr. Debrah Pinals, the medical and forensic advisor to the National Association of State Mental Health Program Directors. She's also an adjunct clinical professor of psychiatry and the director of the Program and Psychiatry Law and Ethics at the University of Michigan. Dr. Pinals.

DR. DEBRAH PINALS: Yes. Thank you so much, first of all, for inviting me to speak. And I'm excited that I'm following my colleague Stacy Nonnemacher and all the excellent speakers that came before I think many of my remarks will resonate with your committee. Next slide. I'm speaking today on behalf of NASMHPD, the National Association of State Mental Health Program Directors which represents over $41 billion of public mental health systems serving 7.5 million people annually in all 50 states, four territories, and the District of Columbia. And we're affiliated with approximately 195 state psychiatric hospitals that serve 147,000 people per year and 41,800 people at any one point in time. Next slide. As you've heard already, we know that people with autism spectrum disorder can often have co-occurring mental illnesses just like people without autism spectrum disorder, although the prevalence rates may be a little bit higher.

And we also know that behaviors masked as or interpreted as mental illness become treated as mental illness across systems, which is not always ideal and not often ideal as we heard in the examples that came before from people with lived experience. So, there is critical importance for increased understanding of the population and individual needs and increased resources to treat individuals across and within systems. Next slide. There has been a historical gap between departments of mental health and departments of developmental disability and for persons with autism spectrum disorder in many states, individuals with ASD may not fit neatly into either of those siloed agencies. There have been many shifts recently across the states in how things are organized in large part related to Medicaid and spending for services in the public system. Next slide. But we know there are many systems issues that we need to tackle. There are not enough staff, period, and not enough staff with training or supervision around these types of issues, not enough leadership that really understands the complexity of ASD or co-occurring ASD and mental health. Improper placements for groups of individuals who are often placed in more restrictive settings than necessary to address their needs. There can be over-reliance on medications and psychopharmacology, and at the same time, there can be opposition to medications and psychopharmacology that can be helpful. And so, trying to find the right spot of what medications might be useful to help address mental health symptoms is going to be really important for that population. And there has not been as much family engagement available for lots of different reasons. But there needs to be more engagement by the service system so that families can participate for both youth and adults. Next slide. These are just some of the things that I've identified. We also know that people with co-occurring behavioral health and intellectual and developmental disability conditions struggle to access integrated care to meet their complex needs.

Again, part of that is related to funding structure and system structure where we have on the one side. Often, fee for service types of arrangements with narrow eligibility criteria and medical necessity criteria that limit access to and coverage for behavioral healthcare for people with ASD. And then we also have on the other side where there's departments of developmental disabilities often, we have targeted Medicaid waiver programs but that may be limited to special needs populations. Next slide. As you heard already, this is my slide that has a lot of blank space because we don't -- the requirements for training in general psychiatry and many other mental health specialties is virtually nothing. And that is something that we really have to address. And the Link Center is one of the strategies I think that the Administration for Community Living has highlighted to try and address some of the gaps. Next slide.

So, again, you've heard about some of the barriers. We have opportunities to improve how things are working. For example, migrating from targeted populations in limited waivers to population health basis for service delivery and payment reforms is going to be one strategy. There's more looking at administrative care organizations, behavioral health and long-term support services, and provider partnerships in emerging service delivery structures. We also are working to reexamine the need to regulate markets and specialty care, and there are many exciting innovations. For example, I worked in Michigan in our MC3 and our recently funded MC3 connect program that is now expanding to more school-based interventions. But it allows for psychiatric -- child psychiatric consultation to pediatricians, primary care, and OB-GYN and other providers to help address the needs of people with -- of youth with ASD and co-occurring ASD and mental health who come to their provider -- for providers for care who may feel overwhelmed and not sure of how to provide that type of care.

And there are opportunities more and more for cross system collaboration. And what Dr. Nonnemacher presented right before, is one example where we have partner organizations between NASMHPD, NADD, and NASDDDS all partnering together on the Link

Center along with others. Next slide. So, what are some recommendations for your consideration? Next slide. First of all, we really have to enhance psychiatric treatment options along a continuum of care that is eligible and available for people with ASD. We don't want to just use inpatient hospital beds or state hospital beds, which are not equipped to manage the needs necessarily. But we do want hospital beds available when they are needed and appropriate, but we need to enhance options along an entire continuum of care. We have to recognize that conditions can occur at the same time in a person. And so, we have to be able to adapt and address whatever the person is experiencing to best meet their needs.

We need to develop organizational structures to meet these needs, and we have to enhance our workforce knowledge and availability. We certainly have to foster trauma-informed and person-centered care to address the needs in the best way possible and consider biology, social circumstances, and even environmental issues. I'm involved in helping in the construction of several facilities where we are looking more and more at modern environments to help address how to best meet the needs of populations with who have complex histories. We also have to develop alternatives to law enforcement, arrest and incarceration whenever feasible and safe. One of the areas that I spend a lot of my time with is in the forensic system as a forensic psychiatrist, and it is clear that we have an overrepresentation of people with ASD who are being arrested and brought into forensic systems when that is not the best place for them to get their services met -- their needs met. We have to therefore expand crisis services through 988 and other avenues to address the needs of people with ASD. And we have to promote examples like the one I described before through HRSA of pediatric mental health care access programs to try and intervene as early as possible. Next slide.

I just want to point out some of the work that NASMHPD has been doing through SAMHSA the Substance Abuse and Mental Health Services Administration. This is work that's been taking place for many, many years but we like to call it our Beyond Beds effort. It's starting in 2017 where there was a big push in the media speaking about needing more institutional care. And from a policy perspective many of us have been working hard to address that that framework to say, no, we need a continuum of psychiatric care that begins in the community before we identify that we need more hospital beds as the sole solution to some of the public mental health needs. From there, we have produced a number of different papers. These are what we have produced. They're available on the NASMHPD website for anyone looking for them.

This year's series, the 2023 series is called *Connected and Strong* to address issues of social isolation and loneliness, as well as the need to strengthen the behavioral health workforce in working with complex populations. Next slide. These are two of the papers that come under those series that you might be interested in. One is a paper that was published in 2017 called *The Vital Role of Specialized Approaches*, persons with Intellectual and Developmental Disabilities in the Mental Health System. It was turned into two academic peer reviewed papers that were published in Psychiatric Services more recently. And then there was a paper *Crisis Services Addressing Unique Needs of Diverse Population* that speaks to these issues as it relates to 988 and other types of crisis services that are being built out and that you heard about before. So, I would urge you to look at those papers for your edification. Next slide. Workforce development in the community must include attention to personal support, behavioral supports, techniques such as ABA and an understanding of bio-psychosocial issues and the requisite training, as well as salaries that support the challenging work to minimize disruptions in treatment. We need to encourage advocacy and planning for a workforce that can work by developing training models and early exposure in training and clinical rotations. Next slide. I want to thank you again for inviting me to speak, and I look forward to if there are any comments or questions. Thank you.

DR. GORDON: Thank you. We will certainly have comments and questions, I'm sure at the conclusion of the panel. Let me introduce first the final panelist, Mr. Jonah Cunningham, the president and CEO of the National Association of County Behavioral Health and Developmental Disability Directors. Mr. Cunningham, thank you for joining us.

MR. JONAH CUNNINGHAM: Thank you for having me and thank you to the IACC. I've learned a lot today, and I appreciate the invitation. As Dr. Gordon said, I'm Jonah Cunningham. I have the Honor and Privilege of serving as the President and CEO of the

National Association at County Behavioral Health and Developmental Disability Directors or NACBHDD, if you just want to save your breath. Also, in this role I serve as the Executive Director of the National Association for Rural Mental Health, and we'll talk about both those associations here in a moment. We can go to the next slide.

MS. GASSNER: Can you pull your mic?

MR. CUNNINGHAM: Yeah. Is this better? Perfect. So, basically, I have three goals for this presentation. First, to introduce you to those two organizations, NACBHDD and NARMH, as well as provide an overview of the local Intellectual and Developmental Disability system, or IDD systems and behavioral health systems. And then lastly, highlight a lot of challenges and opportunities that have already been spoken about by my colleagues for collaboration, specifically surrounding 988 and crisis response. So, we can go to the next slide. So, about NACBHDD, the origin story, I'd like to say, in the mid-20th century with Deinstitutionalization, a lot of states looked to establish local authorities to provide community-based services for those with intellectual and developmental disabilities or behavioral health concerns, including substance use and mental health. Now, it's not apples to oranges, I'd like to say it's apples to apples, but there's a wide variety of apples, right, from Gala to Pink Lady, to my favorite, golden Delicious.

Think of that like states where there's a wide variety of these local authorities. Some are county based, some are regional, some are state administered. There's Medicaid Carve-Ins, Carve-Outs, taxation authority, levy authority, some are merely advisory, some oversee Medicaid contracting. We try to represent all of those apples, or I should say authorities. Now I'm hungry for an apple. But the bottom line is that we focus on those local authorities and trying to empower them through building community and advocacy. And we are an affiliate of the National Association of Counties, or NACo again, another acronym, I apologize, let me go to the next slide. And the other organization I have the opportunity to lead is the National Association for Rural Mental Health. Now, unlike NACBHDD this includes a wide variety of members from service providers, to students, to academics, to advocates. All with a focus on increasing access, availability, and acceptability of behavioral health, so mental health and substance use services in rural communities. And it's an affiliate of NACBHDD so, I think of it like Russian nesting dolls. Now, NARMH is an affiliate of NACBHDD, NACBHDD an affiliate of NACo, and so on. With NARMH, I'll also note we just completed our 50th conference last month in Pittsburgh and with our friends at APA, we published a quarterly journal, the Journal for Rural Mental Health. We can go to the next slide.

So, just want to give you kind of a

quick overview of the local systems and how they might look like -- how they might look. So, we engaged in a project, we can go to the next slide, but when we talk about the local mental health system in particular, it sounds like synergistic solutions to scale. We know what those words mean individually, but we don't know what that means when we're it's actualized. So, we actually, two things -- We looked at two states and their local mental health systems to compare and contrast. We did Michigan as well as Texas. Michigan's 46 community mental health service programs, Texas’ 39 local mental health authorities, and we looked at three things and try to make it a very succinct report. First, an overview of the system. What is it? What are their authorities, their funding streams, do they provide services? Do they oversee services, et cetera? Secondly, their relationship with Medicaid since Medicaid's the number one payer for mental health services. And then lastly, what is the relationship with crisis

-- the crisis response system, since that's an emerging, we've seen the launch of 988 which I'll get to in a moment, but how is it positioned to help provide services, if not, at least coordinate the delivery of those services. So, we have a QR code, if you're interested in reading it; I tried to make it very succinct and digestible since we're trying to do 50 of these things. So, going to the next slide. One of the big things we know -- we learned from this report, you know, the populations obviously can overlap with behavioral health and IDD. These things don't happen in a silo, but also the location of leadership matters.

Often, we see IDD services or at the IDD department, either co-located with the older adult services, which makes sense through a Medicaid lens with home and community-based services. Or it can be -- it can be located with behavioral health services, and there are pros and cons of each. It's easier to, to design systems and programs that deliver to both these populations or to those with comorbidities, I should say. And lastly, funding streams. There are different funding streams. The renewable nature of those funding streams, whether it's Medicaid reimbursement, whether it's a state appropriation, a federal grant, those all have sunset. Those all have political tensions, but those matter in the long run, those services deliveries to our communities. Let me go to the next slide. So, kind of taking a step back, and I don't want to sound like too Pollyannaish or have my Ruby colored glasses -- rose colored glasses.

I haven’t had my coffee yet, so I apologize. But it's a time of transformation really. Last year, last July, we launched the 988, which is a crisis response. It expanded the National Suicide Prevention Lifeline. It's no longer a 1-800 number, but it also spawned this new framework for crisis response of someone to contact, someone to respond, and somewhere safe to go. Now, it's still being built. Obviously, you, you look at a patchwork system, when we talk about crisis response, it oftentimes matters on local leadership, the structures and systems in place, and the funding in place. But three kinds of pillars for that. Someone to--someone to contact, someone to respond, somewhere safe to go that I wanted to highlight, obviously, 988 which is a system administered by Vibrant, then mobile crisis response. There was recently through the American Rescue Plan Act to allow for an enhanced FMAP, an enhanced Medicaid match, to develop a mobile crisis response system to actually get providers out into the communities.

And then lastly, somewhere safe to go, there's been an expansion of the Certified Community Behavioral Health Clinics, or CCBHCs, I apologize, another acronym, but these are currently in 12 different states. It's set to be, it has the opportunity, I should say, for this demonstration grant to go nationwide in all 50 states by 2030. And that was through the Safer Communities Act of last year. Now, there are limitations within all these we've already talked about with 988 making sure it, it's accessible to all, everyone within the community. There's also concerns about law enforcement as well, and simply geo routing is one, is a major issue currently where if I'm from Utah, go Utes, but if I call, I have a Utah number, it's going to go straight to the Utah call center and then has to be routed to Maryland. So, that's an issue that's been -- that been talked about. Let's see, with CCBHCs, it's not 2030 and there might not want be one in your state, and we can go to the next slide. Now, building on those challenges and opportunities, again, I don't want to sound too Pollyannaish. We can go to the next slide.

If I talk to any of my members, whether they're on the IDD side of the fence, the behavioral health side of the fence, the number one concern is workforce, workforce, workforce. It's a battle for talent even with supplementing with credentialed or some peer professionals it's even more dire for those on the IDD side of the fence, where there's a lot of turnovers, especially in direct support professionals. So, we need to really focus on that. There's a lot of programs, whether it's a national health service Corps or other loan repayment programs, but there also might be opportunities to look prospectively as well. I mentioned funding again I know our brother sisters and non-binary friends in the public health sector have experienced this boom-and-bust cycle of funding, right? If you recall, Ebola, they got a ton of funding, then it slowly went away.

The patient -- the prevention fund was rated. Now behavioral health is different, but we also are getting a lot of money currently, whether it's through the opioid settlement funds, through their enhanced funding we've seen with 988. But we want to make sure that we're building the system that we need. So, that's one. Then lastly, coverage. Medicaid redeterminations are currently happening. There's been an estimated seven million people who have lost coverage. We haven't seen a significant uptake or anticipated uptake in the individual market. So, something to be aware of I know CMS there was a note about CMS and some of the things that they've done specifically for children and making sure that they continue their coverage, but that's going to be a continued issue. And I'll also note as well, for coverage in the context of crisis response for surprise billing ground ambulatory services are exempt from that law. So, this backing up, that was a law that if you go to a facility that's in network, but your provider's out of network, you wouldn't be hit with a surprise bill. This has -- this could have great ramifications for crisis response and for access for those services.

Let me go to the next slide.

Shifting to opportunities, I think because of 988 and that new rubric of someone to contact, someone to respond somewhere safe to go, there's been enhanced collaboration between sectors, whether it's behavioral health, law enforcement, education, older adults, public health. There's a need for this collaboration, and through this collaboration, there's also been some new approaches that have occurred and continue to emerge. And lastly, and I've heard it here all day, the engagement with community, ensuring that there's nothing about us without us needs to continue. And there's strong traditions both in the behavioral health and the autism world, and the IDD world, and we need to amplify that further. Now, I'll shift, we can go to the next slide. I'll shift to what I jokingly refer to as some shameless self-plugs. These are a couple other products that might be of interest.

One pro -- one project we did with the National Association of Counties was to look at all the funding that could go towards that rubric of someone to contact, someone to respond somewhere safe to go and try to identify federal funding streams, state funding streams, local funding streams, and non-governmental funding streams. And if that wasn't enough to also try to include county examples of how they're utilizing that to build up a crisis response system. Now, a few interesting takes that we've learned; The Department of Education, for example, has funding that could go to a crisis response to, to the crisis system. The Department of Agriculture can also develop a lot of the brick and mortar crisis response systems. But one glaring thing that I'm going to go and triple check that might be of a, an avenue of advocacy is that there weren't many -- I don't recall any funding for IDD or autism spectrum disorder, so wanted to flag that. The next product that we just released last month and go to the next slide, is our messaging doc. So, these are -- this is supposed to be complimentary to the funding chart where we highlight and we focus on specific populations that are key to building out that crisis response system. The first are county elected officials so, we highlight some counties that are doing innovative work, quotes from leaders to hopefully provide inspiration for the next county as they try to -- they grapple with this idea of how to build out a crisis response system that's responsive to their community. The next report, which is-- will be released this month, hopefully by the end of -- end of this month, knock on wood, is focused on intellectual and developmental disability directors, or IDD directors. We're very excited about it. Stay tuned for that.

But if you're curious on the first messaging document there's the QR code. Believe I'm at my time, we go to the last slide, but there's my contact information. If you -- if we can be of any help moving forward, please don't hesitate to reach out. There's also our website please note on my email, just to make it easier on everyone, we drop one of the ds. So, thank you again for having me. It's been an honor.

DR. GORDON: Thank you very much to really all three of the panelists to talk about the services that are on offer and the, and the work to try to offer quality services for individuals with autism who have mental health needs. I will now open up the conversation to members of the committee. Yetta, go right ahead and start us off.

MS. MYRICK: So, thanks everyone for presenting both here in person and online. I think as many of you all have shared throughout the day, the common theme that we're hearing is that we really need trained professionals and to build capacity and to offer, and I want to quote accessible resources, not just available, but accessible resources and services. And I definitely want to make sure that this is something that we include in our next strategic plan. I think -- I think everybody at the table here and online agrees with that. I did have one quick question about the Link Center. So, I recognize that it's only been a year since this project has been funded. It's a five-year grant. I love the idea of this one-stop shop, but my question is, what happens after that five-year grant who is going to be maintaining that website?

DR. NONNEMACHER: Yeah. So, as partners, we hope for additional funding moving forward. And, you know, as those of you know, when grants end, but definitely something that we want to keep our eye on maintaining and sustaining post five years, for sure.

DR. GORDON: Dena?

MS.. GASSNER: Throughout these presentations, and I mean this with no disrespect, but I'm just curious. I didn't hear any mention about autistic people informing the work that you're doing. I'm hoping that it's a question that doesn't need to be asked. I'm hoping that it's automatically incorporated in everything you do, but I'd really feel more comfortable if I heard that out loud.

DR. GORDON: Any of the panelists care to talk about the involvement of people with lived experience and the work that you or the people that you represent are doing.

DR. NONNEMACHER: Well, this is Stacy. I’m happy to respond to that – and great question and valid question. The steering committee that we have, that guides the work of the Link Center has several autistic folks that are, represented on there and are representing the autistic community.

DR. GORDON: Any other responses?

MR. CUNNINGHAM: And I'll flag one of the messaging docs things we highlight is an example from Champaign County where, for the last -- this will be the 14th year. They've had a disability conference, and it's designed by those with intellectual and developmental disabilities, autism spectrum disorder, and a host of others. They design the -- they design the program, they bring in vendors. They also bring in state and local government, and it's around 250 people. But it's been a great event, but it's designed by them for them.

MS. GASSNER: We're talking about day-to-day operations policy decisions.

DR. GORDON: Thank you very much, Alycia.

DR. HALLADAY: Hi. I was just on the website looking up the Link Center because that was really taken by this idea. What are some of the resources that you hope to generate? And then also, how will they be studied in terms of whether they're helpful or not helpful, or whether they work or don't work?

DR. NONNEMACHER: Yeah. So, our primary focus with resources is to really elevate what's out there. And perhaps if needed, adapt what's out there. We're hoping that we don't have to do too much creation of resources, acknowledging that that may need to be what we do if there are certain gaps. I can give you an example. So, we have really set a framework for the Link Center based upon, as I mentioned before, relevant and timely topics that were you know developed along with our steering committee. And the first topic that we're tackling because of our engagement with SAMHSA has been around crisis services and supports. And one of the things that we've noticed in what is out there, is that there are a lack of crisis plans or crisis templates, if you will, for people identifying when they're feeling okay as some folks have put it in my company. How, you know, what do they need when they're not feeling okay? And so, one of the things that we've done is we worked with our partners at Communication First and some folks on the steering committee to develop a crisis plan, develop solely by people with lived experience, based upon their own, unfortunately, experiences with the crisis system. And you know that that really was based upon some of the things that we were seeing really lacking in the field. While people may have been involved with researchers than others there was nothing that was solely developed by the community. I'm not sure if I answered all of your question. I'm sorry.

DR. HALLADAY: No, sorry, sorry, maybe I wasn't clear. So, all of the tools that you are either sharing or putting together are based on lived experiences. But how many, and how will they be, will they be kind of, if they're shared with the broader community, how will that be expressed that this was based on a couple of lived experiences? You know what I mean? How many --

DR. NONNEMACHER: So, the how many will sort of evolve as we go based upon where we're identifying there's a gap, right? We have a pretty strong vetting process right now in identifying resources and vetting those resources. But how many we're developing, again, is going to be determined as we sort of dig into these, as I said, the topical framework. So, you know, can't predict that out. But currently, with, like I said, with our focus on crisis and crisis planning, we've just been focusing on giving people individuals and families tools. Because we notice that, you know, while there are some out there, it's A, hard to access them. So, accessibility being the issue again, and B, a lot of tools that are out there haven’t been developed with the community or people with lived experience. So, we’re, you know, again, we’re providing a few different templates based upon people’s experiences along with some samples as well.

DR. GORDON: Mitchell.

MR. MITCHELL BERGER: Yes, thank you. Where my question to the panelist is where and to what extent does substance use disorder fit into your work?

DR. GORDON: Any of the panels scared to

respond about how substance use disorder fits into the plans that you have.

MR. CUNNINGHAM: I will say for most of my members, it's often co-located with behavioral health. So, with mental health, I should say, so, they might provide services. They might also administer Medicaid contracting for it. They might provide oversight of those providers.

DR. GORDON: Thank you. Any other responses? Go ahead.

DR. NONNEMACHER: Yes. So, I was just going to mention that we acknowledge substance use being, you know, a high proportion of, folks that we're talking about when we talk about individuals with IDD and co-occurring mental health. We also acknowledge that there's a dearth of treatments and research out there. So, we have been closely partnering with our colleagues at NASHIA the National Association of State head injury administrators. And they've been digging into this a little more than we have, but it's something that we've identified that we want to specifically target on the website.

DR. GORDON: Thank you, Scott.

DR. SCOTT ROBERTSON: Thank you, Dr. Gordon. I just want to say first that I appreciate these presentations in terms of looking at sort of systems change, mental health services. And by the way, Stacy, it's good to see you virtually speaking, I guess. We interacted a lot with things in Pennsylvania, and glad to see you're doing things at the national level. And I'm glad that these important topics, you know, have been raised in this space. I did want to also highlight that related to the earlier comment in terms of autistic people being involved that there's a lot of barriers to entry for autistic professionals serving in these mental health roles and leadership roles, organizational roles, et cetera. I do believe in having folks on advisory boards as well, but I think we also need to enhance access to the workforce for autistic people in the mental health service systems.

And I think that'll help show some improvements, I think, and enhancements, I think in terms of having that diversity of input and thought leaders who are autistic can really benefit the systems. I did also wonder if you all could speak to potentially -- if you have any ideas or suggestions of what we could be doing better federally as far as resources, policy, practices, input, collaboration, partnerships. I mean, very different ways that us as agencies here in the federal government for our focus is on the workforce, on community living, on education, housing, et cetera, the healthcare system, how we could be supporting you all since mental health and health and wellbeing cuts across so many of our agency roles. And so, what can we do in the government to help you all be more successful and in what your accomplishment in, in terms of systems enhancement, innovation, looking at policies and practices for, like systems change?

DR. PINALS: If, if I could just jump in, this is Dr. Pinals, and I apologize, my internet went down, so I'm calling in. Can you hear me?

DR. GORDON: Yeah, we can hear you. Thank you, Dr. Pinals.

DR. PINALS: Great. Yeah. I mean, I think you know, really coordinating amongst the federal agencies is very good right now, but I think there could always be improvements certainly between DOJ, SAMHSA, ACL, those agencies could, you know, can continue to work together around crisis services and looking at diversion from criminal legal settings. I would think that in, you know, in addition, looking at, you know, Medicaid and working, you know, continuing the partnership between Medicaid and SAMHSA and other federal agencies is going to also be important as we look at how to best serve complex populations and reduce the silos in funding.

DR. GORDON: Anyone else care to respond

to that from the panel?

DR. NONNEMACHER: I'll just make a very quick comment. You know -- Hi, Scott. And knowing where you sit in the federal government, I think one of the things that really, I've been thinking about and was you know, there's some affirmation. Because just recently, there was an article published around mental health counseling rated as most helpful by autistic adults. And, you know, there finding suggested a need for integrated mental health and employment services, and we often don't talk about those together. And how critical employment services back to Lisa, I believe said, you know, the purpose and meaning and how important that is, and thinking about how they can really go hand in hand. So, thanks for that question.

DR. GORDON: Thank you. We have time for one last question. Go ahead, Tom.

DR. FRAZIER: Thanks. Great talks. As we think about services, one of the biggest drivers to get appropriate services is to actually screen for and identify mental health issues. And I'm just curious if you guys are aware of -- or undertaking, and I haven't looked at everything you've provided today, but sort of broad-based screening approaches. What I've seen in the communities where I've been involved has been more idiosyncratic when it's present or frankly just missing co-occurring mental health conditions in people with autism. So, are we aware of any broad-based attempts to standardize or use screening processes? I bring it up in part because what drove a lot of the advances in autism was actually just implementing screening practices. So, I just wonder if we know anything about that.

MR. CUNNINGHAM: With the safer Communities Act. Last year they also established a TA Center, a technical assistance center at the Center for Medicare and Medicaid Services for schools for screening, and hopefully help advance the reimbursement for services within schools.

That's one resource I'd flag.

DR. GASSNER: I just have to remind everybody on the panel and everybody here that if you don't know Lisa Conner's work, she's already created everything you're trying to build in terms of crisis intervention, instruments and measurements and tools. She was our panelist down here in the plaid jacket, so I really encourage you to find her when we can be in the meeting. She's got some great resources.

DR. GORDON: We heard thank you from Lisa in the back for those of you couldn't hear that. Well I want to thank our panelists both the three panelists we just heard on services, but also the panelists speaking from lived experience and community perspectives and the earlier panelists from research. We clearly heard today that there's a great need for attention to be paid to mental health services mental health care for individuals with autism. And it was encouraging to hear first about some of the early research that is that is showing promising, although early results in addressing some of the mental health needs of individuals on the spectrum. But we also heard from those very same researchers from the panelists and with lived with community perspectives and from the services perspective as well, that we need a lot more options. We need better treatments. We need focusing those treatments on individuals, and we need increased accessibility and implementation of evidence-based services. So, thank you very much. It was a tremendously informative afternoon that will inform what we voted on earlier, which is the revision of our strategic plan, which will pay attention specifically to these issues. And I look forward to working with you all over the coming months as we revise that plan. With that, I'm going to turn it over to Susan to close out the meeting and remind us about when our next meeting is. But thank you all for joining us today, both in person and those of you who joined us online.

DR. DANIELS: Yes. Thank you indeed for a wonderful afternoon, robust discussion on mental health issues, which has been a high priority for this committee. And we appreciate all the input and we'll certainly be taking that into account as we prepare the next version of the strategic plan update. So, with this, we will be closing this meeting. The next full committee meeting is scheduled for January 24, 2024 10:00 a.m. to 5:00 p.m., and we're planning it as a hybrid. And we hope the weather cooperates with us and people can make it in. So, just check back for the website, and we will also be sending out emails and so forth about that meeting. And in between, I mentioned some emails that will come to you regarding some of the follow ups from our committee business so, I'll be sending those out. And so, now I'd just like to take a moment to thank our team, so the Office of National Autism Coordination Team that you see here in the room, in person. Thank you all for your work to support this meeting and to support our members of the IACC and our viewing audience. So, we appreciate you and also the Rose Li and Associates contractor that works with us on these meetings, NIH Events Management, and the NIH Center for Information Technology supporting the meeting. Thank you so much, and we'll see you next time.

[meeting adjourned]