

INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, APRIL 13, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 1:00 p.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

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

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

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

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

SKYE BASS, L.C.S.W., Indian Health Service

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

KRISTIE BRACKENS, Department of Justice (DOJ)
(representing Maria S. Fryer, M.S.)

PRESENT: (continued)

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

JUDITH A. COOPER, Ph.D., National Institutes
of Health, (representing Debara L. Tucci,
M.D., M.S., M.B.A., F.A.C.S.)

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

AISHA DICKERSON, Ph.D., Johns Hopkins
University

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

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

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

ALYCIA HALLADAY, Ph.D., Autism Science
Foundation

ELAINE COHEN HUBAL, Ph.D., U.S. Environmental
Protection Agency (EPA)

CRAIG JOHNSON, Champions Foundation

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

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

PRESENT (continued)

ALISON R. MARVIN, Ph.D., Social Security
Administration

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

YETTA MYRICK, B.A., DC Autism Parents

LINDSEY NEBEKER, B.A., Freelance
Presenter/Trainer

MORENIKE GIWA ONAIWU, M.A., Rice University

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

JENNY MAI PHAN, Ph.D., University of
Wisconsin-Madison

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

JALYNN R. PRINCE, Madison House Autism
Foundation

AMANDA REICHARD, Ph.D., Administration for
Community Living (ACL) (representing Jennifer
Johnson, Ed.D.)

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

SCOTT MICHAEL ROBERTSON, Ph.D., U.S.
Department of Labor, (representing Taryn
Mackenzie Williams, M.A.)

PRESENT (continued)

ROBYN SCHULHOF, M.A., Health Resources and
Services Administration (HRSA)
(representing Lauren Ramos, M.P.H.)

STUART SHAPIRA, M.D., Ph.D., Centers for
Disease Control and Prevention (CDC)
(representing Georgina Peacock, M.D., M.P.H.,
F.A.A.P.)

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A., University of Washington

TERESA SOUZA, Ph.D., U.S. Department of
Housing and Urban Development (HUD)

HARI SRINIVASAN, University of California,
Berkeley

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

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

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt
University

PAUL WANG, M.D., Simons Foundation

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

STEPHEN WHITLOW, J.D., Merakey

NICOLE WILLIAMS, Ph.D., U.S. Department of
Defense

TABLE OF CONTENTS

Welcome	7
<p style="margin-left: 40px;">Joshua Gordon, MD, Ph.D., Director, National Institute of Health, NIMH) and Chair, IACC</p> <p style="margin-left: 40px;">Susan Daniels, Ph.D., Director, Office Of Autism Research Coordination, NIMH, and Executive Secretary, IACC</p>	
Autism Awareness Month Greeting from The National Institutes of Health (NIH)	17
<p style="margin-left: 40px;">Tara Schwetz, Ph.D., Acting Principal Deputy Director, NIH</p>	
Updates on Disability Housing Programs	35
HUD Supportive Housing Programs & Research	38
<p style="margin-left: 40px;">Teresa Souza, Ph.D., Social Science Analyst, Office of Policy Development And Research, U.S. Department of Housing and Urban Development</p>	
Overview of the Housing and Service Resource Center	52
<p style="margin-left: 40px;">Lori Gerhard, B.S., Director, Office of Interagency Innovation, Administration For Community Living (ACL)</p>	
Autism and Homelessness: Experiences From the Bergen County, New Jersey Housing, Health & Human Services Center	65
<p style="margin-left: 40px;">Julia Orlando (Presented by Susan</p>	

Daniels, Ph.D.), Director, Bergen
County (NJ) Housing, Health and Human
Services Center

Discussion of the IACC Charge 105

Joshua Gordon, M.D., Ph.D., Director,
National Institute of Mental Health,
(NIMH) and Chair, IACC

National Autism Coordinator Update 116

Susan Daniels, Ph.D., Acting
National Autism Coordinator, Director,
Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC

IACC Committee Business 131

Susan Daniels, Ph.D., Acting
National Autism Coordinator, Director,
Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC

Autism Awareness Month 131

IACC Strategic Plan 133

IACC Summary of Advances 190

Adjournment - Day 1 231

Joshua Gordon, M.D., Ph.D., Director,
National Institute of Mental Health,
(NIMH) and Chair, IACC

Susan Daniels, Ph.D., Director, Office
Of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

PROCEEDINGS

DR. JOSHUA GORDON: I want to welcome members of the Interagency Autism Coordinating Committee and of the public, to this meeting of the Interagency Autism Coordinating Committee. This meeting is available publicly by the NIH Videocast and so I want to make sure to remind all our members that you will be speaking live via the web to a large audience who are interested and engaged in what we have to say.

I want to welcome everyone to this meeting, which is taking place, as is our usual habit, during April Autism Awareness Month. During this month we recognize that we need to take time to reflect on and commit to increasing our understanding of inclusion and acceptance of autistic people, of their families, communities, and to take actions to meet the challenges faced by these

individuals and their families and communities.

It is also a month where we celebrate the strengths, accomplishments, and contributions of people on the autism spectrum, as well as their communities, across the globe.

In that spirit I want to take a moment to acknowledge some happy updates about our committee members. We hope to make this a tradition to recognize important accomplishments of IACC members. If any of you on the committee have similar announcements you would like share at future meetings, please let Susan and the IACC staff know. But today I am pleased to announce Sam Crane, who is serving on the IACC for a second term and was the long-time policy director of the Autistic Self-Advocacy Network, has taken a new position as the

legal director at the Quality Trust For
Individuals With Disability in Washington,
D.C. Congratulations, Sam, on your new
position.

Second, I am really pleased to be able
to congratulate Hari Srinivasan, who is a
member on the IACC, and a senior at the
University of California, Berkley, for two
things. First, he was recently accepted to
the Vanderbilt University's PhD Program in
Neuroscience. And having just visited there
last week, and actually received Hari's email
saying he had been accepted while I was
there, I was able to convey to them at
Vanderbilt your enthusiasm and hear from them
about their enthusiasm for you joining them,
Hari.

Hari has also been selected as a
recipient of the Paul and Daisy Soros
Fellowships for New Americans, which is a

merit based graduate school program for immigrants and children of immigrants. The recipients are chosen from a pool of over 1,800 applicants. So really congratulations on both affects, Hari. And again, we hope to make this a tradition at future meetings.

To get onto the meat of the meeting today, we have a lot of things to look forward. A variety of presentations. We will be hearing updates about housing programs from the Department of Housing and Urban Development and the Administration for Community Living. We will also hear a few remarks from Dr. Tara Schwetz, who is representing Dr. Larry Tabak, the Acting Director of the National Institutes of Health and a member of this committee. We will also be working on our two key assignments, the IACC Strategic Plan and the 2021 Summary of Advances.

Tomorrow the meeting will continue as we will be hearing from and discussing public comments and hearing presentations about the diverse communication needs of individuals on the autism spectrum.

Once again, I thank all members of the committee and members of the public for joining us today and I am going to turn it over to Susan for some opening remarks and approval of the minutes from the January meeting. Susan Daniels.

DR. SUSAN DANIELS: Thank you, Josh. I want to echo Josh's welcome and welcome to everyone at the meeting, people who are viewing in our listening audience around the country and around the world and to our committee members for being here today as we mark Autism Awareness Month, again, as a month that we reaffirm our commitment to acceptance, inclusion, and empowerment of

people on the autism spectrum and as well to addressing challenges and opportunities for autistic individuals and their families.

Later in this meeting, we will be highlighting some Autism Awareness Month activities and I encourage you all to check out the Autism Awareness Month webpage on the IACC website for more information on these and other activities that are sponsored by the government agencies as well as the nonprofits around the US and worldwide.

We want to remind the committee members to please keep your microphones off unless you are speaking and also to keep your cameras off during presentations and breaks. You are welcome to turn your cameras on during committee discussions. And if you are a committee member that would like to contribute a written comment during our discussion period, please raise your hand

using the Zoom raise hand function and let us know you would like to comment and then use the chat feature to send the text of your comment to the OARC staff member who is using the Zoom screen name, send comments here, which we thought would be easy for everyone. And when it is your turn to be recognized, the OARC staff member will read your comments on Zoom.

For this meeting, Mr. Steven Isaacson, who is a member of the OARC team, will be reading member comments send through the chat in the meeting.

Now, I would like to continue with the approval of the minutes from the January meeting. I would like to take a moment to ask the committee members if you have any comments on the draft minutes of the January 2022 meeting that was in the meeting materials. A couple of members sent in some

corrections that have already been incorporated. Does anyone have anything that they need to see corrected or updates you would like us to make? I am not seeing anything. If there is no further discussion, can I get a motion on the floor to approve the minutes?

MS. YETTA MYRICK: This is Yetta Myrick. I will put a motion on the floor to approve the minutes from the January meeting.

MS. DENA GASSNER: I will second.

DR. DANIELS: Thank you, Dena. All in favor, can you please raise your hands in Zoom? Thank you. Are there any opposed to accepting the minutes? You can put your hands down from the previous and if there is anyone who is opposed, let us know. I think I have two iPad 4, which I do not know who iPad 4 is. Ivanova, do you have any specific

concerns about the minutes that need to be addressed?

MS. IVANOVA SMITH: I thought that was a vote to approve the minutes. I apologize.

DR. DANIELS: No problem. Just clarifying. iPad 4, did you have any specific comments that you needed corrected in the minutes?

MR. CRAIG JOHNSON: No. I am sorry. This is Craig Johnson. I am using a different iPad today so sorry about that.

DR. DANIELS: No problem. Thank you. And is there anyone who is abstaining from the approval of the minutes? The majority approves. We are in favor of accepting the minutes. The motion carries and we will be accepting the minutes and posting the final ones to the website just after this meeting or actually probably by tomorrow. Thank you so much and I turn it back over to Josh.

(Minutes approved.)

DR. GORDON: Thank you, Susan. It is my pleasure now to introduce Dr. Tara Schwetz, who is the Acting Principal Deputy Director of the National Institutes of Health. Dr. Schwetz is a biophysicist by training and has served in multiple senior roles at both the National Institutes of Health as well as in the White House Office of Science and Technology Policy where she was the Assistant Director for Biomedical Science Initiatives.

In this role, she led the effort to stand up the Advanced Research Projects Agency for Health or ARPA-H. On returning to NIH, we were very pleased when Dr. Schwetz was selected to fill in for Dr. Larry Tabak, the Deputy Director of NIH and the current Acting Director of the National Institutes of Health. Dr. Tabak is a statutory member of the IACC but was called away to a meeting at

the White House today so was unable to join us and asked Dr. Schwetz to join us in his stead.

DR. TARA SCHWETZ: Thanks, Josh, for that introduction and good afternoon or good morning to everyone, depending on where you are across the country across the world. I want to start by thanking both Drs. Gordon and Daniels for their leadership and commitment to the work of this really important committee of the Interagency Autism Coordinating Committee and of course their support for the autism community over the years.

I also want to take a moment to recognize and thank Dr. Courtney Aklin, who is the Acting Associate Deputy Director of NIH, who is serving as the representative for NIH on this committee and Dr. Tabak.

As Josh mentioned, Dr. Larry Tabak, the Acting NIH Director, is unfortunately unable to be here today. But he sends his regards. I want to emphasize that both he and I applaud the efforts and commitment of this committee and of the new and returning members of the IACC who I am told make up the largest and most diverse committee to date, which is great.

Your work, the work that this committee does, provides a really important guidance to the Secretary of Health and Human Services on priorities and gaps and opportunities for autism-related research services and supports.

And just recently on April 2, we observed the 15th Annual World Autism Awareness Day and continuing throughout the month of April, which, as Josh mentioned, is National Autism Awareness Month. We unite to

celebrate, recognize, and support people on the autism spectrum, which in our nation includes about 1 in every 44 children and 1 in every 45 adults.

As part of this celebration, I want to emphasize that NIH promotes acceptance, understanding, and inclusion to create a world where all people with autism have the support that they need to pursue the lives that they want to lead and reach their full potential.

NIH celebrates the strengths and the talents of autistic individuals and the unique contributions that they make to our society. Being a research organization, of course, NIH is committed to funding research that supports the health and well-being of people on the autism spectrum and their families. We strive to achieve this by supporting a research portfolio that includes

a wide range of projects and activities that cover the lifespan of autistic individuals.

I am sure many of you on this committee - this is why you are here, but you are familiar with a lot of our efforts but just to take a moment to call out a few examples. We have the Early Autism Screening Initiative, which focuses on developing and validating screening tools to detect autism in the first year of life. We also have a flagship NIH Autism Centers of Excellence program that supports a variety of different areas of research, including understanding the biology and the genetics of the autism spectrum, improving developmental outcomes, increasing access to services, and developing novel interventions and innovative delivery methods.

NIH also supports research to benefit transition age youth and adults with autism

with a focus on improving employment opportunities and developing strategies to manage co-occurring health conditions. And very importantly, we are dedicated to diversifying the autism research workforce through career development and enhancement awards.

In closing, I would like to extend my gratitude to each of you who serve on the IACC for your dedication to addressing a really long list of challenges, including mental and physical health, education, employment, housing, racial and ethnic disparities, and services and supports to improve quality of life.

NIH looks forward to the upcoming new addition of the IACC Strategic Plan for Autism Spectrum Disorder, which is going to highlight a wide range of vital issues. Together, we will work to ensure that people

on the autism spectrum benefit from advances in biomedical research and receive the best evidence-based services and support and also that they have enhanced opportunities to participate in their communities.

With that, I will thank you and I think we are going to take a moment, if I understand, to do some Q&A. I am happy to answer any questions.

DR. GORDON: thank you. Thank you very much, Dr. Schwetz. We are happy to take any questions from any members of the committee who would like to ask Dr. Schwetz about NIH's role in autism research or other matters of relevance. Please just raise your hand or you can just unmute.

DR. SCHWETZ: While people are formulating their questions, I will take a moment to congratulate Hari for getting into Vanderbilt. I also have a connection to

Vanderbilt. I did my postdoc there. It is a great place.

DR. GORDON: I note Hari's wave and thank you. Dr. Mercedes Avila. Mercedes, please.

DR. MERCEDES AVILA: Just a quick question. We recently received an NIH grant that we are working with vulnerable populations, and we know that NIH is looking at having some common elements, identifiable information of participants who are part of research in NIH grants. There has been a big discussion in our grant that we just had this morning around many aspects of identifiable information is a deterrent for working with vulnerable populations. It has taken us decades to build trust with communities that do not trust researchers or do not trust academia or schools of medicine and now looking at that change in requesting that long list of common elements that

participants need to provide is going to affect the trust that we have built. I was wondering if you have any thoughts around that or anything that can be done from an advocacy perspective to educate agencies around understanding the importance of building trust for working with vulnerable populations. Thank you.

DR. SCHWETZ: That is a great question. That is always a thing that we want to ensure that in order to really fully engage communities in research, we really have to have that trust built up and that trust relationship. I think sometimes we use the phrase or the saying that these things move at the speed of trust. You cannot also just - it is not something that you can throw additional resources at and just expect things to speed up. It does take time to build relationships.

I know that these kinds of things are often program dependent and something that we have talked a lot about in our RADx, our Rapid Acceleration of Diagnostics, underserved populations program. Across the board, this is something that is being considered for a lot of programs. I would encourage you to - if there are any specific questions about your current project to reach out to your program staff and work through some of the issues you may have or questions you may have.

DR. GORDON: Thank you. Two more questions. I just want to remind those who might need communicative assistance that we now have a place you can send comments to in the chat. It is labeled send comments here. Please do that - or questions. But let me first turn to Amanda Reichard, who is from the Administration for Community Living.

DR. AMANDA REICHARD: So many acronyms. I know. In addition to representing ACL, I am the co-chair for the - I always have to think it through. Interagency Council on Disability Research. And not that council but the subcommittee and that is focused on disability statistics. We are trying to figure out what is the priority in terms of data and statistics around research. I wondered if you have any comments about what ways we can best support data efforts or statistics in either case to improve access for the researchers that you support in autism research.

DR. SCHWETZ: I think there are obviously some of these similar questions that apply across the board and just more broadly across all of biomedical research. This is a really important question. I do not know that there is standard one size fits all answer to. But

I will say that we are launching next year in January some efforts around data sharing and revising our policy or implementing our revised policy there. I think we need more conversations probably offline to work through all the details and there is probably I am sure unique challenges for each area of science and this one is no exception.

DR. GORDON: Thank you, Dr. Reichard. Dr. Scott Robertson from the Department of Labor.

DR. SCOTT ROBERTSON: Thank you, Dr. Gordon. I was wondering - I guess my question is more about at the top-level leadership. Are you exploring creative, maybe brainstorming creative ways for newer ways down to the pipe to empower research for focusing on autistic adults specifically since we talk about a lot at the IACC meetings and other settings on how there is not a representation of that life course

focus? I do not know if there are newer things that might be coming down the pipeline as far as at NIH that you might be considering or new pursuits or activities or maybe that is something that could be coming later. I have seen some very innovative things and including to cross connect, for instance, to employment and social determinants of health and some NIH research. Just curious about your thoughts about to expand that life course focus related to quality of life and integration at the NIH research portfolio enhancement therein.

DR. SCHWETZ: We are always looking to explore opportunities around how to make sure that we are engaging the research workforce but also thinking about type of activity that cuts across the entire lifespan and this area is no exception. Josh is probably much more of an expert in that space than I am to talk

about things that you might be considering that are specific to autism. But the life course I know has been a priority in previous strategic plans that have come out and I think will continue to be. I do not know if Josh or Susan want to elaborate further.

DR. GORDON: Yes. Thanks, Tara. And, Scott, thanks for the question. I know that this is an issue that this committee in previous iterations have dealt with and you know what I am going to say already, which is that we have been trying to build a workforce in this area. We have been somewhat successful of late in terms of trying to get more people to pay attention to these life course issues. We continue to work hard on expanding opportunities.

I think we have time for one more question. I do see Dena Gassner's hand up. Please, Dena, take it away.

MS. GASSNER: Thank you. I wanted to piggyback on what Scott had to say. One of the things that I saw that was missing across the board in our Strategic Plan and in our research portfolio about adults is a disparity between early intervention-based diagnoses where we put an emphasis on intensive supports at the time of diagnosis but people who have been missed because of a prior iterations of the DSM not including them are now well into adulthood in their 40s, 50s, and 60s and they get a piece of paper and a confirmation and they are sent on their merry way. In terms of our portfolio, I think looking at the value of intensive intervention regardless of the age of diagnosis might really strengthen our research portfolio especially I notice that Alicia Halladay was referring to the idea of systems navigators. Adult do not come to a

diagnosis in the best place. Having support, intensive support to plug them into services like we do with people whose kids get diagnoses at 2 and they get early intervention comparably. I think that might be a real strength to the portfolio.

DR. SCHWETZ: We often focus on adults or children and I think there is - my understanding is there is a continued focus on that transition space but hitting those folks that might be caught in the middle of the transition that you were just mentioning of the differing diagnostic criteria and when it happens as an adult, you are going to have very different needs than if you are a young child.

DR. GORDON: I want to thank Dr. Schwetz for joining us today and for representing Dr. Tabak, who we hope to have come visit us at a future meeting. I do want to point out that

Dr. Tabak does have a representative who attends all these meetings on his behalf and keeps them apprised of our activities and that is Courtney Aklin, who I believe has joined us today also.

Ivanova, did you want to ask a question. I thought I saw your video coming up. Hi Courtney.

MS. SMITH: I do have a question real quickly. Thank you. My question is I just want to ask - if the NIH is considering making sure that the policies and recommendations that are putting out around the pandemic also does not allow for discrimination against autistic people. For these last two years, the mandates have caused a lot of discrimination for autistic people. I just want to make sure that they do not do that in the future and that we can work on policies that accommodate autistic

individuals that cannot have things over their face. A lot of autistics have been isolated and segregated because they cannot have things covering their face or they cannot go through certain medical procedures. I just want to make sure that we are not leaving those folks behind and allowing for that discrimination to continue. I would like to know if the NIH has considered that. Thank you.

DR. SCHWETZ: That is a are really important point. I know that we are supporting some research and certain aspects of that and the impact of the pandemic. I am sure obviously there is more that we can do. This is, I think, a great and really important topic in which we can leave this on but it needs obviously a lot more exploration and discussion around what more we can do to further enhance whatever policies that we are

putting out, in particular, as the NIH, but then of course how we can utilize our role as a research agency to better enhance the knowledge and learning what has worked and what has not worked. We are still in this very dynamic phase in the pandemic. We are still within it and have opportunities to be able to explore that further. Thank you for that attention.

DR. GORDON: Thank you, Ivanova. Thank you, again, Dr. Schwetz and really appreciate you coming and joining us today.

DR. SCHWETZ: Thanks so much. Good to see you all.

Agenda Item: Updates on Disability

Housing Programs

DR. GORDON: Moving right along, we are a few minutes ahead of schedule. But do we have all our guests for the next section ready for us? Susan, do you know?

DR. TERESA SOUZA: Yes, I am here.

DR. GORDON: At the very least, we can get started with Teresa and then we also have Lori Gerhard. Let me introduce this next segment. I want to again thank Dr. Schwetz for joining the meeting and for fielding those questions, which have as usual given us some food for thought for future discussions here at the IACC.

I will point out with regard to that last question that Dr. Schwetz sort of mentioned this peripherally. NIH does not set policies. That is the CDC, the FDA, and other organizations in the government. But we do provide the research backbone to demonstrate the need for those policies. And it is certainly something that this group could do to recommend alterations to those policies that would better take into account the needs of individuals with autism and their families

and communities. That might be something we want to discuss as the federal government moves on from this pandemic to think about planning for future pandemics.

But to introduce these next presentations, we are going to switch from the NIH and research to updates on disability housing programs. I am really pleased to - we have two speakers joining us today from the federal government side. We have Dr. Teresa Souza, who is a social science analyst in the Office of Policy Development and Research at the US Department of Housing and Urban Development. I will just add that NIH has just had a really great conversation with HUD about a number of different areas of overlap and interest and we look forward to continuing those collaborations.

We also have Ms. Lori Gerhard, director of the Office of Interagency Innovation at

the Administration for Community Living joining us today. Dr. Souza and Ms. Gerhard will be updating us on federal programs affecting housing for people with disabilities.

These presentations will be followed by a video from Ms. Julia Orlando, the director of the Bergen County New Jersey Housing, Health and Services Center, that is going to be presented by Dr. Daniels since Ms. Orlando could not join us today live. But we are really pleased she was able to contribute that video presentation. At the end, we will have time for questions and discussion amongst the IACC members.

I just want to note. I am going to apologize. I have another obligation at 2 o'clock. I will be stepping away for just a few minutes at that point but will be back thereafter and will otherwise be here for the

whole presentation. With that, I turn it over to Dr. Souza.

DR. SOUZA: Thank you, Josh. Hello. My name is Teresa Souza and I am a social science analyst in the Office of Policy Development and Research at the US Department of Housing and Urban Development. I will give some examples of HUD's supportive housing programs for people with disabilities and related research.

These are the major topics that I will cover in my presentation today. I would like to start by sharing HUD's mission, which is to create strong, sustainable, inclusive communities and quality affordable homes for all. And the first thing that is important to keep in mind is that HUD serves only a fraction of the people who need and are eligible for housing assistance. According to the latest report to Congress on the US

worst-case housing needs, there were 13.3 million unassisted renters with very-low income in 2019 before the pandemic. Those are represented by the squares on the left side of the slide, both the light and dark green squares. Of those, 7.8 million households have what HUD defines as worst-case housing needs. These are households who pay more than 50 percent of their income towards rent, live in severely inadequate housing or both. The households with worst-case housing needs are represented by the dark gray squares on the left.

On the right, you can see that HUD assists about 4.6 million households represented by the blue squares. This means that HUD assists only one-fourth of the need for rental housing assistance.

HUD has three major housing assistance programs. The largest one is the Housing

Choice Voucher, which assists over 2.3 million households. This is generally rental assistance that goes to a family or individual who then finds an affordable housing unit in the private market.

The second largest program is the Project-Based Rental Assistance, which assists over 1.2 million households. This is a rental assistance that is tied to a property or a unit that is owned by a nonprofit organization.

And the third largest program is public housing, which assists over 800,000 households. This is a rental assistance that is tied to a property that is owned by a local, public housing agency.

In addition, HUD has two smaller supportive housing programs, the Section 202, which is targeted to older adults and assists over 120,000 households. And Section 811,

which targets people with disabilities and assists over 30,000 households. But you can see from the column on the right that people with disabilities are assisted across all HUD programs.

Over the years, the share of older households has increased as the assisted population ages and remains in assisted housing. However, the share of non-elderly households with disabilities has remained relatively stable. That is the blue line on the slide. Over the past ten years, people with disabilities represent about 34 to 35 percent of HUD-assisted households according to HUD administrative data.

The Section 811 program allows people with disabilities to live as independently as possible by subsidizing the rent and connecting residents to appropriate and voluntary supportive services. The Section

811 program can operate in two major ways. First, in the traditional way by providing capital grants and operating subsidies to nonprofit developers of affordable housing for persons with disabilities. And second in a new way that was authorized by law in 2012 by providing project rental assistance to state housing agencies. Today, I am going to focus on the second form of assistance given to state housing agencies.

The new Section 811 Project Rental Assistance program also known as PRA was first implemented through a demonstration in 2012. Under this program, state housing agencies that have entered into a partnership with state Medicaid and Health and Human Services agencies can apply for grants that subsidize the rent for people with disabilities in affordable housing developments.

The program subsidizes up to 25 percent of units in a property to ensure that people with disabilities are fully integrated in the community. Participants must have extremely low income, which is income at or below 30 percent of the median income in the area. They must be 18 to 61 years old at the time of admission. And they must be eligible for Medicaid or other health and human services.

HUD awarded over \$340 million in rental assistance grants since 2012. And over 3000 households have been assisted since the program started.

The population assisted is split between two major groups. First, people experiencing homelessness or at risk of homelessness and second, people transitioning out of institutional care or at risk of placement in an institution such as a nursing home.

HUD conducted an evaluation of the Section 811 PRA program that assessed its effectiveness compared to similar households in other HUD programs and without housing assistance. The evaluation was limited to six states that had made more progress moving people into assisted housing. And the evaluation found that the program was very well targeted.

811 PRA residents have lower incomes, and more health care needs than residents in any other HUD program. In those states, the program served the population with very high health care needs and this is a testament to the success of the housing and health partnerships at the local level.

811 PRA residents reported high levels of autonomy and an independence, which validates the community integration focus of the program. And neighborhood quality

indicators were mixed in the study. We found that 811 PRA residents lived in neighborhoods with higher poverty rates but with greater access to public transit and with higher access to walkability compared to similar people in other HUD programs.

I also wanted to share some results from an in-person survey where we heard directly from residents about their experiences in the 811 PRA program. In this presentation, I am going to focus on two areas that we were interested in. First, whether 811 PRA residents were supportive in their housing search and living at the property. And second, whether residents were connected to community-based services. We found that a majority of 811 PRA residents report receiving tenancy support and other services that meet their need.

We also found that a majority of 811 residents report a positive experience with their home-based care. But residents report gaps in services such as with assistance with bathing, meals, and medication. The study addressed many other areas and if you want to learn more, I included a link to the report on this slide.

The Mainstream Voucher Program also assists non-elderly people with disabilities. The program targets people transitioning out or at risk of institutional care and people experiencing homelessness, previously homeless, or at risk of homelessness.

Local public housing agencies administer the funds and they are encouraged to partner with homeless assistance and health and human services agencies. HUD awarded about 67,000 vouchers to public housing agencies and there are currently 45,000 households assisted and

another 20,000 vouchers available to new households.

The Emergency Housing Voucher is a new but temporary form of assistance that was created under the American Rescue Plan to provide 70,000 vouchers to subsidize the rent of individuals and families facing housing instability during the pandemic. The program targets people experiencing homelessness, at risk of homelessness, recently homeless, or people who are fleeing or attempting to flee domestic violence, dating violence, sexual assault, stalking, or human trafficking.

This program recognizes the higher barriers faced by this target population to be placed in assisted housing and provides \$3,500 for housing assistance services that can be used for security and utility deposits, moving expenses, landlord

incentives, and other housing-related expenses.

HUD has never provided this type of assistance other than for limited mobility demonstrations. And we anticipate that this funding will help improve success rate of families using units.

Like all housing vouchers, the program is administered by local public housing agencies. But in this program, housing agencies are required to get participant referrals from homeless assistance agencies. Over 16,000 households have been assisted and another 27,500 households received a voucher and are now looking for a rental unit.

I talked about three major HUD programs that target people with disabilities in different ways and some of the related evaluation. And now, I am going to focus on two research areas that are critical to

understand the needs and barriers that people with disabilities experience in the rental housing market. The first is the Housing Discrimination Research. There are several federal non-discrimination laws that provide housing protections for individuals with disabilities. And HUD's Office of Policy Development and Research, PD&R, has been studying the presence and the extent of housing discrimination in the rental market for over 40 years.

Here are some examples of housing discrimination research on the basis of disabilities. This study assesses housing discrimination against people who are deaf or hard of hearing, people who use wheelchairs, and people with mental illness and intellectual or development disabilities. All the studies found evidence of unfavorable treatment during the housing search process.

For a full list of all housing discrimination research, you can check out the link on this slide.

Another research area that has been critical to understand the prevalence and needs of people with disabilities in HUD-assisted housing is the effort to link health and housing data. One example is the ongoing collaboration between HUD and the National Center for Health Statistics, NCHS, to link health survey data to HUD administrative data. This is an ongoing collaboration that updates housing health linkages continuously. In the link shown in the slide, you can find more information about the content of the linked data and also information about how researchers can access it.

Here are some examples of technical reports that have used HUD and NCHS-linked data to create a picture of HUD-assisted

adults and children's health. And you can access the reports by clicking at the picture on the slide.

These are some examples of studies that have used the linked data to understand the prevalence and health care needs of people with disabilities in HUD-assisted programs. In this study, for example, we found a higher prevalence of disabilities among HUD-assisted households compared to HUD administrative data. And we also found that HUD-assisted adults with disabilities are significantly more likely to be connected to the health care system than those without disabilities. But they have higher odds of reporting unmet care and have higher odds of going to an emergency room visit in the past 12 months.

We encourage researchers to use the linked data, these and other ones, and help us refine our understanding of the connection

between housing and health and improve our programs as they serve more people that are more vulnerable and have higher health care needs. Thank you.

DR. GORDON: Thank you very much, Dr. Souza. We are going to hold questions until the end of the presentations. We will move right along to Lori Gerhard from ACL.

MS. LORI GERHARD: Sorry. It took me a little bit to get to my unmute button. Good afternoon, everyone. It is exciting to be here with you today to share information on our newly formed Housing and Service Resource Center. Today, I will share specific information round housing and services challenges, solutions and opportunities, and the New Housing and Services Resource Center and HHS/HUD partnership.

It is difficult to find and obtain affordable and accessible housing. More than

15 percent of US households include someone with a disability. But only 6 percent of homes nationwide are accessible. Under 1 percent of the US housing stock is wheelchair accessible and less than 5 percent can accommodate individuals with moderate mobility disabilities. This is a challenge that we confront.

A 2021 report found that there were only 40 affordable and available homes for every 100 extremely low-income renter households nationwide. Forty percent of renter households were cost burdened, and more than 20 percent were severely cost burdened. HUD defines rent burden as spending more than 30 percent of your income on housing and severely rent burden as spending more than 50 percent of your income on housing. Severely cost burdened renters must make difficult tradeoffs on how to spend their limited

funds. For instance, severely burdened renters in the bottom expenditure quartile, the lowest income, spend 38 percent less on food and 70 percent less on health care than otherwise similar renters living in housing that they could afford.

Homelessness is growing among people with disabilities and older adults. HUD's 2018 annual homeless assessment report indicates that 48.5 percent of single adults and heads of households who use homeless shelters over the course of a year report having a disability. That is approximately 550,000 people. And per the same report, the number of sheltered homeless aged 51 to 61 increased from about 216,000 in 2007 to 249,000 in 2017. The number of people experiencing sheltered homelessness also rose for those 62 years of age and older from 46,000 to 76,500. Older adults now make up 23

percent of the sheltered homeless population up from 16.5 percent in 2007. The numbers are going in the wrong direction. Homelessness is a significant national policy challenge affecting many people. Nearly 900,000 people fall into homelessness each year. These are people who have a home, and something occurs that they no longer have a home and become homeless.

The 2020 point in time count found that over 580,000 people experienced homelessness on a night in January. And between 2017 and 2020, the point in time count showed an average of 562,430 people experiencing homelessness. People experiencing homelessness are nine times more likely to die from an opioid overdose than those who are stably housed.

And some of the root causes for homelessness include poverty, domestic

violence particularly for women, acute physical or behavioral health crisis, transition from other systems and institutional settings.

In addition to some of the challenges we confront with housing, there are also challenges in finding, navigating, and obtaining services. People often are not aware of the services and programs that can help them. The array of programs and funding streams that provide services are complex and difficult to navigate. Workforce shortages impact service availability. And program innovation and disability, aging, health and housing sector success strategies occur and may be solutions for additional states and communities. We know that in some pockets, they have solved this challenge, but we do not always know how to spread the innovation across the country.

There are several things underway to begin to help us on this path to finding the solutions. The first is the American Rescue Plan Investment. As Dr. Souza just mentioned, there are additional housing vouchers that were issued under the American Rescue Plan. Particularly, I want to call out those 70,000 emergency housing vouchers. We have heard from states that these emergency housing vouchers with some of the wraparound supports that they provide are really instrumental in helping people obtain stable housing.

The Money Follows the Person program has also received the ability to be expanded. On March 31, just recently, CMS announced the availability of \$110 million to expand access to home and community-based services through the Medicaid Money Follows the Person program. And the Money Follows the Person

program helps people transition out of institutions back into the community.

CMS also announced that the agency is increasing the reimbursement rate for the Money Follows the Person supplemental services. These services are now being 100 percent federally funded with no state share. Further, CMS is expanding the definition of supplemental services to include additional services that can support an individual's transitions from an institution to the community, including short-term housing and food assistance. These changes will help further address critical barriers to community living for people who are eligible for these programs as well as increase community transition rates and the effectiveness of the Money Follows the Person demonstration overall.

An open-door forum will occur on April 19th that will provide more information on these initiatives. We have information on how you can listen to that call on the Housing and Services Resource Center website. We suggest that you visit the What's New section to obtain call-in information to listen to this open-door forum.

In addition, the Older Americans Act also received an additional \$400 million to increase the availability or access to home and community-based services and assistive technology.

In July of 2021, HHS and HUD formed a partnership to rally together on how we collaborate and coordinate the implementation of the American Rescue Plan Investments and further strengthen our partnership on supporting states, communities, organizations, and helping people obtain and

maintain stable housing and the services they need to engage in the community.

With that, one of our collaborative efforts is the Housing and Services Resource Center. We announced the Housing and Service Resource Center in December. And the Health and Human Services agencies include the Administration for Community Living, the Assistant Secretary for Planning and Evaluation, the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the US Department of Housing and Urban Development. We announced the Housing and Services Resource Center and it is a federally coordinated approach to providing resources, guidance, and technical assistance and creating partnerships among the state Medicaid disability and aging agencies, the state and local public housing agencies and

authorities, disability and aging networks and providers, behavioral health providers, housing and homeless providers. One of our first products is the HSRC or Housing and Services Resource Center website. That website is at acl.gov/housingandservices. The website is a single location that includes links to federal resources related to housing and services.

The Housing and Services Resource Center will coordinate technical assistance, facilitate partnerships, recognize and share innovations, and leverage and align resources. We know that it will take all of us working together in order for people to obtain and maintain stable housing and services that they need.

Thank you for your research and the work you do each day to serve people with disabilities, their families, older adults,

and caregivers. This is the HSRC What's New page to learn about upcoming webinars and/or review recorded webinars and remember the open-door forum coming up on April 19th.

Please email us at hsrc@acl.hhs.gov to tell us about your partnerships with the disability, aging, health and housing sector and how you are helping people stay stably housed, transition out of institutions, and/or obtain, maintain accessible, affordable housing and services. We really want to know what partnerships are out there and what is working and what we might be able to hold up for further replication across the country.

If you would like to ask a question of the Housing and Services Resource Center, you can email us at hsrc@acl.hhs.gov or if you would like to be added to our Housing and Services Resource Center email list where you

will receive updates as we update the website, please email us again at hsrc@acl.hhs.gov. Thank you for the opportunity to share this information about the Housing and Services Resource Center. This concludes my presentation.

DR. GORDON: Thank you very much, Lori, for that informative presentation. For the final presentation of this panel, I am going to turn it over to Susan Daniels, who will introduce the video.

DR. DANIELS: I am here. Can someone turn on my video for me because I cannot? Thank you. We are going to hear a little bit about autism and homelessness, some additional information and experiences from the Bergen County New Jersey Housing, Health and Human Services Center. We are going to be hearing from Julia Orlando, who is the director of the Bergen County Housing, Health and Human

Services Center. The mission of this nationally recognized and award-winning center is to end homelessness in Bergen County. In 2016, Ms. Orlando provided leadership for the successful community-wide effort to end veteran homelessness in Bergen County.

She also provided leadership that led Bergen County to become the first in the nation in 2017 to successfully reach functional zero for chronic homelessness in Bergen County and it is the only community to date to sustain that zero for more than one year.

I have had the pleasure of talking with Ms. Orlando since before the pandemic about this situation. She reached out wanting to connect with the IACC to talk about the situation she was facing in her homeless program with receiving people on the autism

spectrum into the program and wanting to hear from the IACC about how they might be able to be helpful.

I am going to share a video with you that she recorded for us and then provide some comments after that.

MS. JULIA ORLANDO: Hello. My name is Julia Orlando. I am the director of the Bergen County Housing, Health and Human Services Center, which is located in Hackensack, New Jersey. We provided shelter services and social services for persons experiencing homelessness who are aged 18 years or older within our community.

I wanted to share with you today our experience working with people with autism and developmental disabilities within our homeless population. If an adult with a developmental disability is not connected as a resource as a child or before the age of

18, it is very difficult to get them linked to services once they are an adult. We have had several individuals over the years that have had dual diagnosis or co-occurring disorders, which include severe chronic mental health diagnosis and they are also on the spectrum.

The problem for those individuals in shelter is that they are often targeted and become the victims of theft, of abuse. They are picked on and they are taken advantage of by other individuals who are staying in the shelter.

They also struggle at times with impulse control, which makes it very difficult for the staff to manage them here safely in this environment. In some cases, we have had single parents with an adult disabled child. This is a barrier as the parent needs a setting where they can care for this adult

child. At times, there have also been physical limitations that require more than assisted devices and unfortunately, we are not a setting for that, and we cannot manage those individuals here. Unfortunately, there really is not anywhere to send a family unit like that for shelter within our community. There are incredible barriers for that.

When we encounter someone who is nonverbal, it can be very difficult for them to navigate the shelter in terms of communicating needs and following directions. This is due to this being a very independent environment in the shelter. Even though we have very many people who have disabling conditions, they still need to be able to manage themselves independently and cannot rely on hands-on support from any of our on-shift staff. We do not have specialized care for people that were able to do that.

We have also had instances where parents have had their own disabilities and health conditions. They are no longer able to care for that adult disabled child. And at times based on the parent's own disability, they also do not connect the child to appropriate resources, including their benefits, including services at DDD here in Bergen County.

For what we have observed, the biggest barrier is when parents have not linked that child to appropriate resources early on. This results in there being no plan for them once something happens to the parents if the family becomes homeless.

The second barrier is that there is no facility that is built to serve this population when they are homeless. Family shelters that take minor children are equally ill equipped to meet the special needs that

these individuals bring to the facilities. There is a need for toolkits and training for homeless shelter employees to help recognize the signs that someone may have a developmental disability, to provide a list of best practices and resources that can be used to help individuals in that situation and to provide DDD agency contacts in each state who can assist with these cases.

We feel very strongly that if we can begin to effectively address this issue, which is growing within our population, especially in light of COVID, families and individuals becoming displaced from moratoriums that are ending. If we can have these resources and have the attention that is needed, we would be able to more successfully serve these individuals to help get them back into housing safely and keep them there stably so that they can have a

meaningful and productive life. Thank you very much for listening to my remarks today.

DR. DANIELS: We thank Julia for sharing those remarks with us. Just in summary based on conversations that I have had with Julia and that she has had with other federal staff behind the scenes, to summarize some of the problems that she has described, there are two primary groups that she is concerned about, including youth and young adults with autism and IDD whose families are unable to care for them and in some cases the parents themselves have economic hardship, autism or IDD themselves, mental illness, substance abuse disorders, health issues or other complex needs. And a population of middle-age to older adults with autism or IDD who may have been living with their parents but then whose parents have passed away and did not have care plans in place for them.

And some of the specific challenges she named were that both groups are not connected to DD services earlier and that there are major barriers in trying to connect them after the fact if they were not connected prior to adulthood.

And some of the major challenges that she has found in the shelter environment include social and emotional skills, communication challenges, lack of self-care and independent skills, high levels of anxiety, co-occurring conditions, and vulnerability to unsafe situations with others in the shelter population.

Finally, her asks were some help with finding a way to provide homeless shelter staff with more guidance, training, toolkits or roadmaps to help identify individuals with autism or IDD, and to understand how to best address their needs and connect them to

social services and supports that could make them more successful in assisted housing. Thank you, Julia, for sharing that with us today.

I believe that Josh is away right at this moment. We have some time for discussion with the committee. If anyone has any questions, feel free to ask. You can raise your hand in Zoom.

MS. JALYNN PRINCE: Thank you. You are getting into one of our favorite areas right here. And thank you very much for the presentations that you made today. Some of the observations though - someone needs to become homeless or institutionalized to qualify for the 811 housing assistance. This is dramatic. Is HUD looking at housing navigation services paired with housing assistance that can help transition people from elderly parents' homes, so they do not

first have to become homeless? That is coming from our housing director asking that question through me.

There are so many things about housing and some of the people that we are working with that are working with homelessness are stating that it is easily 20 percent of the homeless population that happens to be individuals that are on the spectrum from what they have assessed with the tools that they have at hand, which is very concerning and we do need to work with those that do not have homes but in a way it seems like we are having the ambulance in the valley rather than putting a safe guardrail up above the cliff so people do not have to experience homelessness before they are able to transition into a home.

DR. DANIELS: Teresa, would you like to answer that?

DR. SOUZA: I am happy to answer that. I think it is important to clarify that the programs target not only people who are homeless and are in an institution, but individuals who have are at risk of becoming homeless have some form of housing insecurity or are at risk of moving to an institution when they reach adulthood, for example, and are leaving their parents' house and need a lot of services and supports to live in the community. There are many cases like that. I just wanted to clarify that the program tries to target populations, not only the ones that are already in this severe housing insecurity situation but also individuals that could potentially become vulnerable to them.

In terms of the homeless population that is in the spectrum, we do not know. We recognize that we need more research to try to understand the different needs that people

with disabilities have among people who have experienced homelessness. We are committed to try to learn more about it and do more research around that.

MS. PRINCE: Excellent. I would like to follow up with a comment too. Some of the situations about housing for individuals impacts the individual but it also impacts the families because mother and father are getting older. They are not able to take care of situations. They may be dealing with serious illnesses of their own. They are able to perhaps work with helping their adult child and securing the appropriate housing. But it is made very difficult, or it has made a tremendous burden that they do not always have help with. In some situations, parents will leave a house perhaps, but they will not ensure that there is enough money to take

care of taxes and maintenance and those types of things, which also cause homelessness.

There is a number of different ways that homelessness can come about. But there is a huge need across all economic boundaries to have options to be able to find appropriate housing for themselves or for their loved ones. How is HHS working with those things?

DR. SOUZA: Lori, do you want to comment on that? I would say on the housing side, we recognize the need for more housing assistance. As I mentioned, the resources that HUD receives only allows HUD to assist a fraction of the people who need and are eligible for housing assistance. We have income limits. In terms of your comment about different economic boundaries, I think that that is something that were limited by statute.

But I think that what can be done is better connect housing and health and that is something that this partnership between HHS and HUD is what they are trying to do. It is what we are trying to do is make sure that the connections between the supportive services and the housing work hand in hand to put people in a situation that is stable and that is in the community and that it has the supports that the person needs to live independently.

MS. PRINCE: But housing definitely is a situation that needs more than the four walls. It needs all sorts of supports.

There is another question that comes up frequently as I talk to builders that would like to get in to doing things with affordable housing that include disabilities. But there is so much red tape that it is not worth their financial investment to be able

to go ahead and build more apartment complexes where there is even a portion of the individuals there that can be with disabilities. It is very hard for a lot of these grants and for the procedures there. Can there be any work done to make certain that we could expedite these things because there are people that really want to do things but they cannot afford to in their business models?

DR. GORDON: JaLynn, I am going to interject here and move things along. Let us come back to your question if there is time. There is a number of IACC members who have additional questions. But I appreciate the point as well. It is an important point to be raised.

According to my order here, I think Dena Gassner is next.

MS. GASSNER: Thank you, Josh. I just wanted to express that living in poverty in and of itself is a trauma. So many autistic people who are living on SSI, some even on SSDI have such limited income and some of these housing programs - I tried to apply for one for the elderly actually asked me to submit a co-signer and for government-supported housing, I think that is an outrageous request. But I did want to say that I appreciate all of the information we got. But it suggests to me that we really do not know the level of housing issues as it affects specifically autistic people. Much of your statistical information was more broadly applied.

My question is first of all, can we get some more specific information exclusive to autism. And the other thing I am very concerned about as she expressed about New

Jersey as the same in New York. If you did not get a DD diagnosis even though it was not available to you before the age of 18, many of these programs are not available to you. The DSM-V recognizes that autism could have been present historically but unrecognized. Yet we do not see a policy change to support that reality. How can we help housing people to be more sensitized to that, more caring, less disrespectful to people? The way I was treated was really bad and I have big girl panties. I think for some more vulnerable people who are at the brink of homelessness, this kind of treatment becomes a little abusive. How can we help to facilitate enhanced understanding as a body and as a community?

DR. SOUZA: I am sorry about your experience. I am not sure I know the specifics to be able to address it. But in

terms of the limited research that is specific to people with disabilities with autism, we are trying to do more, and we are in conversations with other agencies with Susan and trying to find ways with linked data and other forms to try to better understand what are the different types of disabilities, what their needs are in HUD-assisted programs, and what are the barriers to receiving housing assistance and being successful in housing.

MS. GASSNER: Thank you.

MS. GERHARD: Ms. Gassner, if I could maybe just jump in too. I think the question that you raised is really important. Increasing people's awareness of the needs of people with autism is really essential. We experienced similar situations as sometimes when emergencies/disasters occur and helping to train up emergency staff and our assistive

technology programs have been quite instrumental in helping to increase education about the needs of people with autism and what assistive technology might be available to help engage with them.

Oftentimes, not oftentimes, but sometimes people are noncommunicative but yet they are very capable of communicating if they have some devices to be able to interact with people who can communicate verbally.

So we found that those have been strategies. But we know we have a lot of work to do and will take all of us to continue to increase knowledge around how we can better interact and understand people with autism and be responsive to their needs.

MS. GASSNER: Thanks for your efforts.

DR. GORDON: Morenike, you are next.

MR. STEVEN ISAACSON: Hi everybody. This is Steven. I will read Morenike's comment for

her. As an autistic adult of color like many in our community has experienced homelessness. I wholeheartedly agree with many of the barriers that have been shared. These settings are absolutely not equipped for our needs. First, sometimes it is nearly impossible to get helped in the first place because there is a bureaucratic barrier unless you know where five million documents are, which you might not have in a central place, when you have executive functioning issues and might not have always had access to all your own legal and medical documentation. That is a challenge. If you are a transgender nonconforming and your deadname is all over your documents, that can also be a problem.

The places are also a sensory nightmare. Loud, bright, horrible smells. Being forced to have certain roommates and/or chores,

being forced to engage in certain activities, having to wait extended period of time for an overburdened case manager to try to figure out how to help you. Only to be handed a huge packet of updated resources and instructed to call this place or go at this time to apply to that place. There are generally not alternative means of communication available to you to help navigate a cognitively inaccessible process.

Your stimming, vocalizations, and/or movements can often be misunderstood by others as violence, as you being inebriated, not to mention you might find yourself easy prey for predators in these programs. It is extremely easy to be physically, verbally, and/or sexually assaulted in these safe places. For many people, it might be safer just to couch surf or to engage in survival

sex to have a place to crash that night or to stay with your abuser.

There is little to no understanding of the unique needs that might exist in the autistic population and there also seems to be little effort made to address them. This is also exacerbated if you are from marginalized racial, gender, or sexual identity. It is already traumatic to have instability in one's housing in the first place. These situations often re-traumatize you.

DR. GORDON: Thank you, Morenike, for those comments. Any reactions from our speakers?

DR. SOUZA: I could start by saying that we recognize that people with disabilities and people in the autism spectrum have different needs, have higher needs. One of the studies that I did not share today but I

could mention. We are doing a study that is looking at search assistance, successful approaches in the housing search process for people with disabilities, trying to identify what are the major barriers for people with different disabilities and coming from different settings and having other different situations and trying to understand what are successful approaches that help them apply for housing assistance, look for housing, search for housing, visit units, identify the units, and then move into units. We understand that each of the steps present barriers and we are trying to learn about where the resources and where communities have been successful at transitioning people into assistive housing.

I believe the partnership that Lori was talking about is also an important effort in that direction of identifying specific needs

and connecting the services and housing side. I think that the new allocations - the way that new programs are now setting aside resources for housing search is a recognition that certain populations need special help in applying for housing, in looking for housing, and in moving into housing. That is something that - it is good to see that we are getting the resources to be able to do more of that. The Emergency Voucher assistance is doing that. The Mainstream Voucher program just issued a Notice of Funding Availability (NOFA) last week that is giving an extra \$500 for PHAs to help with the housing search process and with incentivizing landlords to participate more in HUD programs. I think that all those efforts hopefully can make things better.

DR. GORDON: Ivanova, you are next.

MS. SMITH: This is Ivanova Smith. My question is are there thoughts about looking at the policies that make shelters inaccessible for people and is there a way that we can look at allowing - making it so that people not being - it sounds like some discrimination is happening like indirectly. How do we address that with the shelters to make sure that there are ways to modify things to accommodate autistics? Thank you.

DR. GORDON: Thank you, Ivanova.

DR. SOUZA: HUD has the Fair Housing and Equal Opportunities Office that is devoted to enforcing fighting against discriminating, fighting discrimination against people with disabilities. I know that the case of people with autism is something that they also address. It is something that - I have seen them working on cases like that and finding

resolutions and ensuring that there is no discrimination in the housing market.

MS. GERHARD: I would just add to that. ACL funds protection and advocacy organizations in every one of the states and territories that are available to support people with disabilities who may be feeling as though they are not being treated appropriately or being discriminated against. They are there to help and support you through those processes.

In addition, through the Older Americans Act, we also have a network of elder rights services throughout all the states and territories that are available to help support individuals who might be experiencing discrimination. I would offer those resources too.

DR. GORDON: Scott Robertson from Department of Labor.

DR. ROBERTSON: Thank you, Dr. Gordon.

Thank you, Teresa and Lori. I am so bad with names, the person who presented as far as by video from New Jersey. I had a quick comment and just a couple of brief questions. The comment was on the toolkit that was mentioned earlier in the presentation as far as the possibilities on homelessness and autistic people and other folks with developmental disabilities. NIMH funded with a research grant several years ago, research that led to a toolkit for health care access for autistic adults. It is at autismandhealth.org. It is like a portal site that is set up for both health care providers so service providers are one-half of the page and then the other half that you can connect for resources is for autistic adults and allies as far as accessing the health care system. I am wondering if that is maybe something that ACL

and HUD could potentially explore interagency with your sister agencies like ASA as far as the cross connection especially since ASA interests us because of the employment focus because obviously connecting and having stable housing just like transportation is really cross connected to being able to maintain and attain gainful employment.

I just also wondered on the data end. I am a big fan of having better quantitative and qualitative data and a lot of our data on homelessness and autistic people comes from the United Kingdom rather than here. Lori and Teresa, is most of the disability data that we do have in housing over at ACL and at HUD - is that mostly cross disability or maybe broader development disability or marked as cognitive disability? Do we have anything that is autism specific in the data on housing and homelessness? And do we have

anything in the data that interconnects back to employment and workplace learning like for a pass for folks?

DR. SOUZA: Thank you for that resource, Scott. We will look into that. It is great to know about it. In terms of more granular information about data on disability, of course there is the American Community Survey, the American Housing Survey. Those surveys include six questions about disabilities that give us a little bit more information about people that have cognitive disabilities.

Also, with the linked data with the health survey, that is a great opportunity to look in more detail. I think that right now the first studies were really looking at disabilities in general. But I think that the survey really presents an opportunity to look more closely at children with autism, for

example. That is a question that the National Health Interview Survey has. We could do more research there. And we hope researchers would access the data. The data is available to researchers and researchers with more expertise in that area are welcome. We encourage them to access the data and help us understand more what the needs are, what the extent of people in the autism spectrum in HUD assisted housing.

DR. GORDON: Thank you.

MS. GERHARD: I would just add. Scott, thank you for sharing that toolkit. Yes, we would be absolutely very interested in partnering up with DOL and continuing to build our toolkits and provide supports and resources as we can.

On the data piece, I am going to have to consult our colleagues that work in our Administration on Disability to get you a

specific answer on that question. But one of the things that I will share is that we also fund the University Centers for Excellence on Developmental Disabilities who are all working on different types of research in addition to the work that Dr. Reichard mentioned with NIDILRR that is funded to continue to learn more about people with disabilities and how we can better support them. I would offer that as a response. We look forward to continuing to work with DOL.

DR. ROBERTSON: Thanks, Lori. We appreciate our partnerships with our sister agencies.

DR. DANIELS: I would like to just add, Scott, that the Federal Interagency Workgroup on Autism is also happy to help facilitate on that end too.

DR. ROBERETSON: Thanks, Susan.

DR. GORDON: Sam Crane.

MS. SAM CRANE: Hi everyone. Sam Crane. I wanted to follow up on the questions about enforcing accessibility in public services, including homeless shelters. I am a little bit concerned that simply using the FHA would not be adequate to address some of the more structural barriers that we see in shelter programs without a fundamental alternation. There are some things that make shelters programmatically inaccessible to autistic people as Morenike and some of our presenters were pointing out. They are not particularly safe for autistic people. They cannot accommodate personal care assistance or home and community-based service providers coming into the shelter to assist people. The shelter staff do not provide services themselves. Someone who has technology might not be able to access the shelter because it is so likely to be stolen.

I really want to ask that we also think about Title 2 to ensure that localities - if they are going to be providing shelter services to the general population might really have to explore options to provide equivalent programs to people with disabilities who really cannot access a homeless shelter, including Housing First approaches and getting people into individual housing as soon as possible so that people do not spend significant time in shelters that are just not going to work for us.

DR. GORDON: I believe now we have a comment or a question to be read out loud. Steve.

MR. ISAACSON: Hello. This question is from Lindsey Nebeker. In the overview about the subsidized rent program and vouchers, you mentioned the age qualification to participate is 18 to 61. Why is the age

cutoff currently at 61 and is there a strategy being created to provide support for individuals over the age of 61?

DR. SOUZA: Yes. HUD - at 62, HUD considers that target population, the population of older adults. We have a lot of programs that target that population. We have Section 202. In Section 202, supportive housing for older adults. There are a lot of other services that can be provided. We have service coordinators. And across HUD programs, we serve older adults with disabilities and older adults in general as it was shown in one of the slides. It is not a population that is not served but we have specific programs by statute that are targeted to older adults. We have specific programs by statute that are targeted to what we call non-elderly people with disabilities so the people that are 18 to 61 years old and

have disabilities and need supportive housing.

DR. GORDON: Thank you for that. Jenny and then Yetta and then we will come to a close just in time for our break.

MR. ISAACSON: Jenny requested that I read her comment for her.

DR. GORDON: Please go right ahead.

MR. ISAACSON: Thank you for reading my question and to the speakers for the work that you do. My question is related to displacement due to natural disaster events such as tornadoes, hurricanes, fires, and power outages, et cetera. Are there toolkits or protocols in place to assist autistic people and their families who are displaced due to these events?

There is a second part. Please share any information that your teams have on following up with autistic people and their families to

transition into temporary housing during these events and then thereafter into more permanent housing. Thank you.

MS. GERHARD: Maybe I can start, Dr. Souza. Thank you for that question, Jenny. Assistive technology programs work very closely with the emergency management agencies to help provide training and technical assistance to the staff that work in those programs. We know there is more work to do but to be able to better interact with people with autism and provide the appropriate supports. We can get back to Dr. Daniels with some additional information that we use in that approach.

And then I think your other question was about helping people transition into housing when they are in an emergency. I do not know if Dr. Souza has anything to mention. But I do know that the aging and disability

agencies that ACL funds and our regional offices and staff are very engaged in responding to emergencies and trying to assist people to get some temporary housing if they are impacted by emergencies and temporary services and help support them on the path back to stable housing and services.

Dr. Souza, I do not know if there is anything more you might add from the HUD perspective.

DR. SOUZA: I will have to talk to my colleagues and provide - I am sure that there is a lot that HUD does. HUD in cases of disasters has the CDBG disaster assistance that is authorized by Congress whenever there are situations like that, and HUD provides assistance to local governments to address the need for housing assistance after a disaster. And that assistance has rules that allows the funding to move more quickly. But

I will have to go back to my colleagues at FHO and the program offices. I am sure that we have training and guidance to help the local agencies that administer HUD programs to address the needs of people with disabilities and in the autism spectrum during disaster emergency situations. I will get back to Susan with some of the resources that we have.

DR. GORDON: Thank you. Yetta Myrick.

MS. MYRICK: Thanks, Josh. Thanks to all the speakers today. No one can deny that there is a number of challenges as it relates to the autism community and housing. However, as I listened to Ms. Orlando, I was thinking about the individuals and families who were not connected to resources. My mind immediately went to the families who are supporting autistic adults who may not have been diagnosed. Their families basically

slipped through the cracks. No one was there to help them to access resources to get diagnosed in the first place, which I think is contributing to why they cannot get these resources as adults. If you have resources, if you have the money, fine. You can get a diagnosis in a different circumstance even though it should not be. But that is unfortunately how these things go.

I really appreciate her comments about the training and the toolkits that support these providers. I also want to take this opportunity to say that really more work needs to be done to train and educate providers who serve individuals who are often marginalized. When we think about doing research and who are we doing this research on, we could talk about the specific agencies. But I think oftentimes we do not necessarily think about homeless population.

We do not think about necessarily families who experience abuse. And of course, as COVID have come up, we know that a lot of people that might have been mandatory reporters who could say there is something going on in a specific household. We are not necessarily reaching these individuals and families. Who knows what the outcome is going to be after COVID?

I just want to say that in the work that I am doing in DC, there is specific interest from the DC Child and Family Service Agency and then we also have something called Family Success Centers that are located in DC's Wards 7 and 8 that serve families that are lower resourced. And they also have an interest in autism.

I think there is a need for autism knowledge and training, and we just need to think more strategically about how we can

reach out to these groups, include them in the research and the work that we are doing to really uplift the community as a whole. Thank you, all, again for presenting and for allowing me to share my comments.

DR. GORDON: Thank you, Yetta. We do appreciate the active conversation between the IACC and our presenters. We also appreciate the opportunity for the presenters to talk about the programs and for the public to hear about these programs. Clearly, we have a lot of work to do. But we also have a lot to offer. That is really an excellent demonstration of what the IACC is all about.

We are now right on time, which will allow us to take a 15-minute break.

(Whereupon, the Committee members took a brief break starting at 2:40 p.m., and reconvened at 2:55 p.m.)

DR. GORDON: We are about to start a significant section of our meeting where we are going to have lots of discussions amongst the IACC members. Since our last meeting, I have been getting lots of questions and comments about the role of various IACC members and asking about what our charge is and what is the purpose of this meeting. I realized that that is something we probably should spend a little bit of time thinking about. I wanted to reiterate and clarify what we are all trying to do here and that will serve as a good starting point to then the next section of our meeting today that is going to be about business that we need to attend to, the Strategic Plan and the Summary of Advances but also lead into tomorrow's meeting where we are going to have a panel discussion on communication because what I really want to talk to you about is the

communication amongst all of us here on the IACC.

Just to remind you all, Congress has mandated specific duties for this committee and the Autism CARES Act of 2019. We are charged with monitoring federal autism research, developing a Strategic Plan and a Summary of Advances for that research, making recommendations to the Secretary of Health and Human Services regarding federal autism activities writ large beyond just research, much as we just did in the last segment where we talked about housing policy and the things that the housing policy folks should take into account when considering individual families and communities with autism.

In particular, the Strategic Plan for Research, which covers autism research - sorry. I should say the overall Strategic Plan, which covers autism research services

and relevant policies is one of our primary mechanisms to make recommendations to HHS and to other federal agencies. Much of our team during this meeting and others will be devoted to completing these reports.

In addition to the Autism CARES Act, there are other federal laws that govern our conduct, including the Federal Advisory Committee Act or FACA. These laws are meant to ensure that IACC activities are objective, transparent, and accessible to all. It is my responsibility as chair of this committee and Dr. Daniels' responsibility as the executive secretary to guide the IACC in meeting these obligations and it is a responsibility that both of us take very seriously.

We also know that you all take your responsibilities very seriously and we greatly appreciate each and every one of you on the committee for volunteering your time

to serve. We understand that it is a substantial commitment in time, in energy, and we have to acknowledge in risk being out here talking about issues of importance to the autism community. We want to make sure that this is a worthwhile experience for you and that we make sure that your voices are heard across all of government.

On our end, we are doing our best to make that happen, making adjustments to the meetings and our processes in order to optimize this experience for everyone and to give everyone their full voice.

One obvious example of that is the fact that we have had to adjust to holding these meetings fully virtual during the pandemic. That has been new to us. It has been new to us as a group even if it has become all too familiar for us as individuals in the pandemic environment.

Another adjustment. This is the largest committee that we have ever had, and we have had to adapt to accommodate that. But it is not just technology and it is not just size that sets this particular group apart from previous iterations of the IACC. We have also made significant efforts to broaden the representation on the committee, bringing in both additional federal agencies and additional members from the autism community writ large. Specifically in response to input from a number of constituencies, we are exceptionally pleased that our self-advocates now reflect a broader part of the spectrum that is autism. You all, advocacy members, federal members, research members, all the members of our committee were selected based upon the lived experience and the expertise that you bring to the table. The committee is designed under the CARES Act to bring

together autistic adults, parents, family members, leaders of research, advocacy, service organizations, as well as officials from the federal agencies involved in autism research and disability services.

But as many of you have pointed out, we each serve more than one role. Many of us are persons on the autism spectrum and/or the parent of a child on the autism spectrum and/or a federal agency head and/or a researcher and/or an autistic adult or parent. It is the role and charge for each of us to bring our diverse points of view and expertise to this table and to do two very important things. Share from our own experience and perspectives and thoughtfully listen to others, including committee members, speakers, and members of the public who share their comments.

After we have shared and listened as a committee, it is our job together to identify needs and to look for common ground where action may be possible and to come to consensus on recommendations and advice to the secretary so that those actions can be taken out. If too much time is spent sharing and too little listening or learning, then our focus becomes out of balance. This can lead to polarization and lower the probability of finding that common ground and moving forward. Coming to consensus will require us to be willing to understand the perspectives of others, to step away from the polarized edges of an issue and move toward the middle so that we can make progress.

I want to ensure every person on this committee and all of our public commenters - I want to make sure that they feel comfortable sharing their experiences during

these meetings. We have heard over the years of the challenges that people in the autism community are facing in their day-to-day lives whether that is managing the effects of a co-occurring condition or try to access services like we heard about this morning for themselves or for a family member. Given these issues, it is inevitable that our discussions will get emotional and stressful from time to time. It is inevitable that you may strongly disagree with someone's comments from time given the range of opinions and experiences represented here. But it is our job, as committee members, to listen and to take all comments into consideration.

Importantly, in order to listen, we cannot make assumptions another person's experience. We must realize that we all feel many of the same things, frustration, anger, passion about our views, and indeed

nervousness about sharing these personal experiences; therefore, we want to honor each person's willingness to share and treat that willingness with respect. When it is your turn to share, using a respectful tone is helpful to those who are listening even when expressing issues where we feel strongly. When it is your turn to listen, please remember that we are all here for the same reason. We all care deeply about improving the lives of individuals with autism, their families, and communities. We all want to do the right thing. This is true for both committee members and public commenters. But we also have different communication abilities and styles and we may not always know how to say things in a way that others can appreciate. When you listen, remember that even when you are disagreeing with what is being said, that person is really on your

side. The commenter, the speaker, the sharer is on the same side of trying to help. When you approach listening from that perspective, hopefully that will help us to not get caught up in controversy and instead work towards consensus.

Finally, I want to acknowledge that with the greater representation from a broader part of autism around our table, it may be challenging for all of us to understand and to be understood. Speaking slowly and using plain language can help. So can using sensitive language that avoids terms that might demean others. But of course, we do not always know what another might take as demeaning. If anyone at the table misses something or hears language that they find demeaning, speak up and remember again that we all have good intentions at this table. We are not trying intentionally to exclude or

demean anyone. Simply asking for someone to repeat themselves, to speak slower, or to use different language will help us all understand each other better and work better together.

It is my hope moving forward that we can keep all of these things in mind even though we are individuals with different points of view. The goal of this committee is to create a collective voice. Above all else, it is our obligation to listen to others as they share their experiences and to learn from each other. We are all still learning, and I want to emphasize how much I value this opportunity to learn from all of you.

With that introduction, I am going to turn things over to Susan for the National Autism Coordinator update and then she will follow on with the IACC Committee business. Thanks for your attention.

DR. DANIELS: Thank you, Josh. I am ready to give you the National Autism Coordinator update. Thank you so much, Josh, for sharing those sentiments and I also share those points of view and would encourage everyone to work together on this committee so that we can be effective.

For our update today, I have some updates to share with you from the White House and Global Policy as well as some US Federal Advisory Committee updates. These are here in order for the committee to be able to hear some of - a selected number of updates from around the community that might help you in your work as a committee member.

First from the White House, in March 2022, I wanted to make you aware that President Biden appointed 21 new citizen members to the President's Committee for People with Intellectual Disabilities. This

committee is managed by the Administration for Community Living and advises the president and secretary of HHS on issues related to people with intellectual disabilities. Some of you may be interested in following their work and we will be posting their meetings on our website as well if you want to see that.

On March 15, 2022, you all may be aware but President Biden signed into law the \$1.5 trillion Consolidated Appropriations Act of 2022 that sends federal agencies \$14.5 billion for special education and \$6 million for home and community-based services.

On April 2, President Biden issued his 2022 Presidential Proclamation for World Autism Awareness Day that you may be interested in reading. In that proclamation, he reaffirmed his administration's commitment

and support for opportunities for people on the autism spectrum and their families.

Also this month, the United Nations observed World Autism Awareness Day. In his statement, the UN Secretary-General Antonio Guterres affirmed the UN's support of the rights of people on the autism spectrum to fully participate in society in accordance with the UN Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development. The Secretary-General acknowledged that COVID-19 has exacerbated many inequalities and highlighted the critical importance of community-based support systems, such as systems for inclusive education.

Following that, the UN's special event this year took place last week on April 8 and the theme was Inclusive Quality Education for All. It was organized by the UN with the

support of civil society partners including the Autistic Self Advocacy Network, the Global Autism Project, and the Specialisterne Foundation. We have also provided the link in case anyone wants to go back and watch that.

We also wanted to bring to your attention that the World Health Organization or the WHO has launched its Online Caregiver Skills Training package. In advance of World Autism Awareness Day, this online training was announced, and it is for caregivers of children with developmental delays and disabilities. And this program has been piloted in more than 30 countries and teaches skills that can be used to promote the well-being and development of children. The online training includes recorded sessions on a variety of topics and also has information to help caregivers improve their own well-being.

In April, WHO is going to be launching companion manuals for facilitators of in-person trainings. Lastly on this, I would like to acknowledge that this program was developed in collaboration with Autism Speaks.

Another update I wanted to bring you was on the Canadian Autism Spectrum Disorder Alliance. I was able to be a part of their meeting this past week and wanted to share with you a little bit about what they have been doing. CASDA is an alliance that was formed in 2007 focused on addressing the issues that autistic Canadians and their families face across the lifespan and has been in the forefront of calling for the creation of a comprehensive national autism strategy like our Strategic Plan addressing funding and policies for the autism community in Canada.

Over the years, CASDA has been doing a number of consultations with stakeholders bringing in stakeholder input and in 2019, they issued a Blueprint for a National ASD Strategy. And in 2020, they issued a Roadmap for a National Autism Strategy that focused on the process and timeline for that national strategy. In the future, they hope to form an advisory committee with broad representation from across all the provinces in Canada.

CASDA also oversees the national Ready, Willing & Able inclusive employment program with Inclusion Canada. And that might be of interest to some of you who are interested in employment.

As I said, they recently held their 8th annual Canadian Autism Leadership Summit on April 4 and 5 and they covered a number of themes, including equity, diversity, and inclusion in policy development, including

indigenous and other underrepresented populations. And some of the other topics they covered were employment, housing, non-speaking autism, and the experience of adults diagnosed in later life.

The meeting also included a panel on the discussion of autism strategic plans from around the world, including perspectives and lessons that have been learned. And the countries and organizations included were the US, UK, Malta, Autism Europe, and the Public Health Agency of Canada. I was able to share with them the role of the IACC and our IACC Strategic Plan in shaping federal autism policy in the US. The links to all of that are on this slide.

Next, I would like to share some updates from US Federal Advisory Committees that are working on disability-related issues. First, the Federal Partners in Transition. They

recently held a meeting on March 17, 2022. And their meeting featured presentations from the Department of Labor's Office on Disability Employment Policy and included representatives of the Center for Advancing Policy on Employment for Youth or CAPE-Youth. You may be interested in that.

With the Interagency Committee on Disability Research or the ICDR, they recently published their 2021 ICDR Accomplishments Report and this report highlights research throughout FY2021. Also, the ICDR Executive Committee held a meeting on February 24 where they brainstormed and asked for input on how the ICDR could shape its focus on three new areas, which are equity, disability data and statistics, and COVID-19 and disability rehabilitation research.

The National Council on Disability, which is a federal agency, importantly published in February 2022 a new Health Equity Framework for People with Disabilities and they held a virtual meeting to share this with the public. This framework is a blueprint that is going to help policymakers to address disparities and inequities within disability. It included input from National Disability Advocacy Organizations.

There are four core goals or pillars to this framework including the designation of people with disabilities as a special medically underserved population so to establish that this is a disparity population. Standardizing and implementing comprehensive disability clinical care curricula to train providers on all disabilities across the lifespan, which also relates to the IACC's interest in training

for adult providers. Requiring accessibility of medical diagnostic equipment and improving data capture by including indicators of disability status in all public health surveillance systems so any kind of tracking and surveys that are done and capturing data across the lifespan. You may want to check out the framework and the link is provided here.

Also, the National Council on Disability published a report on Medicaid Oral Health Coverage in Adults with Intellectual and Developmental Disabilities. You may want to check out that report.

And update on the RAISE Family Caregiving Advisory Council that is managed by the ACL is that they recently held an open call for nominations for this council that just closed this past Monday on April 11. They are going to be adding up to 15 non-

federal voting members from several different groups, including family caregivers, older adults who need long-term services and supports, individuals with disabilities, health care and social service providers, providers of long-term services and supports, employers, professional workers, state and local officials, accreditation bodies, veterans, and other kinds of experts. You can be watching for an announcement in the future about who will be joining this important council.

Also, I have some updates from the Interdepartmental Serious Mental Illness Coordinating Committee as some people on the autism spectrum also have co-occurring mental illness issues. Some people may be following this committee as well. They will meet on April 13, which is today. They may be meeting right now. And the full agenda for this

meeting is provided on this link and it is on our website as well. And the agenda includes a presentation on how state courts address mental illness and several working group reports from various working groups that they have in ISMICC.

And lastly, I wanted to share an update from the Disability Advisory Committee of the Federal Communications Commission. Currently, they are seeking public feedback on the implementation of the Twenty-First Century Communications and Video Accessibility Act. They are preparing a biannual report that is due in October. They are asking for comments on a number of different topics. I have provided a few here, including compliance with mandates for telecommunications and advanced communications services or ACS, equipment used with these services, Internet browsers built into mobile phones, and to be

accessible and usable by people with disabilities. In addition, they are also looking for information on barriers to access to new communications technologies for people with disabilities. If you are inclined to provide feedback, feel free to access that link.

That concludes my report. If there are any questions, I am happy to answer them, or we can move to the next section.

DR. ROBERTSON: Thanks, Susan, for sharing that. Could I add one other committee that you might want to consider monitoring? HHS - your Office of the Assistant Secretary for Preparedness and Response. They recently launched the National Advisory Committee on Individuals with Disabilities and Disasters. It met jointly last month with the committee that is focused on that context for seniors. They met together. I assume that the

Committee for Individuals with Disabilities will be meeting separately in the coming months. That might be of interest especially since not only does that focus broadly on disasters but also that is inclusive from my understanding is for medical and health-related ones such as what we have right now with COVID-19 in preparation for future potential public health emergencies including if there are other epidemics or pandemics that could occur in many years to come. It is of interest and importance for accessibility for folks with developmental disabilities, including autistic people.

DR. DANIELS: Yes. A very important topic. Thank you for sharing that update and we will include it in our list for next time. Thank you for highlighting that. If anyone else on the committee is on another disability committee that I did not highlight

and you want to share an update, feel free to join.

DR. ROBERTSON: Thank you, Susan. I will get you the URLs from that.

DR. DANIELS: Thank you. I would appreciate that. Anyone else? Thank you. All the links are here and we have things on our website. But if you have any questions, feel free to send us an email.

DR. DANIELS: We will move on to the next section, which is IACC committee business. I will kick this off. For committee business today, I have a few different issues to discuss. One is Autism Awareness Month to give you a little bit more detail, some upcoming meetings of the IACC, a Strategic Plan discussion, and then we will be talking about the IACC Summary of Advances.

As you all know, April is Autism Awareness Month. I would like to invite

everyone to join us on April 27. OARC and the NIMH are hosting a special event for Autism Awareness Month that is called Animating the Future for Exceptional Minds. We are going to be hosting a wonderful organization called Exceptional Minds on the West Coast that trains young adults on the autism spectrum for careers in animation, digital arts, and entertainment. They will be sharing some of their animation. They also will talk about their work and will be doing an interview. We would love to have you join us for that.

Also, check out our new April 2022 edition of the OARC Newsletter. We just sent it out yesterday and it is also posted on our website. We have several interesting and important updates from around the community that you might want to see.

In addition, our office has an Autism Awareness Month page that we have used to

collect information from across federal agencies and other organizations that are hosting special events during this month. We would welcome you to look at that and check out what is going on around the country and even some international events.

In terms of upcoming IACC meetings, you will be receiving emails but wanted everyone to know. Our current plans are to have a Strategic Plan Workgroup Meeting that will be virtual on July 13-14, 2022. I am sharing some of these updates before we get into discussion so we do not run out of time at the end.

Also, that the IACC Full Committee Meeting that is coming up next is going to be on October 26 and it will be either virtual or hybrid. We do not know yet. But we will keep you informed of that. Please check our website for other updates.

Let us start with the IACC's Strategic Plan discussion that we have planned for today. This is the discussion of our timeline and process. I wanted to share with you that the timeline so far on the Strategic Plan is that in October through November of 2021, our office collected feedback on the Strategic Plan from the general public through a request for information. We presented these results at the January IACC meeting and discussed them there.

And then in January 2022, IACC members were able to discuss several aspects of the Strategic Plan in our discussion. And we decided that we were going to be adding a section to the upcoming plan that addresses the impact of COVID-19. And members said that you wanted that to be very much forward facing and that we would also add a cross-cutting objective to address disparities and

extend the timeline on the current budget recommendation by five years. Those were some decisions that we made at the last meeting.

From November 2021 to March 2022, our office also had a survey that we sent out to IACC members to collect your feedback on what you want to see in the next Strategic Plan. I am going to walk us through that today.

We are going to talk about that today and what happens after this meeting is that in April through June, OARC staff are going to take the input that we have received and prepare a draft of an updated Strategic Plan incorporating your feedback and the feedback of the community that we have received. And our plan is to also share that in July.

In May, we plan to send out another survey to the IACC to ask you for feedback on the mission and values statements to see if

you have any updates for those as well. Be watching for that.

Our plan is to send out the first draft of the Strategic Plan to IACC members in early July prior to the July 13-14 meeting. And that meeting will be open to all IACC members. You do not have to have a specific membership on the Strategic Planning Working Group. But any member can come to that meeting. We know some people maybe on vacation because it is in the summer. But we also will have a survey monkey survey that you can use to fill out any feedback that you want to share.

We will ask for global feedback because, as you can imagine, to do 44 sets of line edits is not going to be an effective strategy for getting this done. We are going to give you an opportunity to look at all the different sections and give us your global

comments that we will try to incorporate into the draft.

During July through September, our team will be revising that draft based on whatever feedback we heard. In October, we will be meeting again with the goal of approving a draft of the Strategic Plan. We hope that we can get it into shape where it would be able to be approved. If not, we would have a Plan B to continue discussions until we can get it approved. But I know that the whole committee of course is also eager to put together a Strategic Plan because once it is in the hands of federal agencies, it can be used. We do want to try to move that process along but we also want to be sure to incorporate all the feedback that we hear.

In November to December 2022 if things go successfully in October, we will be preparing the approved draft for publication.

That is the timeline as we see it now but we will continue to give you updates if that changes.

Now, we have some time to talk about IACC member feedback that we received in the survey monkey survey that we sent out to members. And what I would like to do is talk through all the feedback once through and then at the end, we can go back and talk about each question area separately and get your comments. But I want you to see the full picture of it before we start the discussion.

One of the first questions that was in the survey was on the title of the Strategic Plan. We asked the committee what you would like to see us use as the title. The current title is the IACC Strategic Plan for Autism Spectrum Disorder. In the old older days, it used to be called the IACC Strategic Plan for Autism Spectrum Disorder Research. But in

2014, the CARES Act changed the Strategic Plan and required it to address issues related to services and supports as well as research and by extension policy. It is a broader strategic plan now. The last name was that middle one that is on this slide.

But we proposed a couple of ideas either going with the title that we had before or the IACC Strategic Plan for Autism Research, Services, and Policy and also left a blank in case anyone wanted to provide an alternative.

Of the feedback that we received, it looked like we had 28 votes toward the IACC Strategic Plan for Autism Research, Services, and Policy and a few votes for some of the others. It looks like the majority of the committee wants to go ahead and change the name to make it a little more clear about the scope of this Strategic Plan.

Some of the general overview comments that we were able to put together from the feedback - by the way, for anyone who is watching this online, if you want to see a summary of the themes that were pulled from the surveys that were given to the IACC members, that document is online as well as the full text of the information that we received.

The general comments we received included an increased need for inclusion in research, as well as including community-based participatory research, addressing disparities, addressing the entire spectrum and the entire lifespan, emphasizing actions and solutions where possible, emphasizing commitment to equity and elimination of stigma and discrimination. There were some comments on language considerations, which we summarized as moving away from deficits-based

language and towards more neutral and strengths-based or inclusive language while also balancing the importance of maintaining accuracy when referring to issues that may be scientific, medical, or clinical in nature.

To share some of the themes next from Question 1 on screening and diagnosis, there were a number of themes that we pulled from the comments, including biomarkers, universal screening, availability of and access to services, disparities, detection and intervention or support before behavioral differences are apparent, telehealth approaches, tools that include milestone tracking, translating research findings into practice, medical practitioner training, caregiver engagement, and systems navigation.

In Question 2, which is focused on the biology of autism, the themes that we were able to pull out were biology across the

lifespan, co-occurring physical and mental health conditions, sensory and motor differences, cognition and behavior, brain function and connectivity, sex differences, including the female protective effect, human neuroimaging studies, longitudinal studies, translational studies, the microbiome, and the ethics of human studies.

On Question 3 that is focused on genetic and environmental factors, some of the themes were interactions among multiple genetic, epigenetic, and/or environmental factors, large genetic and epigenetic studies, inclusion of diverse populations in genetic studies, deeper understanding of genetic variants, common factors that impact both autism and co-occurring conditions, modifiable environmental factors including maternal diet, influence of genetic factors on response to medications and interventions.

On themes that were pulled from Question 4, which is on interventions, we saw that there was interest in medical, behavioral, educational, and complementary approaches, interventions that focus on improving the quality of life, personalized and culturally-competent interventions, naturalistic developmental behavioral interventions, pre-emptive intervention for challenging behaviors, parent/caregiver-mediated interventions, communication tools, alternative and augmentative communication, or AAC, outcome measures and biomarkers, community access to information about safety and efficacy approaches, telehealth approaches, and technology-based interventions.

On Question 5, the themes were scaling and implementing interventions, health system integration, community-based service

delivery, identifying and reducing disparities, family dynamics, support, and engagement, also parent and sibling perspectives, services workforce training and development, person-centered services, systems navigation, Medicare, Medicaid, and Social Security policies.

On Question 6 on lifespan, some of the themes were adult diagnosis, transition age youth and young adult outcomes, employment, housing, safety, family dynamics and trauma, community inclusion, aging autistic adults, and how issues such as those that I just listed act as social determinants of health.

In Question 7 that is on infrastructure and surveillance and by the way, in some of the feedback we have been receiving from the public, it sounds like there is some confusion about surveillance. We are not talking about surveilling people in their

homes or anything like that. That is epidemiology and looking at prevalence. Improvement and expansion of systems that track autism prevalence, public-private partnerships, data banks and biobanks, privacy guidelines, adult prevalence studies, community outreach and dissemination of information, research and clinical workforce development, and support for early career researchers.

There were two special topics that we asked about, which were COVID-19 and disparities. On COVID-19, the feedback we received was that you would like to see a section on COVID-19 cover how we are going to mitigate increased risk of COVID-19 in autistic individuals, what the impact has been of disruptions in school, access to interventions and services, mental health supports, the impact of switching to remote

school, work, health care, and services, and the impact of the pandemic on the autism research community.

And the last topic that was discussed in this survey was disparities and some of the feedback that you gave us was that you would like to see a focus on reducing disparities in diagnosis and access to services and supports, including the categories of race and ethnicity, gender, sexual orientation and gender identity, disability status, socioeconomic status, and geographical location. You also would like to see increased inclusion and engagement with underserved communities, increasing diversity in research and clinical workforce, and also increasing cultural competency of educators, medical practitioners, and other service providers.

I will stop there and go back to where we started and let you all have some time to discuss what was shared. Does anyone have any comments? Hopefully, you were able to jot things down if there were things that you wanted to bring up.

MS. GASSNER: Hi. I saw a couple of things that I think are painfully missing and I hope we can address this. One is trauma-informed care. I think we need a much more around trauma-informed care.

I would suggest that we might also want to address something related to pay for direct support persons in terms of policy.

I would suggest in terms of community-based services that we in some way acknowledge or recognize that there are very few autistic adults who do not require some level of support but that can be monetized and individualized based on individual needs.

And then lastly, the other note I took that I think is a topic we may want to discuss is the intense efforts and desire to look at gender as a binary problem for study and research. My concern is being a social worker that is in the field, what we are finding is that autistic males who present less externally who present more if you will under what we are calling the female phenotype are experiencing the same delays in diagnosis and the same lack of supports and services as what we projected that autistic females experience. When we look at gender, we have not yet examined in the research what the experiences of this subset of autistic males is. I am concerned that projecting that this is exclusively a male or a female challenge is going to marginalize yet another subgroup of autistic people.

I think when we talk about gender, maybe we need to focus more on the presentation of internalized autism versus externalized autism, in lieu of female and male explicitly. It also leaves little room for people who are gender nonconforming, gender nonbinary, and other gender identity minorities. But overall, I think we covered just about everything.

I did note on page 24, someone suggested a better job on equity. I wanted to offer that the Arc US, our Diversity, Equity, and Inclusion Committee, has worked with the HRC to be much more inclusive there. Maybe I could help to collaborate something for the committee if we want to work on that. Thanks, everyone.

DR. DANIELS: Thank you. Thank you so much for sharing those comments. By the way, we are taking notes and wanting to collect

additional feedback during this session. We are taking note of what you are telling us. If there are specific resources that you want us to have, feel free to send those to us.

MS. CRANE: I want to back up what Dena is saying. I am sorry my camera will not turn on. But I want to back up what Dena is saying and also say that sometimes - I think that it is a little bit presumptive still to assume that disparities and diagnosis are caused by phenotypic differences. We also know that gender stereotypes change how practitioners and parents view and interpret traits and behaviors. There are people that - who would have clearly met the DSM criteria for diagnosis who have had all of the stereotypical behaviors. But it was not recognized as autism because of public perceptions that autism is something that you see in boys. I think it would be worth being

more open and defining the scope of research on gender differences so that we include the possibility of differences that are based in other people's perceptions, in different ways that people are socialized, in non-biological differences as well.

DR. DANIELS: Thank you, Sam. And likewise, if you have any resources on that, feel free to send them.

DR. GORDON: Sam, I really appreciate you pointing this out from the perspective of the need for more research both in the gender area and in other areas that were mentioned earlier. It is important that we recognize the Strategic Plan where we are asking for questions to be answered like the issue of gender disparities and also the issue of needing to consider more than just the binary conceptualization of gender, an issue by the

way that is really being wrestled with throughout biomedical research.

I will point out that there are few articles in the Summary of Advances discussion later that deal with issues of gender disparity and so making sure that we recognize what we are learning and what we need to learn as the two previous speakers have discussed is going to be important to the Strategic Plan.

I have a question for Dena actually, and maybe also for others particularly some of the scientists on the call who have done the treatment research about what is meant by trauma-informed care in this particular case. Trauma-informed care is a really important perspective in terms of making sure that care is informed by the fact that many people and many autistic individuals have undergone trauma. But in many cases, it does not often

mean an evidence-based approach whereas something more specific might be something better.

My question for you, Dena, is whether you are suggesting that we need more research into appropriate ways to deliver trauma-based care or whether you are aware of studies that demonstrate those appropriate procedures to do so and we are going to be recommending those. Like I said, there may be others who want to respond to that question as well.

MS. GASSNER: My suggestion in terms of the research, Josh, is we go a step before that, which is the reality that in much of the trauma literature, we are continuing to reject the idea that the chronicity of lower grade trauma of constant micro-aggressions, constant need to prove worthiness for accommodations, denial of school-based services, social isolation, cumulatively meet

the same criteria for trauma as what we would call a big T trauma like threat to health and welfare, right.

I think we do not even have the foundational information. There are very few studies, I will pull up what I have, that really look at how autistic people experience trauma because we can't build trauma-informed interventions if we do not embrace that, right.

DR. GORDON: That is a really helpful clarification, Dena. And I will point out that those studies are happening in some other areas. For example, a number of studies are coming out now about the cumulative effect of microaggressions and other lower - not lower, other less chronic or less severe, sorry, more chronic but less severe forms of trauma with regard to race and ethnicity. Building on those methods that have been used

to explore the relationship between these, as you point out, chronic but perhaps lower intensity traumas and their effects and also how to mitigate them in autism would be of help.

MS. GASSNER: I also think that we experience a form of PTSD that is unique in that. For me, it is airports. I have had so many denials of accommodation supports in airports that even though I have paid for CLEAR, even though I have TSA pre-check and global entry, I still experience a PTSD-like anxiety response traveling through an airport. I am not so sure that the low-grade - I hate to call it that because it is not experienced as a low-grade experience. It is really an intensive experience. But those kind of cumulative micro-aggression experiences create a PTSD-like reaction to re-exposure. Even a word can be a trigger for

someone who has experienced a trauma. I think we first need to examine how is it processed through the lens of an autism experience before we can really meaningfully look at interventions. There is work being done but we need to do more. I just do not want our Strategic Plan to leave trauma out.

MS. CRANE: Can I add something? Sorry. This is Sam. I think it is really important that in addition to researching specific trauma-informed interventions, we also need to make sure that mental health measures are included in the efficacy measurements of interventions that we are already doing research on because we have a lot of people who say that the treatment itself has caused trauma. But we do not have any data on that because when the efficacy measures are decided on and people decide what to measure when researching the efficacy of an

intervention, mental health and trauma are not included in that list. We need to make sure that it is incorporated into a lot of research that is already being done.

DR. GORDON: I wonder if any of the scientists on the committee who are doing this kind of research might want to comment in response to that query. I want to make sure to include them in the discussion, not to put anyone on the spot.

DR. DANIELS: Julie.

DR. JULIE LOUNDS TAYLOR: I would say, Sam, scientifically, I think we are starting to see some movement in that direction and there have been some really nice publications that have come out over the last year or two where - maybe the other scientists will remember who led these publications. I am blanking. I know there is some involvement here at Vanderbilt, about really thinking

through unintended consequences of interventions and sort of unintentional harms and noting that that is really measured and really, really considered and really calling on the field to think about these things more carefully as they are doing intervention work.

I have heard over the last couple of years a lot more discussion that I had previously among the scientific community, about the importance of really thinking holistically about the impact that an intervention is having not only in terms of your kind of primary outcomes that you have to specify at the start of the study to say this is the thing that I think will be impacted by this intervention. But I think we are being pushed more and more in that direction to really be specific and careful about measuring the outcome instead of just

measuring a million things and then saying this works because random outcome number 22 seems it would have an effect, but also to be thinking really carefully and broadly about measuring harms in addition to potential benefits of interventions.

I have heard a number of conversations over the last year and few to none before that, at least in my circle. I think things are moving in that direction.

DR. DANIELS: Julie, is there a specific initiative you all have going on at Vanderbilt that you might want to mention around this?

DR. TAYLOR: Susan, I will track down the articles that I am thinking of. I wish somebody could step in. I think even at the last INSAR or the one before, I think one of the authors that is sort of leading a lot of this work, got an Early Career Award for

that. Alice, do you know? I can't believe I am blanking on this. I will be really embarrassed if they are listening to this discussion.

DR. ALICE CARTER: I am actually not sure who you are referring to but some of my colleagues, Marisa Petrucelli, was a lead author. She did not get an award at INSAR. It was a different set of papers.

But we actually tried to write a paper looking at a framework for looking at harms and benefits in screening and I think these points are really important, both about harms and benefits but also about mental health because I think for the first one in terms of harms and benefits, I think people have been very busy promoting screening, promoting certain interventions and really not wanting to mention the possibility that there could be harms because they so want to get the

interventions out in the community. I think that is problematic because we really need to look at unintended consequences and unintended benefits.

I think also in terms of mental health outcomes, given the very high prevalence of a wide range of co-occurring challenges, I just think it behooves us to start including even if we cannot do full-on structured diagnostic interviews or qualitative interviews about mental health changes, we have a lot of symptom checklists that work quite well that can be pretty broad that it would not be very hard to include along with other outcomes.

MS. GASSNER: I think in our suicide prevention studies, Alice, I think we are getting some good information, but I do not think much of it is looking at this chronicity piece. It is looking at someone who is in a crisis, preventing suicide. But

the quality of life that is impaired over an extended period of a person's lifetime has really not been looked at I do not think. That is kind of what I am concerned that I am missing. I think the preventative suicide and preventative mental health piece is good. But it does not go far enough for me.

DR. CARTER: I would also say in addition - people have become very interested in ACEs lately but that seems to be very separate literature from the actual trauma literature. There is old literature in autism on how kids are at much higher risk for abuse and all kinds of other very difficult situations with peers. There is good reason and old literature would support looking at trauma or potentially traumatic events is important, really important. We also know just from the general trauma literature, it is often the accumulation of those events rather than the

one offs that really have significant mental health impacts.

I think three disparate but intersecting points that you all have just raised are super important, looking at potentially traumatic events, definitely assessing mental health when we are looking at even interventions that are not specifically focused on mental health and then also thinking about harms and benefits.

DR. DANIEL: Thank you so much. Let us go to Scott.

DR. ROBERTSON: Thanks, Susan. I think the research perspective and for practices and policies so important in this space on trauma and adversity and I would add in burnout and some of the facets that autistic people - that we have described over the years like in terms of the impact, in terms of on resource units and spoon theory and

things like that that have not made their way into research like we need a lot more of this focus on trauma and then also solutions as well.

I think maybe I mentioned at prior meetings that the under focus in terms of positive psychology-type elements as far as the resilience, courage, tenacity, et cetera. It is not unique to autism. It is complexity and a lot of the other psychological literature. There is really on the research on these positive psychology elements. But I think it is something that I think we could have a lot of opportunity and solutions on that as far as how to help folks in terms of handle these adversities and complexities that come up and will continue to come up because of the barriers that we already know and will be mentioned, for instance, in the gaps in the Strategic Plan and the lack of

access to supports and services a lot of folks need to survive and handle adversity and challenges and barriers and especially right now in exceptional circumstances with COVID-19 and other life complexities and physical and mental health complexities that a lot of folks experience fully across the lifespan. I just want to concur on that with the trauma-informed approaches, trauma-informed care.

And also related to gender, I do not know whether they are still meeting. There previously had been a federal committee on women and trauma. I think disability sometimes had come up in a focus on there. Maybe that is something to look into as far as - in terms of what pursuits that committee has had and how cross connected it is to disability.

DR. DANIELS: Thank you. I can look into that. I am going to go to JaLynn next.

MS. PRINCE: Thank you. This is part of what I was trying to send in and I noticed that some of the points were not necessarily addressed. In some of the summations, there are some excellent things here and the comments that have been made are wonderful.

There are three areas that I want to touch on quickly about supports. There is a huge need for supports in families and people need to have places to turn, to navigate, to find help, to help with their children by the time that they are contending with lack of sleep, aggressions, dietary requirements and other family members, some of which may also have special needs of their own. It is very hard for families to navigate. There are very few things in communities where someone could have someone come in or work with them. There

are sporadic things or if you are fortunate enough to get on the phone and find a place, you are a lucky parent. But there is a lot of angst there.

We also need things as supports for individuals and I think some of these things can come from greater training in universities and community. I am very much in favor of things that can be done in community. I think community colleges, undergraduate work in universities and training more people, not necessarily MSWs and going on for PhDs, which are so important, but people that can encounter people every day and help individuals, help the individual develop the abilities that they may need to be able to reach the goals that they have if it is in work or if it is in community. It is so hard to find somebody that is not just - and I do not want to say

just - caregivers are so important but going beyond and teaching and instructing and guiding people to other plateaus. I think a lot of this training can come about in colleges and universities.

There is also another area that I have not seen addressed fully yet too. It is the same kind of track, more trained people in medicine. The trauma that people happen to be finding as they go to physicians that do not know how to deal with the sensory needs though people are going to have typical medical conditions along the way. And doctors - I get reports frequently about doctors who will not take patients or they are reluctant or they say they do not have the expertise. They are reluctant to get the expertise and we have had someone very good working with us that has been doing grand rounds at Georgetown and GW and other places. It can be

done. Informing GYNs about how to deal with sensory issues, especially for regular visits but also in childbirth for those on the spectrum that become parents. Are there certain things that need to be taken into consideration? It seems that often those things are not.

It goes back to the comments that were just being made. I think many of these interventions could help with the mental well-being of a family and if the family and parents are doing well that there is a greater likelihood of the individual on the spectrum while they are in their households. I just put these things down as supports that usually are not necessarily looked at. They are not necessarily federal. They could be funded federally. But they could also be things that could be developed within communities.

DR. DANIELS: Thank you so much for sharing those important points. We have noted them. I think they do connect to some of the things that are in there now. But we certainly can try to beef those up. Thank you.

I see that Alice and Dena still have hands up. I do not know if there were other people that wanted to comment. I will go to Alice next.

DR. CARTER: Sorry. I just did not take my hand down.

DR. DANIELS: Dena.

MS. GASSNER: I just wanted to mention that in terms of the gender issue, one of the biggest barriers we have is 8-year-olds being measured for incidence rates. We talked about that before but we really need to be evaluating adolescent and adult rates of

autism in some of our centers to look at gender as well.

DR. DANIELS: Yes. I know CDC is working on some of those issues. But we can certainly mention the importance of that in the new plan. Are there other comments from members of the committee about what is here or what might be missing or new things that have come to mind since you filled out your surveys earlier? I know it might be a little difficult to think about it on the fly as you look at the slides. We have Yetta.

MS. MYRICK: Thanks for giving me the floor again. One of the things that I have been thinking about as we do this work and we think about the Strategic Plan is I know we have a section that talks about really making sure that there are diverse groups being studied. But I really want to implore the research community to really be assessing and

working towards including different groups. I think this is going to be key because we do not necessarily know how certain interventions might work or what the effects are in various communities if 60 percent of the research has been done. I am looking at a Spectrum News article that was recently published where they talked about the intervention studies in autism research, how basically 60 percent of the participants in the autism intervention studies are white. How do we really know if an intervention works in different groups if we do not study different groups?

As we talk about trauma specifically, for me as someone who identifies as African American, you cannot necessarily separate. If I was someone who was autistic and I am also African American, there is this intersectionality that I think also needs to

be addressed. As we are looking at these different topic areas, I really want to ensure that all of these different intersections are being reflective in how research is being done. I know that this is something that is the hot topic right now. I have to hit it while the fire is hot and people are interested in this. Now is the time. Because we do have this interest nationally, internationally with what is going on with the world. I think this is something that we really need to be focused on and figuring out how we can weave into the plan going forward.

Another thought I had too that kind of popped up as you were going through, Susan, and I do not necessarily know if this is autism research but more research in general. But in some of the work that I have done in working with researchers on different

projects is this idea of providing stipends or payment to participants. If you really want to diversify who is able to participate or if you want families to be involved in your study and support the work that you are doing, I think it is important to ensure that there is some type of stipend or the individual. There is some type of stipend to support them because there is value in what we bring to the table. I think that that needs to be recognized. I often hear from people in the community that it is federal money. I cannot necessarily do that. I do not know how that gets changed or what the process is. These are the things that I am hearing. I think that is another piece that is also important as we think about diversity in this work. Thank you again for giving me the floor.

DR. DANIELS: Thank you. Thank you for those important comments and we will be sure to note them as we know diversity is an important theme in the Strategic Plan.

DR. GORDON: I will just interject that in many studies, subjects are actually recompensed for the time that they spend in the study. But I assume you might mean more substantial recompense than that.

MS. MYRICK: Yes. I do. Thanks, Josh.

DR. DANIELS: Thank you. Let us go to Craig Johnson.

MR. JOHNSON: Thanks so much, Susan. When I was looking over the Strategic Plan, obviously it is very much research based and I love the research. I think it is so important.

I think one of the questions I have and especially as I am understanding the committee, I am still in this process of

understanding all that we do. How long does it take from going from research to meeting tangible needs, providing solutions? Because that is really where I am at. I am with the families. We are with those tangible needs, those solutions. Many people that get on the public forum - they look at it and they do not fully understand all the research. If you talk to anybody that I would work with, they would not even know there was research going on. They just have needs. They have multiple types of needs. The research helps us obviously meet those needs and identify the areas that really need to be focused on.

What I am trying to figure out is are we all research based or does the research ultimately get to tangible solutions to help families who I am working with on an ongoing basis right where they are at, right where

they are dealing with these issues and many of the people that come on the public forum.

DR. DANIELS: The Strategic Plan is a broad document and it covers any and all and we are not waiting for certain research to be completed before we take action on things that can be done in the here and now and we do have services agencies on our committee too. Josh, do you have something to add?

DR. GORDON: I just want to add that, Craig, I really appreciate the opportunity to respond directly to your question, how long does it take. And the answer is that it depends upon the research. Pretty much most of the things that we do right now for individuals with autism whether we are talking about screening in pediatric practices or some of the supports that we do have available for housing, for jobs, and the

like have all been pioneered in research settings and then applied to the community.

If we are talking about some of the important genetics work that is being done that you will read about later in the Summary of Nominations, that might be decades away from affecting new interventions. But on the other hand, the screening practices that are in there or some of the services stuff and also taking into account gender differences, et cetera. These are all things that could have impact in the next year or five years, depending upon what we are talking about. I think there are different timeframes for translation.

But certainly one of the purposes of this committee is to recognize when an advance has been made that we would recommend it be taken up. And you heard some of that today in terms of paying attention to the

fact that individuals with autism have been exposed to traumas. It does not take - while we need more research and the extent that it is the case and the right way to mitigate it, ensuring that people are cognizant of that in care is a recommendation that we can make, which does not require any further research.

MR. JOHNSON: Thank you.

DR. DANIELS: We also have more representation on our committee of additional agencies and departments that can help us on some of the services and supports issues that are really immediate to the community. We look forward to getting input from some of them.

With that, I will call on Amanda Reichard from the ACL.

MS. REICHARD: Thank you. Actually, I wanted to comment on Yetta's comments and Craig's as well briefly. And I just wanted to

highlight that at ACL in the past year and a half, we really have stepped up the emphasis on intersectionality and doing what we can - trying to discover what we can do to increase that not only through the services but also at NIDILRR, which is where I am housed, which is the research wing of ACL. We are incorporating that. In fact, this year in all of our funding mechanisms, we included a requirement that people have to include race and ethnicity proportional to the population that they serve and talk about how they are going to do that and how they are going to do that not only with their research participants but also with their staff. It goes all the way from the top of ACL down to the services to the research to the grantees. We are really trying to get that pushed through.

The other thing that is exciting that you may not know about is that a year ago, more than a year ago now, the president put out an executive order to focus on data related to underserved populations. There is a data committee for that. I am not a part of that. But from what I understand, it is really going across a lot of different vulnerable populations, recognizing the people who have multiple vulnerabilities and that can be exponential rather than additive, the effects of that. It is something that people are talking about now finally. I did not know if you were aware of what was going on in ACL and NIDILRR in that respect. It is the most progress I have seen in my entire career. I am pretty optimistic about it.

And then Craig, I just wanted to respond also. I am not sure if you are familiar with NIDILRR's research portfolio and the website

that we use. I can share that with everybody. NARIC is our website where we share all of the research findings. We require all of our grantees to not only to include the input of people with disabilities in designing their research and throughout their research, but also to create products that are usable for a wide range of stakeholders, including people with disabilities and their families so that they are not just writing research papers and publishing them in peer-reviewed journals. They are expected to also write fact sheets or blogs or podcasts that are going to attract and be useful for families and people with disabilities directly, including interventions.

That is the other thing I was going to say is we really - NIDILRR has a focus on stages of research. We really pay attention to, well this topic has come up a lot but we

are not going passed the exploratory stage. We need to figure out what kind of funding mechanism we need to offer to get it to go to the next level so that it is going up to ways that it gets out to a larger population when has been an evidence-based product and ways to make it more useful directly to the people who need it. Thank you.

DR. DANIELS: Thank you, Amanda.

Next, I would like to take a question from Steve Whitlow or a comment.

MR. STEPHEN WHITLOW: Thank you. I just wanted to comment on what Craig has said and also reinforce a little bit. In our experience in providing services, a lot of times the research obviously is important but the practical application of the programs that actually exist become much higher on the urgency scale than some of these things. I would just like to address the coordination

between services and identifying a plan for the family and the individual that is either diagnosed or a young adult or whatever stage they are in their life, develop a plan, identify the resources that are out there and then have the ability to follow through on that plan so that the family is not through a stage in their life and met head on by another unanticipated hurdle later on.

And this was discussed in the housing discussion earlier where the precedence of homelessness rose when there was not planning for what happens when folks got older, that is a coordination of services issue and a planning issue. Where it says address the whole spectrum and whole lifespan, I think just the practical aspect of identifying those services that are available and connecting those families to those services would make a tremendous impact on the ground.

I think it should be an important part of what we suggest for a plan moving forward.

DR. DANIELS: Thank you, Steve. We certainly will look to people like you and Craig and others on the committee that have experience in those areas to give us feedback on that. Thank you for sharing that.

Scott, do you have another comment?

DR. ROBERTSON: Yes. Sorry. I was more focused on the trauma things before and I had not mentioned - in addition to what I had shared before, that intersectionality piece I want to concur with that. I wondered if we could include that emphasis in the Strategic Plan in terms of referring back to the specific, for instance, the executive orders that are out there right now. There are six executive orders in that space right now recently on diversity, equity, inclusion, and accessibility. I think it has become so much

a huge priority for us across the federal government that I hope it interconnects there to the focus on the Strategic Plan to make sure that race, ethnicity, gender, gender identity, sexual orientation, social economic status, et cetera is woven into the tapestry of what we are thinking with the Strategic Plan development.

I wondered also - it sounds like this might be the case is that there are some things that I have left out I think on the comments that we had originally on that survey. Can we send you additional - one of the things that I left out as I should have put on there is there are some specific studies that I think might be good to cite. I should have done that on there. I just did not think of them at the top of my head when I was filling that out. Is it possible to send you some additional info that could be

helpful for the development of the Strategic Plan on some of these focuses and specific articles that might be good to cite?

DR. DANIELS: Absolutely. We would welcome any further feedback after the session. Again, I know that it sometimes is challenging to think on your feet as you are looking at all of this and it is a lot of information to take in. If you have additional comments, you can send them to us. I do not know if it would be easier to just send us emails about it or if you would like to have like a survey type opportunity open to put things into categories. Do you have a thought about that?

DR. ROBERTSON: I think for me just like maybe a Word document where I could just add some additional bullet points and stick in there some research articles that, for instance, in the employment space, work-based

learning career paths would be some of the better articles to cite as well as - one of the things that I left - I think I left out too was transportation stuff. I tried to give some coverage to that because we do not yet have representation on the committee from the Department of Transportation. And I am familiar because we have collaborated a lot with DOT before. That is another thing I could put.

I am okay with just sending stuff in a Word document. You might want to see what the other committee members think too and whether that would be okay if folks were interested in reopening like a structured survey kind of thing if that is okay with you all as far as it is not too much complexity for you and your staff to do.

DR. DANIELS: I think that we would be able to handle that. Our goal is to get all

of the feedback in so that we can get the drafts as close to what the committee wants as possible. We will try to do everything we can to bring in the feedback and would really appreciate any articles that you all would share with us or websites or other sources of information and certainly do plan to mention things about major federal initiatives that are going on such as what you mentioned with some of these executive orders.

We have a little bit more time. Are there more comments from anyone else from the committee who might not have spoken or Josh, would you like to chime in?

DR. GORDON: No. I was just open to wrap this part of it up if we are done. Please, if folks have more comments or questions, please raise them. I will remind you all that of course the Send Comments Here chat section,

Steve is standing by if you prefer to use that for any reason.

We remain right on time, Susan. I would suggest we take now a seven-minute break. At 4:25, we come back to the discuss the Summary of Advances, which is the next task for the committee.

DR. DANIELS: That sounds great. Thank you so much, everyone, for your feedback. We appreciate it.

(Whereupon, the committee members took a brief break starting at 4:18 p.m., and reconvened at 4:25 p.m.)

DR. DANIELS: I am going to just give a quick introduction to the IACC Summary of Advances discussion before we get into it. But as a reminder, this is an annual report that is required by the Autism CARES act of 2019. The final product of this committee works on is a summary - a document that has

lay-friendly summaries of the 20 most significant advances in ASD or autism biomedical and services research that were selected by the Interagency Autism Coordinating Committee. And members have been working to complete the 2020 version and the 2021. You all have voted now on the content for the 2020 and we are in the process of publishing that one. That will be coming out probably sometime in May. We will happily inform you and we will send out the message on our email and Twitter as well when that comes out.

Today, we are going to be talking about the 2021 Summary of Advances. You all have submitted nominations for that. This is just rehashing the process we went through and we are right now at the very final stage of preparing the final publication. We thank the committee so much for your hard work in

making those nominations and discussing them and getting us to this point where we have an almost final publication. Also, thank you to the OARC staff for your work on this.

As I said, the publication date is May that we are anticipating. And the articles will cover all seven topic areas of the IACC Strategic Plan. And something new that we would like to say is that this year we are going to be issuing an easy read version of the Summary of Advances that contains one-sentence summaries of each of the top 20 advances that are written in very easy-to-read language. That will be a new addition this year.

On the 2021 Summary of Advances, our process is - today, we are going to work on looking at the articles that have already been nominated. You have given us a full list of nominations. We are going to talk about

them. After this meeting, we are going to send out ballots to the IACC members so you can vote on your top 20. After that, we will follow through that same process of working toward getting a publication together and prepare summaries of the articles and provide the final publication, which we hope will come out in the fall of 2022.

Now, we would like to have some time to talk about the nominations. Josh, if you would like to take it from here.

DR. GORDON: Thank you, Susan. Just to remind you all of what this process - of the process that we are going to follow for today. You all received a packet, a lengthy packet. I am very pleased at the number of nominations that you all submitted, over 18 pages worth of nominations. Each one of them in that packet is described by a summary that was submitted by the nominator, justifying

their nomination for inclusion in the document.

Our goal today is to go through each of the seven questions and have some discussion on any of the articles in there that members would like to flag as being particularly noteworthy and/or flag as for one or more reasons maybe that members would like to flag for potential removal from the list or otherwise comment about.

We are going to go through each of those questions in turn. Some of the questions have quite a lot of nominated articles. We are not going to go through each and every nominated article. But I want to make sure to give everyone an opportunity to raise for discussion any articles they would like to raise.

The first group of articles. These are just the first four of them. There are more -

are on screening and diagnosis. That is Question 1 of the current Strategic Plan. There were a number of articles that were nominated. As we go through the list, if anyone would like to make any comments, please do so. We have four articles on the first page. Race/ethnic inequities in conjoint monitoring, computational methods, effect of family navigation, which I will just very briefly point out. This is exactly the kind of research although it is for children - exactly the kind of research that was suggested would be helpful for adults with autism. It certainly is meeting a need. And next slide now. There are three more in this Question 1. Would anyone like to flag any of these, promote one that you nominated or that someone else nominated as being particularly important or otherwise make comments?

DR. PAUL WANG: This is Paul Wang from the Simons Foundation. I am not the person who nominated that article that, Dr. Gordon, you just touched on specifically, the Feinberg et al. article on family navigation. But I also agree that this is important work that shows the value of a specific kind of support in promoting recognition and diagnosis.

I have not read the article very recently. I am looking at the description here that was submitted by the HRSA nominator. I believe this article may even have gone further. Maybe the project went farther, and it is coming out in another paper that they look not only at recognition and diagnosis, but also whether families actually got connected with further services.

DR. GORDON: I think the nominator was HRSA. I do not know if the nominator would

like to make any additional comments regarding that.

MS. ROBYN SCHULHOF: This was HRSA. I was not involved in that. I am sorry I cannot comment on that particular item.

DR. GORDON: Thanks any way, Robyn.

Any other comments on any of these first seven articles for Question 1?

DR. MATTHEW SIEGEL: Sorry, Josh, I just wanted to look at the second slide for a second and the reason is because I think - this is Matthew Siegel from Maine Medical Center. I will not turn on my video because I am in an airport. The one thing that strikes me but I did not nominate and would need to relook at the literature from 2021 is the - one of the timely questions here is was any good work published on remote or telehealth forms of diagnosis, which became a burning need during the pandemic and is an area of

some controversy. But the question is has there been good work published. It just appears - it looks like a hole given our current - the world we are living in.

DR. GORDON: Matthew, the good news is we did - I am pretty sure NIMH funded a supplement to look at that. But none of these publications reflect that and perhaps reflecting the amount of time it takes to conduct such a study and publish it.

If we go back one slide though, there is a paper that speaks to the possibility here and that is the Chang et al. paper on Computational Methods to Measure Patterns of Gaze in Toddlers with Autism Spectrum Disorder. I would point out from that title that you might not be so excited about it and is it really that relevant. But what this is is it is a group that is funded by some NIH grants and actually some grants from other

organizations, trying to develop easy, automated methods that could be used in remote settings and in primary care settings to determine a screening approach.

In this particular case, these investigators who are at Duke developed an app for mobile devices that can just track the gaze of individuals with autism and - sorry, individual toddlers who have not yet been diagnosed with autism and asked whether toddlers who will be diagnosed with autism versus typically developing toddlers might differ in their eye tracking. This is an early stage of development. But theoretically, this method could be used in remote settings. It speaks to it, not exactly what you asked for.

DR. SIEGEL: Thank you. We will look to 2022 for more.

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

DR. CARTER: There are some 2021 papers that talk about remote diagnosis. I could send some. I just sent one to Susan, but there are several more. People were really struggling with this in the beginning of the pandemic, and by 2021, they were starting to publish papers about it.

DR. GORDON: Unfortunately, it did not make it in time for this one.

DR. CARTER: I am also not sure they would meet the real criteria of new - there are reflections, but I am not sure there was sufficient new data. And the other thing that is complicated is in the pandemic it was really tricky to do any kind of comparison between in person and remote diagnosis.

DR. GORDON: Right and obviously that is what you would really want. You would want to

show the ability of a remote procedure to work relative to an in-person procedure.

Alice, you have unmuted yourself. Go ahead. Alice Kau from NICHD.

DR. ALICE KAU: This is a very exciting report. It is reported that - the data supports a mobile app that was successful in distinguishing toddlers diagnosed with ASD from typical developing children based on their eye movement while they are watching a video. Obviously, it needs further development to be able to be used. I think they have more data coming out. We will have to wait, like you said.

DR. GORDON: Alice, I think so. You are speaking of course about the Chang paper. I would highlight that as being one that is at least relevant to the current question. Anyway, we have discussed that already.

Let us move on. I will just note that we had comments about the Feinberg and about Chang. We will move on to Question Number 2. Question Number 2 is on the biology of autism. There are a number of different studies here. The first five or so are on the first slide. Early social communication, growth differences in the brains of infants who will go on to be diagnosed with autism spectrum disorder, longitudinal studies of social communication, long-term maturation of organoids. I can discuss that if you would like in a minute but why that might be relevant to the biology of autism. Quantitative and qualitative sex modulations. Any questions or comments. Dena, go right ahead.

MS. GASSNER: I am sorry. I am trying to follow along in my printed materials. And page 2 had the four articles we just talked

about, the HRSA article. But I did not see page 3. Did I miss it?

DR. GORDON: I have it in mine. I do not have it printed. I have the PDF. Maybe there was some challenge in printing. On page 3, I have Sichertman and Wetherby.

MS. GASSNER: I just had a comment on Wetherby but you can just tell me when it is a better time to make it. I think I --

DR. GORDON: Let us do that now. Let us go back one slide. Go ahead and make your comment.

MS. GASSNER: I just wanted to report that I have not had time to read it but there was a recent study that just came out of Germany that shows that highly structured, highly academic preschools are getting better short-term outcomes but long-term outcomes are worse for children, all children, not kids with disabilities per se. But I think

that is a significant thing that we need to discuss in terms of these screening tools that come at such an early developmental stage. I know that we are hoping to mitigate some of the impairment-related issues of autism. But I am really worried that some of these early diagnosis studies such as this one, are going to result in kiddos that might need just more time for play, might need more time for socialization and outdoors instead of such intensive normalization and compliance training. I do not know. I just wanted to mention that because it shines a light on this from a different trajectory.

DR. GORDON: I am not familiar with that paper but it is a very good point, Dena. And I think that is one of the points that was echoed in the US Preventive Services Taskforce recent decision on screening and that it has been backed up in a number of

different areas that we really do need to demonstrate not just the ability to identify individuals earlier but also to demonstrate that identification using these kinds of tools will result in better outcomes.

I will point out. There is fairly good not super good but fairly good data as others have presented here to earlier iterations of this group that early intervention does result in better outcomes. But it could be better and it needs to be demonstrated in the context of these screening procedures.

MS. GASSNER: I would refer people back to Sam's comments related to this as well.

DR. GORDON: And I think Sam would like to make a comment perhaps about this very issue because her hand went right up as soon as I said that. Go ahead, Sam.

MS. CRANE: Yeah, I just wanted to say that this also connects back to some comments

I had on the Strategic Plan in which there was the question on early identification. It had language saying that the goal is to identify kids as soon as possible. That might have been reasonable back when the question was between identifying kids at age 3 versus age 8 or later. But now, we are seeing studies that are identifying kids at age 12 months. And that we do not have the evidence that those - what I would call super early identifications are connected to better long-term outcomes because we do not have research on those early interventions on kids as young as 12 months.

DR. GORDON: Sam, I would reiterate what I just answered to Dena, which is that we need that evidence before we would put it --

MS. CRANE: I think that that is why we need to also edit the language in the Strategic Plan to reflect that --

DR. GORDON: Fair enough. Fair enough.

That is an excellent point. I would just add that of course we cannot do the studies to determine whether we could get clinical benefit until we identify them earlier. There is a second reason why these early identification studies are being done just to be clear. We know from the genetics that the biology of autism starts very early in life but we do not understand how that unfolds at earlier ages because we have not been able to identify individuals earlier. It is not just about treatment. It is also about understanding that we need to develop - I should not say that we need to. That these studies that are aimed at identifying children earlier who are at risk for autism will allow us to understand that biology because even though of course what we are talking about is trying to improve the lives

of these children, improving the lives still relies on understanding the biological unfolding earlier on. I appreciate that.

Let us move back to Question Number 2, which is relative to what I just said, which is on the biology. Here are the first five. Any comments or questions on any of these first five? Dena and Sam, I would appreciate if you could put your hands down just so I make sure - unless you want to make a comment on any of these five. Anyone want to make comments on any of these five? I will just note that several of them were from our colleagues at NIDCD and NICHD.

I did want to make a comment about the Gordon A et al. paper, Long-term Maturation of Human Cortical Organoids. I am not necessarily advocating as a major advance but just to understand - to help you understand why this is important even though it is not

specific to autism. I will just say at the outset - A. Gordon - no relation. This paper is one that seeks to again understand biology as it unfolds early in life when we know a lot of the risk factors for autism be they genetic or environmental are acting on the brain. It is really hard to study the brain in human beings very early in life. And what this paper shows is that you can actually do that using cells in a dish without having to resort to studies in infants or pregnant women or having to translate from animal studies. That is an advance at least in terms of being able to make further inferences as to the biology of early events in autism.

I see hands up from Dena and Elaine. Let me just ask if either of you are responding to this particular article first.

MS. GASSNER: No, it is the next page.

DR. ELAINE HUBAL: I did want to just respond to this because it sort of comes up later with the - risk factors is that having - having models like you are talking about to study biology in addition to helping in terms of whatever interventions is actually really important for being able to study these risk factors especially when we are talking about modifiable environmental factors - have these experimental systems. That is really where we are going to get the evidence for whether or not some of these chemicals that we are all very concerned about are things we should do something about. I am just raising that now because there are some papers that are looking at epi-evidence of chemical risk factors and I do not actually think that level of evidence is where it needs to be.

DR. GORDON: Right. But we need these biological models to be able to study them

further. Thank you very much. Always glad to have input from the EPA here.

Next up - Dena, I guess you wanted to make a comment about the next slide so let us move along to the next slide. It is one of these four articles. Is that right?

MS. GASSNER: Yes. It is the one that Alycia provided to us, this first one on the age of walking and intellectual ability. At first, I got really excited about this one because this would give us a very externalized expression of delay at least to maybe help parents to know what to expect to make that early referral but then to suggest that this is limited to people with intellectual disabilities seemed short sided to me because we know that motor delays in autism encompasses the entirety of the spectrum. I do not know. I just wanted to see if Alycia might have any insights or ideas.

DR. GORDON: Alycia, do you want to comment on that? I will note that in your description of the paper, you state that they found that the relationship between walking was not present in ASD children without lower IQ.

DR. ALYCIA HALLADAY: Hi guys. I am not going to show my video because I am in the car, but I am listening. I did want to just put a plug in for this paper. This is part of a conversation to studies that is looking at developmental milestones in general in addition to genetic factors that really help support early diagnosis, which we know is important for early intervention. I do not know what else I can say other than I think this was an important paper in 2021. Dena, I feel like I did not answer your question.

DR. GORDON: I think you would have to look at the details of the paper and what we

will do is we will make sure that the summary does appropriately reflect the data. It is possible, Dena, that despite other data that might suggest motor issues across the spectrum that this particular way of looking at these motor issues does not detect relationships with ASD and those without intellectual impairments. But we will make sure that it is accurate when we do. If it is selected, we will make sure that the description accurately reflects the findings.

Scott, did you want to talk about this paper or another?

DR. ROBERTSON: I just also wanted to mention if it is okay to mention a related thing to that paper on motor issues. That also reflects back like a concern among many folks that like the diagnostic criteria sort of do a disservice because of the fact that it is mostly social communication in the

diagnostic criteria, that motor, sensory, and executive functioning has been so underemphasized. It is always good to see these papers like this that are examining that cross connect to motor. And we already know there is some in the literature that even go all the way up to adults looking at motor issues. But we still see that gap. I do not know if that could be something that could be emphasized separately from the Summary of Advances, Strategic Plan in terms of the importance of getting more research on these other aspects of autism in terms of other than social communication as far as motor, sensory, and executive functioning.

DR. GORDON: Thanks. I am pretty sure it is in the plan. We will back date that comment to the previous discussion on the Strategic Plan. Thanks, Scott.

We have a comment that came into Steve. Steve, would you like to read it please?

MR. ISAACSON: Dr. Susan Rivera will give the comment.

DR. SUSAN RIVERA: Thank you, Steve. And thank you, Josh. I just wanted to encourage us. It is kind of a side comment but important to bring it up while it is going on, I think. Really in our discussions in the IACC think about our language carefully and maybe using the term predictive factor rather than risk factor to try to decrease or avoid stigmatizing language. I have heard that term come up a couple of times. I just wanted to put in a gentle acknowledgement of that and request that we stay on target there.

DR. GORDON: Thank you very much, Susan, for pointing that out and also for doing exactly what I asked us all to do an hour ago or so when we first started these discussions

to try to just respectfully call out language that might be perceived as others demeaning. I get the point there. It is really about risk implies a value judgment on the outcomes. Predictive is just as - the term predictive is just as germane to the issue that we are trying to understand but without that value judgment. Thank you.

DR. RIVERA: Thank you.

DR. GORDON: We should make sure that the Strategic Plan uses that predictive factor. We often talk about risk and resilience for an illness. I guess your point here is that that may not be the language that would be preferred by individuals with autism. Thank you for that.

DR. RIVERA: Precisely.

DR. GORDON: We can talk about prediction of outcomes perhaps.

Next, we will move onto the next set if we could advance the slide. Maybe someone already did. I do not think so. Let us move to the next group. Go back up. It should be Romeo. There you go. This is the next set still on questions of biology. Any comments on any of these? I just want to thank Alycia Halladay for nominating a number of these articles. I am curious which one she would vote for amongst this group. There is quite a lot of them in there. Some of them are really like the Tran, focused on neuroscience and development of the brain. Others like Rosen about experiences in early life, for example, in terms of the involvement of siblings on adaptive trajectories. Quite a breadth here.

You know me. I cannot avoid talking about the genetics but maybe I will ask Joe if you want to just briefly highlight the

Willsey paper and why you chose to nominate that.

DR. JOE PIVEN: Josh, I would be happy to defer to you.

DR. GORDON: You are defeating my purpose trying to get everyone involved. This actually - if you think about it, it gels well with the other one that I want to talk about on organoids in terms of identifying. The question is where and when are genes are acting. In this particular one, it is not only talking about genetic influences but also the influences of sex hormones in particular with estrogen and the suggestion from these data although it comes from model organism data as opposed to human data. It would really need to be validated there. Many of the autism genes which confer significant predictive value for the diagnosis are expressed in neurons early in life and in

fact have to do with the generation of neurons and that some of the alterations that are induced by these genes can be reversed by estrogen potentially explaining the difference in rates in boys versus girls. It is all very suggestive. It is all very much again really raising the hypothesis rather than confirming them. That is the Willsey paper.

I think we have a comment from the Autism Science Foundation. I am not sure the person behind that. Go ahead and speak.

DR. HALLADAY: It is me. Alycia. I am probably the one that nominated the Rosen paper. It is not really biology and I probably put it in the wrong place. I would put it under lifespan issues. It does not decrease my enthusiasm for this paper. This does come from a strengths-based model. It looks at longitudinal data collected over

several decades and it focuses on the presence of a sibling. And of course, the study needs further refinement. Every study does. This was really important. It probably does not belong in biology. It probably belongs in a different category and that was my fault.

DR. GORDON: We can move that for the voting. Thanks for the shout out for that paper.

If there are no other comments on this one, we will move on to the next question. I apologize for the title. Risk factors. But let us say predictive factors instead of risk factors and we will make sure that we get that into the issue. I am just reading a note to me from Steve. Let us first - if there are any questions on the first group.

MS. GASSNER: It is me. I just wanted to mention on the Lawrence article, again, the

female protective factor. Again, we are looking at very young children where autism may not be yet presenting when we are looking at young children. The submission starts when there is a four-to-one disparity in males versus females. But the field is not finding that in adults. We are seeing that in research coming from all over the world that those numbers are not holding up in adulthood. I do not know. I have some concerns again about gender in these kinds of studies.

DR. GORDON: Let me look at that. You are talking about the Lawrence. Correct?

MS. GASSNER: Correct.

DR. GORDON: Okay. One thing to be aware of is the question of gender versus sex. We have to acknowledge that sex is also not binary. But I just wonder what is used here and whether they are trying to affect a

biological explanation or a gender-based explanation. I think those are really two different kinds of questions. What I am reading here is they found genetic risk affected by connectivity in males but not females. I think actually it is kind of relevant to either question. You could imagine that that would arise through biological factors even prenatally that have to do much more with sex than with gender or it could be actually a gender effect. I think it is a little complicated. I think you are right in pointing that out.

I, myself, wanted to raise and maybe, Joe, you might want to respond is some of the nominations particularly the Klei and maybe another one here are really commentaries as opposed to scientific advances. Again, we had this discussion I think back in September about whether we wanted to continue with the

previous policy of not including commentaries unless they break new ground.

DR. PIVEN: I just said something brilliant. Try and do it again. I am not familiar with the ones that you are referring to but I would agree. I think it is acceptable to have a commentary if it really is kind of transformative or breaks new ground or gives a very new perspective on something. I do not know if that is what is happening in these articles or not.

DR. GORDON: The one I am thinking about right now is the Klei and McClain, that first one on this list.

DR. PIVEN: I think that is actually more than just commentary. We have had this big advance in the field over the last 15 years of the recognition of the single-gene disorders as if that is all that is happening is the mutation in that single gene and not

taking into account all the other genes that are impacting. We see kids with Fragile X and we say one-third of them develop autism. The real question is why do some have autism and some not have autism and some have something in between. I think this paper really begins to move the conversation forward beyond either these rare genetic events or common variation to thinking about the true state of nature, which is a combination of both. I think in that sense this moves the conversation forward.

DR. GORDON: Alright. We will leave that in there for now. It will be on there as a potential voting one.

I have two comments left. But Susan, I also realize it is 5 o'clock and we are only halfway, not even halfway through this Summary of Advances discussion. We kind of

have to end because people have an expectation to go.

What I would like to do if it is okay with you is take these last - I see three comments - take these last three comments and then close. And then you and I will have to confer about how to do the rest of work whether we want to do it via email or try to devote some time tomorrow to it.

DR. DANIELS: Thanks. We will do that.

DR. GORDON: If you do not mind, I am going to ask you all to be brief although I realize it is unfair because you all have been waiting for a while but to the extent that you can be brief.

DR. HUBAL: Very briefly and I guess the papers I am referring to are on the next slide. This goes back to my comment about what sort of moves us forward in terms of understanding impacts of environmental

chemicals as predictors of autism. I am concerned. I am actually going to ask that maybe we think about removing the Oh and the two Patti's. I actually thought the Oh study was a nice one but I did not introduce or did not nominate it because I am concerned that we put these things forward and in fact they are probably more hypothesis development studies that then if we had the other tools, if we had the experimental tools that we could then go and understand better how these chemicals may or may not be working, it would be more useful. But I am afraid that we put this out as evidence, and they are signals but they are not strong signals. I do not know what other people think.

DR. GORDON: Thank you for bringing that up. You know what I am going to do - I think that might trigger more discussion than we have time for today. Let us come back to that

issue either over, email although either of the remaining commenters have points about it, please do underscore that.

We have tried to avoid prematurely promoting a conclusion as being definitive by inclusion here than in the past for precisely this reason.

DR. PAUL WANG: First of all, I just want to confirm that that Klei article that Dr. Piven and you were talking about does indeed present new analyses. It is not just a commentary.

On the other hand, the last article for Question 1 on screening by Zwaigenbaum et al. - it calls itself a commentary. It addresses COVID and telehealth kind of issues but it does call itself a commentary. I would suggest removing that from voting.

Here, on Question 3 on the first slide, the last paper, I nominated Mitra. I just

want to highlight that. It talks about a new class of genetic difference. I think that most people are familiar with, for example, genetic deletions or mutations where one base pair is substituted for another. People have heard of CNDs or a chunk of DNA is deleted or duplicated. This paper highlights a new class, which they call tandem repeats and their association with autism. I thought this was an important advance in understanding the genetics of autism.

DR. GORDON: Thank you for bringing that up, Paul. Unless there are objections, given that the other one calls itself a commentary, I am going to suggest that we do remove it from voting. Please raise your hand now if you object to that. While you are doing that, we are going to go to Morenike. I do not know, Morenike, if you are going to read your comment or speak your comment or you are

going to have Steve do so. It looks like Steve is unmuting.

MR. ISAACSON: I will present Morenike's comment. I would agree with opting not to include commentaries except in the case of matters relevant to underrepresented and/or marginalized communities who are notoriously ignored by researchers. Sometimes gray literature and/or commentary is all one has in some cases and to ban commentaries would be to deprive many of an opportunity to have issues of relevance discussed. I strongly agree with removing the two Patti papers and the Oh paper for the reasons just mentioned.

DR. GORDON: Thank you very much for those comments, Morenike. I note that the Zwaigenbaum paper is not specifically though it may very well deal with underrepresented minorities not specifically cited for that. We will look into that and remove it unless

there is reason to bring it back to you.

Thank you for the comments on the Oh paper and the other chemical papers, which we will come back to in one way, shape, or form whether over email or in person. I thank you. I apologize to all of you that we have gone over by a few minutes. But we obviously have more to do in terms of the work on the Summary of Advances. Susan and I will figure out how we are going to accomplish that. I look forward to seeing you all, am I correct, Susan, tomorrow at 1 o'clock.

DR. DANIELS: Yes, tomorrow at 1 o'clock.

DR. GORDON: See you all then.

(Whereupon the meeting adjourned at 5:06 p.m.)