

INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, JANUARY 14, 2025

The Interagency Autism Coordinating Committee (IACC) convened virtually, at 2:00 p.m., Shelli Avenevoli, M.D. Ph.D., Acting Director, presiding.

MEMBERS PRESENT

SHELLI AVENEVOLI, Ph.D., National Institutes of Mental Health (NIMH)

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

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

SAM CRANE, J.D., Autistic Self Advocacy Network (ASAN)

THOMAS FRAZIER, Ph.D., Autism Speaks

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

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

CHRISTY KAVULIC, Ed.D., U.S. Department of Education (DOE)

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

YETTA MYRICK, B.A., DC Autism Parents

LINDSEY NEBEKER, B.A., Independent Contractor

MORÉNIKE GIWA ONAIWU, Ph.D., Autistic Women &
Nonbinary Network

ANNAPURNA PODURI, M.D., M.P.H., National
Institute of Neurological Disorders and
Stroke (NINDS)

JALYNN PRINCE, B.F.A., Madison House Autism
Foundation

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

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

IVANOVA SMITH, B.A., University of Washington

HARI SRINIVASAN, Vanderbilt University

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

PAUL WANG, M.D., Simons Foundation

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

IACC ALTERNATES

MITCHELL BERGER, M.P.H., Substance Abuse and
Mental Health Services Administration
(SAMHSA) (representing Nikhil Patel, M.D.,
M.P.H., M.S.)

KRISTINA HARDY, Ph.D., M.D., National
Institute of Neurological Disorders and
Stroke (NINDS) (representing Annapurna
Poduri, M.D., M.P.H.)

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

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

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

JANE SIMONI, Ph.D., National Institutes of
Health (NIH) (representing Monica
Bertagnolli, M.D.)

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PROCEEDINGS

DR. SHELLI AVENEVOLI: Hello, everyone. Good afternoon and Happy New Year. It's really a delight to see you all again. I want to welcome you to this special meeting of the Interagency Autism Coordinating Committee. So, just a reminder, I'm Dr. Shelli Avenevoli, and I am the acting director at NIMH right now and also the chair of the IACC.

Just to refresh your memories, the purpose of today's meeting is to discuss articles that have been nominated for the 2024 IACC Summary of Advances. And as you probably remember, the goal of the Summary of Advances Report is to highlight significant progress being made in autism research across the topic areas of the IACC Strategic Plan. And Susan is going to tell you a little bit more about that. So, I am going to pass it over to Susan -- Dr. Susan Daniels.

DR. SUSAN DANIELS: Thank you so much, Shelli. So, welcome, everyone. Looking

forward to this meeting today, and it'll be our last meeting of this iteration of the IACC.

So, this is a working meeting today, and we're not going to be having all of the usual parts of the full -- the full-length full committee meetings that we normally have. So, this is going to be a focused meeting that is in place so that we can get our work done around the IACC Summary of Advances. But I'll also give you a couple of updates.

And if we happen to be ahead of schedule, and we have time at the end, we might have a few minutes for round robin as well. We scheduled this meeting for a couple of hours, but we may or may not need all of that time. So, we'll keep track of that and try to keep that moving as needed.

I also want to take a moment to welcome our new Federal IACC member, Dr. Annapurna Poduri, who is from the National Institute of Neurological Disorders and Stroke, replacing Walter Koroshetz, who is still at NINDS, but

Dr. Poduri is joining us. And if you are on, Dr. Poduri, you are welcome to say a few words and introduce yourself.

DR. ANNAPURNA PODURI: Thanks so much. It's great to be here. As some of you know, I'm a child neurologist by training. So, the IACC is certainly an area of high priority for me personally. And my work has been in the genetics of epilepsy and neurological and neurogenetic disorders of childhood. And I think the interdisciplinary nature of this group in particular has been very appealing. So, when Walter asked if I was interested, it was a resounding yes, and I am grateful to be here. Thank you.

DR. DANIELS: Thank you so much. We look forward to working with you.

And some housekeeping notes that I'd like to share with you. So, closed captioning is available in Zoom for IACC members and members of the viewing public. And IACC members, you're welcome to turn your camera on during the discussion and unmute

yourself to speak.

You also can submit written comments to the panelists labeled "Send Comments Here." And that's -- Steven Isaacson from the ONAC staff who is our neurodiversity liaison, and he will read the comments aloud on your behalf.

Also, for everybody who's listening to this meeting today, the meeting materials for this meeting are posted on the IACC website, and the link is given here on the slide. But you can also just navigate to our website, go to Meetings, and the first meeting that you'll find is this meeting. And just scroll toward the bottom of the page, and you'll find all the meeting materials.

So, I'm going to start with a brief update on the Autism CARES Act of 2024. So, I know that everyone in this group was probably very happy to hear that the Autism CARES Act of 2024 was signed into law by President Biden on December 23rd, 2024.

So, now, the IACC is reauthorized to

continue its work through September 30th, 2029. However, with this authorization, we will need to reconstitute the committee. And so, we will be putting out a Call for Nominations for that. And I'll tell you a little bit about that in a minute.

But as a brief update, just, the reauthorization did not make major changes to the IACC responsibilities for membership requirements. However, there are some updates around different autism-related programs in the law, and we'd encourage you to check that out. And we have that link up on our website. We have a specific page that is dedicated to the Autism CARES Act of 2024. And so, you can go to that page, and you'll see the actual legislation link there and some additional information.

So, with regard to the IACC Call for Nominations that some of you may have questions about, or you may be wondering how this is going to work, the Department of Health and Human Services will be issuing a

Call for Nominations for new IACC members very soon. And public IACC members who have only served one term so far are eligible to serve for a second term, but you will have to put in a nomination.

And public IACC members who've already served two terms are now term limited and won't be able to serve again. But of course, we tremendously appreciate people who have served two terms for their dedicated service for that long period of time.

The Call for Nominations is going to be posted in the Federal Register online and also on the IACC website when it comes out in the coming weeks. And it will include the eligibility requirements for the committee, required application materials, and instructions on how to send that in. Electronic is best. But if you need to send it by paper or mail, there will also be an address for that.

We will have descriptions of the responsibilities of the IACC and the deadline

for submission. And so, you will be seeing announcements coming out through the IACC email list. And to join that list, if you're not already on it, for anybody in our listening audience, visit our website, and at the top -- actually, if you're at the top of our website page, there's -- there are buttons about contact IACC, and you click on that, and you subscribe to the IACC email list.

And once that comes out, feel free to share with your networks. It'll also be shared on social media. So, we hope that the word will get out, and we will leave ample time for people to put their nominations together and send them in. And we look forward to hopefully having a large number of people who are really excited to serve on the next committee. Maybe I will pause there for a minute, if any IACC members have questions about that.

DR. DENA GASSNER: Susan, this is Dena.

DR. DANIELS: Sure. Hi.

DR. GASSNER: Hi. I know I, for one, have been in the midst of so much chaos in my life. I don't even know how long I've served. So, if we could be informed about that, that might be helpful.

DR. DANIELS: That's good. Yes. So, you're a one-term person. So, people who have served since 2021 are just for one term so far. We actually only have two members who will be rotating off the committee, Julie Taylor and Sam Crane, who have served two terms. And thank you to both of them for their length of service. It's been really wonderful having them on the committee. But everybody else is a first termmer that's on our committee right now. So, that means --

SAM CRANE: Thanks, Susan.

DR. DANIELS: You're welcome. So, everyone else is -- among the public members -- is eligible for being renominated. And it's also open to the rest of the public. And usually, the Secretary chooses a mix of

previous members and new members to staff the committee. So, we look forward to what the new committee will hold but, of course, have really enjoyed working with this committee. So, thank you so much. And there will be more information as the Call for Nominations is released. So, just be on the lookout for that.

I also wanted to give you an update on some of the closeout items that we're working on right now. So, the 2023 IACC Summary of Advances document is just ready to be published. It probably will be out within a week. So, keep your eyes open for that. It will be released soon. And then we're here to finalize the nominations for the 2024 IACC Summary of Advances. And we'll be discussing the articles today and voting after that.

And also, we are working on the 2024 -- and I guess it will go into 2025 -- IACC Strategic Plan Update, which you approved with some changes back in September. And we're still working on getting those final

edits in so that we can get that out to the layout and final publication. So, be expecting that in the near future as well.

So, today, for the -- oh, sorry. Let me backtrack to doing the roll call. I'm sorry. I got all excited about all the work that we have to do, and I skipped doing the roll call. So, we will go back and do the roll call for today. So, everybody knows who is attending. So, we'll start with the federal agencies. Shelli Avenevoli.

DR. AVENEVOLI: Present.

DR. DANIELS: The Administration for Children and Families, Allyson Dean or Amanda Bryans. AHRQ, Justin Mills or Robyn Sagatov. The CDC.

DR. KARYL RATTAY: Hi. This is Karyl Rattay. Present.

DR. DANIELS: Hi, Karyl. Welcome. CMS, Centers for Medicare and Medicaid Services.

MS. JODIE SUMERACKI: Hey, this is Jodie. Present.

DR. DANIELS: Thank you, Jodie. The FDA.

HRSA.

MS. LAUREN RAMOS: Hi. This is Lauren Ramos.

DR. DANIELS: Hi, Lauren. The IHS, Indian Health Service. NIH.

DR. JANE SIMONI: Yes, hi. Jane Simoni, representing Monica Bertagnolli, the director.

DR. DANIELS: Thank you so much. NICHD.

DR. ALICE KAU: Alice Kau is here, sitting in for Dr. Bianchi.

DR. DANIELS: Thank you, Alice. NIDCD. NIEHS.

DR. CINDY LAWLER: Cindy Lawler, sitting in for Rick Woychik at NIEHS.

DR. DANIELS: Thank you. NINDS.

DR. PODURI: Anna Poduri, present.

DR. DANIELS: Thank you. SAMHSA.

MR. MITCHELL BERGER: Mitchell Berger, present.

DR. DANIELS: Thank you. Department of Defense.

DR. NICOLE WILLIAMS: Hi. Nicole

Williams with the Autism Research Program.

DR. DANIELS: Thank you. Department of Education.

MS. CHRISTY KAVULIC: Hi. Christy Kavulic, Department of Education.

DR. DANIELS: Thank you. The EPA.

DR. ELAINE HUBAL: Hi. Elaine Cohen Hubal, Office of Research and Development.

DR. DANIELS: Hello. HUD. Department of Justice. Department of Labor.

DR. SCOTT ROBERTSON: Hi. This is Scott Robertson from the U.S. Department of Labor's Office of Disability Employment Policy.

DR. DANIELS: Thank you. Social Security.

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

DR. DANIELS: Hello, Alison. And the Veterans Administration. Thank you. And people may also be joining a little bit late. So, we'll try to make sure that we check Zoom to see if other people joined and mark their attendance if they join us later.

So, then now, we're going to do public members. Maria Mercedes Avila.

DR. MARIA MERCEDES AVILA: I'm here. Hi.

DR. DANIELS: Hi. Nice to see you all.

Alice Carter.

DR. ALICE CARTER: Here. Nice to see you all.

DR. DANIELS: Thank you. Sam Crane.

MS. SAM CRANE: I'm here. Thank you.

DR. DANIELS: Thanks, Sam. Aisha Dickerson.

DR. AISHA DICKERSON: I'm here.

DR. DANIELS: Hello. Tom Frazier.

DR. THOMAS FRAZIER: Present and good to see everyone.

DR. DANIELS: Good to see you, Tom. Dena Gassner.

DR. GASSNER: Here. Thank you.

DR. DANIELS: Morénike Giwa Onaiwu. Oh, I see your hand raised. So, welcome. Alycia Halladay. Craig Johnson. Yetta Myrick.

MS. YETTA MYRICK: Happy New Year, everyone. Here.

DR. DANIELS: Happy New Year. Lindsey Nebeker.

MS. LINDSEY NEBEKER: Hello, everyone. I'm here.

DR. DANIELS: Hi, Lindsey. Jenny Mai Phan.

DR. JENNY MAI PHAN: Hi, everybody. I'm here. Happy New Year.

DR. DANIELS: Hi, Jenny. JaLynn Prince.

MS. JALYNN PRINCE: Pleasure serving with all of you. I'm here, JaLynn Prince.

DR. DANIELS: Thank you. Camille Proctor, I think, might be running a little bit late, but -- oh, is she on?

DR. AVENEVOLI: Yeah, she's there.

DR. DANIELS: Susan Rivera.

DR. SUSAN RIVERA: Present. Great to see everyone.

DR. DANIELS: Good to see you. Matthew Siegel. Ivanova Smith.

MS. IVANOVA SMITH: Hi. I am Ivanova Smith. I'm here.

DR. DANIELS: Thank you, Ivanova. Hari.

MR. HARI SRINIVASAN: Hi.

DR. DANIELS: Hi, Hari. Helen Tager-Flusberg. Julie Taylor. And Paul Wang.

DR. PAUL WANG: Hi, everyone. Present.

DR. DANIELS: Wonderful. And if there are people who are arriving late, you can always just signal us in the webinar chat, and we will try to make sure that your attendance is noted.

So, my next order of business is to let you know that we have a couple of editions of the minutes, the minutes from the July meeting and the September meeting that we posted on the IACC website. I'm not sure if people feel like they've had a chance to review them to the extent that they'd like to. Can I get a sense of the room, whether you'd like to try to approve the minutes here in this meeting, or if you'd like more time and just do it by email?

DR. GASSNER: Email, maybe.

DR. DANIELS: Email?

DR. DICKERSON: I would prefer email.

Because I haven't had the opportunity to review them thoroughly.

DR. DANIELS: Okay.

DR. CARTER: Email.

DR. DANIELS: Sure. Okay, sounds like I have a few emails there. So, that's totally fine. We will just include it with the ballot for the Summary of Advances, so that you can just check the box. But we have the draft minutes posted on the website, and we'll include the link in our email correspondence afterward.

But the drafts are there. If there's anyone from the public who wants to see, in general, what was discussed at those meetings in a minute's format, you can look at those drafts. But we will finalize them as soon as we get the votes from the committee to finalize them. So, thank you so much.

All right. So, now, we will turn to our IACC Summary of Advances discussion. There's a little delay with the slides. There we go. Okay. So, the 2024 IACC Summary of Advances

process. The IACC members, you all nominated articles from January 2024 to January 2025 or to the end of December, actually.

And so, we have all your nominations. We looked at that first batch in April. So, we had 18 nominations that we discussed in April. So, those are not being discussed today. But you all submitted another 98 nominations, which is wonderful. We have a nice number of nominations that cover all seven questions of the IACC Strategic Plan.

And our goal today is to give you an opportunity to discuss those nominations. If you'd like to put in a few words for certain nominations that you're very excited about or if you have any concerns about things that have been nominated and whether they either meet the criteria or just rise to the call for something that is considered in advance, you're welcome to discuss that. We can have that discussion.

And then after this meeting, our team will be sending you an email ballot, as we

have in past years, and you'll have a chance to select the top 20. And you also have the opportunity to look at it however you like. Some people prefer to vote based on their expertise and vote for things that are within their expertise. Other people feel comfortable looking across the whole strategic plan.

And I know all of you, having been on the committee, most of you for three years now, are pretty familiar with the whole scope of our strategic plan, and you've helped create that. And they also feel comfortable voting for items across all seven areas or a subset of areas. So, however, it works out, we have a large enough committee. It should be able to cover the whole seven questions.

And we will take those top 20 articles, and our team will work with our contractor to develop summaries of the top 20. And the final document will have those summaries of the top 20 in lay language, as well as a listing of all the nominated articles that

made it through today's meeting and that were not eliminated, that stayed on that list. And then we'll produce a publication.

And so, the 2023 version of this is about to be published. And so, this will be the 2024. So, IACC members will also have an opportunity to preview and comment on the draft publication, if we have enough time. Hopefully your -- you -- all of you will have your terms expire in March. And so, our aim is to get that to you for a preview before your terms expire. And that's based on Federal Advisory Committee policy.

Unfortunately, we can only extend terms for 180 days. And so, we will go to the 180 days. But you, hopefully, will have a chance to preview the next volume. And then our team will be able to continue working on it after you have stepped off the committee. And then we'll prepare the final publication for spring to summer 2025. So, that's the process we're going to be following. Next slide. There we go.

And so, the goal of today's discussion is to look at the list of -- I think that should say 98 nominated articles. And the selected articles should represent significant advances or progress in the field of autism across seven topic areas of the IACC Strategic Plan. And this can include biomedical research and other types of research, including services research.

And during the discussion, you can note whether you find these nominated articles noteworthy. And if you have ones you'd like to speak to, feel free to raise your hand, and you'll have a moment to speak about them. And also, to determine if there are any studies you feel are too preliminary to be considered in advance.

Or if the sample size is too small. We did try to eliminate review articles. So, there shouldn't be any on the list. But let us know if you feel otherwise. Also, commentaries were not eligible for workgroup recommendations. We have other ways that we

can acknowledge those in other types of publications, [inaudible comments].

So, we're going to start now. And Dr. Avenevoli will also be helping us with this discussion. And we open the floor for discussion of Question 1. And Shelli, I don't know if you have any comments or if you have anything else you want to say, other than --

DR. AVENEVOLI: I do not.

DR. DANIELS: Okay.

DR. AVENEVOLI: So, let's open it up to the larger group.

DR. DANIELS: So -- and I know there are a lot of slides. I will try to go through the slides, so you can have a moment to kind of take in what's on these slides. I'm sorry. I can't see the screen. Okay. Did you have a comment, Yetta?

MS. MYRICK: It was before you guys started. If I could just backtrack for one moment, just to ask.

DR. DANIELS: Sure.

MS. MYRICK: Once you got -- once we all roll off in March, and you all finalize it, even though we would technically have rolled off, would you all then email the group to let us know that it's available?

I know, like I'm on the list. I'll get information. But would we get information as previous members about the Summary of Advances and get information to share out?

DR. DANIELS: You are going to be on our email list until you tell us you don't want to be on it anymore.

MS. MYRICK: Okay.

DR. DANIELS: So, you will receive that email and be notified. And your names will also be associated with that publication because you did the work to put this together. So --

MS. MYRICK: Okay. I just want to make sure that I have, like, the appropriate language to share with the community. We've had these conversations before, but I just want to, like, make sure I call that up once

I --

DR. DANIELS: So, you can feel free to repost the social media posts. Or if you'd like to forward emails or if you need any other type of publicity item, you can always write to us, and we can help you with that and make sure you have what you need.

MS. MYRICK: Sounds great. Thank you.

DR. DANIELS: You're welcome. Okay. So, I'm just going to just move to the next slide. I wanted to give people time to be able to skim some of these. You also have the list that is online, so several different papers that are on the topic of screening and diagnosis, including some recommendation by members.

DR. GASSNER: Susan.

DR. DANIELS: Yes, go ahead.

DR. GASSEN: Just a functional, like clarification. So, when you put the slides up, if we have an observation about any of the research articles, we're just supposed to raise our hand and jump in?

DR. DANIELS: Yes, just go ahead and raise your hand. And you don't have to be on the same thing that's on the slide. If you have anything for Question 1, feel free to raise your hand, if you have any --

DR. GASSNER: Okay. Can we go back to number 2 -- research number 2? I'm sorry. I didn't quite know how we were working this.

DR. DANIELS: Okay. Because there's so many, I'm not always going to be perfect about things. But I'll try.

DR. GASSNER: No, this works fine. This works fine. I did want to convey a concern about this particular study in that -- and I would be encouraging researchers in these abstracts to be more explicit about this information. But in this particular study, it seems a little gender slanted because 78 percent of the participants were male.

And you know, given that we're increasingly seeing higher and higher rates of missed diagnoses in females, I just have concerns about studies that are not doing

more intentional recruitment of people who are not only female, but gender nonbinary or gender non-conforming or transgender. And if those people are included in the studies, the researchers really need to be explicit about that.

I think it leaves us wanting to know more about that sample population. And I'm going to say that I'll probably raise my hand about that on a couple of studies that have that same concern for me, either the information's not there, or they didn't do that recruitment that I think is so critical.

DR. DANIELS: Thank you for that comment. Does anybody that has maybe a little more expertise in this type of area have any comments about that?

DR. ALYCIA HALLADAY: Me. Do I need to raise -- sorry. I'm technologically --

DR. DANIELS: Thanks, Alycia.

DR. HALLADAY: Sorry. Okay. Sorry. I apologize. I actually logged in earlier, and it said that I was Morénike, which is a huge

compliment, but somehow, I'm technologically impaired. I would say that I completely understand Dena's comment. But the reality is, is that there is still a four to one or whatever, three to one -- there's a disparity in diagnosis. And so, we kind of have to meet people where they are in terms of what their recruitment is like.

And the reality is -- right now is that we are going to recruit more males versus females. So, that -- we can't necessarily ding that against them, because they didn't recruit 50/50. Although people are trying to do that. And this did come from a study that is exactly trying to do that as well.

DR. DANIELS: Do we feel like this should stay on the list, or should it --

DR. AVENEVOLI: Morénike has her hand up.

DR. DANIELS: Oh, sorry.

DR. HALLADAY: Yeah. I'm not suggesting -- so, I just want to say that I wanted to answer that question. I --

DR. DANIELS: Right.

DR. HALLADAY: Whatever I say for the next couple of hours is not meant to sway anyone's vote, and people should vote their conscience. But I just wanted to --

DR. DANIELS: Okay, not a problem. Morénike or -- sorry. I guess Kristi is first. I can't see you on my screen, but I can see you on the big screen.

DR. KRISTINA HARDY: Yeah. Sorry. I just happened to look at this article yesterday. So, these kids were one to eight years old. So, I think that also limits the -- our ability at this point to look at nonbinary or people who identify in other areas of gender for this. Because we don't see that represented very well in that age group yet. So, I don't think we should dig [phonetic] for that.

But I also agree, like we -- this group is trying to make sure that they're sampling adequately across gender and biological sex. But I think the other thing is that we're probably -- that's more difficult among

younger children with these, even though that -- this needs to happen if this research moves forward. I think we should consider it, and everyone will be able to read and determine whether this was fairly represented.

DR. DANIELS: Thank you. Morénike. Is that one coming in on chat? Or is it --

DR. AVENEVOLI: None on chat yet.

MR. STEVEN ISAACSON: No, nothing here.

DR. DANIELS: Or did you want to speak about that, Morénike?

DR. ONAIWU: Not at this time.

DR. DANIELS: Oh, okay. I think your hand was raised. Okay. Oh, somebody else may have your name. Alison. Alison Marvin.

DR. MARVIN: Yeah. I was just trying to hit the unmute button.

DR. DANIELS: No problem.

DR. MARVIN: So, yes, I'm actually agreeing with what the other previous comments that, yes, as somebody who's been involved with recruiting for autism studies,

the fact that there is a four-to-one male-to-female ratio in diagnosis means it's -- it becomes much harder to recruit girls. And I think this is perfectly legitimate, and they're doing their thing.

And also, the comment about being the under eight -- the one-to-eight-year-olds, yes, it's -- you're going to have -- not going to be having a lot of people with gender dysphoria or any issues. So, I just wanted to agree with that. I think we should keep this in and let people read it and then -- and make their own decision.

DR. DANIELS: Okay. Thank you for that comment. Aisha.

DR. DICKERSON: Yes. I'm looking at the whole paper. Because as we go through it, that's probably what I'll do. So, it looks like they're recruiting the participants from an ongoing study, which means that they don't really have the opportunity to decide who they're recruiting. So, even if they want to recruit more females, that's not really an

option. They were just taking data that was previously provided.

My assumption is that would be the case for a lot of these studies. Because people aren't able to get money for cohort studies, they're to do a secondary analysis of whatever is already ongoing. So, I wouldn't use that as a limitation for why something shouldn't be included in this list.

DR. DANIELS: Thank you. So, something we can keep in mind as we look across all of these nominations too, that this might be true in more than one case. Ivanova.

MS. SMITH: This is Ivanova, and I think that -- I'm nonbinary myself, and I didn't really understand that stuff until I was a teenager. And I wasn't able to express that. So, that makes sense that it -- kids wouldn't be able to express that. Because I didn't -- but we should still look out for like signs of like the -- if the child is expressing a different gender expression that that doesn't get counted against them in like ABA

treatment.

Because sometimes, like, people will say that's just the person being -- we're not complying, like not -- trying to be non-neurotypical, like -- and I think we should just honor people's expression and make sure that we're not forcing gender roles on people who are little like that. Like we should make sure not to force gender roles on them and help ABA providers understand that.

That there's actually a higher percentage of people with intellectual -- a lot -- there's a lot of autistic people that identify as non-binary, and they're not able to say when they're kids. But they say it through their expressions. And sometimes, ABA providers will try to get them to stop doing that as a way of trying to normalize. And we should try to work on not doing that, just as my thoughts. Thank you.

DR. DANIELS: Thank you so much.

Lindsey.

MS. NEBEKER: Okay. Before I have my

question, I think that there's been confusion, and Morénike and I -- with our names on our profiles and things.

DR. DANIELS: Okay.

MS. NEBEKER: I actually noticed -- I think right now, it shows Morénike has my name as well as -- but my name's been corrected now. But I think Morénike now has my name listed on their profile. So, I'm not sure how that -- I just wanted to point that out.

So, I -- my question is, I don't really quite recall when we're analyzing each of these articles, but I'm wondering if we, as part of the -- our analysis, was including how the studies are titled. So, for example, one of the, you know, research studies that we're reviewing has a title that's called Factors Associated with Confirmed and Unconfirmed Autism Spectrum Disorder Diagnoses in Children Volunteering for Research.

So, I have to admit, the actual title in

itself is kind of confusing. Because I am not sure if that -- personally, if that indicates children are actually volunteering. So, I don't know. Again, I think the question is more of, are titles one of the things that we consider when we're reviewing these articles?

DR. DANIELS: So, something I would say is the titles are something we can't control. It's really what the researcher put there as a title. And so, I'm sure that when people nominate things, they're reading the abstracts and articles and looking at the [inaudible comments].

So, some people may decide not to nominate something if they don't like the title, but others may look more into the content of the overall article. And that might be different from one person to another. So, feel free to express any concerns.

I think, with this article, number 3 here, about children volunteering for

research, most likely that is referring to just children who are enrolled in studies, and they're considered volunteer participants, even though they may -- they have -- may have had a parent allow them to be in the study. And they wouldn't have signed off on it themselves.

MS. NEBEKER: Okay. Yeah, that's helpful. I mean, that wasn't like -- I think I meant to clarify that I didn't view it as like, whether to nominate or not kind of criteria. I'm just wondering, in certain articles where titles might have some confusion, if we do have a little room to put a little, like clarification note or something like that. Does that make sense?

DR. DANIELS: We do have -- yeah. We have descriptions already written. But if anyone feels like they want to revise a -- well, actually, we're probably going to be sending them out. But if -- during this meeting, if you identify a description that needs to be updated, you can flag us and let

us know. We can try to help out with that before it gets sent out for the ballot. So, maybe that would help out. Aisha.

DR. DICKERSON: I don't want to belabor this point, but looking back at the abstract, they focused on sex assigned at birth. So, this isn't a gender versus -- a gender enrollment type of issue.

They're very clear in the abstract. As far as the titles go, sometimes I like to make my titles a little more exciting with song lyrics and things like that. So, I wouldn't want to put much emphasis on that either. I'm hoping that as we move through these, we focus on the science that's presented in both the title and the abstract. And hopefully, that'll help us move right on through it.

DR. DANIELS: Sounds good. All right. So, I'm going to keep going through the slides -- go ahead. Is there another --

DR. AVENEVOLI: Alice.

DR. CARTER: Yeah. I was just going to

say, I actually think this article is important. Because a lot of the community cases were not confirmed by the researchers, and it kind of highlights that in their conclusions. They highlight both under- and overdiagnosis. So, I actually think it's an important article in terms of this category of screening and diagnosis.

DR. GASSNER: Alice, are you talking about number 3?

DR. CARTER: The -- yes, the confirmed and unconfirmed.

DR. GASSNER: Yeah. My only concern with that one is that the diagnoses were confirmed or disconfirmed by doctoral level students. And having gone through assessments with my own son, using doctoral students, I can tell you they were wrong every single time. And so, I just -- I really wish they would have used community-based providers who had a wealth of experience in ascertaining these diagnoses rather than students. But that's just my take.

DR. CARTER: So, I'll read it again. But I don't know if the graduate students were the assessors and then supervised by more senior clinicians, which is typically what happens. Because usually, the grad students, like in my group, they'll be doing the assessments, but there are licensed clinical psychologists or other licensed people in the background actually assigning diagnoses.

So, I'm happy to look at that again and -- but yeah, it would be unusual if grad students were assigning the diagnoses. They're probably doing the assessments, and that's a clear distinction.

DR. DANIELS: I will keep scrolling through. Any other comments on Question 1 items?

DR. WANG: This is Paul Wang.

DR. DANIELS: Go ahead.

DR. WANG: If I can also chime in on article number 3. I have not read it in detail. I've only looked at the abstract and reacted to the title. I can understand other

people having reactions to the title as well. So, I don't know the methodology exactly and what -- I can't confirm or disconfirm what Dena said. I take her on her word for it.

I think it's important -- an important article, though, because it does show the diversity of autism and just the idea that a community diagnostician could and often does come to a different conclusion than perhaps a rigid academic diagnostician.

So, it's just a reminder that there is this variability based on who diagnoses, based also on potentially self-identification of autism. And it's important to keep that diversity in mind when reading other papers and really think about how the subjects were selected.

DR. GASSNER: Hari, did you want to contribute?

DR. DANIELS: Thank you, Dena. Okay. I did hear you, Hari. I wasn't sure if you were trying to -- oh, you said you're good. Okay.

So, I'm trying to scroll slowly. I don't want to rush anybody, but we'll, you know, just keep moving along. But you have the actual list. So, you can see what's there. Does anyone have another -- any other articles for Question 1?

MS. CRANE: Yes. I was just trying to say I put some comments in the chat about Question 1.

DR. DANIELS: Okay. So, would you like to read it? Or would you like us to read it? Or [inaudible comments].

MS. CRANE: I'm just -- I'm in, like a not ideal --

DR. DANIELS: Do you mind if I read it?

MS. CRANE: Yeah.

DR. DANIELS: So -- okay. So, you said, "I think that both articles 1 and 2 are very important. Number 1 is really particularly noteworthy to me because it identifies a potentially very significant driver of missed diagnoses in children assigned female at birth."

DR. AVENEVOLI: There's one higher, too.

DR. DANIELS: Oh. [inaudible comments]

DR. AVENEVOLI: I'll read it. Another comment from Sam is, "I am similarly concerned that with some of the disconfirmed diagnoses, it's not clear who is actually committing the error." So, I think that's number 3 -- article number 3.

DR. DANIELS: Thank you so much, Sam. And our team, feel free to signal me if I'm not reading the webinar chat well, and I'm missing some of that. I'm trying to pay attention to the raised hands as well.

And I see that Hari has a comment here. "I found Dena's comment on grad students doing assessments to be amusing." But anyway, yes, grad students are often doing work in labs, but the point was well taken. And people will have a chance to look at the paper.

DR. AVENEVOLI: Anna, go ahead. Anna, sorry, go ahead.

DR. PODURI: Yeah. So, a quick question,

in terms of, there's so much material here, and there's so many good articles, is there a goal of how many would you'd like to highlight in the report? I mean, I'm just wondering if we should be kind of reading them or just say just yes or no, include. Or is there a limit on how many would be highlighted?

DR. DANIELS: So, in this meeting, our goal is to look through all 98 -- I mean, not to necessarily discuss all 98, but just to determine whether they should even be on the ballot. And then you're going to have a ballot to vote for the top 20. And that will be done by email.

DR. PODURI: Great. Thank you.

DR. DANIELS: So, if you see anything that needs to be eliminated or something that you want to support, and you think this is a really great paper that you would like to highlight for people that you might want to consider voting for, feel free to do that.

DR. AVENEVOLI: Dena. Go ahead, Dena.

DR. GASSNER: Thank you. I just wanted to point out; I tried to review article number 6. And it talks about using the STAT, the Screening Tool for Autism in Toddlers and Young Children. And it is not available online. So, it was very difficult for me to evaluate the study itself without looking at the instrument.

And let me give you another example that demonstrates why I'm concerned about the instrument itself. A lot of the articles that are in this section also use the M-CHAT, and I have been able to secure that online. And it just stresses me that it is highly notable that it's looking for outwardly demonstrable, externalizing expressions of autism.

And as a result of that, it may be less sensitized to what is actually the vast majority of autistic toddlers that may have language, maybe without intellectual disability. And so, it's just -- without being able to see the instruments, it's

difficult to assess the research studies.

So, anyway, that was just my feedback. And of course, that influences my concerns about some of the articles that are dependent on the -- these instruments that we haven't always been able to see.

DR. DANIELS: Thank you so much. We'll continue scrolling through Question 1. And if you have other comments, feel free to make them. And if -- it doesn't matter. We can go back on the list but trying to balance keeping us moving while also allowing everybody to have a say and be able to share what your thoughts are.

Are there any other articles in this group that you have either concerns about or things that you'd like to highlight as being particularly noteworthy papers?

DR. AVENEVOLI: Alycia.

DR. HALLADAY: Sorry. I just want to recognize that a number of these are using, like, either a new technology, like the Wilson paper, or some online version or

machine learning prediction. And so, I think -- I'm just making a general comment that I think that that's probably a new direction in autism that we should -- that this committee should probably at least keep their eye on and that should be made notable to the higher ups in Congress as part of the report.

So, I'm not sure how to do that exactly, but there is -- there are a lot of technologically driven -- which I think is a good thing -- submissions.

DR. DANIELS: That's great. We can highlight that in the press release that goes with this and/or introductory material that might be [inaudible comments]. Great point. So, thank you. Alice.

DR. CARTER: You know, I noticed the same thing about a lot of new technologies, and I guess I wondered about them. Because at one point, when we were reviewing papers for this same process, we were trying to avoid things that were, like, brand new and not well tested. So, I actually really like Alycia's

suggestion.

I mean, I wonder if there's a way to -- like some of these very new things that have worked in one sample and not yet replicated don't seem to meet sort of the -- you know, sort of status for what this -- you know, the best 20 are, I don't think, based on previous discussions. But I could be wrong about that.

But I do think some kind of summary about these new innovative technologies coming down the road -- it is really exciting. And you know, some of the machine learning predictions that have yet to be replicated are still really exciting because they're very consistent with what one would expect based on a variety of theories.

So, I'm -- so, I guess there are two questions in there. One, if it's not included, can you include it in sort of a brief paragraph, in addition to the 20 they had nominated? But two is, should that be a criterion for selection that something that's

new and just tried out once is, like, maybe not something that should be highlighted so much because it's further away from translation?

DR. DANIELS: So, I don't think that we've really gotten into that in the last -- some of the discussions we had previously. I know that innovation is one of the factors. And so, there's a balance between something that's innovative and something that may have a lot of weight behind it already.

So, I think that you all should be able to make that determination of whether it would serve as an advance that we want to highlight. And anything that's not selected will just be listed basically in the back of the volume as a paper of note. But hopefully, as we all have these discussions, the committee will be able to select the ones that you think are the most noteworthy.

Dena.

DR. GASSNER: I second what Alice says about, you know, the innovation component of

this. I think it is exciting. I did want to convey, though, like with machine learning, it specifies in the abstract, researchers noted the model's ability to accurately identify autistic individuals with more symptoms and lower cognitive levels. Again, very externalizing observable criteria.

And my concern with machine learning is that we may not be -- again, we may be self-fulfilling this underdiagnosis of less externalizing individuals with machine learning and other tools that are dependent on something dramatically observable, instead of it being this probative interview approach that would allow things to become unearthed, that are not necessarily readily observable.

I see -- I think there's room for new and innovative research that's kind of like not proven. Or in this situation where you're looking at using the SPARK database, which many families will not participate in, I think we have to, you know, maybe categorize them differently.

DR. DANIELS: Thank you for that.

Alison.

DR. MARVIN: Hi. I'm kind of speaking as branch chief of the Division of the Analytics Center of Excellence and as a statistician with staff members who are actively involved in data science and machine learning.

But -- so, I've probably about three comments I wanted to make. The first is that we've had a lot of machine learning-related articles. Last year, we've had them, the year before. So, it's not new that we have machine learning articles proposed.

The second thing is that, yeah, machine learning is -- it's actually quite -- it's an established science. It's -- the series of tools one uses in machine learning, the methodologies -- it's mature. It's not like somebody discovered it last week. It's been going on for a while.

And the third thing is that the typical methodology is -- what it's doing, what many of these studies are doing, the theme is,

what can we do to make it easier to get diagnoses done as quickly as possible? So, you actually have your normal -- these are kids with autism.

What can we do to identify them early, so we don't have to have the clinicians do -- you know, the expense of the ADOS? We can just do something with more basic data or use machine learning to look at other physical characteristics. There's the video one.

So, what can we do to try and speed up the diagnosis of kids, so kids aren't waiting two years or three years for an evaluation to get a diagnosis? Here, we can fast track kids as much as possible to try and get them in. And the more kids we have available, we can fast track this kid, get them at maybe a faster evaluation, and that will also increase the amount of data we have -- training data we have to improve the model.

So, I think these machine learning studies are actually really useful, and I'm in favor.

DR. DANIELS: Thank you. And Steven, do you have one to read for us?

MR. ISAACSON: Yes hello. So, this comment is from Hari. "They say that AI depends on the kind of data set it's trained on. So, there's potential for bias. But they say it's here for the future -- it is the future, and here to stay. We just can't ignore it."

DR. DANIELS: Thank you. All right. So, I -- JaLynn.

MS. PRINCE: In relationship to that, with AI, there's still a huge debate in general with AI. Because so much of the information that has been put in has been gender-biased toward males. And so, that could add to diagnosis with women and girls, unless we do have more qualified people who are able to put in the data for women and behaviors and observations of young girls and women.

DR. DANIELS: Thank you. Paul.

DR. WANG: I'd just like to add another

comment on AI. Indeed, a really powerful technique and one that has the potential -- sorry for the alarm in the background -- has the potential to really allow us to scale approaches that are incredibly time consuming and costly. If it can be done by AI, that's fantastic. But as JaLynn points out, and others, I'm sure, it depends on the data going in, the training data. If you have bad data going in, you'll come to an incorrect conclusion.

Also, very important with AI is that it will almost always find something. And so, for every article, every study using AI, it is important to ask whether they did a validation of their finding, potentially with a separate population, a separate data set, to make sure that what was found in the initial analysis really holds true.

DR. GASSNER: Yeah, Paul, that's what my concern is about this. And another study we talked about is, you know, if someone who is assigned male at birth manifests with a lot

of hyperactivity and a lot of externalizing behaviors, is the AI -- is the machine learning going to pick up on a girl who twirls her hair as her sensory input? Right? Is it going to be nuanced enough to capture that as effectively?

I would agree that anything that can identify the individuals who have significant externalizing manifestations of autism, the earlier, the better. But I also want to make sure we're making sure that everything is sensitized, so we're identifying other autistic expressions, so that we stop leaving girls and children of color behind as dramatically as we have.

We keep putting this four-to-one ratio, but that seems to disappear in adulthood. And it really doesn't disappear. We've just done a really bad job of identifying them early on. So, that's my overall concern about, you know, AI, is that I don't think it's sensitized enough yet.

DR. DANIELS: Okay. Just as a reminder,

we have -- we're almost at 3:00 p.m., and we still have the other six questions to go. So, I don't want to curtail the discussion, but maybe we can keep this brief, so we don't want to give short shrift to the other areas. Although these comments, I think, also apply to more than one area. So, Alycia, go ahead.

DR. HALLADAY: Oh, I would just say that that's the purpose of the research, right? So, if you don't necessarily like a study -- you think the study itself is poorly designed, and that's one thing. But the purpose of this research is to improve these tools. So, yes, we can make judgments about the individual studies, but I wouldn't exclude a whole class of say, AI, because it's not necessarily accurate enough. We need to do more research to improve it.

DR. DANIELS: Do we have any other comments here? I'm going to move to Question 2, the biology underlying autism. So, do we have any comments about some of the articles here? Jenny.

DR. PHAN: I have a few articles to comment on, but I'll start with one and then let others comment. The first one is number 18, antisense oligonucleotide therapeutic approach for Timothy syndrome. I -- that's a complicated research article. I tried to read it, and it's not easy to read. But the article uses cells from patients with Timothy syndrome. It's not exactly an autism paper. So, I want to raise this as a paper to potentially get removed from -- to be reviewed and voted on.

DR. DANIELS: Yes. And that has been one of our criteria in the past. And we have removed papers that weren't specific to autism, even though Timothy syndrome can have autism as part of it. But we wanted the articles that ultimately end up in the Summary of Advances to be focused on autism, and we have other places where we can name other articles. So, in the past, the committee has agreed to remove those types of articles.

DR. AVENEVOLI: Alycia wants to comment.

DR. DANIELS: Go ahead.

DR. HALLADAY: I'm so sorry; I didn't unmute myself. So, I think this is part of a bigger discussion, and I don't think we should -- we have time to talk about it on this call. But I think there is a bigger discussion to be had that I know is kind of controversial, which is the degree to which genetic syndromes associated with autism or have a high prevalence of autism, like Timothy syndrome, like Angelman syndrome, like, you know, Phelan-McDermid syndrome -- just rattling some off -- are relevant to autism?

Are they their own syndromes that in fact, are not autism specific? Do they -- should they belong in -- should the discussion of them belong in -- a role of the IACC? I know that this has been an ongoing discussion and probably one that we need to continue to have.

I'm not going to comment about this

paper in general, but I do know that whether or not a genetic syndrome with a high prevalence of autism, whether that is part of autism is -- or should be included in an autism discussion has been raised before. So --

DR. DANIELS: So, we have discussed it before. We have other venues for this. For example, our new Strategic Plan Update, that's going to be talking about cooccurring conditions, does talk about genetic syndromes. And they are mentioned in other strategic plan additions that we've had and come up in other documents, including our portfolio analysis.

Sometimes some of the grants may be related to some of those other syndromes. So, I think there are places for them. However, it may be confusing for Congress if, for example, that type of an article was selected for an advance in autism. It might be a little confusing. Anna.

DR. PODURI: Yeah, I'm conflicted about

this as well. Because we have the same issues in epilepsy. And I think, you know, on the one hand, you could be really strict about which things got included, and does it have to be only generally about autism?

But then we have all these syndromes now that include and are increasingly recognizing that individuals with those conditions have autism. And it seems like that -- as that genetic discovery goes up, there'll be more and more people who are more in these individual groups, rather than in the broader group.

So, I would hate to take a groundbreaking discovery out of the running for being included because it's about something specific, if it could be -- like the platform could be relevant or the method of treatment could be relevant, even if it's not that specific one.

I guess one question is, does it involve -- should it be in the Biology section? Or maybe could there be a therapeutic section

that this would be better suited to, where it wouldn't be confused as, okay, we're saying all of autism has to do with Timothy syndrome? It's more that this is an example of a precision therapy for a syndrome in which autism features.

DR. PHAN: Can I chime in real quick to Annapurna's point? It might not belong in the Biology section. Perhaps -- maybe the Genetics section would be more fitting. But my concern is still that this article isn't relevant to the Summary of Advances initiative here, because they didn't have any indicators of autism in the paper. Though what -- to your point, Annapurna, there could be some overlaps with autistic traits, but that wasn't in the paper.

DR. PODURI: And that's a fair point, if they're not highlighting it.

DR. DANIELS: And that also corresponds to, in the Summary -- or in the portfolio analysis, the determination for whether grants belong in the portfolio. If the grant

may be on a syndrome but it doesn't mention anything about autism, then it would be wrong for our portfolio.

DR. AVENEVOLI: I'm noting a lot of agreement in the chat --

DR. DANIELS: Okay.

DR. AVENEVOLI: -- regarding this article.

DR. DANIELS: All right. So, we'll remove that article from consideration for this particular item. But it may pop up in other places as the IACC continues. Okay. So, I guess, Jenny, do you have any further comments for Question 2?

DR. PHAN: I have another comment about a different article in Biology. This is number 20, titled, Trajectory of Depressive Symptoms over Adolescence in Autistic and Neurotypical Youth. I took a glance over the article and wondered if Biology is the correct categorization for this article.

And I also want to raise the question to the group, if the article is observing mental

health symptoms, does that belong in Biology, or does that belong elsewhere, in a different category?

DR. DANIELS: According to our portfolio analysis, that's where it would fall. It would be a cooccurring condition, but the cooccurring conditions are covered in Question 2.

DR. PHAN: So, I guess this is another follow-up to that second question. We know from the literature that depression is associated with genetic and environmental factors. And yes, we could argue the same for biology. But I think a broader -- the broader literature ties depressive -- actually, depression as -- clinical depression being tied to genetic and environmental factors. Would articles that focus on depression fall more under that category?

DR. DANIELS: As I mentioned, they generally, because they're a cooccurring condition, fall in Question 2, in the way

that it's categorized for the portfolio analysis and how those categories are set up in the criteria for those categories.

For genetic and environmental issues, they really focus on specific genetics, epigenetics, and environmental toxins and those types of issues. And so, unless those were mentioned here, then that -- in terms of the categories. So, thanks for that. Dena.

DR. GASSNER: I'm just having a logistical problem. Number 20 on your screen is number 17 in my printed materials.

DR. DANIELS: It's -- the list was updated because some late-coming articles got added. So, sorry about that. But the list online is accurate to this. Yes. Which article did you want us to pull up? Was there a particular --

DR. GASSNER: It's fine. I was just trying to follow along with Jenny's comments. I found the article but thank you.

DR. DANIELS: Okay. So sorry about that. Okay, more comments around Question 2?

DR. AVENEVOLI: Paul has one.

DR. DANIELS: Okay. Paul, go ahead.

DR. WANG: Thanks. I wanted to speak in support of number 32 --

DR. DANIELS: Okay.

DR. WANG: -- which was not nominated by me, but by Helen Tager-Flusberg, who I think may not be on today. This is basically an evaluation of individuals with autism, showing that at least in a subgroup, there's greater variability in their motor performance from one trial to another.

There is a general theory about autism, about variability in CNS function, but this has mainly been based on, sort of electrophysiologic EEG measures, say like auditory-voc responses or visual or something like that. To my knowledge, this hasn't been shown with actual neural behavior performance of, you know, like a real-life action of some sort. And so, I think this article is important in demonstrating that.

DR. DANIELS: Thank you so much. JaLynn.

MS. PRINCE: One of the things that I was -- stepping back just a little bit, I think we have to be careful with some aspects of things too. Say, if someone has autism and somebody has a mental health condition of one sort or another, are there things that can be done in one population that may not be done in another?

So, if we separate things too much with the coexisting conditions, we may be missing out on specialized ways of dealing with different types of things, not just mental health, but other types of things, that could be a complicating factor.

So, I think it is important sometimes to put these things together, so people that are looking at things that may have a diagnosis of one thing but also be autistic, which is the largest proportion of whatever it is, and what are the treatments that are available? And I think with some of these things that are a little bit more rare, it would be very gratifying, perhaps, to physicians or

families to know that some topics have been addressed.

DR. DANIELS: Thank you so much, JaLynn. Dena.

DR. GASSNER: I just wanted to champion also -- my numbers are not going to be right, but it's the Literacy in Nonspeaking Autistic People, Jaswal. I have it as number 23.

DR. DANIELS: Yeah, 27 on the slide.

DR. GASSNER: 27 on yours? I just wanted to say that I feel like this is really meaningful research in regard to how we may be underestimating or not providing effective access to different kinds of learning for nonspeaking people. So, I was really excited to see something with a true, genuine application. So, yay for that.

DR. DANIELS: Thank you. Other comments on Question 2? Elaine.

DR. HUBAL: So, I think the article -- is it 39 that is looking at -- it has a mechanism for BPA. I guess my question, if I have the right article number -- no. I

thought I took this off --

DR. DANIELS: What's the title?

DR. HUBAL: The title is -- oops.

DR. DANIELS: Can you share the author?

DR. HUBAL: Symeonides? The title is --

DR. GASSNER: It was promoted by SAMHSA, and it was number 39 in that first handout.

DR. HUBAL: Yeah. Okay. Male autism spectrum disorder is linked to brain aromatase disruption by prenatal BPA in multimodal investigation. Is that one still under --

DR. WANG: Number 45.

DR. HUBAL: 35?

DR. WANG: 45.

DR. HUBAL: 45. Okay. Is that still under Biology? So --

DR. DANIELS: [inaudible comments]

DR. HUBAL: Oh, here it is. Yes. Thank you. Okay. So, I appreciate that -- so, it's listed right now under Biology. And I'd sort of like to suggest that it go under -- I mean, I don't know that there's a big

difference, but it'd be nice to see it under Gene Environment.

It does introduce a mechanism, which I think we want to raise the expectation in the Gene Environment section that we're not just looking for associations, but then there is follow up to look for mechanism and, you know, sort of causal explanations. So, I appreciate the article and just suggest that it be potentially moved to the other section.

DR. DANIELS: Thank you. We'll review that. We'll also review the one that Jenny mentioned about the categorization and correct it if it needs to be corrected. Thank you. Any other comments on Question 2? And are we ready to move to Question 3?

DR. AVENEVOLI: I don't see any questions.

DR. DANIELS: Okay. So, we're in Question 3: Genetic and Environmental Factors. Any comments on any of these articles? Sorry. We're [inaudible comments].

DR. AVENEVOLI: None online either.

DR. DANIELS: Okay. So, sounds like there were no comments on Question 3 articles. There's a short section here. So, we're going to move on to Question 4 which is on interventions. Any comments on any of these? Yes, Alycia.

DR. HALLADAY: Sorry. It might be for Question 3. The article is Schendel. It's listed under 42. So, it might be -- it's not under Interventions. It's the Three-Generation Family Histories of Mental, Neurologic, Cardiometabolic, Birth Defect. It's 42. Yeah, number 42.

DR. DANIELS: There we go.

DR. HALLADAY: I want to just kind of call out something that this group did that I really appreciate, is that they didn't just report out on the data in the supplemental section. They tagged in a tableau -- a set of tableau graphs. So, anyone -- and this is an open-access study, and everything is open access -- can go in and look at specific

hazard ratios based on the relationship between the person with autism and, say, an aunt or a grandparent or a cousin or something like that.

So, there's a lot of information on here. But I really appreciated the way that the authors kind of made it accessible, at least more accessible, to the community, by providing a set of tableau graphs, and hope that other scientists continue to do that in the future.

DR. DANIELS: Okay. Thank you. Let's get back to Question 4. Any comments on anything in the Intervention section?

DR. GASSNER: Can I ask first to just slow down for a minute and let us catch up, since our numbers aren't aligning?

I just wanted to bring up the article by Harbin, looking at inclusion models in public schools. It was so exciting for me to see something directly associated with the people who deliver educational services.

And similarly, I wanted to promote the

one after that that Sam Crane talked about. The first authors are Hersh and Dwyer, looking at autistic perspectives on -- I'm sorry. I'm in a dark room, and I can't read -- relationship building in autism.

DR. AVENEVOLI: It's 60. So --

DR. DANIELS: Are you still on Harbin, or did you move through that one? Hersh et al.?

DR. GASSNER: So, the first one was Harbin, and the second one was Hersh and Dwyer as the first authors.

DR. DANIELS: Thank you. We're there. Any other comments on Question 4 articles? Alice.

DR. CARTER: Yeah. I want -- there's a really nice article about motor problems with kids and how it relates to daily living skills, but it's not an intervention study. And I wondered if it should be in Diagnosis as opposed to in Intervention.

DR. DANIELS: Okay. We'll note that, to take a look at whether it needs to be recategorized. Which study was that? Does

the team have that?

DR. CARTER: It's in the early 40s. I can check. It's 44, nominated by NICHD. It seems like an important study. But you know -- and -- but I feel like it highlights assessment of motor skills, as opposed to an intervention that shows that if we intervene -- you know, it seems like it's calling for occupation therapy interventions, but it's not really evaluating whether skills -- improvement in motor skills will lead to gains in daily living skills.

DR. DANIELS: Okay. Thank you. We'll take note of that. It seems like I'm not seeing more for Question 4. Oh, Jenny.

DR. PHAN: Hi. I just wanted to ask a clarification question again. We're reading empirical articles. Systematic reviews and meta-analyses articles are okay, right? I'm asking because, though a good article, I don't think it's an empirical article. It's number 66, Bridging Priorities between Naturalistic Developmental Behavioral

Interventions. It's more of a technicality question.

DR. DANIELS: Okay. We'll take a look at that to make sure that it meets the criteria. If it doesn't meet the criteria, we'll remove it. Although, whoever nominated that, if you want to say anything about that. Or if not, we can internally look at it.

All right. Thank you. All right. So, if we don't have anything else on Interventions, we can move to Question 5: Services and Supports.

DR. GASSNER: This is Dena. I don't have any comments about any specific articles. Although I think that this section is the most exciting for me. But I would just say that for me personally, this is where the rubber meets the road, right?

All the other things we've looked at are interesting and fascinating and may have future implications way down the road. But this section here reflects research that's actually changing people's lives in real

time. And I just wanted to emphasize the value of that and just -- and as we start to prioritize our top 20.

DR. DANIELS: Thank you. Any other comments regarding Question 5 articles, Services and Supports? All right. So, I'm going to move to Question 6, which is articles regarding the lifespan, the transition from adolescence into adulthood. Any comments about any of these articles?

DR. GASSNER: Dena again. Yay for menopause. Finally, there's some really good studies here on menopause.

DR. DANIELS: Scott.

DR. ROBERTSON: Yeah. I had -- Susan, I hope this isn't an issue, is I had a couple that I thought I had sent earlier in December, and your team suggested that maybe I could bring them up, since the ballot hasn't gone out to folks yet.

DR. DANIELS: Yes, you can bring them up.

DR. ROBERTSON: Okay. I put them in chat for you. I can also speak to them here. So,

one of them is on disclosing an autism diagnosis improves ratings of candidate performance and employment interviews. And this was a study that had like a -- sorry, I think I wrote control group in there, but maybe I should have said, like, you know, comparison group. So, I don't know if I should address the description after the meeting to fix that in there.

But it's -- basically, it had three different comparison groups, one of which did not know about the diagnosis, one of which knew about the person's diagnosis, and one of which knew about the diagnosis and knew about additional information about autism.

And they had to -- these three different groups of participants were known as raters and had to rate the hypothetical autistic worker or autistic job interviewer on different sort of aspects of motivation and things like that.

And the raters who knew about the diagnosis were more likely to rate them

actually higher as -- in terms of their perception of the of the person's abilities in the job interview. And it had the -- it had a pretty significant sample size for the raters. Did I include that here? Sorry.

And then the second one is about the double empathy problem and perceptions in an autistic employee in the workplace. And this looked at how the perceptions of a worker in terms of hypothetical story about an autistic worker and the challenges they were having in terms of acclimating to the workplace and how it differed for perceptions by participants who are autistic versus nonautistic.

And a significantly larger percentage of the autistic participants more accurately interpreted the big net or story about the autistic person having challenges when compared with the nonautistic participants. And the difference was pretty significant in terms of like 50.7 versus 31.2. And that provides some extra support for -- in the workplace setting, for the double empathy

problem.

And that one did have a sample size of -
- what is that, like 250, so like 173
nonautistic people and 81 autistic people.

DR. DANIELS: Thank you. So, we will
make sure that those are on the ballot as
well.

DR. ROBERTSON: Okay. Thank you.

DR. DANIELS: Alycia, you had a comment?

DR. HALLADAY: Oh, it's fine. It's fine.
Sorry. We can keep moving. Oh, no, just
question, when you say lifespan -- there were
a couple of studies that were in Biology that
were longitudinal studies. So, I guess it's
kind of you're under the purview of your
staff to determine whether or not it's a
biology study or a lifespan study, just based
on the content?

DR. DANIELS: Well, lifespan doesn't
really mean longitudinal. Lifespan, as it
was defined by the committee a long time ago,
was more just like adolescent to adulthood
related studies, in terms of -- especially

services or --

DR. HALLADAY: Yeah.

DR. DANIELS: So, it's employment,
housing --

DR. HALLADAY: Did we ever discuss why we
don't just call it adolescence and adults?
Was that ever -- I can't remember. I'm
sorry.

DR. DANIELS: This committee has not
discussed that in --

DR. HALLADAY: Okay.

DR. DANIELS: That hasn't been discussed
in a while. It could be brought up in the
next committee if --

DR. HALLADAY: Yeah. I'm not -- yeah. I
just -- I feel like -- okay.

DR. DANIELS: We can certainly do that.
But it wasn't brought up in this last
iteration of the committee. So, yeah. So,
that's not --

DR. AVENEVOLI: I'm noting Sam's
comments. And some agree with her about
number 79. I think you kind of addressed

that. But it's not clear why this is in Lifespan and not Services. But -- yeah.

DR. DANIELS: Yeah. To me, it looks like it belongs in Services, but we'll -- with all of these, if there's any question about reassignments, please do bring them up. And we'll just double check them and then reassign them if they're needed.

It's a little challenging to do on the fly. But we really appreciate you bringing them up -- everyone that has brought up those questions. And we'll make sure that things get moved around as needed.

Okay. Other comments about this section that's about kind of the adolescence through the full lifespan to -- into adulthood and older adulthood?

DR. AVENEVOLI: Jenny's hand is up.

DR. DANIELS: Oh, Jenny, go ahead.

DR. PHAN: Hi. Susan, I know that you and your staff are going to review the -- our earlier article on depression that was in the Biology category. There's another depression

paper, number 91, nominated by the CDC. And I think their focus was on adolescence. And it has, not exactly but kind of a similar tone to the previous article that I raised, the Corbett et al.

DR. DANIELS: Okay.

DR. PHAN: So, I wonder if those two papers belong in the same category. Otherwise, why are they in different categories?

DR. DANIELS: Okay. Thank you for pointing that out. Again, we'll have someone review those and make sure that it gets in the right section if it's not in the right section. So, appreciate you bringing that up.

Any other comments about any of these articles that are in this section? Okay. So, then I will scroll to the next section, which is Question 7, on Infrastructure and Prevalence, so studies around research infrastructure, including research workforce, and prevalence studies.

And this is -- as a reminder, since we are talking about where these categories came from, they came from, years ago, the committee, as it was developing the strategic plan, trying to divide up how -- at first, actually, the first strategic plan was on research because that's what Congress required of us. And so, the research was split up into these categories.

But now, we also cover Services and Supports and also are maintaining these categories, partially so that we can go back in time and compare things to each other. So, we -- the committee, so far, has not changed the categories around. We've kept them in place so that we can have that tracking that goes back all the way to 2007.

So, in this section, we have studies that are about the research workforce and research resources and studies on prevalence. Any comments about these?

DR. GASSNER: This is Dena. I just wanted to say number 92 is such a critically

important article. It's been incredibly difficult for students who are trying to do research. I had 92 people apply to my qualitative study, and only some of them were valid applicants. And so, you know, reducing fraudulent participation in these studies is really important.

I also want to take advantage of looking at these last two studies on epidemiology and the health issues related to autism's increasing numbers and point out how dramatically these studies talk about increased diagnosis for autistic female and adults compared to males. 450 percent increase in number 93 is cited.

And so, I'm going to keep saying, we need to do better among people assigned female at birth and people who have cooccurring conditions or trauma that may camouflage a proper diagnosis.

DR. DANIELS: Thank you so much. Other comments or any -- if there are comments in the chat that anyone wants to have spoken,

please let us know that you want us to read them or if you want to share them yourselves, if you would like. Any other comments about things that are in this section?

So, I'm not seeing anything. Have we satisfied ourselves in terms of the opportunity to discuss these articles? Any questions you have, concerns about anything on this listed here? So, the committee has only removed one article from the list. Oh, JaLynn.

MS. PRINCE: Yes, there are a few things. You were going through fairly quickly, and my head is swimming on a few things here. One, I'm very pleased to see that there's some information about the judicial system. And I think that is very, very important.

There is something that I see the thread through here, and my awareness has been heightened because of conversations with people in the Department of Education, with The Arc, and with other organizations. So many of the things that we're talking about

here have a huge component that we don't necessarily address, but I think we -- because we have a larger group of people listening to this too, that we need to be really aware of what's happening with the Department of Education.

Because when there is a diagnosis, very often, the first people that will be working with a child will be teachers. And what is going to happen as things perhaps unfold as they're indicated that they may, and how are we going to respond in community and state as stakeholders in this? Because our teachers are so vital with spending time with our developing loved ones on the spectrum.

And if that changes or -- especially changes, perhaps in rural areas because of funding changes and everything else, there's huge implications to this. But it's very much part of the health care situation by having schools, teachers, psychiatrists with schools and so forth, psychologists, that play into so many of the topics that we've

been looking at.

And I just want to say we need to be aware and see what we can do, perhaps individually within our communities, to make certain that these resources can remain. Because now, we're dealing with adults with autism, and I see how much education in their earlier years have helped various people more than others because of the different school districts or different teachers that they have had, and the intensity of expertise and the types of teachers that they have had in different school systems.

And certainly, there's individuals with -- or differences with people, but so much of this does have to deal with education also with people that are going and handling these clinical trials, writing these things, and how are we going to make certain and be aware as a society to make certain that these things can continue?

I know I've taken a little bit too much time, but I think it's a very important

topic. Thank you.

DR. DANIELS: Thank you so much. And does anyone have any other comments about what we've discussed in the Summary of Advances, any final plugs you want to make, any global comments? Alycia.

DR. HALLADAY: Hi. Sorry. I had sent a late-breaking paper, and I don't see it represented on the list that --

DR. DANIELS: Let us know --

DR. HALLADAY: I'm just looking at it again. It is --

DR. DANIELS: Let us know what it is. And you can certainly talk about it.

DR. HALLADAY: Yeah. So, the first author is Matuskey, and this was a study that used a novel -- and again, I -- it was a late-breaking one. So, I didn't -- it didn't -- didn't make it -- a novel method to look at synaptic density in autism. Most of the work that's been done so far --

DR. DANIELS: You can talk about it.

DR. HALLADAY: I don't know if it's on

there. I just wanted to put in a plug for it. Because it's utilizing a novel biological marker to look at something that has normally only been visualized or only -- has been established over and over again but in postmortem tissue. And so, this opens up the ability for it to be studied in treatment studies as a marker. So --

DR. DANIELS: Thank you. Okay. We'll make sure that it's on the list for people to --

DR. HALLADAY: Yeah. It wasn't on. It was -- again, I apologize for it being late. I think I submitted the end of last -- [inaudible comments].

DR. DANIELS: It was a challenge --

DR. HALLADAY: I know. I know.

DR. DANIELS: It was a challenge for everybody because we -- no, I'm just saying that for everyone, it was a challenge. Because we're having this meeting on January 14th. We were trying to keep things moving. But I know that some late-breaking papers

really were published right at the end of December, and those got in. So, I know some things have been trickling in here. And we tried our best to capture everything that you wanted to see on this list.

DR. HALLADAY: Yeah, I know. It's not anything other than the calendar. And I get it. Because ASF does a year-end summary, and we always -- there's always something that gets missed at the end of each year because it wasn't published until the end of the year. And then I start writing it before. So, I totally get it.

DR. DANIELS: Yes. So, just make sure that you email us the title, and we'll make sure that's on the list. Any other global comments about what we've discussed here?

So, thank you so much to everyone for all your nominations. It does take some dedication to look through the literature and to even just note things that are coming across your inbox that you think are notable to send forward for these and to write up the

justifications and descriptions for the group. So, we really appreciate that.

And so, now we have everything. We are going to create a ballot for you and send it out for you to vote. You also will have a chance to vote about the minutes for the last two meetings to make sure those are approved. So, that's our next item on the list of tasks for this committee.

And you know, moving toward the closing, we will have, hopefully, a draft of the Summary of Advances to share with you before you sign out in March. And we'll keep you updated. We'll continue to send emails to the public. We'll continue to post items on our website and send out email updates. And you will be hearing about the Call for Nominations.

But given that -- the time right now, we do have a few moments if anyone wants to share some round robin comments of updates you want to share with the committee, given that this is our last meeting.

DR. GASSNER: Susan, when was our last meeting?

DR. DANIELS: When was the previous last meeting?

DR. GASSNER: Yeah.

DR. DANIELS: September. I think it was the 23rd? Yeah, that's what I thought, September 23rd.

DR. GASSNER: Thank you.

DR. DANIELS: The previous one. And then this is our final planned meeting. I don't anticipate convening the group, or Shelli would not be convening the group unless we have an urgent need. And we'll do the rest of our business by email. Jenny.

DR. PHAN: Hi, everybody. For anyone who is in the Los Angeles area, I want to send my thoughts to you, if you're having to -- if you're affected by the fires over there.

And I bring that up because the Autism Intervention Research on Physical Health -- there's a group that I work with called ANSWER. I still cannot remember the acronym.

But it's a group of autistic and neurodivergent scholars. We're putting together a resource page for autistic people living in the Los Angeles area to find resources.

I will drop my email in the chat. If you happen to know of resources that would be beneficial for those in the area, please email me. We're putting it together, and we're going to distribute it through the University of California, Los Angeles. Thank you.

DR. DANIELS: Thank you so much for that, Jenny. Scott.

DR. ROBERTSON: I just wanted to first concur with what Jenny mentioned in terms of -- with our solidarity with folks in California and the fires going on. And I hope folks are able to, you know, get out with, you know, emergency evacuations and get the support they need.

I just have a quick question, Susan. And maybe you might not be able to answer

this, but with the legislation having passed a little bit later than it has, sometimes historically, is that going to affect your -- in terms of like -- like, is that going to delay the reconstitution later this year to much later? Or is it not going to have a significant impact? Or maybe you might not know that at this point, as far as the processes for, like, you know, the nominations and, you know, resetting up the committee again?

DR. DANIELS: Yeah. Historically, it's taken a little bit longer to set up the committee. So, in the past, when we've been reauthorized by August or September, we've been able to restart by the next July, unless it was a pandemic, in which case it was delayed more.

DR. ROBERTSON: Yeah.

DR. DANIELS: We hope we won't have any more pandemics. So, given that we got our reauthorization several months after that, I don't think that we'll be restarting in July.

DR. ROBERTSON: Okay.

DR. DANIELS: We will just have to wait and see how this administration handles things. As you know, with the election, there's a lot of turnovers in positions. And people will have to be in place to approve all of these items before we can get it together. But we will have some additional activities.

The work of the office will continue. So, ONAC will continue its activities. We will be hosting some events that we'll be sending out information about in the next weeks and months. And so, you'll be welcome to join us for those activities. And we'll send out news updates as well. So, we'll try to keep activities going, and communications with the public.

And within the government, we will still have the Federal Interagency Workgroup on Autism meeting to implement the strategic plan and work on other cross-agency and cross-departmental projects. So, there will

be continuing activities while we're waiting for the committee. So, we'll do it as expeditiously as we possibly can. Alison.

DR. ROBERTSON: Great. Thanks, Susan.

DR. DANIELS: Oh, thank you. Alison.

DR. MARVIN: Hi. I just wanted to mention that the Social Security Administration's ARDRAW small grant program is going to be up. We -- back up again. We had a slight hiatus while we were looking for a new program management organization. We have one -- a very good one in place now. And so, we're planning to get up those ARDRAW small grants for students, grad students, this year.

So -- and it's -- the grant has now gone up to \$15,000 from 10,000. So, I will make sure that, you know, the IACC knows about this when we go live, so that we can get the word out. And so, students will be able to take advantage of this program.

DR. DANIELS: Wonderful. Thank you so much. And if you'd like to send us the link,

we can make sure that it's available on the website too. Any other updates anyone wants to share with the rest of the committee?

One update that I will share is that there is a document that's going to be coming out shortly, the Federal Evidence Agenda on Disability. That is going to be issued by the White House Office of Science and Technology Policy. And this has been noted in other press releases and items. So, keep your eyes open for that. It'll be an interesting document, I think, for this committee.

I don't think I have any other updates, other than to say it's been such a pleasure working with this group of IACC members. We really, really appreciate you bringing your time, your dedication, your expertise, your personal experience, into this room and working collaboratively to advance this work on autism that's so important to all of us.

So, I deeply appreciate you. And thank you so much for your service. Look forward

to staying in touch and continuing the work even after the committee has completed its work. And I'll turn it over to Shelli for some last words.

DR. AVENEVOLI: Thanks, Susan. And thank you to all of you, first, for your attendance and undivided attention today, for your contributions to the Summary of Advances and your very thorough review. There were a lot of articles to review. It's amazing how much we've accomplished through the IACC over the past year.

But also, I think a large number of articles you're seeing is a reflection of the concerted effort over several versions of this committee. So, thank you for your service today, but thank you for your service, as Susan said, to the community by serving on the IACC. And I do hope that our paths cross again in whatever roles we all may be playing. So, thank you again.

DR. DANIELS: And I have a slide here just showing the number of people who have

served on the committee over the last --

DR. AVENEVOLI: Wow.

DR. DANIELS: -- three years. It's the largest and most diverse group of people who are dedicated to autism. We really, really appreciate all of you. So, thank you so much.

And a final word to say thank you to the ONAC staff and our meeting support team that supported us through all of this, helped us with all our reports. Thank you to Rose Li and Associates, our contractor who has helped us conduct all of these meetings that are on site, IT team as well. So, thank you to everyone.

(Whereupon, at 3:45 p.m., the Committee adjourned.)