# INTERAGENCY AUTISM COORDINATING COMMITTEE

## FULL COMMITTEE MEETING

WEDNESDAY, JULY 13, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 1:00 p.m., Susan Daniels, Ph.D., Executive Secretary, presiding.

PRESENT:

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

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

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

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)

JENNIFER JOHNSON, Ed.D., Deputy Commissioner, Administration on Disabilities, Administration for Community Living

PRESENT: (continued)

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

YETTA MYRICK, B.A., DC Autism Parents

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

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

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

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

SCOTT MICHAEL ROBERTSON, Ph.D., Senior Policy Advisor, Office of Disability Employment Policy, U.S. Department of Labor

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

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

PRESENT: (continued)

MARTINE SOLAGES, M.D., Medical Officer, Division of Psychiatry, Center for Drug Evaluation and Research, U.S. Food and Drug Administration

HARI SRINIVASAN, University of California, Berkeley

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

ANNA E. TSCHIFFELY, Ph.D., U.S. Department of Defense (DoD)

PAUL WANG, M.D., Simons Foundation

STEPHEN WHITLOW, J.D. Merakey

TARYN MACKENZIE WILLIAMS, M.A., U.S. Department of Labor

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## PROCEEDINGS

DR. SUSAN DANIELS: Welcome, everyone, to members of our viewing audience and members of the IACC and alternates, to this meeting of the Interagency Autism Coordinating Committee Strategic Plan Working Group. I'm going to give you some background on what we're going to be doing today. I'll start with some meeting logistics and housekeeping items to remind people who are in Zoom to please keep your microphones off unless you're speaking. And you're welcome to turn your cameras on when you are speaking, but you can leave them off if you prefer that. And during the discussion, please give your comments briefly, approximately 1 to 2 minutes, to enable other members to have a turn speaking. And we should have plenty of time over the next two afternoons for everyone that is in these groups to be able to make a few comments, if we keep them brief. And please forgive me in advance if I end up interrupting, if any comments go on a little too long, I might cut in to try to get us back on track. And so not to be rude, but I just want to make sure that everyone has a chance to talk. So please keep that in mind that we want to give everyone a turn.

And for committee members that would like a comment read aloud, we're going to have someone from the OARC staff, who is using the screen name, "Send Comments Here." And if you want to send them your comments, that person who is Mr. Steven Isaacson from our team. Steven, would you like to say hello?

MR. STEVEN ISAACSON: Good afternoon, everybody. Thanks for being here.

DR. DANIELS: So Steven will be happy to read your comments aloud. And if you have a really long comment, you may have to break it up into two or three pieces so he can receive them, and then he'll read for you if you want that. And as a reminder, both to our audience that's listening on NIH Videocast and to members of the committee, we do have closed captioning. In Videocast, you can press a button for closed captioning. And in Zoom, you can go down to the bottom of your screen and click "CC Live Transcript" to be able to get closed captioning.

Next, I'd like to share a little bit about the purpose of this working group meeting today. As you all know, we're working hard on the IACC Strategic Plan, which is the number one task of this committee as we convened last year. And we're starting to work on those Strategic Plan. So we're going to be focusing exclusively on the Strategic Plan at this meeting. Other regular committee business will not be discussed at this meeting, and so we won't have sessions like public comment and some of the other sections that we normally have in our regular meetings. And attendance at this meeting is voluntary, so it's an optional meeting, and not every one of the members is going to be here.

Although, we had a lot of people that decided that they were going to be able to be here, and perhaps this didn't interfere with summer vacation plans and are going to be here. And instead of going around and having everyone introduce themselves, we've prepared a slide with the names of everyone, because it's a really big group.

But we have representation from several different federal agencies, including SAMHSA, the EPA, NIDCD, NIH Office of the Director, the Administration for Children and Families. Administration for Community Living, NICHD NINDS, AHRQ HRSA, CDC, FDA, HUD, CMS, NIDCD, and the Department of Defense. And then we have a large number of our public members also who are scheduled to be on today. And there may be a few people who would be joining late or popping in for part of the meeting, which is fine, but we wanted to give everyone a chance who had time to be involved in this meeting. And we will be coming back to discuss the Strategic Plan more at the

October meeting. So at that point, all members will also have another opportunity.

For our agenda today, I'm going to give you some background on the Strategic Plan just to, again, get everyone on the same page about what our goal is. And then we're going to have time to discuss questions one through four of the Strategic Plan. And I have a few discussion questions prepared, and you can feel free to raise your hand and share, if you would like to share some comments based on those discussion questions. And we actually built quite a bit of time into the meeting, and so there may be a little bit of extra time. If so, then I'll allow for some extra time with anything that we have time for. I wanted to, again, remind us all, get us all on the same page about what the purpose of the IACC Strategic Plan is. And this plan is required by Congress in the Autism CARES Act of 2019. And it serves as a guide that outlines priorities and directions for autism related efforts across federal agencies and also as used by private partner organizations. One of the main ways that the IACC provides advice to the Secretary of Health and Human Services, which is part of the mandate of the IACC, is through the Strategic Plan and the recommendations contained within the plan. And it includes a number of what have been called objectives in the past. I will be sharing with the IACC in October. I'm going to be suggesting that we rename them recommendations because actually, under the Federal Advisory Committee Act, each of those objectives is a recommendation to the Secretary. And it just might make it a little clearer for people to understand that. And these objectives or recommendations address research services and policy activities. And we also are required to provide a budget recommendation and that is also part of the CARES Act. So the process that we're using to create the Strategic Plan is first, we have done a few things to solicit public input. We've been receiving public comments on a regular basis at our meetings. And I know everyone has heard those public comments or read them, if they were submitted as written comments. And we also put out a special request for information for input from the public on our Strategic Plan, or on what they would like to see in the Strategic Plan. We also have been gathering input from members of the committee and we sent out a survey that was used to provide some of that input. And we've also been listening to you all during committee meetings. And the process will involve consensus. So we're all going to be coming together, putting our ideas together, and coming into consensus about what belongs in this plan. And we'll make an effort to resolve any questions, concerns, and conflicts in this process so that we come up with a plan that everyone can agree on. And then the final draft will be reviewed by the full IACC. This is just a working group meeting where we can discuss some ideas and share some input that would be put into a draft. But the full IACC will accept the final Strategic Plan by majority vote. And the Strategic Plan, once it's published, can be used by federal agencies and other community members. And it's meant to be a document that keeps track of what's changing in the field and how we should constantly shift our directions based on what's being learned, what's new, and maybe some new challenges and emerging issues that have come up so that we can keep it relevant.

The timeline I'm also going to review with you for the Strategic Plan is we convened as a committee last year, in July 2021, and we started talking about the Strategic Plan. So we introduced this process. And in October, we did the request for information from the public and that closed in November and we shared the results with you in January. And in November, we also issued a survey to members of the committee that closed in March of 2022, and we shared the results of that in our April meeting.  Those are some of the data gathering activities we've done so far.  And as of yesterday, we've published the first draft of Strategic Plan chapters on the IACC website.  And this is a first draft.  And those of you who may have had time to browse through those chapters, if you see anything that you feel like needs to change, don't be concerned overly much.  It's a first draft and we're going to be continuing to work on the drafts as we hear more input from you all.  And so at the this July working group meeting, IACC members are going to have a chance to provide that input.  And then we're going to be sending you another survey that you can complete between July and August that will give you a chance to look more carefully at some other components that we haven't highlighted so far, including the mission and vision statement, the core values, and some other parts of the Strategic Plan.  So you'll have a chance to really look at those.  And our team has taken an effort to try to revise them based on what we've been hearing from you as a committee. And in early October, we will provide new drafts of the Strategic Plan chapters online for you to review, and that will be something available to you before our October 26th meeting. And at the October 26th meeting, we'll again discuss the Strategic Plan. If it is in a place where the committee feels like they could approve it with some small changes, we would like to approve it. And if we cannot, then we would schedule another time to make a last pass at the plan. But we hope that we will be finishing it within this calendar year, hopefully, or at the latest by January of 2023.

And as a reminder, of course, the Strategic Plan is most useful when it's finished and published and can be used. We do want to get it out as soon as we can, but of course, to make sure that it's done the way we all will feel good about. So some notes about the Strategic Plan itself include that each IACC Strategic Plan chapter provides an overview of relevant topics, recent advances, changes and trends in the field, and remaining gaps and opportunities for research, services, and policy. And again, when you look at these chapters, it's not a full literature review of everything in the entire field, so we have to keep it somewhat readable and compact. And so we try to provide highlights of things that are really significant, things that may have changed and that might influence the direction of federal agencies or organizations that are working on autism. And the plan also presents diverse perspectives from the community and from this committee. And we try to present that in a respectful and inclusive manner throughout the plan. And the Strategic Plan is advisory to the Secretary and federal agencies and can be used to guide federal agency efforts.

I'll pause for a moment to allow for any questions, if anyone has any questions about any of that. And it's mostly review, but again, I wanted to make sure we're on the same page, as we're still a one-year-old committee at this point.

Okay. I'm not seeing any raised hands, so I'll keep moving. So the seven question areas of the Strategic Plan, these are organized around community-based questions. So we have seven topics. Question 1 is on screening and diagnosis. Question 2 is on the biology of autism. Question 3 is on genetic and environmental factors. Question 4 is on interventions. Question 5 is on services and supports. Question 6 is on lifespan issues. And Question 7 is on research infrastructure and prevalence.

So some additional sections of the plan, including some new ones, are that the new IACC Strategic Plan will also include two cross cutting themes that are connected to all seven topics. The sex and gender section, it was there from the previous

Strategic Plan, but it was focused on women and girls and that's been expanded to have a fuller understanding of gender. And a new section that will be on promoting equity and reducing disparities, to highlight that issue. There also is a section on the impacts of COVID-19 on the autism community and research services and policy and what lessons we've learned from this experience. There also is a section on describing progress made on previous Strategic Plan objectives. And a budget recommendation which is required by the Autism CARES Act. And we've made an effort throughout the entire Strategic Plan to include themes of acceptance and inclusion of individuals on the autism spectrum. And the next draft will also include revisions for plain language. If you look at the drafts that are online now, if you feel like you have concerns about plain language, our team is going to go back through once we have the content worked out and try to work on the plain language aspect to ensure that it's as readable as possible. We also will create some kind of an executive summary or a shorter version that can be an easy read version.

With that, I don't know if there are any questions about any of that that I just shared, we will be ready to start in on Question 1. And so we're actually a little bit ahead of schedule and that means that we might have a few extra minutes throughout today to be able to talk about some of these areas. With Question 1, again, as each chapter has an associated community-based question that captures the theme in a brief, accessible, and overarching goal. The proposed new text for Question 1, which was taken by our team and shortened and we just tried to make it brief and easy to understand, is how can we improve identification of autism?

And within this question, it covers screening and diagnosis research, tools, and technology. Early signs and biomarkers.

Disparities in autism screening and diagnosis. Access to screening and diagnosis services, systems navigation, and workforce needs. And it also touches on adult diagnosis, although that is elaborated upon more in Question 6. And so the discussion questions that I have for you are, are there any other important topics or points that need to be included in this section? And so not necessarily saying that with the chapter that is online, because I know that you didn't necessarily have time to read it. But I want you to bring out any really important points that you want to see included in this chapter. And if you feel that there have been recent significant changes in this field since the last Strategic Plan was issued that would impact the direction so that we can make sure that we're completely up to date.

I'm going to first go to Steven as he has a comment that was shared by somebody who would like their comment read. So, Steven.

MR. ISAACSON: Hello. This question is

from Dena Gassner. The question is, "How much time will we have to review the October draft?"

DR. DANIELS: So you'll be receiving the October draft at the beginning of October. The meeting is on the 26th. So it will be a couple of weeks, about maybe three weeks or so?

MS. DENA GASSNER: Thank you.

DR. DANIELS: You're welcome.

MS. GASSNER: I do have a question on this one. Is it within our wheelhouse or appropriate in any way to talk about workforce development and training as it applies to providers who would be doing diagnostics? I know that the American Dental Association has mandated that we do provide training for all dentists to work with people with intellectual and developmental disabilities. I know they were in a conversation with the American Medical Association and the INSAR, autistic researchers' group is writing supplements to

Pediatrics, the journal. But I don't know if it's within an appropriate framework for us to talk about the fact that so many people -- so many children are not diagnosed in a timely fashion because autism is an afterthought or a specialty, rather than it being part of generalized training for providers.

DR. DANIELS: Yes, so that is relevant. Thank you, Dena. And we have more of that in Question 5. However, we do have some information about workforce needs that are specific to screening and diagnosis here. So thanks for that comment and we will take that into consideration. Next, Jennifer Johnson?

DR. JENNIFER JOHNSON: Yeah. I have a couple of, well, one, a suggestion and then a question. One area that we might want to think about including, even though it's not specifically related to diagnosis of autism, but is important, is also diagnosing for any cooccurring conditions that an individual might have. We're hearing a lot about the difficulty in being able to adequately identify autism versus something that might be like a mental health disability, or when they may be cooccurring. So I think that is an important issue that the committee might want to consider including in this question. So I just offer that.

And then a question about access to screening and diagnostics. Does that include anything related to publicly funded supports that might be available to pay for access to screening and diagnosis? I just can't remember if that's in the plan or not.

DR. DANIELS: You can -- we can mention something about it. Do you have something specific in mind?

DR. JOHNSON: Well, I know there's Part C and Child Find. I don't know if there's any research, and again, I can't recall if it's in there or if there's any questions related to that. And then also EPSDT under Medicare and Medicaid. Sorry, Medicaid. And whether that, again is referenced in the plan. And if not, I think we should make sure that those kinds of things are included.

DR. DANIELS: Okay, thank you for both of those comments as well. We will -- and I agree that it's been a theme with the committee now for several years on co-occurring conditions and we've tried to weave that into many parts of the plan but we could highlight the need to accurately diagnose cooccurring conditions and also distinguishing them sometimes from autism features is really important.

DR. JOHNSON: Thanks.

DR. DANIELS: Thank you. Alice Carter, do you have a comment?

DR. ALICE CARTER: Hi. Thank you. Here I am. Yeah, I wanted to second the co-occurring mental health conditions and the differential diagnosis because a lot of times autism clinics are set up sort of as autism or not, and not looking at the whole child. But then also in terms of workforce development for screening, a lot of times, there's a lot of focus on the tools and the technology and there's less focus on training people to have the conversations of explaining the, like, limits of the tools, but also helping people along in the process of understanding what it means for a child to have autism. And so in our work we're using tools that are evidence based. But the biggest work we've encountered is helping clinicians feel comfortable, whether it's pediatrics or it's early intervention, helping clinicians feel comfortable talking about autism with families and also recognizing that there is a process that families are going through and they need to, while nudging gently, also give parents time to move at their own pace. Like you need to rely on relationships to help families move through with screening to diagnosis process.

So I just would want the relational piece and the difficulty of learning how to have these conversations as part of workforce development in with these other tools.

DR. DANIELS: And do you think that specific trainings that, say, are CME type trainings, would be needed or what kind of --

DR. CARTER: I mean, I know -- It would be great to have that. I don't know that there are trainings out there that are packaged already for this. Because we were working in early intervention, which is not historically a site for screening for autism. And some early intervention programs like avoid talking about autism because the providers aren't allowed to diagnose. Like we just did a ton of work to help the providers feel comfortable having these difficult conversations. But that was, I feel like, the hardest work. Like training people to do an assessment tool when they're used to doing assessments, not that hard. Understanding what autism is when they're professionals and working with autistic kids a lot, not so difficult. You can help refine their understanding. But the real part was opening the conversation because they were just really not prepared for that.

DR. DANIELS: Right. Thank you. We'll take that into account. All right, I will move on to Scott Robertson.

DR. SCOTT MICHAEL ROBERTSON: Yeah. Thanks, Susan. So, I concur with what's been said as far as cooccurring conditions, mental health conditions, et cetera, and educating providers. And I think also that fits into the space in terms of biases that are out there about autism that I think is really important on the diagnosis part of this section of the Strategic Plan is really, really important. And I know we're only talking about new topics, but I think that fits into there's language in here, for instance, gold standard for the ADOS and things like that, that I think there are ways to, when we get to phrasing, that could be adjusted to be a little bit more neutral in terminology. But one of the also newer kind of elements that could be included in here too is trainings on how to address sort of biases around autism as far and sometimes prognostication. I know I'm going to use a complex word there, but sort of assertions by clinicians of oh, you're not capable of doing this or that. That's very commonly happening for children, adolescents, and families when they received the diagnosis that clinicians are making assertions about autism that are frankly not true. And in some cases, these clinicians who have not interacted with autistic people, don't have a really good understanding about autism across the lifespan and the human lived experience and supports the services and access and the human rights elements.

So I think that's a key element too for the diagnosis portion is trying to address these biases that are really prevalent among clinicians. I'm constantly, having interacted with families and autistic people over the years on really, really, really worrisome and concerning assertions that were made by clinicians when individual especially was young. It tends to be sometimes more prevalent when a kid is younger where folks will state things that, well, they really have no idea about, what the long-term pathway is going to be like for that individual. They're just stating things that under their belief system that are often just not true. I wonder if we could fit that into the Strategic Plan section here on the diagnosis portion, these biases among clinicians and what could be done to help address that. And I think that fits into research too, is more research on the area on helping to address biases about autism, quality of life, the lived experience and health and wellness among clinicians, including in the diagnostic process and diagnostic tools.

DR. DANIELS: Great. Thank you for that comment. And it sounds like it could fit in with some of the things Alice was talking about too, but you also described that it could fit in other aspects of the Strategic

Plan. Thanks for that comment.

DR. ROBERTSON: Thanks, Susan.

DR. DANIELS: You're in agreement, Alice?

DR. CARTER: Yeah, I really agree. And, yeah. And I think having to process with families about sort of things that providers have said to them is not atypical, unfortunately, or uncommon. Yeah. Great. Thank you. And I'm going to go to Steven for a comment that somebody wrote in.

MR. ISAACSON: This comment is from Jenny Mai Phan. "This may fall under disparities for autism screening and diagnosis. The question is, will we be able to empathize, as the subtopic, cultural competency trainings for diagnosticians and professionals? A second subtopic that perhaps could be emphasized is language interpreters/translations for non-English communicators."

DR. DANIELS: Thank you. And I believe that is in the chapter, but it's certainly an important point. So, thank you for sharing that. And I believe it's also in the disparities section, but we can go back and look at that. Next, I will go to Paul Wang.

DR. PAUL WANG: Hi, Susan. Thank you. I just wanted to underscore or potentially elaborate on a couple of points that have already been made by you and the other committee members. First, the fine point that Scott made about the ADOS. I think it's really important not to enshrine that an ADOS assessment is necessary for everybody in the diagnostic process. I believe strongly, and I know others agree, it is not always necessary. So the wording is just going to be careful there.

The other points that I wanted to make is that I think it's really important to address the gap between screening and diagnosis. We know there are many children, unfortunately, who screen positive and yet are not referred for thorough diagnosis. And there are others who are referred for thorough diagnosis but never make it there. So this is potentially related to systems navigation, but that navigation issue is important to think about even before diagnosis, not only after diagnosis on the way to service, because there is that gap between screening and diagnosis. The other point, and it's related to all of this, of course, is the workforce needs. I frankly think that one of the factors that results in the diminished workforce, the inadequate size of the workforce that we have, is the inadequate compensation for people who are engaged in diagnoses. I think that is an issue that needs to be looked at and thought about and potentially addressed.

DR. DANIELS: Thank you so much. Also important points and everything everyone is sharing so far is really helpful. So, thank you. Next, I'll take a comment from JaLynn Prince.

MS. JALYNN PRINCE: Excellent. Thank you. Can you hear me?

DR. DANIELS: [affirmative]

MS. PRINCE: Thank you. I have questions. I know we're going to get more specific later on about adults. But I would see that there could be something very important to track and do a study, longitudinally, as much as possible, to see how autism is manifest in an individual as a child and then as they become an adult. And see how those things differ, if they do, if there's particular educational processes that they go through that may help them compensate in particular areas or whatever that process is. Because I'm seeing, on a regular basis with the sites and things that I monitor, anywhere from four to five adults a day that are talking about a recent diagnosis. And I'm wondering what their autism may have looked like as a child. And how do we say that there is a diagnosis of autism? Is it different in an adult than it is in a child? Or is there a progression to get to a particular point? I think there's a lot of subtle questions in here about what it means to have a diagnosis as an adult, and who does it, and why don't we have more availability for that. But what it means also in children as they do age and what autism looks like. So it would be a deeper study and probably many, many individuals involved in that, and if there could be funding for that type of thing.

DR. DANIELS: Thank you, JaLynn. And I think that that touches on things that are in a few different chapters. And Stuart may have something to say about this too. But in Chapter 7, which covers prevalence studies, I know that we have a little bit in there. And Question 2 has some things about longitudinal studies. And Question 1 does have some work on trajectories, I believe, as well. So all of those would play into that. But thank you for that comment. And I will move over to Stuart to see if you have anything to say in response and also whatever else you wanted to share.

DR. STUART SHAPIRA: Well, yes. Thank you, Susan. My comment is specifically to follow up on JaLynn's comment because these are very important questions to know more about the trajectory of individuals with autism and how things change over time. So, the CDC is conducting such a longitudinal study, which is the follow up study from CDC's study to explore early development, which initially enrolled children at ages 3 to 5 years with autism and has followed up in early teenage years and will be following up again later on. And many of the questions that you ask are being evaluated as part of this study. And although it is a single study, so I agree that more is needed in this area. But the SEED follow up studies and the SEED team study, I think are shedding a lot of light in order to answer these questions that you raised. So, thank you so much for raising those.

DR. DANIELS: Thank you, Stuart. I know that we do have a little mention of some of that in Question 7, but we'll make sure that we cover that as well. Next, it sounds like there are no new people asking questions, so I'm going to go to Dena.

MS. GASSNER: Thanks. I've been kind of jotting down a couple of notes here. But one of the things I think that's frequently missing when we're talking about systems navigation, and I appreciated the comments about pacing to the parents' capacity, we're often not informing those providers that are delivering that diagnosis, the reality of the high rate of parental disability within this population. It may be autism that was never identified. They may have the executive function or processing issues related to ADHD. They may have an anxiety disorder. There could be a bazillion other things happening in the broader phenotype of these parents that make delivering the intervention and the systems navigation information too overwhelming at that time. So I think what we would rather suggest is that that diagnostic process needs to be a multi series process to help parents absorb that information over time, rather than handing them a packet and sending them out the door, which frequently happens. I think we need to talk about wait list. We have outrageously delayed wait list, particularly in regard to adult diagnosis. I think we need to encourage the delivery and that information that it needs to include multiple intervention tools and not just ABA. There's sensory processing support, there's speech language support services. And I think that people just go to ABA without a lot of information, just assuming it's the best step. And for many people, it's not. Let's see. And I totally think that we need for anybody who writes a report related to someone who is on the autism spectrum needs to learn how to write to the audience it's being delivered to.

For example, when you write a diagnostic report for a school system, you're probably going to have to promote strengths to get the school to buy into investing resources into that student. However, if you write that same report in the audience of social security, strengths is not what you want to lead with. Obviously, you're not going to misrepresent anything, but you're going to be focusing on deficits for Social Security. With rehab, you have to walk a line between deficits and capacities. And I don't think that diagnosticians are being taught how to adapt their reports to consider not only who's going to be using the information, but how it's going to be utilized. So I don't know if it fits here or somewhere else, but as somebody working with a specific government system, I find the reports to be nearly unusable in the standardized template that psychologists are trained on, for example. Thank you.

DR. DANIELS: Thank you. Thank you for those helpful comments. I do think it fits in here and probably in some other places as well. We appreciate that. Next, I'm going to go back to Steven. It sounds like you may have comments from someone who wrote in.

MR. ISAACSON: Hi, there. Yeah, I have a comment from Dr. Scott Robertson. He says, "I want to clarify also regarding the ADOS, that it has major limitations and sometimes misses autistic people because of biases about autism and the lived experience. It has more limitations for diagnosing adults and older adolescents, but sometimes autistic children are missed by the ADOS too. That is my main concern regarding or referring to the ADOS or any other screening instruments as the gold standard. One should recognize the inherent limitations and cultural and gender biases and other biases for adaptations among autistic people that may hinder recognizing traits and characteristics of autism. ADOS and some other screening instruments are also very subjective at nature in the sense of clinicians' interpretations of human behavior and communication."

DR. DANIELS: Thank you, Scott, for those comments and we will take note of that. Jennifer Johnson, do you have additional comments?

DR. JOHNSON: Yeah, I had just thought about another population that we might want to think about being incorporated into the Strategic Plan. I'm not sure if it's already in there. But also screening and diagnosis for people who are incarcerated, because there is a lot of crossover there as well, and a lot of people who are not diagnosed or maybe diagnosed but misdiagnosed. So just incorporating anybody who's incarcerated into the population that are covered under this question.

DR. DANIELS: Thank you. And I don't think that we have anyone from DOJ on the call today, but we can always check in with them and see if they have comments on that as well to help us with that. That isn't a population that we've ever talked about in the plan before.

Okay, do we have more comments about screening and diagnosis related issues? Does anyone else have anything that they want to share?

MS. GASSNER: Just second-generation families. There's a lot of grandparents raising children in this population.

DR. DANIELS: And what about that?

MS. GASSNER: I just think that the supports and services are going to have to be increased for the second-generation parents that are in their 60s s and 70s raising toddlers. They're going to need additional kind of help that we don't talk about very often.

DR. DANIELS: Okay. That may fit a little more in Question 5, but we can take note of that. And I think that in the caregivers committee, they have been talking about that issue as well, so that's helpful. Does anyone on the committee have any comments about new technologies in screening and diagnosis and the direction that that's moving in and what we might want to talk about in the plan with regard to that? Oh, and Alycia, you have a comment.

DR. Alycia HALLADAY: I have a comment about the research tools and technologies.

DR. DANIELS: Okay, great.

DR. HALLADAY: My first comment was I want to reiterate everything that Paul Wang said. I had my hand raised and then I lowered it because he said everything that I was thinking in terms of making sure that we have well trained clinicians and a workforce. And to think about payer issues and why these doctors only have a certain amount of time and they can only get reimbursed for a certain amount of time to see sometimes complex cases. But I did also want to make a comment about the screening and diagnosis research tools and technologies where I'm actually seeing, in the last few years -- and maybe I've been living under a rock -- but in the last few years I've just been seeing a whole lot more come through in terms of ideas, papers, new companies that have started up, places that are taking their initial pilot to market. And I think that we probably need, and I don't know if this is an IACC thing, but we kind of need to have some coordination among them. A lot of them are not very specific, but that's not always a bad thing. They may not be specific to autism, but they may pick up other things. But there's a proposal that may be used in all sorts of different environments which I think could really risk their accuracy as well.

So this could include everything from these tools, which have cameras for eye tracking. People are considering new genetic tests, other biomarkers. Biomarkers, not just for diagnosis, but for intervention trials. And I think my major takeaway is that it would be great if we could integrate them all together, find kind of like the magic number or the magic combination, which I know is a hard thing to do. But maybe that's what we need to strive for instead of saying, this is the one that everyone should have. Where we should really be open to kind of like a mix of different things.

DR. DANIELS: Thank you for that. And do we have any sense of what the IACC might want to recommend in terms of trying to cut down on waiting lists? And I know that that issue was mentioned, but is there anything that we might want to bring out in the Strategic Plan as ways that we can assist with getting these waiting lists cut down?

DR. HALLADAY: I'll just add to that that we really, really, really need to boost the workforce here. I think it's a combination of the number of providers and the time and the training they get. But they're expected to do so much that I think that we need to think about ways to better train individuals to make that diagnostic evaluation. And also in terms of waiting lists, there are systems that allow individuals to receive early intervention before a diagnosis is made. So the diagnosis says a lot. But at kind of those early ages, even that there's a concern or we think more broadly across whether or not it's autism or something else. Because if it's just autism that's getting kids into intervention, or it's just autism that is getting them mental health services, then that's something that needs to change.

MS. GASSNER: But that's not in any way true for adults, just to reinforce that. I know you know that, Alycia. You can't get anything without the label first in adult services, for the most part. Thanks.

DR. DANIELS: Thank you. And I'll go to Mitchell Berger, who is from SAMHSA.

DR. MITCHELL BERGER: Yes, good afternoon. I would just want to mention among the various comorbidities, substance use disorders as something that providers should screen for both those treating autistic patients and those in substance use disorder facilities. And I believe I sent you some references on that.

DR. DANIELS: Sorry, it was really hard to hear. Did somebody else catch that or can you say it again? I'm sorry.

Yes, I was just going to say that substance use disorders is something that should be screened for both by providers of care to autistic persons and those in substance-use facilities. I would just note that it's a comorbidity and I believe I sent you a couple of references on that.

DR. DANIELS: Okay. Okay, I got it. Thank you. Appreciate that. And Matthew Siegel.

DR. MattHEW Siegel: Hi, Susan. Thanks. Just following on the prior comment, I think we could make a statement under Question 1 on the need to foster more research on using tools and technologies to expand diagnostic capability and measure the efficacy and effectiveness of that. And of course, that relates to the comments people made about that directly relates to waitlist training and communication around diagnosis. Thank you.

DR. DANIELS: Great. Thank you. All right. And I saw your hand raised for a moment, Hari. Did you want to use your AAC or did you want to send something to Steven? Or Steven, do you have something from Hari?

MR. ISAACSON: Yes, Hari did send me a few comments. He said, there's a need to train people downstream with lower qualifications and requirements to do some of the more routine tasks. This will take the burden off fully qualified personnel. And he also said, but the cost to family should not be increased. Just task delegation to decrease the waitlist.

DR. DANIELS: Okay, thank you for that comment, Hari. And, Scott? Do you have another comment?

DR. ROBERTSON: Yeah. Thanks, Susan. I concur on the workforce development supporting better workforce development and more providers out there, including the support diagnosis across the lifespan. I know that fits into some of our focus here with the Department of Labor is that we're big believers on having enhancements to like talent development and workforce development on that space. And I think technology will help. I just think that folks should be careful and I think this is where it can help with partnering with autistic people and families with technology and new tools to address biases and to make sure that folks address issues that may come up in terms of how those tools look for and examine and consider traits of autism characteristics. And I'm thinking partially, for instance, use of artificial intelligence, machine learning, some of this newer emerging tech that is coming up. And we focus on a lot of that at the Office of Disability Employment Policy because of the impact on people with disabilities, is that those technologies, by their nature, have had many limitations in the last 5 or 10 years, and have had issues already with how they consider disability and the lived experience.

So I think it's something that can be helpful. I think technology is going to be fruitful in that space for a diagnosis in childhood, adolescents, and adult life. But I think it should be something folks should be careful and strategic about and thoughtful about. And as I say, partner with autistic people and families. And I just wanted to mention just very briefly, Susan, and I concur with what was mentioned on substance - use among autistic, for instance, adolescents and adults. I hope it's not really happening too much as far as substance-use among younger kids. Is that that's an area where research that it could be called out, among other areas in the plan where we have under researched focuses, the research is very limited on substance use issues and barriers, including alcohol use and drugs, et cetera, among autistic adolescents and adults. And I think we need a lot more research there and how that cross connects to things like mental health and the lived experience of folks and challenges experienced as folks age through development across their life. And then I just also wanted to mention briefly. And while I concur the comment that JENNIFER had mentioned earlier as far as folks from juvenile justice or prison populations, for instance, is also under researched as far as quality of life, health, and wellness, et cetera, and what that means across the lifespan. If it is mentioned as a topic focus kind of in there, I would refer to folks as contacts with the justice system. Since there are certain terms like incarcerated that can create extra stigma for folks. And so that fits into the longer-term discussion in terms of making sure to use sort of neutral and strength-based inclusive language. Thanks.

DR. DANIELS: Great. Thank you. And do we have any comments regarding reducing disparities in autism screening and diagnosis? I know that we have some information in the draft, but if there are things that come to mind that we should make sure that we mention, it would be great to get a couple of comments about that. Dena?

MS. GASSNER: I would point out two things. I think that diagnosis for women is still a very high priority. I also think diagnoses for people who are gender diverse is still very much complicated because they see the gender diversity versus they just don't see the autism side. I would also say we have a huge void in examining the potential delay in diagnoses for males who have low support needs. We talk all the time about how much more common diagnosis is for males. However, as someone working in the adult community, I continue to hear from males that the thing we've stereotyped as a female experience of ADHD camouflaging it, masking being a barrier, is happening as well to males. But no one is doing any research to see the frequency of that, to see if it parallels to the similar experiences of autistic women, to see if they're experiencing incorrect mental health diagnoses, which is common among women. And so I think, quite often, we assign these things to these binary gender statuses when we really haven't done the complete research on that. So I think that that's a gap in terms of screening and diagnosis. And many of those people, again, are saying, their kids never got any services in public school because they were diagnosed with ADHD instead of autism. And then they get their autism diagnosis in middle school or high school when they're much more emotionally fragile.

DR. DANIELS: Thank you, Dena. Great comments. Also, JaLynn, would you like to make some comments?

MS. PRINCE: Yes. I wonder about who it is that comes up with the diagnosis. And we ended up in a big debate this last week. Is it the pediatrician? Is it a psychiatrist?

Is it somebody in psychology? Is it a general practitioner? And what is the difference between rural and urban areas, and the qualifications of the physicians? Because parents were even debating, well, that child doesn't look autistic because they were diagnosed by X rather than Y. And does that also carry into things, again, with adults? Who does this? And we may have various markers, but are they consistent with the training of various groups of people in running these examinations? Because I know with some universities like the children's hospital here in Washington, they had a whole team. Whereas some parents I know have walked out of the pediatrician's office, where there are hours of examining a child. So I do think there's a lot of disparities there. And I'm very interested too in seeing if we could get some more incentives into being able to help people get into this field, as we also need in many other aspects of autism, we need more professionals in many, many, many more areas. Thank you.

DR. DANIELS: Thank you for those comments, JaLynn. And it sounds like it is the theme about the workforce needs and we'll make sure that we emphasize that in the new Strategic Plan. I don't see any more hands raised on Question 1. Any last comments about this question? But it sounds like we've had a good -- oh, there are a couple more. I spoke too soon. Hari?

MR. ISAACSON: Hari sent me more on comment. He said, "On comorbidities, there's an earlier need for mental comorbidities mentioned. There's a need to look at health comorbidities, some of which covered in biology section, many with poor health but often unaddressed due to diagnostic overshadowing."

And I also have another comment from Scott Robertson. He said, "I also meant to note regarding waiting lists and barriers that we need systems navigators for autistic children, adolescents, and adults and their families. Optimally, autistic people would have opportunities to work as systems navigators to help empower fellow autistic people, including children and youth, after diagnosis. Systems navigators would go a long way towards helping address barriers after the diagnosis that are faced by autistic people and their families."

Great. Thank you for those comments, Hari. And I see a comment from Mitchell Berger also saying autistic persons as peer supports, being a part of the workforce is important. Building on that comment, okay. I'm not seeing any more hands raised on this question. We're a little bit ahead of schedule. And I'll ask the group, would you prefer that we go right onto Question 2 or take our 15 minutes break right now? How many people would like to take a break? Raise your hand. Okay. I'm not seeing any hands raised or not seeing many anyway. Alright, so what we will do is we'll just move right on to Question 2, and then we'll take our break after that. And my slides seem to have disappeared, so I might need help from the tech team to put them back, and hand me back the controls again. Thank you. And then that will get us back to where we were.

We will move right into Question 2, which is on the biology of autism. The proposed and shortened Question 2 text that our team provided is what is a biology underlying autism? So that simplifies that question. And the different kinds of topics that are included in this section, include molecular mechanisms and genes implicated in autism. Structure and function of brain circuits. Sensory and motor differences. Cognitive and communication differences. The immune system and development of autism. Sex and gender differences. Longitudinal studies. Cooccurring conditions. And research policy issues including data sharing, ethics, inclusion of diverse research participants and autistic individuals across the entire spectrum and across the lifespan. So, those were some of the topics we touched on in the draft, but similar to last time, it's the same two discussion questions that I prepared for each of these sections. Are there any important topics or points that we need to include within this? And are there some recent changes, shifts in the field that could impact the direction since we last updated the plan in 2017? So think about that, anything that you think should inform us about what the new direction should be, if there is going to be some shifts in certain areas.

Okay, so I will take the first question or comment from Dena Gassner.

MS. GESSNER: Two things I think that might be missing is co-occurring physical disability conditions. The recent interest in the study of, say, for example, Ehlers-Danlos, POTS, other kinds of conditions such as that, the intersectionality with long haul

COVID is an area, and the intersectionality with the physical and emotional implications of both short-term intense and long-term chronic trauma.

DR. DANIELS: Thank you for those. I know that we did have something about Ehlers-Danlos. I don't think we have anything about POTS. Long haul COVID is something that we can take into consideration and trauma is included in another section, but we can see if there's any overlap needed here in Question 2. Thank you for all those comments, but I know in previous meetings you had mentioned trauma as an area, and we did try to make sure that was included in another part of the strategic plan.

MS. GESSNER: Thank you.

DR. DANIELS: We appreciate that. Looks like Steven has a comment.

MR. ISAACSON: Hi, there. Ari sent me a comment about intersectionality with movement disorder.

DR. DANIELS: Okay. Thank you. I don't

think that's ever been covered before in a previous strategic plan. Okay, so other issues that come to mind of things that you feel are important for us to mention in the new strategic plan related to the biology of autism and the biology of co-occurring conditions and we do include both physical and mental health conditions? Scott?

DR. ROBERTSON: Yeah. What I just wonder too is whether it may be helpful to think strategically about how this chapter is named, given all the topics that it encompasses and that when folks think biology, they may not necessarily be thinking about cognitive and communication differences or some sensory motor differences, etc. So I don't know if that's something that the committee could consider. I know this has historically been called biology section, but I think it's grown to encompass some other areas that may not fit as neatly into biology. I would put in as that functioning I think would fit in there too as far as where sensory motor differences are vastly understudied and autism and as that functioning even more so among children, youth, and adults. We have a major issue area there with -- that I've seen with review papers recently and I can send you the literature, Susan, is on executive functioning and the sensory and motor is that it is very common for clinicians and others to be still thinking of autisms singularly as social and communication and leaving pretty much everything else out about the lived experience. Even though as that kind of functioning sensor in motor, there are significant challenges that folks often experience in these areas. I think that's really helpful for autistic children, adolescents, and adults, and our families for supports and what happens for research practice and policy change in this space is really, really key for addressing that area in terms of the gaps on the literature in that space.

I think also cognitive adaptations that folks may make as they grow up through life too. I know that's here covered by cognitive differences, but I think also that this fits into masking and camouflaging autism is how does it shift as far as how do some folks learn to adapt? And what would be helpful from learning from that that may be helpful for other autistic people for supporting empowerments for autistic people in our families as folks age through childhood, adolescence, and adult life. I think that's also been understudied and under focused in practices, what the adaptation process looks like, what resilience looks like, what handling challenges looks like. There are maybe lessons learned from what's helpful for certain autistic people that we could be like, oh, how can we apply this in some ways where it's happening well for the empowered adaptation process to help empower other folks for navigating challenges and difficulties.

DR. DANIELS: Thank you for those comments, Scott. We are open to other suggestions. It has been historically, the question has been named biology just for something short. We could do something like biology and behavior, but that still might not have enough in it. We were trying to go for something that's not overly long, but if you have a suggestion or if anyone else on the committee has a suggestion of something short that would capture more, feel free to suggest it. It doesn't have to be done now, it can be done in the survey when you get it. But next I'll move to JaLynn Prince.

MS. PRINCE: I have questions too about different types of mental health and mental wellness. If there is a biology where someone has a molecular situation, and I'm trying to be very general in this without getting overly specific, but something that is part of their system at birth that would cause mental health issues as opposed to acquired mental health issues due to stress, loneliness, depression, isolation. It seems like we need to look at the biology of one aspect, but that how we can prevent mental health issues from developing.

DR. DANIELS: Yes, that makes sense. I

think that in Question 6, I believe it is, we did try to bring out more, as Dena had mentioned, the trauma aspect, but some of these acquired or environmental stressors, so we can make sure that there is some crosstalk about those between Question 2 and Question 6.

MS. PRINCE: Thank you.

DR. DANIELS: That is really important and certainly does contribute to quality of life issues for people. Next I'll go to Steven, do you have a written comment?

MR. ISAACSON: Yes. Just a brief comment from Susan Rivera. She said, "I think we should consider the title Biology and Behavior for question number two.

DR. DANIELS: Okay. I think that would be a quick and easy. It's still not overly long, but it would be understandable. For now we'll change it unless anybody else brings up anything different. Dena.

MS. GASSNER: I just wanted to point out that the DSM-5 eliminated executive function as part of the criteria for autism. So in order to get services to address executive function, which isn't really always capturing cognitive differences in autism, you have to have a secondary diagnosis of ADHD. And so I think, I don't know if or where that might be addressed, but I think that was a huge failure in terms of the DSM-5 criteria. I did also want to just, again, champion the idea of trauma appearing here, even if we just cross reference it over because we know with especially intergenerational trauma, that there are hardcore biological changes in the neurology when someone experiences trauma, especially a chronic type of trauma, which living with autism in a world that's not adaptable could definitely be part of that profile. They have done a couple of studies with the ACES, Adverse Childhood Experiences Studies, that show that autistic people have huge numbers there. I don't know. I think we like to keep things into neat boxes, but sometimes it's not easy. I appreciate that effort, but I think I'm just going to have to yell a little louder for trauma here.

DR. DANIELS: Thank you. I don't think we have anything, for example, about epigenetics of trauma and whatnot. I don't know what's in the literature about that, but we could look into that and see if there's a place to make a mention of that somewhere in the plan.

MS. GASSNER: Thank you.

DR. DANIELS: I believe I saw Paul Wang's hand up, so I'm going to go to Paul.

DR. WANG: A quick comment again to say I'm very glad to see sensory and motor differences called out here. I'm regularly surprised at the number of autism researchers albeit many of them are molecular cellular researchers who don't appreciate that sensory symptoms are now part of the diagnostic criteria in DSM-5. This is just an area that I think really should be highlighted. Certainly, should not be given any short shift here when we think about looking at the biology of autism. We know as well from personal testimony of autistic people that these issues are of very great concern for them, including among the subgroup of autistics who require low support. Many of them do still find that sensory issues, in particular, are really problematic, are an issue for them, and they want to see this addressed.

Thank you, Paul. We also, on the team, as we've been listening to comments along with you all in the committee, have heard a lot about sensory challenges and how improving those could really improve people's quality of life. We do want to give a big highlight to that area, which was never emphasized quite as much in previous strategic plans. Thank you for that comment. Next I will go to Ivanova.

MS. IVANOVA SMITH: Hello, this is Ivanova Smith. My comment is that I think it would be really good to visit the things that cause the processing differences in autistic people like our nervous systems are very different and studying our nervous systems to help figure out what causing the sensory issues to process them maintain. Because for me, sensory issues are not irritative, it's painful. It feels like electricity through my body and I would love that to be researched on figuring one other chemicals that are causing that sensory thing and maybe the way that we can find things that can relieve it so we're not having sensory pain all the time because it is actually pain. Thank you.

DR. DANIELS: Thank you, Ivanova. Definitely an important topic and we'll be sure to highlight it in the new plan. Next, I'm going to go to Stuart.

DR. SHAPIRA: Yes, I have just a very brief comment. So, I see research policy issues and various ones listed in this question as well as longitudinal studies. So I would suggest also including in the research policy issues, the informed consent as children age to adulthood in longitudinal studies.

DR. DANIELS: Thank you. I think we had something brief that was related to that but not that specific topic, so we will make note of that. Maybe that might also connect to Question 7.

DR. SHAPIRA: Great, thanks. And, Steven, do you have a written comment? Hi, there.

MR. ISAACSON: Yes, I have another comment from Jenny that says, "I don't know if perhaps I might have missed it in the strategic plan text, but can there be a mention, probably throughout this strategic plan, about mechanisms of risk and resiliency rather than just risk?" To answer that question, we actually tried to remove the word risk through quite a bit of the plan and use alternative language about probabilities and so forth. We did try to highlight resilience and strengths-based type language. We did make an attempt to do that, but we will make sure that we also look back at what we have to see if there's anything more that we can do there. Thank you for that comment. Dena.

MS. GASSNER: Looking at the research policy list there, and piggybacking a little bit on DR. Shapira's observation, there's a lot of community participatory research being done, and I just wanted to let the committee know that I'm part of one of maybe three projects going on around the country that's looking at redesigning ethics training for people with intellectual and developmental disabilities so that they can make a good ethics contributions in community participatory research. I think that it's somewhat related to being able to give an affirmative consent as children age. I think ethic training for individuals contributing to community participatory research validates that they have something to offer. It introduces the lived experience into research, but it also empowers them to be a very strong contributing force in the research on their own conditions.

DR. DANIELS: Thank you for that. Yes, community-based participatory research it's another -- there are lots of issues we're trying to highlight in a different way in the new plan. That's one of them and we'll take that into account.

More comments about Question 2, Biology and Behavior. Scott.

DR. ROBERTSON: Thanks, Susan. I concur with the emphasis on, for instance, what was mentioned on community-based participatory research participatory action research, CBPR PAR, that I hope that can be embraced, just emphasized all across the board because I think it helps a lot to have autistic people and our family members as partners on that research process to be helping shape practices and policy out there. I think that's another area that's would be helpful to emphasize that it's understudied too, that studies are just not adopting CBPR. I think if that's something, and I know that the strategic plan has limitations in how it connects back to what's ultimately funded by NIH and the other agencies. I know these are more recommendations or suggestions than anything, but I think it would be helpful if more research studies across the board could be adopting CBPR and PAR, and just to emphasize that strongly as something that would really help enhance the research process and the quality of research that is out there. I also just wanted to mention briefly as a potential alternative suggestion for the title of the section is maybe something about development like biology and development or biology and human development. Because I think really the section is growing to more than biology. It's really the human development of autistic people. It's especially emphasized for childhood and adolescents in this section because of the fact that there is more focus on adults later on in Question 6 that I think that said that human development element as far as brain development, sensory development, motor development, and the supports and services that can be helpful for that as folks have those differences on human development on that. Maybe that's something that could be ticker to explore is that element of the human development in this section that goes beyond the biology. I just worry a little bit on the behavior term just because this grow in such a association with negative aspects that folks see as non-typical cut areas.

I sometimes have been at conferences and other areas where folks to point out, oh, it's crying, or screaming, yelling that it sometimes stereotypes or stigma around autistic people and generalizations that get lumped into this loaded sometimes with the use of the term behavior. That's one of the reasons that I have often refrain from using the term in many recent years and just have talked about actions and communication and lived experience of folks just because the word behavior has acquired, as they say, such a negative use at times on addressing things that are sometimes stereotypes and stigma and sometimes from the biases among non-autistic people on how they feel about and perceive and their worldview about autistic people as when we are children, adolescents, and adults.

DR. DANIELS: Thank you. Yes. We'll talk in the team about what we can do with the title. I recognize that biology doesn't necessarily connect people to all of these different subtopics as easily, but we'll try to see what we can come up with that's short enough that it's not overly cumbersome. All right. We'll go to Matthew Siegel.

DR. SIEGEL: Thanks, Susan. Prior to the most recent comment that was suggesting maybe behavior should not be in the title, I was just going to say that if it is in the title, and I'm also not recalling if it's covered in a different section of the strategic plan, but if it is in the title or somewhere else in the strategic plan, it did cue me to note that the IACC did a workshop or a special session a couple of years ago on behavior in autism, and specifically on whatever your preferred term might be, challenging behavior, or behavior that challenges, or other terms people use. That is an area that is under-researched in autism and I think would be appropriate in an area that causes major difficulties for some individuals and the systems around them, and so could be an area that the strategic plan calls for more research to focus on. That certainly seemed to be the output of that workshop that was done a couple of years ago, as I recall. Thank you.

DR. DANIELS: Thank you. Yes. A focus on individuals with higher support needs and what they might need to get from research and services is a theme that's woven and in parts of the plan and it could have been on this list of topics here. I believe that there is something about that here, but we will make sure that we emphasize that as we've definitely heard about that from the community and the committee. Thank you for mentioning that. I see we have some other comments about this. Okay, Steven.

MR. ISAACSON: Hi, there. In regards to the conversation about the title of Question 2, Hari had a suggestion to not use behavior because it has a negative connotation. He suggested how about science and development?

DR. DANIELS: Thank you. I know we have some people on the call that may be managing work on this biological sciences, cognitive sciences area. Do any of you have any comments of things that you would like to see in this section? Anyone else? I was just looking down the list. For example, I know we have Nicole Williams and that in your portfolio you have some grants that cover this area.

DR. NICOLE WILLIAMS: Yes, Susan. I was just going to chat. All of the bullet points here already encompass all of our areas of interest that we offer, especially for the current fiscal year. I think we're covered here.

DR. DANIELS: Great. Thank you. Anything else from anyone? Oh, Susan Rivera.

DR. SUSAN RIVERA: I don't have any bullet points to add, but I'm reacting to suggestions to change the word behavior. I wanted to throw out an alternative that is lived experiences, biology and lived experiences. One more word, but maybe better encapsulates some of the things that are not traditionally thought of as biology on this list.

DR. DANIELS: Yeah. That's a little bit of a tough one because we have much about lived experience in Question 6 that I wouldn't want to get that confused and for people to expect to see people's experiences with finding housing or something in here that's not going to be in this section, but I know what you mean.

DR. RIVERA: That's good point. I'm just trying to find some alternative because I just don't think biology on its own does us any good. It does a disservice, I think. So, Just trying to brainstorm how we could indicate that some of these things are really behaviors and not necessarily biology. Point well taken, without bringing up that negative connotation.

DR. DANIELS: Right, what about say biology cognition and communication or something like that? It's three words, but it's still short. Is that any improvement or not really?

DR. RIVERA: I think it's worth considering.

DR. DANIELS: I know that both

communication related research and cognitive research were two areas that I think back in the January meeting someone brought up that, "Oh, you don't have anything in the plan about communication," and there actually is research on that topic in this section, but by the title biology it was hard to tell. We could consider that as well. But you can continue to send us comments if anyone comes up with a great idea on that. Matthew, do you have a comment? That hand went down. Alycia Halladay, I don't know if you have anything else. Oh, Matthew, did you have something?

DR. SIEGEL: Yes, I'm sorry. I took my hand down instead of unmuting.

DR. DANIELS: That's okay.

DR. SIEGEL: I did want to comment on this focus on language and assumptions about connotations. The term behavior is an entirely neutral term. Giving a Valentine's card to your romantic other is a behavior. Most of us would probably think is a positive behavior. The term itself does not have a connotation and I think we could all come up with proposals of things that I could propose something has a negative, or positive, or neutral connotation. I think we should just be cautious about ruling out entire terms and pieces of language. I'm not trying to invalidate any experiences Scott has had, but just putting out that there are multiple experiences. I think this committee, I just want to note over the past year, has spent a lot of time talking about language and I think that sometimes that gets in the way of our focusing on what we all, I think, also bring forward, which is the significant and ongoing needs of people with autism across the spectrum. I'm not voting for behavior being in the title, it really doesn't matter to me, but I'm more reflecting on this general theme we have of attributing things to words that may or may not be there.

DR. DANIELS: Thank you. We appreciate that comment and can take that into consideration. Alycia, since I had just mentioned to you, I know that you have a lot of work in this area as well in your portfolio.

DR. HALLADAY: Yeah, I mean, again, I agree with Matt. I want to second what Dr. Siegel said wholeheartedly. I think that I come from a place of if it's offensive to anyone, then we want to avoid using it. But words like behavior shouldn't be inherently. They're not, the word behavior. Again, I don't really have a preference if we use the word biology and behavior. I also think we need to be mindful that when we use words like differences, I agree that things like sensory motor and cognitive communication, we should definitely focus on those. Differences I think it's not as strong of a word as I would use, and to me it doesn't put forth the urgency that this community needs to have in terms of expressing the urgency and some of the really the situations that are not just differences that they are profound disabilities. I'm okay with using the word differences, but I want to make sure that we convey, in all of these sections, that there is a spectrum, and differences doesn't always represent what those are. We should be more inclusive of language and not less inclusive of language, given the heterogeneity across the spectrum.

DR. DANIELS: Thank you, Alycia, for those comments, and we'll keep that in mind. Steven, do you have a written comment?

MR. ISAACSON: Hi there. Yes, I have a comment from Dr. Paul Wang. He says, "For me, the term behavior is neutral. There's a science journal called Brain and Behavior. There's a foundation called Brain and Behavior Foundation. Simon's Foundation Awards grants in the category of human cognition and behavior. Just as brain and cognition are neutral for me so is the word behavior."

DR. DANIELS: Yes. Paul, I recognize that I thought of the same foundation when that came up. We'll give that some thought. Or maybe if we made it three words, if behavior was one of three words, it wouldn't sound as negative to certain people, but we'll figure it out. We'll come up with some ideas and then pitch that the next time. Susan Rivera, did you have anything else to say about that?

DR. RIVERA: Only that I was one that made the initial suggestion, biology and behavior. It is absolutely neutral to me as well as a scientist, as a cognitive scientist. But I do think that it's worth thinking about whether we lose nothing by putting in other words that don't trigger that for some of our constituents. I think it's worth brainstorming. I like the idea of not throwing the baby out with the bathwater, so maybe behavior can be in there. But if we have a number of members of our IACC committee who are saying that triggers a negative connotation for them, is there a way that we can think of other words that do the same service?

DR. DANIELS: Right. I mean, we could do biology, brain, and behavior or something that if it's a part of a series of three, doesn't focus on any one. I don't know. We'll have to come up with some different ones but continue to pitch things if you think of anything for that. Dena.

MS. GASSNER: Susan, I want to thank you for being sensitized. I noticed that none of the people who find behavior neutral are autistic people. And I think if you were to tally the IACC numbers who are on the spectrum, behavior has a lot of historical negative connotations for us. I agree with Alycia that differences is too low ball. I've never liked soft selling the language around these issues. I would encourage us to look very honestly at the word disability or impairment. I think also just development is a very neutral word that covers this as well. That was actually Jenny's suggestion. I don't think it's a neutral word for our community, especially in terms of when we're talking about biology and people being hardwired. I don't know. I just have to say that strongly. Again, Susan, I really appreciate your being sensitive to this. I appreciate it very much.

DR. DANIELS: Thank you. Sensory and motor development and cognitive and communication development probably would work. That's something we could potentially change that to. I think sex and gender differences still sounds better. I don't think development really makes sense there.

Scott, do you have a comment?

DR. ROBERTSON: Yeah. Thanks, Susan. I concur with referring to disability. Obviously, autism is a disability and significant disability as recognized under other laws to the Rehabilitation Act, for instance. I do concur that there may be certain places, for instance, where refer to language like differences, but for instance, under government laws, federal laws, state laws, et cetera, differences could mean something like eye color or et cetera. That it doesn't have the same standing in society as far as the need for supports and services as disability. When I think of disability, I think of it from the social model more in terms of it's not just the challenges within the person itself, it's also barriers within their access to supports and services to help them thrive, and be empowered, and have success and a high quality of life and be fully included. I do think that it is important. I would assert and perhaps disagree from some folks that I think language is really important for the committee. It's really important for the stakeholders who are looking strategic plan, which includes researchers, but it's not limited to researchers with folks in policy, service provision, autistic people and families. A lot of people read this strategic plan and make use of it and a lot of folks, for government, it helps shape the direction of what's focused on for autism under the priorities of the Autism Cares Act.

I just want to reemphasize that I think language has a major important place and it is something that stakeholder communities continually bring up, I notice. Very, very important to autistic people and our families. I think also when consider biases, one should consider biases not just in terms of how researchers use the terms, but also what they've acquired among society. That's when I say things like behavior, there is a major history, as Dena and others have mentioned, is how behavior among the last several decades and what that's meant for autistic people and extinguishing, if you will, sometimes untypical forms of interaction and what's thought of this behavior at times. I just would be careful to assume that because something is prevalent, for instance, among the research community with some of these terms, that that diminishes the extent where there may be a stigma elements for the term among the community. I think that's also the case for some of these other terms in the strategic plan, for instance, where we could consider where there could be a more neutral element as far as, for instance, things like characteristics and traits of autism in this section, some other areas instead of focuses signs or symptoms, which definitively have acquired definitely a stigma to them and are definitely non-neutral and impose definitely a negative element to them versus the traits and characteristics is a lot more neutral.

There are resources I could send also, Susan, as far as your articles that have come out recently on stigma in language, for instance, in the research community, and addressing some of these areas with language that I could share that have recently been published in the last couple or few years that might be helpful to cite.

DR. DANIELS: Thanks, Scott. We have a file going on those if you have any additional ones. We have been trying to keep track and we did actually make an effort to use words like characteristics and traits that are a little bit more neutral throughout the plan, but we will look at those. In this context, this question a lot of it is basic science and some of it is cell-based research and some of it is in humans. Sensory and motor disabilities might not make sense if you're doing a cell-based experiment, but development would apply to both. We'll take all of that into consideration, but certainly disability comes up in other parts of the plan. We will take another couple of questions, another few questions, and then we'll go to our break. But this discussion has been really helpful and is why we wanted to have this meeting so that we can get this context to try to optimize the plan. Ivanova.

MS. SMITH: This is Ivanova Smith, and I just want to talk a little bit about the history that a lot of historical words have one time been neutral and were words that tried to help people.  Back in the 1950s, the word mental retardation was used to replace the word feeble mindedness.  They tried to make it neutral, but because of stigma and negative policies that are still affect people with intellectual developmental disabilities today, these words are no longer neutral.  They are full of stigma and sometimes the community members are triggered by these words.  Like the word behavior, that could be really triggering for self-advocates, because when we hear the word behavior, it usually means that the way reasons to restrict us or reasons why we're a problem, it's behavior.  It's used in a way that's very negative and not neutral for us as autistic people.  Where it may not be used that way for other people, it may be neutral for other people, for autistic people, it doesn't stay neutral.  That's why it doesn't have the neutral status, it's because the stigma that the society has allowed to happen at negative policies put in autistic people have been used in the name of the word behaviors, just like the word MR was used against people with intellectual disabilities who used to put us an institution and sterilize us against our will. These words may be neutral for other people, but they were not neutral for us. They may have hurt us in the past and historically in many ways. That's just my little historical perspective on that. Thank you.

DR. DANIELS: Thank you, Ivanova, for sharing that background. We appreciate it. Steven, do you have a written comment?

MR. ISAACSON: Hi there. I have two comments here. One is from Dena Gassner. She talks about the history of behavior, the word behavior leading to incarceration, institutionalization, and/or conversion therapy for LGBTQAI individuals. And then, Alycia Halladay says that she's going to make the suggestion that we all be flexible with language depending on the section of the strategic plan. There's nothing stigmatizing about the word behavior in question number two.

DR. DANIELS: Well, thank you for those comments. And I know that Joe Piven is logged on and I don't know, Joe, if you're in a position to talk at all, but I know that you work in this area of biology and I haven't heard from you. I wanted to give you a chance if you want to say anything.

DR. PIVEN: Can you hear me?

DR. DANIELS: Yes, I can hear you.

DR. PIVEN: Well, I don't know that I could say anything constructive here. I tend to think maybe more fundamentally about what we're trying to accomplish with this topic area and I think about mechanisms, and etiology, and those kinds of terms. But those haven't really come up in the conversation. So, I'm not really sure what I could add to wordsmithing, the title biology. But again, I think that the main point would be to step back and say, well, what are we trying to accomplish with this set of research ideas?

DR. DANIELS: Did you see anything --are there any major topics or shifts in the field that you would to see in this section that we haven't talked about already in this conversation, or that's not on the slide? Anything that from your experience needs to be said that might not have been picked up in 2017?

DR. PIVEN: I probably want to think about it a little bit longer to answer that question more thoughtfully, but I think my first impression is that this seems very adequate.

DR. DANIELS: Okay. And we do have that survey that we're going to send out and you all will have a chance to reflect on the written documents as well if you want to take more time. I just wanted to make sure everyone had an opportunity. Everyone is doing a great job of keeping your comments brief and passing the baton. We're doing really well on time. I'm ready to go to a break and we can have a few extra minutes. If we want to come back at three o'clock, we can pick up on Question 3. But good job, everyone, and this has been super helpful in terms of all the different perspectives you've shared and look forward to continuing in a few minutes. Take your well-earned break. Thank you.

(Whereupon, the Subcommittee took a brief break, reconvening at 3:00 p.m.)

Welcome back, everyone. It's 3:00 and we're ready to start the next section of today's meeting. We're going to be talking about Question 3 of the strategic plan, which is on genetic and environmental factors. The proposed Question 3 text is, what are the genetic and environmental factors that contribute to autism?

So, the topics that are included within this question are genetic factors, environmental factors, gene environment interactions and epigenetics, studies in diverse populations, resources to accelerate research on genetic and environmental factors, and policy and ethical implications of advances in genetic and environmental science. As a note on this topic, we did hear in the RFI and from members of the committee about the importance of the other aspects of the experience of people on the autism spectrum and that more touches on social determinants of health and topics like that. Our team looked into trying to incorporate that here, but it didn't really mix that well with these topics and so we put that into Question 6, especially social sciences, research types of topics. Didn't want you to think that that had been missed, but we kept it in a separate place. We kept this one still focused on a little bit more of the biological aspects of autism to try not to mix it up in terms of when we use this question to track research for our portfolio analysis. But are looking forward to hearing from you about your thoughts and opinions are about this. I'll use the same two discussion questions. Are there any other important topics or points that we need to include or points that have to do with these different topics that are mentioned here? Have there been some recent significant changes in the field that would impact the direction that we should take in the strategic plan? I will open this up to comments.

Oh, Yetta.

MS. YETTA MYRICK: Hi, Susan. Hi, everyone. Just wanted to ask to the point that you were just describing about the social detriments of health. Let me get that out. Is the plan to briefly explain that in this section? I have not had a chance to review, but I'm wondering if people see studies in diverse populations, if that might -- I don't want to say -- use the word trigger, but make people think to that. Because I know we had some discussion about that early on and I think it might be helpful if you haven't already thought about that.

I'd be curious to know what others think about including just a brief sentence or two about why we plan to address this, but this is why we plan to address it with regard to question number six versus here.

DR. DANIELS: It's possible. We'll see how it plays out in the plan. It may not need an explanation because if people see the entire structure of the plan, they will probably figure that out themselves. But if needed, we could always reference it, but it never was a part of this chapter, so people won't be expecting to see it there necessarily. But we did want to make sure that we said something about social sciences research because I think in previous plans that really hasn't come up. I know we have some social science researchers on the committee and who've contributed to comments. I wanted you to know that we did take that into account.

MS. MYRICK: Thank you for that.

DR. DANIELS: So, Elaine, do you have a

comment?

DR. ELAINE COHEN HUBAL: Yeah. Thank you. I skimmed super fast. What I did notice, and I'm not sure if you want to think about this, but in addition to the way it's written now, again, skimmed very quickly, it's about how the environmental and genetic factors influence development of autism. Although in your objective too you say development and progression. I'm thinking about this coming from a regulatory agency, from a policy perspective, and the authorities that we have, whether or not it's appropriate to add some language or thinking about ASD as a sensitive and vulnerable, as being sensitive and vulnerable individuals to environmental factors, for example, chemical exposures. I appreciate you called out research on microbiome. Differences in microbiome could be conferring sensitivity to particular environmental factors. I think this research, again, is incredibly very nascent research. But certainly, there are signals and you do call out the use of model systems and I think that's particularly where some of these kinds of sensitivity and vulnerabilities might be testable or at least we'd be able to develop some testable hypotheses using those systems. By having it in there, I think we'd be making sure that when we're doing the policy and the development of regulations and doing chemical risk assessments and things, we're making sure that ASD is considered a vulnerability factor and we're able to do those analyses. Then I have just one final overarching thing, which probably will come up again more on the life stages probably over and over. But in terms of when cohort studies are being designed and implemented, really calling out the need to oversample for ASD so that we're not necessarily only considering ASD in specific studies of those individuals and populations, but that we're always oversampling for that group in other cohort studies where we're looking at environmental factors or other kinds of health-related. Well, a lot of the government-led surveys and longitudinal cohort studies. That was that.

DR. DANIELS: Great. Thank you, Elaine. Something that I didn't mention on the slide, it's not on the slide, but we did add co-occurring conditions into this as well and that was not in the previous plan in this section, but we did hear from members and members of the public about the importance of maybe these factors and how they might influence co-occurring conditions with autism. So, that has been incorporated. But we did mention something about vulnerability, but if you have any specific references, Elaine, that you might want to send us on that, we could elaborate it a little bit more.

DR. HUBAL: Sure.

DR. DANIELS: Great. Then I thought I saw more hands raised, but I don't see any right now. Are there some other comments, Scott?

DR. ROBERTSON: Yeah. Thanks, Susan. I know this is beyond the new elements aspect, but again, until language, again, since folks who are non-researchers sometimes may read the plan. Is there any way we could consider something like genetic and non-genetic or something like that? Just because I know that among a lot of scientists, especially I'd say physical scientists, sometimes more so than social scientists using the term environment has been pretty common for many, many decades. I'm well aware of that, that that's what they use to accompany genetic. But I think among the general population in society, policymakers, service providers, even maybe some slice of researchers when they hear the word environment or read it, they think of more of the physical space and don't realize that environment is anything non-genetic, basically. It could be other things as far as that relates to how that human development takes place and not the person's genetics itself. I think that's just something that might be helpful for folks understanding the context of that, that environment is referring to the non-genetic elements in terms of what that looks like for human development, lived experience, upbringing, as you develop for childhood, and adolescence into adult life. Just thought that would be helpful as far as language. If you don't want to perhaps change it, at least some clarity just to make sure some extra context might be helpful there so folks have that full understanding that we're not just talking about just the physical space that we meet. It's a lot broader than that as far as the non-genetic factors that shape the human development what that looks like for autistic people and the co-occurring conditions we may experience. And then I do like how you have the diverse populations element. I think the more we could stress that, the better. I think we do have a history at times that the studies have not often -- and I know there's a lot of issues with sometimes getting a diverse sample in research studies. I'm well aware of that. But it's something that I think we still need to have a major priority on is that study samples should be diverse in terms of background as far as race, ethnicity, gender, gender identity, et cetera. But also among folks in terms of diversity, in terms of what their autism experience looks like, and in terms of support, needs, and co-occurring conditions and whether folks having intellectual disability, et cetera, there's a lot of studies that have tended to roll out folks based on co-occurring conditions. Sometimes the studies may be misleading at times in the literature, including on these physical science elements that you may see something out there. And it may be confusing because of the fact people don't actually read sometimes the full text to the study to know the limitations and shortcomings in that study and realize where it's coming from. And then we can't really address it.

The plan also is that this changes over time kind of thing with the science. We're still in our, I'd say, infancy at times for autism research in terms of the physical science end is something that's going to be changing a lot over time for the research investment in this space, and I hope that folks can be aware of that in the general public. I don't know whether the plan is able to help with that, but just folks to understand that this is in flux. That some of these roles we've been learning in the last 5, 10, 15 years because of the fact of how under-studied autism was overall. Then we knew almost nothing about some of the underpinnings in terms of genetic and non-genetic factors 20, 25, 30 years ago. Thanks.

DR. DANIELS: Thank you. And so, with the word environmental, it does bring up more of a biological mechanisms, which is what we're focusing on in this chapter. We try to keep the social science in Chapter 6, and so we don't want to mislead people to think that we're going to talk about all the social factors that also contribute to the autistic experience in this chapter just because it started mixing too many things together and it might make a shift in the counting of projects when we go back to do the portfolio analysis. But we'll take that into consideration, making sure that we cover some of the issues that you mentioned in the plan. JaLynn.

MS. PRINCE: Thank you. My husband is a major researcher and he has been involved in many different types of things. He brings up a question, and I'm putting it out more as a question because I don't know where this is necessarily going. I'll bring it in with a second point here. About how we look at autism. Will we get to the point that we have done with, say, cancer? I'll bring into that personal thing with my brother-in-law who had a very rare type of cancer where there was about a 4 percent survival rate, but they were able to target particular things to his biology, to what it was that was impacting him, and they were able to treat the subset of the Cancer very successfully. He's now 18 years out. But I bring that in with can we or should we look at how we could encourage looking at different subsets? Because if we could identify types of autism early on, would there be different modalities that we could utilize in helping these individuals? And this may be underway. I've not seen that. I've not done that type of research. But I put that out as a question at the same time as I would like to ask something about this. Because we're involved in the genetics component, I imagine many people here are aware of what is happening with the Sparks Research and the genetic collections that they have been getting from families and individuals. Can we reference any of these things? Is there something or are we going to do something aside of what heavily-funded, large research project that is going on that may be addressing some of the issues that we have listed with our topics?  I've got two points right there.

DR. DANIELS:  Yeah, and so, identifying subtypes.  That's partially in Question 2 and there are some in Question 3 about that as well.  That it's not listed on the slide, but it's something that is touched upon, but we can make sure that it's still there.  We did mention Spark in terms of large studies, and there are some others that we've mentioned as well.  Also, there will be an opportunity to potentially take advantage of other big studies that are not autism-focused but maybe could have an autism question or component somewhere in them.  We will certainly want to reference some of those ongoing projects as well as make room for anything new that might come along.  Paul, do you have a comment about this?

DR. WANG:  Yeah, just for the purpose of clarification, I want to say that in some ways, Spark is a study, and in some ways, it's not a study, it is a resource that is being created. Families, persons who volunteer to participate in Spark don't have to, but one way they can participate is by providing a saliva sample which does undergo genetic sequencing. If there is anything found that is related to autism or related to intellectual disability, then that is reported to the people who submitted these specimens. They're also told if nothing is found that is known to relate to autism or intellectual disability. That's really all that Spark does. In and of itself, it's not quite a study.

However, that resource, the group of all the samples, all of the sequencing data is made available by application to qualified researchers who have ethics approval from their own institutions, and oftentimes in combination with other sequencing data from other projects to look at things that require very large numbers of participants, for example, when you're looking at polygenic factors that might be related to autism.

DR. DANIELS: Thanks for that clarification, Paul. Is there anything else, as long as you're speaking about this chapter, that you think that we should try to emphasize or anything new that we want to take into account? No other comments at this point. Thank you. Okay. Thank you. Dena.

MS. GASSNER: I tried to sit and listen more than anything for this segment. I did want to share that this topic has come up at the RQS. When I came in there, we had a prevention policy, which raised a lot of concerns, and it's since been evolved to causes and effects because it gets easy when you're looking at things like toxicity in the water, lead poisoning, and paint, right? Clearly, someone who has an autism condition that experiences exposure to those environmental toxins are going to experience a much more complicated outcome from that. So in that way, defining environmental causes becomes pretty simple. But I think that some of the genetic studies are quite hampered because the ethics around the purpose around genetic studies isn't always transparent. As a result, many individuals don't participate in genetics research. I think it's because the ethics has not kept up with the capacities of the research. In other words, how do we look at genetics to ascertain the hard wiring of autistic individuals for anxiety? Can we reduce their anxiety? Or are we trying to make them indistinguishable from their peers? The Simons Foundation, when they received their award at INSAR, said that they hope to cure autism. That kind of language and those kinds of trajectories are very, very unnerving for our population. I don't really know what to do with all of that except to say that I think in terms of genetic support from IACC, it needs to be focusing on things that are emancipatory, things that will reduce stress, anxiety, difficulties with communication, intellectual disability, that's quite substantial. To be sure we're delineating between that and trying to eliminate the condition as a whole, because we are human beings. We do contribute to society. We do contribute to research. We would just like life to be easier. I'm not sure that ethics research is able to delineate that quite yet. I just wanted to verbalize that concern. I don't know what to do with it, but I just wanted to convey it. I don't know.

DR. DANIELS: Thank you for sharing that, Dena. We did make an effort to try to address some of that in the chapter, so when you have a chance to actually read it, you can let us know if you see anything else that we should add or anything that still doesn't match. But we did try to address that issue. Something that you all might be interested in being aware of is the National Human Genome Research Institute at NIH is going to be sponsoring a conference on genetics and ableism as it relates to disability in the fall. It's in October, and we can share more information on that. It's available on the website. I think we have it up on our IACC website and it's on the web in terms of NHGRI's website. Someone from our team might be able to put the link into Zoom. The public won't be able to see that, but I think it's already on our website. If you google it, ableism NHGRI conference, you probably will see it. We recognize that and we hope we might learn something from that conference too that we can be able to use for the plan. Alycia, I'll take you next.

DR. HALLADAY: Sorry. I was just going to say take Paul first because I might just copy him. But in addition to what Paul has to say, I want to just reinforce to this group and to everybody that people do not conduct genetics research or want to study the genetics of autism or any condition because they want to eliminate anything. People study the genetics of height, they study the genetics of eye color. This is to have a better understanding. If we need to clarify that in the strategic plan, let's clarify that. But on the whole, genetics research is not aimed at eliminating anything.

DR. DANIELS: Thanks for that comment, Alycia. I do think it has been a change in direction back more than a decade ago. I think that prevention was on the table and it was a part of the first IACC strategic plan. We did make an effort to shift some of that language as we have reflected what's been happening in the committee, what's been happening with funders, et cetera. The field has changed in that respect and we tried to reflect some of that change in the plan. But we'll be open to comments from the committee as you have a chance to review drafts. PAUL.

DR. WANG: I'll just thank Alycia for making the comments that she did and offer a small additional clarification. I actually was not able to attend INSAR in person and was not even able to listen in to the session where Jim and Marilyn Simons were presented an award. But for clarity, the award was given personally to Jim and Marilyn Simons, not to the Simons Foundation. Jim and Marilyn actually, we are greatly indebted to them for having founded the foundation, for having endowed it with the money that allows it to operate. We like to think that we've spent that money in a way that advances the wellbeing of the autism community. I don't know exactly what words JIM used in his personal acceptance of the award, but it is not the mission of the foundation of SFARI to cure autism. That's not a word that we believe in. It's not a word that we use. You won't find it in our mission statement. Thank you.

MS. GASSNER: Thanks for clarifying that. I appreciate the clarification. Thank you.

DR. DANIELS: Thank you. Scott, do you have a comment?

DR. ROBERTSON: Yeah. Thanks, Susan.

It just occurred to me with the discussion and the fact that ethical implications is one of the topic areas here. I was just wondering if there could be a discussion of conferences or symposia on ethical, legal, societal aspects. About a decade ago, you all in the U.S. Department of Health and Human Services, two different agencies, NIH and ACL, funded conferences in this space. One was run by NIH itself. I think, Susan, you spear headed that. Yes. And one was funded by ACL to ASN and it ran a symposium at Harvard Law School on ethical, legal, societal implications of autism research. We haven't really had major conferences in that space since then in the last decade as much, even though there's a pressing need. Maybe that's something that could be mentioned in the description somewhere that fits into that ethical space with the science and the research is having conferences of that nature and also having more input from the public in terms of different perspectives on autism research and these ethical, the policy elements, the societal aspects of what it looks like and how it has an impact on folks. I think that fits into clarifying also what was discussed in terms of genetics because I think it is helpful to provide some context on how the committee approaches in terms of the context for genetics on here. Because, again, there are some folks that when they do see genetics, see some of the history. They're related to genetics and genetic testing and what it can mean as far as for autism.

There is a little bit of a history in terms of some connotation on there. I think that context would be helpful that it's looking at genetics partially for helping support how you could empower folks and help address some of these major challenges as was mentioned earlier by other committee members. And what genetics factors may be helpful for supporting whether it's medical things or otherwise that could help empower folks against difficulties and challenges as they go through that lived experience and human development over time. Because I think some of the general population without context may not understand that. Sometimes they may have a narrow view of genetics, especially non-researchers who may not understand the full purpose and the full set of what researchers and genetics do and why they're looking at these factors. I think the researchers could do a lot better of communicating, I think, that sometimes to the public in terms of what they do in the context here. I think that adding a little more context of why the committee is interested on these genetic factors and environmental factors into this section as far as to help make it more concrete would be helpful.

DR. DANIELS: Thank you. We did try to do that in the section, but we'll continue to look at it over the next few months and see what else we might be able to add. And, thanks for mentioning some of those previous conferences on ethics. I know that the one that the IACC sponsored was a while ago and so some of that information might be a little bit outdated now because we've probably moved further along. But I do think this NHGRI conference may be pretty relevant to some of the work we do. We'll be sure to have some people that work with the IACC attend that and hope that maybe some members of the IACC can attend as well. But keep me updated if you know of things that are happening out in the field and you want us to pay attention. We can look into that too. Joe, do you have some comments?

DR. PIVEN: Yeah. Thanks. I wanted to just see if I could add to this conversation and maybe specifically what Scott was talking about with regards to why this research is happening and the context. Can I start with a question to you, Susan? Is there a section in the strategic plan and specifically around this Question 3 of genetics and environment that goes into some detail about how we used the term autism or autism spectrum disorder in certain contexts like in DSM? But then in other contexts like when you're talking about etiology, we don't think of it as one thing. I think that would be a really important point to get across in some way that would maybe address. Because I think Dena is raising a concern that other people will raise. There's a lot of confusion about that complicated area of genetics and what the goals are. I mean, I do in fact think that the goal of genetics research in some cases is to intervene and to change the course. Certainly, the research at our institutions heavily focused on Angelman syndrome and finding a genetic way to reverse the mutation in Angelman syndrome. But comparing Angelman syndrome to what others might be thinking about in terms of autism more broadly due to common factors, I think it is really confusing to people. I think a little bit of a setup, if that doesn't exist, in the text explaining that, introducing this would be really critical.

DR. DANIELS: Thank you. That's a helpful comment. We can think about that. I don't think we do have anything that explains some of that, and we'd have to find a way to do it in plain language and briefly. But I think that that's a good point and we could try to bring that out either in this section or maybe even earlier in the plan, somewhere in the introduction. We do have a statement up at the beginning of the plan that will be about language, and that in some cases we use autism. Sometimes we use autism, or on the spectrum, we use ASD in particular context where we're talking about the specific DSM diagnosis. We share some of the background of why different terms are used and that they might be used interchangeably in the plan.

Okay. Other comments that people have for Question 3? And I know that we do. Is there anything else from EPA or anything from NIEHS that you would like to say about Question 3? I know you may not have had had time to go over this in detail, but anything that you would like us to make sure that we mention in this chapter as I know you all are experts in this area too. Okay. I'm not hearing anything. Sounds like we're finished with the discussion of Question 3. I had scheduled a 15-minute break now, but we just took a break. You raise your hand if you want us to take a break right now. If I don't see raised hands, maybe we just go on to Question 4 and maybe we would get done earlier than scheduled. So, anyone for a break at the moment?

Okay, I'm not seeing any hands. It sounds like people are comfortable with going on to Question 4. I will move us into that.

For Question 4, this is on interventions, and the shortened new text is which interventions will improve quality of life? And the subtopics included within Question 4 are medical and pharmacological interventions, behavioral and developmental interventions, complimentary and alternative approaches, technology-based interventions and communication interventions including iAC, interventions for co-occurring conditions, outcome measures and biomarkers, and research and policy issues including inclusion in research, disparities in access to interventions, and the needs of individuals with high support needs, and the needs of the workforce in the intervention space. Those are the general categories, but same discussion questions. Do you have any important topics that you would like to see highlighted in this section of the strategic plan? Have there been any recent significant changes that might shift our focus in this strategic plan? Things that might need to be taken into consideration by funders, and researchers, and people that are managing service programs, or writing policy in the area of interventions? Jennifer.

I don't have any comments right now on the topics. I had more of a reaction to the title for this chapter which reference quality of life.

DR. JOHNSON: I reacted to it because the way I heard that is that, basically, people with autism have a lower quality of life and that somehow suggests that that's their fault, which really isn't true. It's more that society hasn't fully included people with autism to adequately support them living well in the community. I'm just wondering if there could be an opportunity here to reframe Question 4 so that it's not putting the burden on autistic people, but more talking about what interventions are needed to support quality community living or something to that effect. I don't know if I have the words to suggest. But, again, I think it's important to maybe rethink that one.

DR. DANIELS: How about something like, which interventions are needed to best support autistic people, or something along those lines? Would that be any better?

DR. JOHNSON: I think we'll have to play

with it a little bit, but I think just something that can better reflect.

DR. DANIELS: Great. If you think of something, just email me suggestions. Definitely open to changing that to be a better fit. Dena.

MS. GASSNER: Maybe something that focuses on the systems itself, right? Which systemic interventions can maximize quality of life or something that has the word systems or systemic in it might be helpful. Can we go back to the prior slide?

DR. DANIELS: Yeah. Well, this chapter covers more than systemic interventions. It includes drug interventions and behavioral interventions and so forth too. It does have systemic interventions, but it's an umbrella for a lot of different things.

MS. GASSNER: So, under research and policy issues, one of the challenges that we haven't been talking about much is the reality that many individuals who subjectively would be perceived as having low support needs, they actually have incredible daily living challenges. Unfortunately, our policies are driven by IQ, by a subjective observation of a person in a situation rather than taking into consideration their reporting of pretty significant impairments related to things as basic as food security, and housing, and the fact that their unsupported autism needs lead into co-occurring conditions like depression, anxiety, suicidal ideation. When we look at the pie, clearly people with high support needs need more interventions more frequently at a higher intensity. But quite often that results in us failing to acknowledge that if you have an autism diagnosis, as few as five to 10 hours a week could be life-altering, right? It should be based on need and not based on these random testing formulas, I guess is what I'm trying to say.

DR. DANIELS: Thank you. That's helpful. In terms of high support needs, that was meant to be pretty inclusive. It could include co-occurring conditions and other things. But wanted to mention that as the public has mentioned the importance of being inclusive across the entire spectrum, and that does include all these different co-occurring conditions too that can make challenges for individuals on the spectrum. But we appreciate that. Thank you.

MS. GASSNER: Well, and I want to be clear about delineating the difference in a co-occurring condition versus unmet support needs, right? What I really think we're missing is that people who have finished academics with intensive supports, people who have part-time employment, for example, may still be having unmet support needs that prevent them from moving perhaps to full-time, or they're not provided adequate interventions and support to just be healthy in a part-time status. Yes, there is a category for co-occurring conditions, but so often, those conditions are a direct relationship to unmet support needs related to the autism itself.

DR. DANIELS: That's an important point. We did try to bring that into Question 6 where we do talk about things like housing, employment, and we mentioned food security and things like that. We didn't use the terminology unmet support needs, but I think that is a good way to describe that, and we can certainly bring that out in that chapter. Here, we had a pretty large group of different types of interventions. But it's a good point, and we appreciate that. Scott.

DR. ROBERTSON: Thanks, Susan. I just want to say, I concur on the need for putting in that unmet support needs, I think is really helpful, even if it's just a small reference here versus the other chapter. I think that also fits into the issue we have now of folks making judgments based on the DSM diagnosis and what level of support was indicated by the clinician, whether you're an L1, L2, L3. Folks are making judgments rather than looking at things based on actual need of the person. I know many autistic folks who are adolescents and adults that's happened to them very frequently. I myself, to be honest, I have many unmet support needs, but folks make judgements because they see me sometimes at these IACC meetings or other webinars and see me speak and hear my job title and they make generalizations about my lived experience. They've never seen me on a daily life basis. I think that's true for a lot of other autistic people in adult life. I would extend that also to adolescents and childhood too, who have very frequently unmet support needs.

As was mentioned, even sometimes just a few or several hours a week could make the difference between enhancing someone's quality of life and having just better health and wellness. It's not always that a person needs 40 or 50 hours extra services, but they may need just a little bit extra support and services. Our systems are just not well set up to support folks in that customized nature that align nature where it may be only a few hours of support. I would also say, do you have the space, Susan, to consider moving around the order of where these appear in the chapter in terms of which subsections come first? Because if you're able to do that, I would move up technology-based interventions and communication interventions in AAC to be earlier or maybe first because it is so under-focused and it's such a major priority among autistic people in terms of communication needs and supports versus the other facets. Medical and pharmacological have been such a major focus of the strategic plan for such a long time. Folks are aware of that. But I think it would help to really call out that technology and communication supports and AAC support for folks is tremendously important to have that earlier, perhaps even, as I said, the first subsection in Q4 to appear before these other areas. I think that would just help to highlight the priority that the major unmet needs there for supports and services for folks to help and enhance quality of life.

I do also concur with that maybe something could be wrapped around interventions to enhance quality of life, or enhance health and wellness and quality of life, or just health and wellness or something like that. Because that's what they're all aimed at doing, is empowering folks to have a better health and wellness, a better quality of life in line with the priorities under the CARES Act in terms of that. The reason you're having these interventions, the reason for supports and services is to boost folks up to address challenges for the sake of the empowerment perspective. I think that it's helpful to have that context in here.

DR. DANIELS: Thank you. Certainly, we can look into the order. I see that Yetta also mentioned that she liked the idea of seeing technology and communication maybe in a different order. We'll see how the flow goes with the chapter. But we did want to make a bigger emphasis on technology-based interventions and communication interventions than has been made in the past. That has been an effort, and we will take another look at that. Alycia.

DR. HALLADAY: I know Dena didn't mean it this way, but I don't want us to lose sight of the issues around co-occurring conditions. While they are not part of the autism per se, we don't really know if they are or not. But things like seizures and gastrointestinal problems and other medical and other comorbidities or co-occurring conditions, are not part of the core autism symptoms and can occur in anyone. However, they are greatly misunderstood in those with neurodevelopmental disorders. We don't even have the right tools to study them. The procedures used to assess them are wholly inappropriate for this community. I know she didn't mean it this way, but I want to make sure that we also highlight the co-occurring conditions.

MS. GASSNER: One hundred percent, I agree with you, Alycia. I was thinking around mental health. Thanks for clarifying that.

DR. DANIELS: I agree. The IACC has been very focused on addressing co-occurring conditions because it is something that autistic individuals and families talk about all the time as really having an impact on being able to live healthy and well. We want to make sure that we address that in a greater way. Jennifer?

DR. JOHNSON: So, I think, one of my comments is probably just addressing the unmet needs and unmet supports. Because when I think of interventions and I look at this list, I think that there are probably some that are missing that, again, would relate to some unmet needs. I think about interventions that might occur related to housing that would improve for what we're calling right now, quality of life. Or employment. Interventions that support one getting employment or staying employed. Also just general home and community-based services that could be viewed as interventions that in ways should be meeting the unmet needs, but oftentimes go as unmet needs. How are we factoring them into this question as it relates to interventions? Another thing that I've wondered about on this list, if it's there, and it may fall under developmental interventions, but what I also think of interventions, I think about what's happening in schools and the different interventions that could happen in schools. That, again, may be under developmental but I want to make sure that we get educational interventions in there too. And then with medical and the pharmacological, is it physical and mental health? I'm just wondering if we need to call out mental health. That's different from behavioral interventions because behavior is how someone is behaving. It doesn't necessarily indicate that somebody has a mental health disability. It may be behavior that's as a result of how they communicate. I just want to make sure that we're incorporating mental health in this question and interventions related to mental health.

DR. DANIELS: Yes. Mental health is in the chapter as well as educational interventions, which in this slide, just for brevity, got included under developmental. But we will make sure that those are there. I mean, I know that they already are there, but we will make sure that it's clear because those are important areas. Mental health is certainly something we've been hearing about from the previous IACC and this IACC, and we want to make sure that's addressed. Thank you for those comments. JaLynn.

MS. PRINCE: Thank you. There have been so many wonderful comments today. There's so many bright people here, and it's very reassuring to hear this many wonderful voices and giving insights. I wonder too about some of the things with interventions that sometimes we don't include because I wonder about the families. And if you'd mentioned this earlier, I had to step away for a moment. I had a situation here. But families. If someone is not living in a healthy situation with parents that can cope, know how to cope, know what they're doing, and interventions that can help siblings. Because if there is tension between siblings even in the most -- I don't know if there is a typical family of the country, though. Everybody has a dynamic. Sometimes I think that dynamic can be exacerbated and be much more dramatic, very much to the points of trauma. If we can look at interventions for families or how we can make those things available, again, that may come in to training more professionals, that could come in and help families learn how they can cope and how everyone can be part of a family and have success in their own way. In so doing, helping the autistic individual have a better environment as well, as well as having other citizens have greater supports in their wellbeing. Thank you, JaLynn.

DR. DANIELS: We do have caregiver supports in Question 5. We have a section that will address all of those, and it does include siblings and specifically named siblings as a part of that. But definitely want to take that into account because there are a lot of ways that we can help the family system to best support someone on the spectrum. Next we will go to Steven.

MR. ISAACSON: Hi there. This is a comment from Scott Robertson. He says, "Also the unmet needs discussion fits into a related area, namely that it's the effort to classify people with disabilities as a medically underserved population group. Like other people with disabilities, autistic people are certainly medically underserved. Autistic children, adolescents, and adults face major barriers to accessing healthcare, and human services, and supports to help foster health and wellness." This is partially covered in Question 6, I think.

DR. DANIELS: Thank you for that comment, Scott. We did make an effort to talk about that issue of the people on the autism spectrum as being a part of the disparity population in themselves. That is in this new section that we'll be talking about tomorrow that's on equity and disparities. But we know that the National Council on Disability, for example, and their health equity framework talked about people with disabilities -- they're campaigning to have that created as an official health disparity population. So autism would fit within that, and we wanted to make sure that that's mentioned in the strategic plan and highlighted along with some of the other disparity and equity issues that we're looking at. Thank you for sharing that. Dayana Garcia.

MS. DAYANA GARCIA: Yes. Hi. Good afternoon. I just wanted to make a quick comment around interventions in the classroom and family-mediated interventions. I would like to see more emphasis on the piece around culturally and linguistically appropriate interventions. In those two sections in particular, there's no mention of linguistically appropriate interventions and factoring in the culture of the family.

DR. DANIELS: Thank you for that comment. We can look into that. That is something that we want to weave in throughout the strategic plan so it does belong in here. We'll see, if it's not there, that we can put it in or emphasize it more if it's already mentioned, but maybe not very highlighted. So, Steven, do you have another comment?

MR. ISAACSON: No, not at this time.

DR. DANIELS: Oh, okay. I'm sorry. I just thought you had a hand raised. Any other questions or comments on this section? Anyone out there that is working on interventions or manages a portfolio of efforts in the area of interventions that you have more comments to make on this?

DR. WILLIAMS: Hey, Susan, it's Nicole. I don't really have anything to add. Again, I think this pretty well covers the types of projects that are funded in our portfolio.

DR. DANIELS: Great. Thank you, Nicole.

DR. JOHNSON: Susan, this is Jennifer Johnson. Just another potential intervention that I'm wondering if it's listed in this section. Is peer-to-peer interventions and peer-to-peer support as an intervention, and research that's being done on that?

DR. DANIELS: Yeah, I think it is there. It's not on the slide, but I think it's in there someplace. We'll make sure that that is mentioned because that is another important category. Additional comments.

MS. GASSNER: Susan, do we have anything in regard to navigating insurance, Medicare or Medicaid, as a family intervention tool? It goes with systems navigation. I'm not sure.

DR. DANIELS: Yeah, so, in Chapter 5 we

tried to include systems navigation. I know that you have probably way too many references, but if you have any key references that you might want to share on that with us, that would help us because that's something that would be new in the plan this time. So, that would be helpful if you have anything on systems navigation that you could.

MS. GASSNER: Yeah, I'll be happy to get those out to you.

DR. DANIELS: Thanks. That would be great. We can make sure that we try to write an adequate section on that. Alice, do you have a comment?

DR. CARTER: Yeah. Hi. I'm not sure if this goes in this section, but I wonder about where we have evidence-based for interventions across all of these domains. Just research on speeding up dissemination because I do feel like there are a lot of evidence-based interventions that are just ignored in a lot of communities and that also relates to health disparities. I just wonder if dissemination, given the interest in this area now, might not be worth mentioning here.

DR. DANIELS: Yeah, and I think we can fit that in with research and policy issues. Are there any great examples that you have of dissemination strategies or efforts that are out there that are helping people?

DR. CARTER: I can get back to you. I'll get back to you.

DR. DANIELS: Yeah, think about it and let us know if you have any examples, but we can fit that into the research and policy section.

DR. CARTER: Thank you.

DR. DANIELS: Other comments?

DR. ROBERTSON: Scott. Susan, I just wanted to mention, related to what was shared about peer supports is, I don't know whether you're aware and maybe it could go into the plan related to peer supports, is as one example out there is Philadelphia has a peer specialist program. They support education and training opportunities for autistic adults to serve as peer specialists for fellow autistic people for navigating system services, education, and workplace. They've been trying, I think, to take it statewide and it's to support autistic adolescents and adults. When I just looked it up right now, the persons they support through the program must be at least 14 years old and qualify for CBH, which is their insurance provider/Medicaid and have an autism diagnosis and reside in Philadelphia. But that's an example of having peer supports that could be helpful for the systems navigation, connecting to supports and services, again, to work, to school, et cetera. And just like with community-based participatory research, it's a good example to follow where you're supporting education and training of autistic people to support fellow autistic people. It may be in some cases to support their broader families too. We don't really have that happening really nationally. I think that's the only example unless anyone knows of any others out there in the United States where folks are training autistic adults and realizing that we can play a valuable role in supporting fellow autistic people, including adolescents and adults, including when folks are just recently after a diagnosis and just for general supports and services too. We've had a lot more advancement in that peer support specialist area in the mental health space.

If you want to know broader, there's some literature on that. When they created that community autism peer specialist program in Philadelphia for training autistic people to support fellow autistic people, they've based it off of how that's been happening for many decades in the mental health community across the United States to help educate, and train, and support skill development for folks with mental health conditions to help empower fellow folks with mental health conditions to support their health and wellness, and quality of life, and help them access supports and services.

DR. DANIELS: Great. If you have a reference or a website for the Philadelphia project, you could put it in the chat or just email it to me for the team. And if you have references for anything else, just send them our way and we'll make sure the team has those.

DR. ROBERTSON: Yeah, I'll put it in the chat for you all.

DR. DANIELS: Thank you. Other comments about Question 4?

DR. WILLIAMS: Yes, Susan. This is NICOLE, again, and this is just something I was thinking about just based on what we've been seeing over the past couple of years. I don't know if it would fit in here as far as telemedicine, utilizing that for interventions. I don't -- do we describe that during this chapter? I can't recall.

DR. DANIELS: It's in the plan. I don't remember if it's in this chapter or not. It probably is and it probably is in more than one place. But that's a really important point because especially during COVID, we've started accumulating some evidence about the effectiveness of remotely delivering interventions. That would be worthwhile to mention, especially if there have been some studies that have suggested that this is a valid way to deliver that could expand the capacity to deliver to more people in more places. Okay, and, I see a couple of the references, Scott, thank you. Ivanova.

MS. SMITH: This is Ivanova. Just speaking of COVID, I just want to make sure that the COVID policies are not harming autistics or causing more trauma, especially autistics that have high support needs and can't tell you that they are distressed by having their routines gone or being put through sensory issues. My comment is about COVID is make it so the regulations around that is not caught in undo harm. Thank you.

DR. DANIELS: Thank you. We have some

information about that in a special section on COVID. I know that we had something about, for example, difficulty for some people wearing masks and things like that. But we can take note of that for the COVID section and we'll talk a little bit more about that tomorrow.

MS. SMITH: Thank you.

DR. DANIELS: Of course. Other comments? Lauren.

M. LAUREN RASKIN RAMOS: Just wanted to agree with the comment on telehealth and was going to raise that as well in the next chapter. Then we really need to think about access to both interventions and then services and supports through either telehealth and other virtual mechanisms as we think about improving access to care.

DR. DANIELS: Thank you. If any of you are aware of new papers that have come out that support telehealth approaches, especially that have been developed during the COVID pandemic, please send them our way and we can use those as references because that is something that has shifted in the past few years and we could talk about a little bit more in this plan.

Anything else? Alice.

DR. CARTER: I just have a very quick thing, which is I wonder if we should also make sure telehealth gets mentioned for diagnosis or even screening and diagnosis because I do feel there've been a number of papers talking about remote diagnosis being very successful. Alice, if you happen to have any on hand, if you could send those to us too, that would be great. I think that would be important. I know I just recently saw one, and so I think that would be good to bring that up. That's another theme of including more people and providing access and also, hopefully, addressing some of the disparities.

Additional comments? It sounds like maybe we have made the comments that we want to today. You all have been extremely efficient and just done a great job in bringing up really important points and topics and things that we want to make sure that we bring up in the plan. Dena.

MS. GASSNER: Did I hear you correctly? Are we going to address disparities tomorrow?

DR. DANIELS: Yes.

MS. GASSNER: Okay. I have a comment about disparities, but I'll wait till tomorrow. Thank you.

DR. DANIELS: Unless it's directly on interventions, we have a section that's on that.

All right. We can talk about that tomorrow.

You've all been very efficient. We are finished early for today and you've done a great job sharing your thoughts and ideas and I hope that everyone feels like they had an opportunity to comment if you wanted to comment. Tomorrow we'll do the same thing. We have a few more topics, but if we're efficient, we should have plenty of time to talk about each of those topics. This is all really helpful input for our team in terms of getting revisions made to these documents.

Unless there are any additional questions, are there any other questions about today and what we've discussed or about what's happening tomorrow? Tomorrow we will be going through Questions 5, 6, 7 and the new sections on COVID, disparities, sex and gender. I'll make a mention of some other pieces that will be in the survey. We have a few more pieces tomorrow, but I think we will still be able to fit well within our time. Scott.

DR. ROBERTSON: Thanks, Susan. Just a quick question. If we also think of any other resource or other things that you can cite offhand, can we just email that to you?

DR. DANIELS: Yes, you can. If you're able to email them to me and or CC the IACC team, that would be great. I can forward things, but just to make sure that nothing is missed, it helps to copy them as well.

DR. ROBERTSON: Sorry, I meant the you as being the broader you. I'm sorry, as far as the IACC team.

DR. DANIELS: You could email IACC team and just copy me. That will make sure that it gets to our team because after this meeting ends tomorrow, we'll have some time to continue making revisions based on what we've heard.

DR. ROBERTSON: Okay, great. I know that in a couple of other cases also with executive function in the sensory motor, for instance, I have references to a couple of key review papers that have come out that I think would be helpful in citing in the references section of those areas.

DR. DANIELS: Great. Thank you. I appreciate that everyone is also sensitive to the fact that we are trying to bin all these topics and it's never perfect and there's going to be crossover between the topics. But as much as possible, we're trying to put them in categories because if we lump everything together, it'll be too confusing to read. We try to make some little distinctions between the different groups, but we recognize that in real life these things overlap with each other. We will do our best to make everything clear. We really thank you today for all of your work on this and we look forward to seeing you tomorrow. So, we will start at 1:00. With that, I think that we can end the meeting for today. So, thank you, everyone, for joining us and we look forward to seeing you tomorrow.

DR. ROBERTSON: Thank you, Susan and your colleagues, for spearheading this workgroup meeting for us to have this active discussion. I think it was very productive in terms of the ideas and thoughts that were shared to help enhance the narrative here across all these areas of the strategic plan and what we also will be discussing for the other three questions tomorrow. So, thank you very much.

DR. DANIELS: Excellent. Well, we

appreciate your comments and everyone's contributions to the discussion today.

(Whereupon, the Subcommittee adjourned.)