INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE MEETING

MONDAY, SEPTEMBER 23, 2024

The Interagency Autism Coordinating Committee (IACC) convened virtually, at 9:00 a.m., Shelli Avenevoli, M.D., Ph.D., Acting Director, presiding.

MEMBERS

CHAIR
SHELLI AVENEVOLI, Ph.D.
Acting Director, National Institute of Mental Health
National Institutes of Health
Rockville, MD

JUDITH A. COOPER, Ph.D.
(for Debara L. Tucci, M.D., M.S., M.B.A., F.A.C.S.)
National Institute on Deafness and Other Communication Disorders

KRISTINA HARDY, Ph.D., M.D.
National Institute of Neurological Disorders and Stroke

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

JENNIFER JOHNSON, Ed.D.
Administration for Community Living

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

CINDY LAWLER, Ph.D.
(for Richard Woychik, Ph.D.)
National Institute of Environmental Health

Sciences

LEAH LOZIER, Ph.D.
U.S. Department of Housing and Urban Development

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

MATTHEW MILLER, Ph.D., M.P.H.
U.S. Department of Veterans Affairs

JUSTIN MILLS, M.D., M.P.H., F.A.A.P.
(for Kamila Mistry, Ph.D., M.P.H.)
Agency for Healthcare Research and Quality

AMBER PARKER, M.J.M.
U.S. Department of Justice

NIKHIL "SUNNY" A. PATEL, M.D., M.P.H, M.S.
Substance Abuse and Mental Health Services Administration

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

KARYL RATTAY, M.D., M.S., FAAP
Centers for Disease Control and Prevention

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

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

EMILY WEAVER, Ph.D.
(for Christy Kavulic, Ed.D.)
U.S. Department of Education

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

PUBLIC MEMBERS

MARIA MERCEDES AVILA, Ph.D., M.S.W., M.Ed.

Parent, Researcher; University of Vermont

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

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

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

THOMAS W. FRAZIER, Ph.D.
Parent, Researcher; SUNY-Upstate

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

MORÉNIKE GIWA ONAIWU, Ph.D.
Self-Advocate, Parent, Advocate; Rice University

ALYCIA HALLADAY, Ph.D.
Parent, Researcher, Advocate; Autism Science Foundation

YETTA MYRICK, B.A.
Parent, Advocate; DC Autism Parents

LINDSEY NEBEKER, B.A.
Self-Advocate, Advocate, Family Member; Marketing Consultant, Independent Contractor

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

CAMILLE PROCTOR
Parent, Advocate; The Color of Autism Foundation

IVANOVA SMITH, B.A.
Self-Advocate, Advocate; University of Washington

HARI SRINIVASAN

Self-Advocate, Advocate; Vanderbilt University

HELEN TAGER-FLUSBERG, Ph.D.
Researcher/Clinician; Boston University

JULIE LOUNDS TAYLOR, Ph.D.
Researcher; Vanderbilt University Medical Center

PAUL WANG, M.D.
Researcher; Simons Foundation

AGENDA

PROCEEDINGS

DR. SUSAN DANIELS: Good morning and welcome to today's webinar of the Interagency Autism Coordinating Committee with our special meeting to discuss the IACC Strategic Plan Update. We're happy to have you here with us, and we'll hear first from Shelli Avenevoli, who is our chair.

DR. SHELLI AVENEVOLI: Good morning, everyone. Great to see you. And as Susan said, welcome to this special meeting of the Interagency Autism Coordinating Committee. It's my pleasure to be here today as well. And just as a reminder, I'm Shelli Avenevoli, chair of the IACC as well as acting director of the National Institute of Mental Health.

So the purpose of today's meeting is to discuss the draft of the 2024 IACC Strategic Plan Update, which is focused on co-occurring conditions and autism. You have all had the opportunity to review the draft. And so, we'd like to hear your comments today. And at the end of today's meeting, we hope to have a

vote to approve the report.

So, really now, it's my pleasure also to turn it over to back to Susan Daniels to lead the rest of today's meeting. Thanks, Susan.

DR. DANIELS: Thank you so much. We're happy to be here again. And thank you to our listening audience who's watching on Zoom webinar. We are not using NIH videocast today because it's a short meeting. And thank you to many people who contributed to this draft. And it's taken a while to make it through the different edits to get it into this current version, and we were really happy to share it with you, looking forward to today's discussion.

Just to let you know, since we're in webinar here, if you see me looking to the side or something, I'm in a room with some of my team. And so, it's not that I'm being distracted by other things. If I happen to be doing that is because I might be looking over to the team for something.

But we will be talking about each chapter of the strategic plan draft. And we also do want to thank members of the public for contributing over 1200 comments to our RFI that helped inform this draft and to the members of the working groups that -- or the working group -- the physical health and mental health working group that contributed to this draft significantly with the last IACC and to the last IACC for initiating this work.

And at the end of the meeting, we will acknowledge all of those people by name on slides. But wanted to let you know that a lot of different people have contributed to this draft. And we also have taken comments from the current IACC. And we're at the place that we are at now. And you have that draft. So, we're going to go through it chapter by chapter to ensure that we have all the comments that we might need to try to finalize it.

So at this time, I'm going to go ahead and take attendance. So, Shelli Avenevoli.

DR. AVENEVOLI: Present.

DR. DANIELS: Thank you. From NIMH. Administration for Children and Families, Allison Dean. Administration for Community Living, Jennifer Johnson.

DR. JENNIFER JOHNSON: Present.

DR. DANIELS: Thank you. Robyn Sagatov from AHRQ.

DR. JUSTIN MILLS: This is Justin Mills. I'm --

DR. DANIELS: Oh, Justin Mills.

DR. MILLS: Yeah.

DR. DANIELS: Hello, Justin.

DR. MILLS: I think I'm officially taking over for her or them.

DR. DANIELS: Okay. Thank you. Karyl Rattay from CDC.

DR. KARYL RATTAY: Present.

DR. DANIELS: Thank you. Jodie Sumeracki from CMS.

MS. JODIE SUMERACKI: Present.

DR. DANIELS: Thank you. Tiffany Farchione from FDA. Or Martine Solages. Lauren Ramos from HRSA.

MS. LAUREN RAMOS: Present.

DR. DANIELS: Thank you. Anyone from Indian Health Service? They're going through a transition. So, I wasn't sure if they were going to be here. Do we have Jane Simoni from NIH? Diana Bianchi from NICHD?

DR. ALICE KAU: Here's Alice Kau, sitting in for Diana Bianchi.

DR. DANIELS: Thank you. Debara Tucci from NIDCD.

DR. JUDITH COOPER: Judith Cooper here, substituting for Deb Tucci.

DR. DANIELS: Thank you. Cindy Lawler for NIEHS. Kristi Hardy for NINDS.

DR. KRISTINA HARDY: Good morning.

DR. DANIELS: Good morning. Sunny Patel for SAMHSA.

DR. SUNNY PATEL: Present.

DR. DANIELS: Nicole Williams for DoD.

DR. NICOLE WILLIAMS: Present.

DR. DANIELS: Christy Kavulic for Ed, Department of Education, or Emily Weaver. The Environmental Protection Agency, Elaine Cohen Hubal.

DR. ELAINE COHEN HUBAL: Yeah, Elaine Cohen Hubal. Good morning.

DR. DANIELS: Thank you. Leah Lozier, HUD.

DR. LEAH LOZIER: Good morning. This is Leah.

DR. DANIELS: Deirdre Assey from DOJ. Or Amber Parker.

MS. AMBER PARKER: This is Amber.

DR. DANIELS: And Amber, welcome to the committee. So, Amber is a new alternate for Department of Justice. And we're really happy to have you here.

MS. PARKER: Thank you.

DR. DANIELS: Department of Labor.

DR. SCOTT MICHAEL ROBERTSON: Hi. This is Scott -- Dr. Scott Michael Robertson from the U.S. Department of Labor's Office of Disability Employment Policy, ODEP. Good morning, Susan.

DR. DANIELS: Good morning, Scott. Alison Marvin from SSA.

DR. ALISON MARVIN: Good morning, Susan.

DR. DANIELS: Good morning. And the V.A., Matthew Miller or Scott Patterson.

DR. MATTHEW MILLER: Present. Matthew Miller.

DR. DANIELS: Good morning.

DR. MILLER: Good morning.

DR. DANIELS: And now I'll read the names of the public members. Maria Mercedes Avila.

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

DR. DANIELS: Good morning. Alice Carter.

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

DR. DANIELS: Nice to see you too. Sam Crane.

MS. SAM CRANE: Present.

DR. DANIELS: Aisha Dickerson might be joining us in a few minutes. Tom Frazier.

DR. THOMAS FRAZIER: Present. I'll be in and out because I'm teaching today, but present for now.

DR. DANIELS: Thank you so much. Dena Gassner.

MS. DENA GASSNER: Present. Good morning, Susan.

DR. DANIELS: Good morning. Morénike Giwa Onaiwu might be joining us soon.

DR. AVENEVOLI: She's here.

DR. DANIELS: You're here. Okay. Sorry. I didn't see it in the chat. Alycia Halladay.

DR. ALYCIA HALLADAY: Present.

DR. DANIELS: Thank you. Craig Johnson. Yetta Myrick.

MS. YETTA MYRICK: Happy Monday, everyone. Present.

DR. DANIELS: Happy Monday. Lindsey Nebeker.

MS. LINDSEY NEBEKER: Saying good morning.

DR. DANIELS: Good morning. Jenny Mai Phan. JaLynn Prince. Susan Rivera. Matthew Siegel. Ivanova, I see you in the chat.

MS. IVANOVA SMITH: I am here.

DR. DANIELS: Thank you. Hari, I saw you on --

DR. HARI SRINIVASAN: Here.

DR. DANIELS: Great to hear from you, Hari. Helen Tager-Flusberg.

DR. HELEN TAGER-FLUSBERG: I'm here. Good morning.

DR. DANIELS: Good morning. Julie Taylor. And Paul Wang.

DR. PAUL WANG: Here. Good morning.

DR. DANIELS: Good morning. Okay. So, we're done with the roll call. And -- oh, I skipped Camille Proctor. Sorry. Camille.

MS. CAMILLE PROCTOR: Present.

DR. DANIELS: Thank you. All right. Great. So, we are done with the roll call. Although, is there anyone that I missed, anyone that we need to come back to? Maybe I passed you before you were able to say hello. And if you do -- if anyone is arriving just now, just put it in the chat so that we know you're here. We also -- our team can see on the Zoom webinar who -- have people been able to hear me? Did I just mute myself suddenly? Everything's good?

FEMALE SPEAKER: We can hear you.

DR. DANIELS: Now it's echoing. All right. So, anyway, closed captioning is available on Zoom for IACC members and our viewing public. And feel free to turn on your camera when you have questions or you want to discuss. Including if we're reading you from the chat, you can also turn on your camera if you wish. But don't feel obligated.

And if you feel Zoom fatigue, feel free to just keep your camera off. You can submit comments in writing on our chat, and Steven

Isaacson from our team will be reading all the chats for us. And so, I will start with a brief legislative update.

The Autism CARES Act of 2019, which you all know is going to be expiring, September 30, 2024, is still working its way through Congress. So, the House of Representatives -- or the reauthorization, the Autism CARES Act of 2024, is still working its way through Congress.

The House of Representatives and the Senate each have their own version of a bill to reauthorize this legislation. And we put the links to those bills in this slide. And a single version will need to be passed by the House and Senate and then signed by the President to become a law.

And so, to tell you what the implications are for our committee right now, so if reauthorizing legislation is enacted before the expiration of the current legislation, then current IACC member terms will be extended for 180 days, just to help

us with any little communication we need to help finish up our reports. We have a couple in progress. We have this IACC Strategic Plan Update. And we also have the 2023 Summary of Advances, which would be sent to you for review.

And once the reauthorization has gone through, we will have a call for nominations for new members to the IACC. And things are looking promising for us to be able to get a reauthorization, but as of right at this moment, we don't have that yet. And in the event of a delay in the reauthorization, our work with members of the committee would pause until the reauthorization has been enacted.

And if it's a short delay, after the reauthorization, we'll go ahead and do the extension and finish the reports. And just so that the public knows, funding for many federal autism research services and support activities will continue regardless of the status of the legislation. Although there are

some specific programs that might be impacted by a delay in the reauthorization.

And the work of the National Autism Coordinator, and the Office of National Autism Coordination, and the Federal Interagency Workgroup on Autism will continue throughout this period. It's not dependent on that reauthorization happening right away. So, we will continue to work. And while the IACC is out of session, the FIWA will still be meeting. I as National Autism Coordinator will continue doing coordination work. And we'll be giving updates to the public through our website and other means.

And following the enactment of reauthorizing legislation, as I said, there will be a call for nominations of new IACC members. And also, current IACC members who've only served one term are eligible to be renominated. And so, the Secretary will select new members. And as is usually the case, there are usually some previous members who are able to serve again. And then there

are also some new people that are given the opportunity to serve. So, it likely would be a mix of different people, just so that you know.

So, that is my update on that. Are there any questions from the committee? All right. I'm not seeing any. So, we're hopeful that the reauthorization will come through soon. So, now the discussion of the IACC Strategic Plan Update.

So, this IACC Strategic Plan Update presents information on a broad array of conditions that commonly co-occur with autism and their impacts on health outcomes. And it identifies gaps in research, services, and supports to improve health outcomes. And in the report, we've highlighted IACC workshops, presentations, and other activities that provided the committee with information on research services and supports to address these conditions.

And the report also summarizes the responses and this very robust response that

we got to the IACC request for public comments on co-ccurring conditions in autism that was issued in January 2024.

So, there are several different chapters to this update, including an Introduction, Chapters 1, 2, 3, 4, and 5 that have content about this topic, and Chapter 6 as well and a Conclusion.

And as a reminder to how we got here, the previous committee -- the IACC that served previously under the Autism CARES Act of 2014, identified this as a high-priority area to look at co-occurring conditions. And they convened a working group and convened some workshops to explore issues related to co-occurring health conditions and began drafting a report that was paused in 2019, after the members' terms expired, and we were waiting to put together a new IACC.

In October 2023, after we were finished with the IACC Strategic Plan Update, the big one, with all the the recommendations that we have currently, the IACC -- this current IACC

voted to focus the 2024 IACC Strategic Plan Update on co-occurring physical and mental health conditions and to pick up this other report and use that as our IACC Strategic Plan Update. And this would discuss impacts on health outcomes and building upon the work that the previous committee had done.

And in January 2024, the IACC -- the current IACC, issued on RFI to collect public feedback on co-occurring conditions. So, as of August 2024, ONAC completed a draft of this report, taking what had been written previously and updating it with all the latest publications and reorganizing it, so it flows properly, and all the sections sort of have a similar feel to them and sent it to the IACC members for review.

And former members of the IACC Working Group on Improving Health Outcomes were also invited to provide feedback on the draft and provide us with any updates on their fields of expertise. And in early- to mid-September, our team incorporated feedback from IACC

members and the working group members to revise this draft. And then we sent it back out to you for further input. And this revised draft is also available on the website. So, anyone who's watching this meeting, if you'd like to see the draft, it's there.

And today, we're going to talk about it and see what your comments are. And in terms of the rest of the meeting, if the IACC reviews and we take in all the comments and chooses to approve the draft today, then ONAC will prepare the final report with an anticipated publication of December 2024.

And if the IACC still feels that this draft needs more work and is not able to approve it today, ONAC will continue to make revisions and finalize the report with the IACC members at a later date, which will be determined based on the status of the Autism CARES Act reauthorization. Because we can't hold meetings until a reauthorization is in place after September 30th.

And we are going to discuss each section of the report for 10 to 15 minutes. Feel free to use the raise hand function in Zoom to be recognized. And keep your comments brief so that all your colleagues can also comment. And let's keep our comments focused on overarching themes, additional topics that might have been missed, notable research that we need to reference or that may have been missed, and any kinds of corrections that are needed.

And please note that we tried to work with all the different comments that were received and balanced different points of view. And this is in an effort to provide a consensus document that represents the diversity of opinions on the IACC and the breadth of expertise and information that we worked into this draft.

So, again, here are the chapters. And so, I'm going to open it now for comments on Chapter One on the IACCs interest in the impact of co-occurring conditions. And this

chapter talks about the formation and activities of the IACC working group, this working group, improving health outcomes for individuals on the autism spectrum, and reviews recent history of IACC activities on co-occurring conditions. Did anyone have comments on this chapter?

MS. SMITH: This is Ivanova. And I just emphasize that this is so important that we look at other things that can affect autistic people, so that autistic people's other medical needs are seen and looked after. Because it's not always autism that affects our behavior but other medical things that could be going on with us.

So, I'm very glad that we had this in our strategic plan. Because it's very important so that we all support all autistic people better. Because all of us have co-occurring conditions.

DR. DANIELS: Thank you, Ivanova. And I think that represents the IACC and why you all chose to work on this report, focused on

these very important issues. Any other comments about this background chapter? Oh, Scott?

DR. ROBERTSON: So, I know that, briefly, just, I'd previously -- when you asked for comment for us with the survey, I just previously noted that maybe it could add some additional context. But otherwise, I think it's mostly here, as far as hitting the mark. I think it just could benefit from a little bit of additional context as far as the committee's interest in this space and why it chose -- in terms of specific conditions, et cetera, for its prioritization.

DR. DANIELS: Okay. And did you see your comments reflected? So, these are comments you turned in as a part of our --

DR. ROBERTSON: Yeah, a couple of weeks ago. I think mine aren’t -- is this draft supposed to --

DR. DANIELS: This draft should have incorporated most of the comments.

DR. ROBERTSON: Okay, I'll crosscheck.

But I don't think my comments were incorporated in this draft. But I'll double check.

DR. DANIELS: Okay. Yes, please do double check. The intention was to incorporate them.

DR. ROBERTSON: Thanks.

DR. DANIELS: Thank you, Scott. Dena Gassner.

DR. GASSNER: I want to begin by apologizing. I've been busy dissertating. And so, I didn't get to give this the attention it deserved. But I did want to take a minute to give you and the staff kudos for, first of all, asking people who are parents that are also autistic.

I tend to walk away from any survey that says I can be one or the other, but not both. And so, I just wanted to give you guys credit for that. I don't know why that's such a surprising thing to so many survey people, but I wanted to thank you for that. And I noticed the effort to switch away from ASD to just autism. Although I caught one on page 7.

So, I want to thank you for that. Is page 15 in the next group?

DR. DANIELS: No.

DR. GASSNER: I'm sorry. I'm trying to navigate two screens.

DR. DANIELS: And I neglected to, at the very beginning of the meeting, Dr. Dena Gassner, to congratulate you for earning your Ph.D. and starting a faculty position at Drexel. And I normally do have that time at the beginning, and you're welcome to say a couple of words about that, if you'd like.

DR. GASSNER: Well, I'm doing minor revisions, and my university won't confer until December. But I'm a senior science researcher at Drexel now and living in Philadelphia and very happy that my defense is behind me. So, thank you very much, Susan, for the recognition.

DR. DANIELS: Thank you. Well, we're all happy for you.

DR. GASSNER: Thanks.

DR. DANIELS: Okay, page 15 is in Chapter 2. So, we'll wait until then for that comment. And then I see that, Steven, you have a comment, a written comment, to share?

MR. STEVEN ISAACSON: Yes. Hello. Good morning. This is from Morénike. They just wanted to concur with Dena and Ivanova as well.

DR. DANIELS: Wonderful. Thank you so much. Any other comments on this chapter? And notice I'm trying to be a little slow so that we give people a chance to process a bit if they need to. And if we start moving forward, and you need us to come back, it's okay. You can just let us know. We just want to try to cover everything in this meeting this morning.

So, I'm not seeing any more comments on Chapter 1. But again, if something comes to you, feel free to let us know. So then I'm going to move on to Chapter 2, which is community perceptions of research and services needs. This is the chapter that

covers the RFI, and we tried to -- our team did an analysis of the RFI comments and tried to provide some additional context, and make sure that this public input was represented in this way in the draft as well.

So, it includes respondent demographics, which Dena mentioned -- we tried to provide some analysis of that -- the different types of co-occurring conditions, the impact of co-occurring conditions, some of the needs in the research space, services and supports needs, the impact of COVID-19, and then a summary of everything. So, were there any comments about the RFI chapter? Oh, Dena.

DR. GASSNER: Yeah. On page 15, you referenced systems navigation. And I think that's fantastic. It would be nice if we could have something in there stating that -- we wouldn't need systems navigators if the systems were accessible. And so, I think systems navigation and case management are Band-aids to the bigger problem.

So, if there would be any way we could articulate that these systems are not necessarily transparent, and that's the core of the problem, and that systems navigation is part of a solution to a bigger picture, that would be great.

DR. DANIELS: Yes, we can make that adjustment and make sure that places that we've referred to that, that we also mention accessibility. Thank you for that comment. Julie Taylor?

DR. TAYLOR: I don't have anything to add to that, except I just want to amplify it. I think that is really important that we talk about navigation. Because we can do something about that, perhaps. But really the solution is to have our systems be more accessible for all people but especially for those with disabilities. So, I love the idea of really incorporating that in very carefully, thoroughly.

DR. DANIELS: Sure. I think that we'll be able to do that pretty easily. We -- and if any of you have specific papers that you want us to cite, feel free to send them by email, and we'll incorporate those. But we'll also look in the literature and see what we have that can support that too. Wonderful. I'll go back to Steven with a written comment.

MR. ISAACSON: Hari has a comment. He said, "Amazing effort again on this report." He's been tied up with qualifying exams, which he passed. Congrats, Hari.

DR. DANIELS: Congratulations.

MR. ISAACSON: So, he wasn't able to provide comments to the survey. He apologizes for that. He added another comment that he feels another co-occurring condition is movement disorders.

DR. DANIELS: Okay. So, we can -- and I don't recall that we have movement disorders really pulled out in this draft. So, we can certainly look at the literature. And if there are any members of the IACC who have

some expertise in this area, maybe people from NINDS or other people, if you might be able to help us out, we can certainly add some material in on that. So, thank you.

And Hari, I apologize for also not pointing out that you passed your qualifying exams. Thank you so much for that. I was excited to hear that. And I know that the committee is happy for you too. It's a big step. Thank you. Yetta.

MS. MYRICK: Thanks, Susan. I just want to amplify what Dena and Julie said around the system navigation. I think another piece to highlight is the systems do not need to be siloed. We need to figure out ways for systems to be working together to lessen burdens. And I'm thinking about FIWA as an example of that, how you all are getting together and having conversations about what you're doing in your agency. So, I just want to flag that as an example.

DR. DANIELS: Wonderful. So, we can certainly check back in the areas where we talk about systems and make sure that we talk about coordination. And would be happy to reference the coordination that's going on in terms of federal agency coordination around this issue. Thank you, Christy. I see in the chat that you said you'd be happy to help out with any information on movement disorders. That would be fantastic. Any other comments on Chapter 2? Oh, another one from Steven.

MR. ISAACSON: Yes. Morénike asked if we have related conditions added, such as Alzheimer's or dementia? And also made a comment about systems navigation and how it needs to be culturally informed.

DR. DANIELS: Yes. We do have some information about dementia in there, and we can look back and just make sure that everything is up to date. And that's another place where we could check in with NINDS to see if there's anything else that we need to add.

And then in terms of cultural responsivity, I know it's mentioned in the draft, but we can look back and see if there are any other areas that we need to strengthen on that topic. And another comment -- and is there another comment from Morénike?

MR. ISAACSON: They also had the question about PCOS.

DR. DANIELS: Of what?

MR. ISAACSON: PCOS,P-C-O-S, as a condition.

DR. DANIELS: Oh. Okay. That one is not in there that I know about. So, we can look at that. I guess maybe reproductive health issues, I don't believe that's in the draft. Okay. Other things? Dena.

DR. GASSNER: I'm sorry if I didn't read thoroughly enough, but since you brought up reproductive healthcare, the research out of Drexel that's looking at the poor reproductive outcomes for birthing parents might be relevant to add in here.

DR. DANIELS: Okay.

DR. GASSNER: Would you like -- if you'd like, I can send you the study.

DR. DANIELS: Yes, please do send me the study. That would be great. And it's fine that we're not like really in Chapter 2 at this point, but we're just taking all the notes. And we'll make sure that things get into the right place. Anything else about the RFI that we need? And then if not, then we can move to the next chapter.

There's a comment that I can't see. Is that maybe related to one of the chapters?

DR. AVENEVOLI: Susan, you mean -- I can read it from the chat. Is that what you're referring to?

DR. DANIELS: Yeah.

DR. AVENEVOLI: It's from Hari. It says, "Does co-occurring also include health issues more prevalent in autism, for example, lifestyle changes, et cetera, high obesity, more diabetes, et cetera. Even common meds routinely used in autism, Risperdal, cause

weight gain, leading to diabetes, et cetera.

DR. DANIELS: Oh, okay. I think it's referred to as -- there are some of these epidemiological studies that have been done, but I don't know to what extent that is pulled out in the draft. But we could go back to some of those studies. And certainly, there are, in terms of issues like diabetes and obesity and so forth and make sure that those are brought out. I know that we did refer to the chat -- the papers in the draft.

DR. AVENEVOLI: Hari also has his hand raised.

DR. DANIELS: Sure. Hari.

MR. ISAACSON: There are no other comments in the chat.

DR. DANIELS: Okay. Thank you. And right now, in terms of the -- oh, I must have skipped slide 2. That is -- that was where we were. Okay. Oh, whoops. All right. So, let's move on to Chapter 3, which is co-occurring physical health conditions. So, this chapter has an introduction. And it covers some of

these issues, so epilepsy, GI issues and disorders, sleep issues and disorders, sensory and motor challenges.

And so, that's where movement disorders could be. But I don't think it went very deeply into movement disorders. So, we could check back on that chapter or that section. Ehlers-Danlos Syndrome, dysautonomia, immune system dysfunction, and physical health conditions in midlife and older adulthood. So, we could -- if we were going to do something with lifestyle and other kinds of health challenges that go along with that or polypharmacy and that kind of thing, we could probably put it in here someplace. Any comments on this chapter?

MS. CRANE: I think this chapter looks really good. And I would say that I was looking it over right before the meeting. And you also do talk about polypharmacy in the mental health chapter. So, I think that it's worth talking about in the physical health chapter because it's -- it shows up in both.

DR. DANIELS: Okay.

MS. CRANE: But I did want to just say that that was helpful.

DR. DANIELS: Great. Thank you, Sam. Dena.

DR. GASSNER: Yes. Overall, I agree. I would suggest that interoception issues interfere with all healthcare. So, I might not limit that to just page 21.

DR. DANIELS: Okay.

DR. GASSNER: And then I would also maybe add something about the way we -- the inconsistent and unexpected ways we respond to medications. Example, many of us need to start at lower dosages for medications, and the polypharmacy often comes from trying to treat the side effects of something we're just taking too much of. Instead of just lowering the dose, we tend to boost the dose. So, any research we can find related to how we respond differently to medication, I think might be helpful.

DR. DANIELS: Okay. Thank you for that.

Scott.

DR. ROBERTSON: Yeah. So, I think also, this is pretty comprehensive, and maybe the -- what was referenced earlier as far as movement conditions, maybe that could be in the area in here where you have, like, motor and Ehlers Danlos syndrome, et cetera. Maybe it could fit well into that section right here.

One thing I didn't notice also earlier, as much -- and maybe it's, I haven't checked the latest limitation kind of on that -- is a lot of the reference on the the sleep conditions seem more limited to kids. Do we have any literature linked in here for sleep conditions related -- as far as the experience from adults?

DR. DANIELS: I don't know what's in the literature on adults. So, we will check --

DR. ROBERTSON: Okay. I can cross-check for you all.

DR. DANIELS: Yeah, feel free. And then we can also check back.

DR. ROBERTSON: Okay.

DR. DANIELS: I think we were going with what was --

DR. ROBERTSON: Available, yeah.

DR. DANIELS: -- based on the literature. But there might -- we could have missed a study if there's something in adults.

DR. ROBERTSON: Okay. Thank you.

DR. DANIELS: Great. Laura Ivanova, I guess. It says Laura on your thing. Ivanova, do you have a comment?

MS. SMITH: Yeah. My comment was also that could be -- there also are birth defects that can happen with autistic people. Like I was born with club feet in both my feet. I don't know if that's in here. But club feet is common, and especially with FASD.

DR. DANIELS: Okay. We do have in the next chapter, I think, reference to various genetic conditions and so -- but I -- club feet was not mentioned, nor FASD. I don't think so.

MS. SMITH: Okay.

DR. DANIELS: You can check back. We have a table there that points out some of the more common ones, but there are so, so many different genetic conditions. So, we'll double check and try to see if there's a way to be more inclusive than it is right now.

MS. SMITH: Well, thank you so much.

DR. DANIELS: Thank you. Alycia.

DR. HALLADAY: Hi, everybody.

DR. DANIELS: Hi.

DR. HALLADAY: So, I'm glad somebody mentioned that table on co-occurring or rare genetic syndromes. Because it's placed in Chapter 4 -- Chapter 5. Sorry, I'm getting the chapters mixed up. But it actually should be -- because there are kind of -- there is an influence of these rare genetic syndromes on not just co-occurring psychiatric health or development but also physical health conditions, and there is research in the literature focusing on the impairments of individuals or the effectiveness in things

like GI issues, sleep, and immune system function in those with rare genetic disorders. So, maybe moving that up a little bit might make sense.

And then also, there is a website. ASF manages the Alliance for the Genetic Etiologies of Neurodevelopmental Disorders and Autism. And we have the spreadsheet, I think, that you're looking for, with the summaries, website links to the different conditions. And so, feel free to go. We're redoing a website right now, but that summary will stay. So, if you want to either reference it or steal from it, go ahead.

DR. DANIELS: Oh, okay. Thank you. Yeah. So, that's in the section that we had on developmental disorders. So, we put that there. It doesn't mean that there might not be some physical conditions that come with them, and those should be outlined in the table. But I think that we thought that that fit best with the developmental and intellectual and so forth. But all of these

things are connected, and it's hard to decide how to organize things.

So, perhaps maybe just a reference in the physical health conditions chapter, to the fact that physical health conditions can be caused by genetic disorders that are discussed in chapter whichever. I think it's 5 that discusses that.

And Alycia, did you have an opinion -- or Paul Wang, I know that you both contributed on the genetic disorders. We tried to do a shorter table that didn't have everything under the sun. But should we try -- should we be trying to capture, like, everything that's in your table and just put it in the appendix? Because for a lay reader, they may not want to read every single condition. But maybe they do. I don't know. So, what do you think?

DR. HALLADAY: I would be in favor of putting it in the appendix only because it relates to several -- so, that way, you can go back to -- you know, you can relate to it.

It doesn't stay in a chapter, and it doesn't seem like it's only relevant for developmental or only relevant for one domain.

You know, the reality is -- and I'll let Paul talk about this -- is that this is ever changing, right? So, new groups are being formed around -- that we're finding new rare genetic variants. New groups are forming around patient advocacy groups around these conditions. And so, you know, I think an exhaustive list may be -- I don't know. It just may be a lost cause because it is going to be updated.

However, I do think that maybe there should be a reference to the different rare genetic disorders, a reference to SFARI Base, a reference to somewhere where they exist, where people can can look at them and see them. But Paul, what do you think?

DR. WANG: Thanks for asking, Susan and Alicia. I agree, a full list is just too long to put in the main body, I think, of the

report. I briefly read the text, and you do reference that there are over a hundred genes that have been associated with autism. So, I think, yeah, appendix is the place to go.

DR. DANIELS: So, would you like it to stay sort of how it is right now but then have a reference to the appendix that has a longer list? Is that -- or would you like it just to refer out to something that's more of a website?

DR. WANG: I think that you -- I'm not finding right now that particular passage of text quickly enough. I know that you have a -- I believe you have a reference there. You talk about there being many, many genes that are associated, as Alycia said, with ID and mental health issues but certainly, as Alycia pointed out, with other physical health conditions as well.

I think it's fairly clear as it is. I'm not sure that you need to have an exhaustive table as part of the appendix. The external references should be enough, I think.

DR. DANIELS: Oh, and it's page 63, I'm told --

DR. WANG: Thanks.

DR. DANIELS: -- is where the --

DR. HALLADAY: I'm pretty equivocal on whether we need a long table or not. So -- as long as we reference out to resources like, you know, SFARI Base, AGENDA. There's also even a group, Combined Brain, whose goals are to help organizations associated with rare genetic disorders and research and advocacy and family support.

DR. WANG: Yeah. I can see a reference to AGENDA already, which is great.

DR. DANIELS: Yeah. Maybe we can put in either like a footnote or a paragraph that describes some of that. So, maybe we can come back to you all to make sure that we get those items. And then we can have web links if people want to go and explore for more information.

DR. WANG: Great.

DR. DANIELS: If that sounds good. Okay. So, I'm going to go back to Steven for a written comment.

MR. ISAACSON: Yes, thank you. We have comments from Morénike and also Hari.

DR. DANIELS: Okay.

MR. ISAACSON: Morénike brings up the idea of skin conditions such as eczema and dermatosis and psoriasis which can exacerbate skin picking and related self-injury. So, we have a few comments here. Morénike also concurred with Ivanova in saying that "FASD is important. We should also consider adding HIV exposure in utero, because some HIV antiretroviral medications increase the likelihood of having a child with DD, developmental disabilities, though the child is typically HIV negative."

And then Hari also mentions "movement disorders needs its own section in relation to autism, especially later in life. This is separate from the sensory motor, where the sensory gets more dominance," he says. So,

maybe there are underlying movement issues already present in autism that are unaddressed in lower age. Thank you.

DR. DANIELS: Thanks. Yes. So, with psoriasis and eczema, we do have some information on immune system dysfunction. I think that there might be a mention of eczema. I don't remember that there is anything about psoriasis. So, we can look at that a little bit more carefully.

And Hari, yes, we'll, we'll expand the motor section to be more inclusive. And we'll work with NINDS on that, as they would have up-to-date information on that area. Thank you. Dena.

DR. GASSNER: Real quickly, I just wanted to point out that on page 32, we talk about how employment is affected by these issues, but all of the issues that we're going to discuss in this strategic plan can affect employment capacities for folks.

DR. DANIELS: As well as education and any other --

DR. GASSNER: Right, right -- across the board.

DR. DANIELS: Maybe that should be referred to in the introduction.

DR. GASSNER: Yeah. Because I know with the women I interview from my dissertation, and with a lot of people, it tends to be more of the like cognitive and physical exhaustion that could be triggered by any of the things we're discussing today, right?

So, you know, in addition to the -- so, we tend to think it's all about social, but it's more often just the demand of that work-life balance and the inability to keep up in every domain in life.

And in addition to that, I would say that, you know, there's a huge problem for people who are trying to work full time, who are making 30 to $50,000 a year, which sounds like a lot, but if you're working full time, it might mean you need to pay for the

services you're giving up when you walk away from a waiver, for example. And that's not enough money to cover costs for that.

So, I don't know how or if we want to address it here, but just the -- you know, the lack of supports for daily living even when employed is a huge void for our population. It leads to a lot of people cycling in and out of employment because they just can't -- they can't get their car washed, keep their house clean, do their laundry, and work 40 hours a week.

So, we need to reevaluate cutting off services just based on income level. It should still be based on functional needs, just like it is for people who are blind. We don't look at them and say, "Well, you have a job now, so you can pay for everything." But we do this for people with intellectual and developmental conditions. So --

DR. DANIELS: Thank you. Yes, we do have some information about social determinants and the interaction of these factors. But

we'll look back on it based on your comments, Dena, and see if we need to enhance some of that.

DR. GASSNER: Thank you.

DR. DANIELS: Thank you. Alice.

DR. CARTER: Yeah. I just want to say something about like, the balance of listing everything versus providing resources. And I think lay readers may be looking for themselves in the report and may be looking for information relevant to them. So, more inclusivity is helpful. But I also think if there's everything, it becomes impossible to process.

So, I like the idea of being really clear that this isn't everything in the report and then providing resources. Because always, we're learning more. And usually, as we're learning more, we're finding more connectivity, you know, not less connectivity.

DR. DANIELS: Right. So -- and some of these overarching issues, I think, should be

in the introduction, if they touch everything, as we don't want to repeat the same issue over and over in every chapter either and make it longer. So, we'll double check on some of those things. And if you have any specific suggestions, Alice, let us know. If you have resources that you think we should be connecting to, we can certainly add some things in. Okay. Scott.

DR. ROBERTSON: Yeah. Just briefly, I did find the studies on sleep, et cetera. So, I'll -- I can send you the additional references for the sleep conditions. And I just also want to concur with what Dena had also mentioned, as far as the cross-connection to like independent and employment. I think iterating that in the introduction and these other spots in the papers, I think is really helpful.

And there's also, like a lot of overlap between the two. Because a lot of -- whether folks are able to maintain their employment is really dependent on independent living and

support in that area. So, I'm just glad that that got brought up, that a lot of this has really an impact as far as folks', you know, overall wellbeing. And, yeah, it is cross-connected, I know, to the social determinants of health. But I'm glad that got noted.

DR. DANIELS: Yeah. And it's been really helpful that there have been more publications on these areas in the past few years. So, we were able to --

DR. ROBERTSON: Yes.

DR. DANIELS: Since the last committee, there were new publications that we could refer to. And so, we'll double check on that too.

DR. ROBERTSON: Great. Thank you.

DR. DANIELS: And I haven't been keeping up with the chat very well. But Steven, are we good on the chat?

MR. ISAACSON: Yes, we are. Thank you.

DR. DANIELS: Okay, wonderful. Any other comments on Chapter 3? All right. I'm going to move --

DR. GASSNER: It's Dena again. I didn't see anything related to light sensitivity. And I noticed that sexual abuse is listed within suicidal concepts. But sexual abuse and trauma, I think, need more attention overall. I think we mentioned trauma, but we -- the trauma is basically around ACEs and early childhood. And there are many, many, many adults who've experienced repeated traumas. So, if we can find anything for that, it'd be great.

DR. DANIELS: Yes. We do talk about ACEs and trauma in the report. So, that would be in Chapter 4. So, we have -- some of the issues that we cover in Chapter 4 include anxiety disorders, ADHD, catatonia, depression, OCD, self-injurious behavior, aggressive behavior, emotional dysregulation, suicidality, bipolar, feeding and eating disorders, gender dysphoria, pathological demand avoidance, schizophrenia, substance use disorder, Tourette and tic disorders, trauma and post traumatic stress disorder,

wandering and elopement behaviors. So, there are quite a few here.

But we can -- in the previous chapter that was sensory, we can check back and see if we said anything about light sensitivity. If not, then we can add something in. And we'll check back about sexual abuse. I would imagine that it's included in the trauma section. But if it's not fleshed out enough, we can always go back and add a little bit more.

DR. GASSNER: Yeah. As I said, you did a great job on the ACEs in terms of early childhood trauma. But the intermittent, repeated trauma that we endure in adulthood, especially after we no longer have supports, there wasn't much there.

DR. DANIELS: Great. And if you have any references for adult trauma, feel free to send them, and we'll --

DR. GASSNER: I'll dig around for you. Thanks.

DR. DANIELS: Thank you. Yeah. I know that trauma, with the committee, that you -- you all have emphasized trauma many times in IACC meetings over the past three years. And so, we tried to include it more here, but we are happy to expand a bit. JaLynn.

MS. JALYNN PRINCE: Yes, good morning.

DR. DANIELS: Good morning.

MS. PRINCE: I have a question too, and I'm not seeing it on here. And I did read through everything, but it's been about three weeks ago. So, pardon me if I'm not remembering everything. But what it happened to be, within this area where we need to mention the need for more trained individuals for diagnosis for adults with autism.

Because I am seeing a huge, huge need. And I'm seeing a lot of people receiving diagnosis and also wanting to pursue it but not knowing where to go or what the costs are. I don't know. This seems like it could be the right area to list some of those things.

DR. DANIELS: So, in the chapter that's about healthcare provision, we have information about diagnosis and distinctions between autism and co-occurring conditions. I don't know what we had about diagnosis of autism itself, since this was more of a co-occurring conditions report.

MS. PRINCE: Yeah.

DR. DANIELS: But we can talk about the difficulty for some practitioners to make that distinction if they don't have proper training to identify those. So, we did talk about the workforce. But if you have particular references that you'd like to send forward, we can take a look and see if we should roll some --

MS. PRINCE: I may have a few of those. Thank you very much.

DR. DANIELS: Great. Thank you. Jennifer Johnson.

DR. JOHNSON: Yeah. Hi. Just adding to the comment about the diagnosis, I'm not sure how clear and explicit it is in Chapter 4,

about the importance of diagnosis and differential diagnosis and that, you know, a lot of times it can be hard to differentiate between autism and what may be a co-occurring mental health disability or disorder.

And so -- I mean, I think it's kind of in there, but I think making that more explicit and -- of tying in around the comments about just diagnosis in general. But then again, getting that differential diagnosis is even more difficult.

And then I'm not, again, sure how much the chapter really speaks to, again, with -- related to diagnosis, issues are related to early diagnosis, again, especially when there might be onset in later years, of mental health disorders such as schizophrenia. And again, you know, being able to adequately identify when those -- the early onset of any of those symptoms that indicate that somebody might also have a mental health disorder that might again develop at a later age.

And then also, you know, this comes up in the diagnosis literature, but again, I think it's important, in this chapter, to -- in talking about diagnosis and the importance of differential diagnosis and being able to diagnose early onset, is also issues related to intersectionality and access to diagnosis and, again, you know, the tools that would be adequate for identifying and differentiating diagnoses.

So, I think just really ramping that up a little bit more and describing a little bit more all those issues that are -- we see with diagnosis would be important, particularly in this chapter. Because it really can be hard to differentiate between the mental health disorder and autism.

DR. DANIELS: Yes. Thank you. And also, that with the missed diagnoses, sometimes people are diagnosed with those co-occurring conditions before their autism diagnosis is identified, and that's another issue. So, we can look back at the whole diagnosis section

and see what needs to be added. But thanks for all that additional context. Sam.

MS. CRANE: I have a couple of very, very small comments. I think that for some of them, there's several points, notably in terms of anxiety disorders and OCD, where we discuss cognitive behavioral therapy, and we do sort of acknowledge that in some people, traditional cognitive behavioral therapy is -- seems to be less effective for autistic people than the general population.

And in next steps, it sort of discusses how, you know, one of the next steps is to explore forms of modified cognitive behavioral therapy that would work well for autistic people. But I just wanted to put in maybe an acknowledgement that it's possible that maybe people should be also looking at new models outside of cognitive behavioral therapy that might be promising.

Because just anecdotally, I think a lot of autistic people don't really seem to work well with the CBT model in general. So,

that's a -- you know, that's something that I think is a possibility that we need to acknowledge when talking about next steps is explore other promising models.

And then the second, which was a very, very small point, is that under gender dysphoria, it's discussing, I believe, suicidality among transgender females. And just the use of the word female instead of women or girls means that it's a little bit ambiguous. I know sometimes in the research on gender, when the researcher says transgender females, they're referring to people assigned female at birth. Whereas other people who are talking about transgender women, of course, are talking about people assigned male at birth.

And so, I think that I would recommend just changing that phrase, depending on which one you mean, to, you know, transgender women and girls or transgender people assigned female at birth.

DR. DANIELS: Thank you. I'm sure that we were probably just taking from whatever the literature was there, but we can --

MS. CRANE: Yeah.

DR. DANIELS: -- define it.

MS. CRANE: It's just very controversial. They know that, like, you know, there's a lot of older literature that uses female to refer to people assigned female at birth. And it can cause some confusion among the community because they don't -- they're not familiar with that convention. And also, it's, you know, can sometimes bother people assigned female at birth who are transgender to be referred to as female. So, that's just a recommendation.

DR. DANIELS: Okay. Thank you so much. So, next I have Dena.

DR. GASSNER: Hi. I did want to bring up two other points. Burnout, I don't see any references to autistic burnout. Maybe I missed it. And then kind of like the universal cost, emotionally, to living in a

constant state of reporting mandates and poverty. Poverty, in and of itself, is its own trauma. And given the low amount of money people can receive from SSI and SSDI and the underemployment of our community, I would say, if we can find anything -- I'll look while we're talking -- if there's -- and Hari just added a new term to the idea of burnout.

But anything related to those topics, I think, would be of value. Because it's just -- I mean, I remember trying to work with a client, and I said, "Can I meet you for a cup of coffee?" And he goes, "I can't afford coffee and a bus fare." So, what kind of treatment and therapeutic support is a person going to get if they can't even afford to get on a bus? So, I think we really need to address that. I'll see if I can find any literature to that.

DR. DANIELS: Yeah. So, we do have some information about poverty there. I don't think there's anything about autistic burnout. That seems like an overarching

theme, like -- or not a theme, but a situation that occurs for a number of different reasons. So, might be something to mention, maybe toward the healthcare section or more generally. Because it may be related to multiple chapters.

DR. GASSNER: Yeah. It's just the idea that we're -- when we come to entities for support services, we are not only dealing with a suboptimal outcome because the system is so inaccessible, but in addition to having a developmental disability and trying to manage that, we're also coming in probably at the lowest functional capacity we've ever experienced. Because we're coming at it from a state of total burnout. And so, I think that the combination of all of those things is huge. But I'll see if I can find anything about poverty. Thank you.

DR. DANIELS: Great. Thank you. JaLynn.

MS. PRINCE: One thing that I am wondering about, because we have been seeing it more and more, we have been working with

about 400 people in Salt Lake Valley and bringing a number of individuals and families together. And one of the terms that is brought up very frequently is neurodiversity.

Now, I think a number of these things here come under neurodiversity, if we want to say that. But there are other things that are being implied. And I don't see us either defining, acknowledging that particular terminology. And that is something that has become much more prevalent over the last year, so before some of these things were written and put forward.

But it is something that, over the next several years and as people are looking at this, seems like it would be a really blatant omission, unless we refer to it in some fashion. And I'm not certain what that is -- having talked to psychiatrists and psychologists, exactly how you define all of that. But at the same time, it is a very real entity in the lives of many.

And I don't know if they're necessarily tagging themselves with all of the things that we've got here, but that there are other things that aren't mentioned here that I have questions about but is part of the conversation currently.

DR. DANIELS: Thank you so much for that comment. I actually, myself, in reviewing it, noticed that we didn't have -- we have all the different conditions that are typically discussed as neurodiversity in separate places, but we didn't bring it together. And it was something that was missing, but we didn't really have time to make that revision. But we'd be happy to do that. Because many -- like you said, many people are familiar with this idea of neurodiversity and that some of these conditions can sort of be connected that way. So, it seems like something maybe in the introduction that could be placed there for people to reference that framework.

MS. PRINCE: Thank you. Very important.

DR. DANIELS: Thank you. Hari.

MR. ISAACSON: Yes. Hari has a comment. He says, “as an undergrad, he saw this presentation by a student where they talked about modified CBT, cognitive behavioral therapy, for younger kids.” He said he likes the fact it's accessible across all ages. He says, "Otherwise, the word cognitive makes it sound inaccessible." And he suggested that we need alternatives to CBT as well.

DR. DANIELS: Great. And thank you so much for that comment, and also to IACC members who are throwing some references to us in the chat. We'll make sure that we save the chat. And then we can just take those references right from there. But if you have additional after the meeting's over, you can always send them to us.

Okay. So, we just heard from Hari. I don't see any other hands. I'm going to advance to the next slide, Chapter 5, on co-occurring, intellectual communication,

developmental, and learning disabilities.

And so, this chapter covers intellectual disability, high support needs, communication disabilities, related developmental disabilities -- which is where some of the genetics issues are -- and learning disabilities. So, those were all grouped together. So, do we have any comments on this chapter? Hari, is your hand still up? Or do you have another comment? Oh, no, okay. Helen.

DR. TAGER-FLUSBERG: Thank you. First, I want to say this whole report is just such a tour de force and such a pleasure to read. And I appreciated seeing some of the changes in response to the feedback I gave earlier. But I realized, in reading this now more carefully, that in my view, there is a serious omission, which I apologize I should have caught earlier, in the section on communication disabilities.

And in particular, what I want to point out is there is no mention at all that among

people who are minimally verbal or speak minimally or non-speaking/verbal. They're -- the vast majority also experience very significant receptive language difficulties. And so, the whole topic of receptive language is not there. And if you read this, it sounds as if, well, all we've got to do is to worry about the expressive problems. And that's just really not the case.

And, you know, there's been some research -- I'll send a citation -- to document the degree and nature of the receptive language problems too.

DR. DANIELS: Wonderful. That is something -- when I was reviewing it, I noticed that as well. But again, we didn't really have time to go back and ask. But it would be wonderful to be able to consult with you, Helen, to make sure that that's properly included. If you have some references and if our team has questions, we could -- if you wouldn't mind us asking you. We want to make sure that that's properly covered.

DR. TAGER-FLUSBERG: Okay. Thank you.

DR. DANIELS: Ivanova.

MS. SMITH: This is Ivanova. And my question with that is, how do we make sure that we're not like conflating a person trying to communicate as like another symptom? Like people that have higher support needs that are non-speaking tend to -- there are times where they've had to communicate with their bodies, and we don't recognize body language as forms of communication. We still call it challenging behaviors and just trying to make the person stop doing it. But that person may be trying to communicate something.

And we need to figure out, how do we acknowledge behavior and body communication as communication? Because there's a lot of people that their form of communication is not being acknowledged, and it's only causing more frustration for that person. And that only causes more distress for that person if their form of communication is not being

acknowledged at all. And we really need to figure that out. Thank you.

DR. DANIELS: Thank you. I think that that's alluded to a little bit in the earlier chapter -- a couple of chapters back in the -- oh, whoops -- in the self-injurious behavior, aggressive behavior area. But it's -- it may be something can be added here. If you happen to know any references, let me know. Helen may also have some references -- I'm sorry I'm moving this too fast -- on body language and kind of body communication. We could use help with some references there. We'll also look in PubMed and see what we can find.

DR. GASSNER: Scott also posted Helen's study on receptive language for you.

DR. DANIELS: Oh, great. Thank you. All right. Steven, do you have a comment from the chat?

MR. ISAACSON: Yes, thank you. From Morénike, a comment for Chapter 5. They said, "We should explicitly note that there is a

sordid history in this country of giving people of color, specifically children of color, labels such as ID, intellectual disability, and conduct disorders," they say, "in order to segregate them from others. Additionally," they say, "assessing cognition in individuals without reliable spoken language is challenging."

DR. DANIELS: Okay. If you happen to also know any references, Morénike, that we might be able to add here, that would be great. But we'll look too, to see if there's something about that that we can acknowledge. So, thank you for that. Other comments on this section?

MS. CRANE: I just wanted to say that the section on community discussion about high support needs was striking a very careful balance, and I'm -- I just commend you for that.

DR. DANIELS: Oh, thank you, Sam. We were attempting to try to capture some of the discussion there. And it's, of course, an ongoing discussion.

MS. CRANE: Yeah. I just -- I thought that worked well.

DR. DANIELS: Okay. Thank you for that feedback. Alice.

DR. CARTER: Yeah. I have a quick comment, and I'll try to do some digging. But echoing on -- well, also, I didn't say last time, it's an amazing report and an amazing amount of work. And it's really well done. So, I'm very excited about it.

But there is also evidence that when toddlers anyway, have both receptive and expressive delays, they also have increased mental health challenges. So, I'll try to find some references to that effect. We did some work in that area a long, long time ago. But so, I do think like increasing the receptive area, consistent with what Helen was suggesting, is really important.

DR. DANIELS: Wonderful. Yeah. We'd love to get some references on that and definitely make sure that's included. And we will try to cross-reference different things where we can

without making it too confusing. But that definitely makes sense.

And any of these, you know, physical challenges can affect your mental health. And mental health challenges can affect your overall physical health as well. So, all of these things are contributors to overall health. Any other comments for this section?

Okay. So, I didn't see any. I'm going to move to the next slide. So, this is Chapter 6, on health care provision. And in this section, we tried to talk about the accessibility of health care, patient-provider interactions, considerations for individuals with complex and high support needs, promoting equity and reducing disparities, the impact of COVID-19, and some of the federal agency activities and initiatives that have been happening recently.

So, those are some of the topics that are covered here. And some of this came out of our physical health workshop, where we had

a section that was on patient-provider interactions and the healthcare system. So, any comments about what was in here? Anything that we missed? Steven.

MR. ISAACSON: Yes, thank you. Morénike has a couple of comments on this chapter.

DR. DANIELS: Great.

MR. ISAACSON: They say they think it's extremely important that to highlight not just provider training, but also compensation for providers, DSPs, who are direct support professionals, are a lifeline for many families. But they say the wages are just not competitive enough to ameliorate the high attrition rate.

Also, in regards to patient and family centered approaches, they think it would be beneficial to discuss the differences between explicit family and natural environment focus in Part C, or birth to 35 months. That is immediately lost from age three to adulthood, even though the family generally continues to

be the primary source of support.

DR. DANIELS: Okay. Thank you, Morénike. And again, my repeated request, of course, if you have any references to suggest, that would be great. And we can also check in with ACL and HRSA on this. I know that we got comments from both. But if there's something -- and I know that they're listening -- if you, from ACL and HRSA, see things that we've missed about compensation for providers, direct support providers, or family-centered activities, please let us know. Dena.

DR. GASSNER: I wanted to champion the idea of adding more information about trauma-informed access to dental care, especially the upcharges we all experience when we're trying to do nitrous or sedation dentistry. It's just -- it -- to me, it seems like there's a huge -- I don't know. It's like charging someone for a disability parking space. So, I think that that's something we could emphasize a little bit more.

Also, the idea that certain kinds of

dental care may appear at first glance to be cosmetic, but I think that people experience greater disparities and greater social impairment when they're struggling to be presentable to society as a whole.

I know my son's missing eight permanent teeth, genetically, and we had to pay out of pocket for cosmetic dentistry because he couldn't do braces. And now, he's having gastro and diet issues because his bite is off. And all of that would be considered cosmetic instead of being considered physical health care, which it should be.

I know my story's anecdotal, but I'm sure there's a lot of other people who have horror stories they could share. So --

DR. DANIELS: Great. Thank you. And we could emphasize dental care a little more. I know, personally, I put in like one or two references about dental health in this draft, but it's just a reference. And it's sort of a part of talking about a number of different issues.

So, maybe dental health could be pulled out more. And that's an area where, at the NIH, I know that they've funded more research in dental health, based on IACC's recommendations from years ago. And so, there's a lot that's been happening there but still some needs. So, we could look at dental health and see if that -- we could pull that out a little bit more here. Okay, Steven.

MR. ISAACSON: Yes. Thank you. I have a comment from Hari. He asks, "Can we recommend research on non-invasive BCI, which is brain-computer interface, for communication?" He says, "Most current applications are only looking at requesting basics and wants, not really that focused on real communication, like what's happening now." He also says that he imagines something like a regular baseball cap that basically does scalp reading. And the speaker's on the visor, so you can turn it off and on.

DR. DANIELS: Great. Hari, we would love

to, again, get references on that. I don't think that we have anything that's in our current set of references about that. So, be good to get some information, but thank you for bringing that up. Jennifer.

DR. JOHNSON: Yeah, just a couple of comments. And my apologies, I had to take a call. So, I missed part of the conversation. But I wanted to -- I know that -- I was on -- we were in Chapter 4 when I had to take the call. And I know that in Chapter 6, there are references to trauma-informed care, which is good to see.

I'm just not sure if all the references to trauma-informed care and the discussion on trauma-informed care in Chapter 4, if it is -- if there's information in this update regarding just overall trauma, the importance of trauma-informed care for people with autism, regardless of whether it's from a health care provider or a human service provider, but making sure that -- especially for people with co-occurring autism and

mental health disabilities and physical health issues, the importance of just, overall, integrating trauma-informed care into approaches to supporting individuals.

So, you know, my apologies if that's a little out of context, given that I missed part of the conversation. And on Chapter 6, I didn't really see anything in here about tools for people with autism to use in communicating with their healthcare provider. We hear -- we've been hearing a lot more about -- from people with IDD, the need to have some tools, questions to ask, or things to bring or how to prepare, like sort of a, you know, toolkit for them.

A lot of this seems to be focused on sort of what the providers need to do. And I'm not really seeing a whole lot in here in terms of, you know, research on tools that people can use to communicate about their own healthcare needs with their healthcare provider. So, just wanted to mention that.

DR. DANIELS: Great. And are you aware of

publications on this area or current grants maybe that are covering this?

MS. JOHNSON: We do have some programs that have developed some of these materials. So, we can take a look for that. And not sure if we published it yet, where we have been -- we're doing a project where we really have been hearing a lot about -- it just keeps on coming up repeatedly -- about the need for tools and resources. So, I can take a look at whether we've published anything on that yet.

DR. DANIELS: Yeah, that would be great. Again, as always, if we have some good references that we can draw from, that will be really helpful. So, thank you for that. JaLynn.

MS. PRINCE: Yes, thank you. Getting into the dental area again, I think there are so many other levels as well, and I'm so glad that it was brought up. Three-quarters of my family have been involved in dental provision, dentists, on and on. We're going into the fourth generation right now. But

there are some things that we have been finding out, and I think it's something that needs to be suggested or talked about. I might be able to get some information from one of the dental schools that we are working with that happens to be doing things for disabilities.

But the rural areas have a tremendous need. Because there aren't a lot of people that are specialists that live in rural areas. And if there's some way to have mobile care, so it's not just once every five years, but there is ongoing care.

And the idea too, of perhaps having trained people that can go in and help communicate with dentists who are willing to work with our population that may have some intrepidation because they haven't had that particular training in dental school, but to help communicate. And that is an area that maybe we need to encourage more specialists to be able to attend medical appointments and also dental appointments, to help in the

communication and to also take notes.

And we have had an advisor with us who is a pediatrician who does recommend individuals taking someone with them to take down the notes. Because even with neurotypical individuals, you're so busy thinking about certain types of things that sometimes you don't take down the information that is necessary. Or you don't relate the message and the information that you need to until you leave the office. So, I don't know how that can be incorporated, but it is a very, very important arena.

DR. DANIELS: Thank you. I know that we have information about ECHO in there, about kind of training by telehealth means or online training to reach rural areas and some programs similar to that. But we can look and see what else we might need to add to make sure that we're including rural health activities in this report.

So, thank you for mentioning that, and also with dental. And I'm not quite aware

whether there is an ECHO-like model for dental or if dental is already included there. So, thank you. Jennifer.

MS. JOHNSON: Sorry, I think I forgot to lower my hand.

DR. DANIELS: Oh, okay. All right, Steven.

MR. ISAACSON: Yes. There's a question from Lindsey here. She said she noticed misophonia, a co-occurring condition that can be found in autism, is not referenced. She wants to know if we would consider adding misophonia in this chapter or one of the other ones.

DR. DANIELS: Sure. We can put that in the sensory area. So, we can mention it. If -- I don't remember any literature I've ever read on it, but we can check PubMed and see what we can find. And if anybody knows of any references to research on misophonia and autism, please send it to us. So, that'd be great. Thank you. And Scott.

DR. ROBERTSON: Yeah. And I'll make sure

to try to compile some of the ones that I had put there in chat. One of the things too, that I hadn't thought about before too, and I don't know if you can reference it briefly, is there was a little bit of evolving literature also on -- in terms of systems interaction for autistic people or parents and like additional challenges in terms of what that may present.

That, historically, has not been captured in the research literature as much as it should be because of the fact of maybe prior perceptions that autistic people were -- you know, in terms of beliefs about autistic people as parents and family members. But that, like has started to grow out a little bit.

So, I don't know if you could reference a paper or two in there. But I can send you that in terms of -- for folks interacting with like the healthcare and educational systems and additional complexity they face as parents.

DR. DANIELS: Excellent. Thank you. No, happy to do that. I also wanted to mention, so in Chapter 4, going back to that, that we had put in some information on learning disabilities, and we were -- we didn't find a ton of resources in that area. And I don't know if some of them might be in the education area, in terms of prevalence of different learning disabilities in autism.

And so, I don't know if CDC or ED might have more information on learning disabilities and autism. But if you do, if you wouldn't mind, please sending those our way, or if anybody else who's on this call has that information. We were a little bit surprised to find that there wasn't a ton of information in PubMed. So, we cobbled together what we could.

But to me, it suggested that there might be a need for more research in that area and -- you know, to give us more of an evidence base for how this co-occurs in autism. And -- oh, Steven.

MR. ISAACSON: Yes. I have comments here from Hari and Morénike. First one from Hari, he agrees that, yes, dental health and coverage are super important. He said, "Many need total sedation for dental work, and it'll be hard to cover the cost of total sedation, which can run up to $7,000. So, dental care gets neglected or indefinitely postponed."

And another comment from Morénike, requesting we add olfactophobia or osmophobia, along with misophonia. They say it can contribute to migrains and/or head banging.

DR. DANIELS: All right. Thank you. So, we'll note those in the sensory area, see what we can find in the literature on those. Okay. So, I think I'm going to move us to the Introduction and Conclusion, which the goal of the introduction is to give an overview of the area and why we're working on it and also maybe to bring out any themes that might run across all of the chapters. And so, we should

probably take a look back at that once the other chapters have been updated.

And the Conclusion, to kind of bring things together and has kind of a forward look for, basically, a lot more research is needed in many different areas, but also much progress has been made since -- when the IACC first came together and started making recommendations that impact physical, mental, and behavioral and other areas of health. So, Dena.

DR. GASSNER: I'm sorry I had to step away for a second. But I did want to say that -- oh, God, is it gone? I'll try again later. Whatever it was disappeared on me. Sorry.

DR. DANIELS: It's okay. Let us know if you think of it.

DR. GASSNER: Oh, communication, is there anything in the communication section that talks about how, sometimes, verbal people can have difficulty communicating under duress?

DR. DANIELS: Yes. We have selective mutism. So, that is, you know, one of the

terms that's used for that. And Helen, you may have other things to say about that, but we did try. I don't know if we got everything. I'm sorry. I didn't mean to cut you off either, Dena.

DR. GASSNER: No, no. That's fine. I would -- just wanted to make sure. You know, we were talking in another situation about the levels, and it's like, yeah, I can be a level 1 most days. But if I have a bad TSA agent or a bad medical experience, I can immediately fly down to a level 3 or, you know, not be able to articulate and protect myself in a situation like that.

So, I just wanted to make sure that that was clear. And our friend Chloe Rothschild reminds us that some people are verbal and use ACC. So, that's important.

DR. DANIELS: Great. I think we tried to cover that. But our team can look back at what's there and see if we need to add anything.

DR. GASSNER: Thanks again.

DR. DANIELS: Thank you. Other comments? And do you have another comment, Dena? Or just -- no, hand going down. Any other overarching thoughts about this whole draft?

I'm really pleased you've brought up a number of issues that may have been missed, that we can certainly go back and add in. I think it will be one of the first times for us to bring this many conditions into one document. So, I hope that that's going to be really helpful for the community and/or the federal government, for us to have this as a reference as well.

DR. AVENEVOLI: Susan, Yetta has her hand up.

DR. DANIELS: Oh, okay. I didn't see it. Thank you. Yetta.

MS. MYRICK: I just want to say thank you to everyone who has worked on the strategic plan, my fellow committee members, you all at NIH, like I just -- and I sent a note, full disclosure to people who are watching. I sent a note when I initially reviewed the

document, and I was like, this really feels like a culmination of the work that we've been doing over the last few years. And I just wanted to say that out loud and share that.

Folks are really invested in this. If people are listening and you hear, okay, this is this. There are a lot of -- you know, it's that -- we want to include everything, right? And I think that -- like that is why our conversation has gone on this long this morning. So, I just wanted to highlight how thankful I am and grateful to have been a part of the committee for this rendition. So, thank you all for your hard work and comments.

DR. DANIELS: Thank you so much, Yetta. We really appreciate that feedback and everyone's participation in this. And I'm really pleased that we also were able to bring in comments, so many different ways, through this online meeting, but also in writing, trying to make sure that we give

people enough time to think about this carefully. So, really happy about that. Shelli, do you have some comments? I see your camera's on.

DR. AVENEVOLI: Oh, no. Sorry. I just joined to announce Yetta. Thanks, Susan.

DR. DANIELS: Oh, thanks. And any other comments? Or Yetta, did you have another comment? No? Give everybody a moment. And if I'm not seeing any other comments, then I'm going to move to the area where we're going to talk about decision making.

And so, there are some options here. We can vote on the strategic plan today to accept it with the kinds of changes that you've discussed here and having us just go ahead and put them together and try to move forward with the document.

If you feel like you'd like to see the document again, we can try to do that. Our -- one of our little issues is that the reauthorization hasn't gone through, and it might take us more than a week to put all of

this together. We will try our best to work quickly this week to do it. And there is a possibility, if we needed to, we could send out another draft. But it might be a little tricky, depending on if the reauthorization comes through on time. Athough we know that Congress is working hard on it, and I'm expecting it to come through.

So, given today's discussion, I'm going to give you some polls to get a sense of the group and how you feel about this. Because we want to make sure you're comfortable. We'd like you to tell us if you are comfortable voting on approval today or if you would prefer to vote after additional revisions have been incorporated into the draft or if you'd like to abstain. So, if you can go ahead and Zoom and respond to that poll. And --

DR. GASSNER: There's a request in the chat. I don't want you to miss that.

DR. DANIELS: Oh, what is -- I didn't see it.

DR. GASSNER: Morénike says she'd like to --

DR. DICKERSON: I can't, yeah, vote.

DR. DANIELS: So, okay. Sorry, that's a technical issue on our end. We will try to figure that out.

MS. CRANE: Yeah. I also can't vote, sorry.

DR. DANIELS: Give us just a moment.

DR. GASSNER: And then Morénike's comment was, "Could we agree to have a third item, where we can approve it with the revisions we've discussed today, without having to look at it again?"

DR. DANIELS: Yes. That would be actually ideal from a timing perspective, so that -- and that's what we meant by the number one, would be comfortable voting on approval, but that is with --entrusting our team to make the revisions that you've discussed here, that you've asked for, but without you having to look at it again. But if you want to look at it again, we're happy to do that. We're

just kind of up against the wall a little bit. But with the reauthorization is the only problem.

So, are we having problems with the poll?

[inaudible comments]

Okay. So, the poll should be good now.

DR. GASSNER: Can we post it again?

DR. DANIELS: It's supposed to be there.

DR. JOHNSON: It popped up -- this is Jennifer Johnson. It popped up for me, and I was able to vote.

DR. DICKERSON: Yeah, I voted. So, it's fine. So --

DR. DANIELS: Is anyone having trouble voting?

DR. AVILA: So, just a quick question. The polling questions that I voted for do not match the polling question 1 and 2 that are on the screen.

DR. DANIELS: We're voting on question 1. So, it says, "Given today's discussion, are you comfortable with voting to approve?" And

it says, either, "Yes, I'm comfortable voting on approval today." And that is with revisions that we have discussed in the meeting today, assuming that our team is going to make those changes and add in all the references and things that you've sent forward and adjust things the way we've discussed today.

And no, it means that you would prefer to hold off on voting until the revisions have been made, and you've been able to look at it first. And/or just abstain. So, for the team, how's the polling going? Okay. Great. Is that something that we'll be able to see on Zoom?

DR. DANIELS: Yeah. Can you share it, please? That would be great. Oh, okay. Good. I see it. Does everyone see it? So, 78 percent said that you are comfortable voting on approval today with the changes that we've discussed in the meeting. 10 percent said no, and 12 percent abstained. So, with that, that is a strong majority.

MS. SMITH: I meant to vote I approve, but the poll just never came up.

DR. DANIELS: Okay. And I also see someone else in the chat who said that they meant to approve but weren't able to do it in the poll. So, anyone else having problems with the voting?

So, it looks like we have a strong majority that would like to just go ahead and approve it with the changes that we've made or that we've discussed making here. So, then what is next?

DR. AVENEVOLI: Sorry, Susan. Was there a second poll for question 2?

DR. DANIELS: So, question 2, yes, there's another poll, I guess, just to confirm. Okay. Hold on. Wait. Next. Right here?

Okay. So, we're just going to take another little poll here. So, do you approve the 2024 IACC Strategic Plan Update with any revisions discussed today? Yes, you approve the report. No, you do not approve the

report. Or you choose to abstain.

So, is that visible to everybody? Yeah?

DR. JOHNSON: Yes, it popped up for me.

DR. DANIELS: Great.

MS. SMITH: I was able to do it this time.

DR. DANIELS: Okay. So, it's popped up. So, we had 86 percent approving the report with the changes that were discussed today, and 14 percent abstaining. So, that is also a strong majority. So, then this report, with the changes that we discussed today, will move forward.

And in the -- you know, before the reauthorization happens and after it has happened, we may reach out to individuals from the committee who had comments today, if we need your help, which is just ensuring that we properly captured the items mentioned.

Oh, thank you. Hari. So, that would be another vote in favor. So, thank you so much for voting on this. And again, we hope that

this is going to be a really impactful report. A lot of information that has gone -- come together by the action of both this and the last committee.

Ivanova, did you have a comment? No, that was just an accidental raised hand. So, I want to acknowledge the people who have worked together on this. We have the previous committee and the working group, so the Improving Health Outcomes Working Group.

Thank you to Julie Taylor for being a co-chair of the group, who is on the committee now, and to David Amaral, who was also a co-chair of this working group. And you can see the many names that are on here, people that met together in special meetings and helped us put together two big workshops on co-occurring conditions and who have also, even recently, helped comment on the draft.

We also want to thank all our current and recent IACC members and alternates. It's a large group of people, a very diverse group with a lot of different kinds of expertise

and lived experience. We really appreciate all of your efforts to help make this draft come together.

And I also want to say thank you to the ONAC staff and meeting support team that have helped with today's meeting and with all of the work on editing all this information and putting it together so that it becomes a very nicely flowing draft document. So, with that, Shelli, do you have any closing remarks that you'd like to make?

DR. AVENEVOLI: Thanks, Susan. Actually, I just really want to add my thanks to, you know, all the people you just mentioned, but also so much, big thank you for your participation today. Your comments only serve to, you know, enhance the strategic plan, make it stronger, and really more broadly applicable to the whole community. So, thanks for putting in a lot of time to review the document and offer those those comments today and previously. So, just wanted to know that your contributions are valued.

DR. DANIELS: Thank you so much. And, again, thank you to the whole committee for your engagement on this very important project that really is a culmination of work that's been going on since the very beginning of the IACC in the first strategic plan in 2009 that talked about co-occurring conditions. And each iteration of the strategic plan got more and more precise on what they wanted to include in terms of co-occurring conditions, wanting to spur research, which now has become a really nice, robust portfolio of research.

And yet, in the production of this document, we've also tried to identify many, many gap areas that still need research and also services and supports to help people in the here and now on these issues. And so, thank you to everyone for that. And thank you to the whole committee, also, just for your service to the community, serving on the IACC. It has been such a pleasure to work with all of you on this, and I know that

we'll be in touch in the next few weeks.

And we would welcome renomination for anybody who's eligible. And we also welcome people who are out in the public who are watching this and want to be a part of the IACC, for you to put in nominations for the Secretary to consider. So, we will be communicating the call for nominations after the reauthorization comes through. And we usually put it out maybe four to six weeks after the reauthorization, just to get all the paperwork done to get that out.

And IACC will be in touch with you about the summary of advances, as we can. And we will work to complete this draft and get it out by December. So, thank you again, and we wish you all the best. Thank you.

MS. SMITH: Thank you so much, everyone.

DR. ROBERTSON: Thank you.

FEMALE SPEAKER: Thank you. Bye-bye.

DR. ROBERTSON: Thank you, Susan et al, as far as your great -- the great work on

this.

MS. PRINCE: Thank you, Susan. Your team has been absolutely wonderful, and it has been a pleasure to meet the people on the committee. There has been a tremendous group of people that you have assembled. It's been an honor.

DR. DANIELS: Thank you.

[end of transcript]