U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

SUBCOMMITTEE FOR BASIC AND TRANSLATIONAL RESEARCH

DSM-5 PLANNING GROUP CONFERENCE CALL

MONDAY, JUNE 24, 2013

The DSM-5 Planning Group of the Subcommittee for Basic and Translational Research convened via conference call from 10:00 a.m. to 11:27 a.m., Geraldine Dawson, *Chair*, presiding.

PARTICIPANTS:

GERALDINE DAWSON, Ph.D., *Chair*, Duke University

SUSAN DANIELS, Ph.D., *Executive Secretary*, IACC, National Institute of Mental Health (NIMH)

LAURA CARPENTER, Ph.D., Medical University of South Carolina

JAN CRANDY, Nevada State Commission on Autism Spectrum Disorders

LAURA KAVANAGH, M.P.P., Health Resources and Services Administration (HRSA)

DIANE PAUL, Ph.D., American Speech-Language-Hearing Association

CATHERINE RICE, Ph.D., Centers for Disease Control and Prevention (CDC) (representing Coleen Boyle, Ph.D., M.S., Hyg.)

PARTICIPANTS (continued):

SCOTT ROBERTSON, M.H.C.I., Autistic Self
Advocacy Network, (ASAN)

JOHN ROBISON, Parent and Author

SUSAN SWEDO, M.D., National Institute of
Mental Health (NIMH)

ANN WAGNER, Ph.D., National Institute of
Mental Health (NIMH)

AMY WETHERBY, Ph.D., Florida State University

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

TABLE OF CONTENTS:

PROCEEDINGS:

Operator: As a reminder, today's conference is being recorded. If there are any objections, please disconnect at this time. I'd now like to turn the conference over to your host, Dr. Susan Daniels.

Dr. Susan Daniels: Thank you.
Thank you, and good morning. Welcome to everyone listening in on the phone and to the Planning Group members, any members of the IACC who might be joining this call.

This is a conference call of the DSM-5 Planning Group, which is a Subgroup of the Subcommittee for Basic and Translational Research of the IACC, the Interagency Autism Coordinating Committee.

My name is Dr. Susan Daniels, and I'm the Executive Secretary of the IACC and the Acting Director of the Office of Autism Research Coordination, and our Chair today for the Planning Group is Dr. Geraldine Dawson, who is the Chief Science Officer at Autism Speaks.

So we'd like to welcome you all to the

call and to this, hopefully, very interesting discussion that we're about to have.

Geri, do you have some comments?

Dr. Geraldine Dawson: Yes. Well, I want to also welcome everyone from both the Planning Group, as well as those listening in today. I know that this is a topic of great interest to many people.

And I just wanted to briefly just outline what I think is going to be the purpose of this call, which is to, for one thing, give a chance to folks who are part of the Planning Committee who were not able to be part of the last call a chance to discuss our recommendations and suggestions that we came up with last time.

We also have three new members of the Group, which we'll have an opportunity to introduce, and then I hope we can leave with some specific actions in terms of where we want to go next.

So I'll turn it back to you, Susan.

Dr. Daniels: Okay. I will go ahead and do a quick roll call and just explain to members on the phone, since this is a

Planning Group, this is allowed to have outside members who are not members of the IACC. So some of the members of the Planning Group are IACC members, and there are four invited members who are not members of the IACC who are also participating. And those four members are Laura Carpenter, Diane Paul, Susan Swedo, and Amy Wetherby. And all the other people are members of the IACC.

So I'll go down and do roll call. Geraldine?

Dr. Dawson: Here.

Dr. Daniels: Cathy Rice?

Dr. Catherine Rice: Here.

Dr. Daniels: In place for Coleen Boyle. Laura Carpenter?

Dr. Laura Carpenter: Here.

Dr. Daniels: Jan Crandy?

Ms. Jan Crandy: Here.

Dr. Daniels: Laura Kavanagh?

Ms. Laura Kavanagh: Here.

Dr. Daniels: John O'Brien is going to be joining us at 10:30 a.m.

Diane Paul?

(No response.)

Dr. Daniels: Scott Robertson?

Mr. Scott Robertson: I'm here. I can only – I can only stay for some of the – the call because I have a conflict that I didn't expect come up. So –

Dr. Daniels: Oh, okay. Thank you. John Robison?

Mr. John Robison: I'm here.

Dr. Daniels: Sue Swedo?

Dr. Susan Swedo: Here.

Dr. Daniels: Amy Wetherby?

Dr. Amy Wetherby: Here.

Dr. Daniels: And Larry Wexler?

Dr. Larry Wexler: Here.

Dr. Daniels: Great. So we have almost everyone in the Group.

I'll turn the call back over to Geri.

Dr. Dawson: Okay. Well, I thought it – it might, even though I hate to take up our precious time introducing ourselves, I think since we do have three new members, it would be helpful to do so. So, but I'd like to do that, you know, very quickly.

So if each person could just say who they are and what group that they represent, I think that would be helpful particularly, so that we all get to know each other, especially the new members.

And I'll just start. I'm Geri Dawson, and I was formerly the chief science officer at Autism Speaks, and I'm now Professor of Psychiatry at Duke University and director of a new autism center there.

And Susan, would you mind maybe calling folks' names and so we could quickly go around?

Dr. Daniels: Sure. Let's do that.

Dr. Dawson: Thank you.

Dr. Daniels: Yes. Cathy Rice?

Dr. Rice: Hi, everybody. I'm Cathy Rice with the Centers for Disease Control and Prevention, and I'm a developmental psychologist and have worked on the case definition and – for our Autism and Developmental Disabilities Monitoring Network prevalence estimates, and I also work on early identification.

Dr. Daniels: Thanks, Cathy. Laura Carpenter?

Dr. Carpenter: Hi there. I'm a clinical

psychologist at the Medical University of South Carolina. I've worked on the CDC prevalence study, the ADDM study for a long time. And right now, I have a – a population-based epidemiological study where we're comparing *DSM-IV* and *DSM-5* definitions.

Dr. Daniels: Thank you, Laura. Welcome.

Jan Crandy? Jan, are you on mute?

Ms. Crandy: Yes. Yes, I'm not a new member, though. I was on the last call. Do you still want me to –

Dr. Daniels: Yeah, do you want to just say just one line about who you are?

Ms. Crandy: I sit on the Nevada State Commission on Autism Spectrum Disorders. I also am a care manager for our state program that provides assistance to families to pay for treatment.

Dr. Daniels: Thank you, Jan.

Laura? Laura Kavanagh?

Ms. Kavanagh: Hi, this is Laura Kavanagh. I'm with the Health Resources and Services Administration, and I head the Division of Maternal and Child Health Workforce Development, which houses our interdisciplinary training program in leadership education in neurodevelopmental disabilities and developmental behavioral pediatrics.

Dr. Daniels: Diane Paul, have you joined us?

(No response.)

Dr. Daniels: No. Scott Robertson?

Mr. Robertson: Yeah, I'm Scott Michael Robertson. I'm the Co-Founder and Vice Chair of the Autistic Self Advocacy Network, an organization – national organization – led by autistic people ourselves.

Dr. Daniels: Thank you.

John Robison?

Mr. Robison: I'm John Robison. I serve on a number of autism-related boards and committees, including the Science Board of Autism Speaks.

Dr. Daniels: Okay. Thank you, John.

Sue Swedo?

Dr. Swedo: Good morning. I am the previous chair of the Neurodevelopmental Disorders Workgroup, and our Workgroup for the *DSM-5* task force had responsibility for all neurodevelopmental disorders, including autism and social communication disorder.

Dr. Daniels: Thanks, Sue.

And Amy Wetherby, one of our new members?

Dr. Wetherby: Yes, hi. I'm Amy Wetherby, and I am Director of the Autism Institute in the College of Medicine at Florida State University and, I guess, former – Sue, I liked the way you said that – former member of the Neurodevelopmental Work – the *DSM-5* Neurodevelopmental Workgroup.

Dr. Daniels: Amy, welcome.

Larry Wexler?

Dr. Wexler: Hi. I'm the Director of the IDEA Discretionary Grants Program out of the Office of Special Education Programs in the Department of Education. Good morning.

Dr. Daniels: Good morning. Well, thanks. That's our whole list of members, and thanks for your doing introductions. I think everybody does appreciate knowing who all of our members are.

So, Geri, I'll turn it back over to you.

Dr. Dawson: Okay. Well, what's, I think, really terrific is the diversity of perspectives that are on this call, and I think that we definitely have a very strong Planning Group here. And so, I really appreciate everybody's participation.

So just as a – to remind folks, the reason why this Group was established was to address issues and concerns around the establishment of the new *DSM-5*, you know, recognizing that the *DSM-5* is, you know, definitely a step forward, and you know, we appreciate all of the work that went into putting together the criteria. But we also want to kind of think thoughtfully about the implications of these changes.

And what we did on our last call was to spend quite a bit of time really just openly discussing the variety of issues that come up as we think about the *DSM-5* starting to be used out in practice, whether that's a clinical practice or in research settings.

And you – and hopefully, people have had time to read the minutes because that discussion is, you know, outlined in a lot of detail in terms of all of the issues that we raised, and there really were many. In addition, I hope you had a chance to read materials that Susan had suggested we read, including, I think, a very helpful set of articles that are posted on the SFARI – Simons Foundation SFARI Web site, which outlines a number of issues from – from different perspectives.

What I hoped that we could first do today is to come back and look again at the goals that we established last time, because we were not able to have everyone in the Planning Group on the call, and in addition, we have brought in different perspectives and expertise. And just in broad strokes, we ended up considering the Planning Group as addressing three sets of goals.

One was around research, and specifically, our deliverable, we decided last time, would be to develop a list of recommendations for the research Strategic Plan for the IACC. So, essentially, perhaps suggesting some more objectives and at least to outline what we think are some very important research questions that should be addressed as the *DSM* is implemented.

And then the second set of goals had to do with policy and practice, and we decided that it would be helpful for the IACC to develop a statement on issues related to policy and practice because there are a number of things that have to be decided, you know, right away before the research really is in place. And we thought that it would be helpful for the IACC to actually make a stand in terms of providing some guidance, or at least opinion, around the issues related to policy and practice.

And then the third set of goals had to do with training and the need for training of clinicians, and also related to that is the need for perhaps some instrument development or interpretation of criteria so that when people start to put the *DSM-5* into practice that there's clarity in terms of how to do that.

So I thought what we could do today is to just open up the discussion again, perhaps going through each of those areas, and give folks that weren't on the call last time a chance to say whether they, you know, think that we're on target in terms of those goals and perhaps things that were missed. There might even be another area that – that needs to be addressed that we haven't even considered yet. And just spend, you know, some time doing that.

We also want to spend the last part of the call touching on the Research Domain Criteria and its implications. And then, finally, I'd like to end with some pretty concrete steps of where we go from here.

So I think, with that, maybe beginning with the issue of research, I'd like to kind of open it up to the general Group. Well, actually, let me – let me take a step back. Let's start at a broader level.

So I've talked about research, policy, practice, and training. Are there broad issues that you feel have not really been addressed with these three domains? If – and so, maybe we could start with that. And if we do think that these three domains capture the range of issues, then we can kind of drill down into each of those areas and make sure that we've covered all of the issues that need to be considered.

So let me just start with that broad question. What did we miss in the last call that people feel we should have included in terms of our Planning Group goals?

Dr. Carpenter: This is Laura Carpenter. I think it looks very comprehensive.

Dr. Dawson: Thanks, Laura.

Mr. Robertson: Geri, this is Scott Robertson. I agree that it's comprehensive, a lot of different areas, and I think it covers a lot of ground that the *DSM-5* is going to have implications on. And if I remember right, you know, part – part of this would be inclusive of the fact that it added social communication disorder. So that's part of the considerations under discussion – that are covered in those three areas, I mean.

Dr. Dawson: Yes, absolutely. In fact, we see that as a very important area to consider from all three of these perspectives.

Mr. Robertson: Okay, great. Yes.

Geri, just one other just comment that I just had on the – I don't know if you also wanted comments on beyond the first area on research, is one of the things I think you mentioned was maybe something coming from IACC on these things. Would that be like a letter or something that would be drafted by IACC's members?

Is that what the possibility was with that or –

Dr. Dawson: Well, that – I think we can make a decision on that today. But I think that the consensus last time was that in terms of research that there would be a list of research objectives that would be described that we will see as priority. And then, in terms of policy and practice, that there would be a policy statement that would be made by the IACC that could be posted on the IACC Web site.

Mr. Robertson: Okay. Yeah, that's what I meant about – by what I meant by the statement. And if there was a statement, it would be by IACC members? Okay.

Dr. Dawson: Yes, by IACC members. So whatever we do in this Planning Group will be taken back to the larger IACC Committee, and they will have also a chance to weigh in and approve and be involved in the final products that come out of this.

Mr. Robison: Geri, this is John Robison here. One of the things I didn't see in the previous notes was any proposal to go back to the *ICD* Committee, because when the social communication disorder was created, there is a – you know, a request to create an *ICD* code for that. And I wonder should the IACC take an official position to the *ICD* Committee regarding where the social communication disorder code should be placed, and do we wish to disagree with the position of the *DSM-5* Committee that it's a communication code?

Dr. Rice: And Geri, this is Cathy Rice. And along those same lines of *ICD*, a question of billing codes I think is an important one as how the *DSM* relates to the *ICD* billing code within the U.S. Because the U.S. is still using *ICD-9* and is transitioning to *ICD-10* this October. So even though *ICD-11* is in development, it's quite a while until that will be put into practice as the way health care providers code for specific conditions that go to billing.

Dr. Swedo: I'll be happy to – this is Sue Swedo. I'll be happy to address that after we've gone around with these initial comments.

Dr. Dawson: Okay. That is very helpful, and I think an excellent addition in terms of things that we should consider.

And I – I'm happy, Sue, to hear your voice because I was going to come back around because I know that you've been – you're, you know, very aware of these issues. So we will come back to you and kind of flesh this out.

Dr. Diane Paul: Hi, this is Diane. This is Diane Paul from the American Speech-Language-Hearing Association.

And just wanted to let you know, too, that ASHA has written an article that will be published soon, comparing – or talking about what the coding implications are and comparing *DSM* with the *ICD-9* billing codes.

Dr. Dawson: Oh, is that something that

you could share as a prepublication?

Dr. Paul: Yes, I think I can.

Dr. Dawson: That would be wonderful.

Dr. Daniels: Diane, if you do share anything, we will need to post it. And I'd like to add – this is Susan Daniels – that some of the links that were mentioned earlier on the call, we haven't been able to yet post them on the Web, but we will put them on the Web for everybody to access.

We're going to create sort of a *DSM-5* resource page on our Web site. So that will be coming up, and we'll send out an email to our listeners to let everybody know when it's up.

Dr. Paul: Okay. Then maybe then it could just be – I can send it after it's published? But I'll find out.

Dr. Dawson: Okay, and perhaps at least we could discuss, you know, some of the issues that came up in that paper –

Dr. Paul: Right.

Dr. Dawson: – so we could make sure to incorporate your – your thinking on that.

Ms. Crandy: Geri, this is Jan Crandy. I

had a couple comments regarding access to treatment.

One, is there concern about the specifiers or the severity scores resulting in – when since there's limited funding, people-picking or people that – states that provide funding for treatment giving the scores that look better or those specifiers, treating those kids and the more severe kids that look like their outcomes are not going to be as good is not getting treated, getting access to funding because of that, with insurance affecting that, too?

And then I know in our state, we have already made the decision for the social communication disorder, because we have so many kids on the wait list, that those kids will not have access now to our state funding. So it's definitely going to have an impact.

Dr. Dawson: In Nevada?

Ms. Crandy: Yes. They have already made the decision that there are too many kids that meet the criteria for autism, that they're not going to add those kids in now.

Dr. Dawson: Is that really the reason? Because there were too many kids?

Ms. Crandy: Because there are so many kids that have – that are going to meet the criteria under autism to add those – we're going to serve those kids first. So those kids won't end up getting served.

Dr. Dawson: Okay.

Dr. Rice: Jan, this is Cathy. Served under which system: education, early intervention, state disability?

Ms. Crandy: This is a – this is a state general fund program that provides funding to families to pay for treatment.

Dr. Rice: Thanks.

Dr. Dawson: And is the treatment – treatment for what age?

Ms. Crandy: So what I'm concerned about those specifiers and the severity scores that are states going to start cherry-picking?

Dr. Dawson: So, Jan, we did – this issue did come up last time about the severity scores, and I know Sue had some comments on how the Committee meant for those scores to be interpreted, you know, with respect to how one would make recommendations around treatment and education.

And so, I do think that's a very important issue, and it seems to me it would fall under policy and practice. So you know, there are a lot of issues like this that just need at least some – an opinion, right, from the IACC about what the IACC feels is the best way to interpret these and implement the criteria.

And so, for example, if this policy statement said that it shouldn't, you know, be used to decide whether a child does or does not receive services, you know, that might then affect a state's decision about how – you know, what they do.

Ms. Crandy: That would help.

Dr. Dawson: But similarly, around the social communication disorder, those are - those are also policy and practice issues. So you know, whether the IACC will have to, you know, make a decision in terms of its opinion that – and really, that's all it is, is its opinion. But it's an opinion of a lot of people that, you know, represent a lot of constituencies about whether, you know, a social communication disorder should be interpreted as not – having lower priority or not – no access to early intervention or other kinds of autism-specific services.

Dr. Wetherby: This is Amy Wetherby. May I make a comment about social communication disorders related to early intervention?

Dr. Dawson: Yes.

Dr. Wetherby: I wanted to clarify information, now that the *DSM-5* is out, if folks can refer to the text and the criteria under social communication disorders. If you look at the criteria, and I realize not everyone has it in front of them, but the criteria are similar to the social communication domain in autism spectrum disorder but also capture a higher level of social communication problems, which really do not develop until 4 to 5 years of age.

And if you look at the text – I believe it's on page 48, at least in the final edition that I have, where it talks about development, of course – it states in the *DSM-5* that it would be rare to diagnose this under age 4 because the kinds of skills that we're describing are continuing to emerge until 4 to 5 years of age.

So when you talk about early intervention, if you mean birth to 3, we would not be able to differentiate these that early. We would be able to pick up on communication disorders, language disorders, autism spectrum disorders but not sift out social communication disorder.

Also the other reasoning is that the repetitive behaviors and restricted interest may be unfolding in the first 3 years of life.

Dr. Dawson: Well, Amy, if you read the – you know, the article by Helen that's on the SFARI Web site around social communication disorder, she discusses the point that you just raised. But she also raised some confusion about another written criterion that said that this was, you know, early onset.

And so you know, again, this is an area where if there's not clarity, we could at least state an opinion, and it's great to have at least, you know, two members of the Neuro – of the Neurodevelopmental Disorders Workgroup – so that you can help us understand, you know, how – how it wasn't in the –

Dr. Wetherby: Well, and keep in mind that we put out draft text and then got a lot of feedback in and incorporated that. So this is what's in the final section. I'm not sure what Helen – I'll actually have the chance to speak with Helen after the webinar.

But I'm not sure. She may have been referring to earlier text, which has since been changed. So I think it's important to refer to the final text that was published and also keeping in mind –

Dr. Dawson: So one other quick question for Amy, as long as we're on this topic. So if a child was, let's say, 2, and that child had all the criteria for a social communication disorder and would, you know, for that particular domain actually meet, you know, the criteria for ASD but had only one repetitive behavior. Let's say this child lined up toys repeatedly, but that was it.

What diagnosis would that child then get?

Dr. Wetherby: Well, I don't think you could give them a diagnosis of social communication disorder because they have to meet four criteria. So they would meet one, what you've described, deficits in communication for social purposes.

But the second is the impairment in the ability to change communication to match the context or needs of the listener, and that really unfolds until 4 to 5 years of age.

The third is difficulty for rules of conversation and storytelling, and that's unfolding until 4 to 5 years. So you couldn't make that distinction at the age of 2.

And then the fourth is difficulties understanding what's not explicitly stated, which is making inferences. And again, that doesn't – and it refers to, you know, nonliteral meaning. These are skills that are not unfolding until 4 to 5 years, so you would not be able to determine that that child had social communication disorder at age 2.

So at age 2, you could pick up a

language delay, and that child might meet criteria for language disorder or might be more broadly communication disorder. But the hope is that we are also – we have better instruments to detect autism spectrum disorder – and I would suspect if you're getting that kind of repetitive behavior, that it's likely that child will meet the criteria for autism spectrum disorder.

Dr. Dawson: Even if – if that child only had one repetitive behavior?

Dr. Wetherby: Well –

Dr. Swedo: Because you'd probably have sensory processing deficit --

Dr. Dawson: No. But what if you didn't – but what if you didn't have sensory. I just saw a child like this last week, and the child did not have sensory –

Dr. Swedo: Then you could give them a nonspecific communication disorder and follow them forward.

Dr. Dawson: And not get early intervention?

Dr. Swedo: No, of course, they can get early intervention.

Dr. Dawson: Well, but they won't qualify, as Jan just said.

Dr. Swedo: In many states they would qualify on the basis of the speech and language delay. In fact, there are a lot of children coming in through that route because it's easier for the 0 to 3 folks to identify that. But you're right, it might not get ABA at that point.

Dr. Wetherby: This is Amy again. I think it's very important for us to think about the state of clinical practice and services now and that, given the average age for diagnosis is somewhere between 4 and 5 years, the majority of children with autism spectrum disorder don't get early intervention. They miss that window.

And so, if we look – I think that if we look at the *DSM-5* definition of autism spectrum disorder, it will help us identify many more children earlier because the criteria are far clearer so that more children can get into that window of receiving early intervention.

Dr. Swedo: And we actually had a

beautiful example of this, how the *DSM-IV* criteria would have missed this little 9-month-old that Sally Rogers had a video for us. And yet the *DSM-5* criteria, because they're more descriptive of the types of symptoms rather than requiring specific behaviors, you could make the diagnosis as early as a year in that child.

So I think, Geri, your point is very good about sort of the RRBs, but if we really probe into the other three sub-criteria for that domain, you end up finding as many children as we did with the *DSM-IV*.

Dr. Dawson: Well, I think that's a really helpful discussion, and I think, you know, all of these – all of this discussion really helps to clarify, you know, the intentions of the Workgroup. It's really, really helpful.

Okay. So it sounds like in terms of just issues that we might have – you know, we want to make sure to get on the table – we talked about the implications for billing. We've also kind of revisited, you know, the issue of social communication disorder and how it's used to make decisions around access to services and when it can be diagnosed. And we also talked about the issue of whether severity scores, you know, how they should be used in terms of making decisions around services.

Are there other issues that people feel should be added to – because then we'll go back, and I'm going to kind of go into each one of these areas and make sure that we haven't – there's nothing we've forgotten. But any other sort of broader issues that we did not get on the table last time that people want to make sure that we include?

Dr. Rice: Geri, this is Cathy. Just along the lines of the last agenda item in terms of where do we go with the Research Domain Criteria, in terms of the IACC research Strategic Plan?

Dr. Dawson: Okay. Yes.

Dr. Rice: And that's already –

Dr. Dawson: Yep, okay. So we're kind of adding that as a – as an issue that we really need to think about as part of this Group.

Okay. That's great.

Okay. Well, let's – let's do drill down into each of the areas, and again, I don't think we're going to try to – I hope everyone has had a chance to review the documents that we – you know, which were the minutes from the last meeting.

But we – last time we identified several issues that we feel are important in terms of research recommendations. These are everything from understanding how the changes might impact prevalence estimate to the need for tool development to reliably assess things like severity and several other things.

So assuming that people – I'm not going to outline all of these but – assuming that people have had a chance to read the minutes, were there any specific research issues that you want to make sure that this Group addresses as we think about this that we perhaps missed last time?

Dr. Carpenter: This is Laura Carpenter. I think one thing that I didn't see in there was the – I think we need more information about the sensory differences that are part of the *DSM-5* criteria. So you know, more reliable methods for assessment, particularly in nonverbal or young children, information about the prevalence and quality of sensory differences in the general population.

And maybe from an IACC perspective, I think mechanistic studies would be helpful.

Dr. Dawson: So let me make sure – yeah, that's fantastic, Laura. I think that's a really good point, and it isn't something we talked about last time.

Yes, so – and Susan, I'm just going to assume I don't have to take notes on all these things because I'm trying to –

Dr. Daniels: Right.

Dr. Dawson: All right. I won't worry about that then.

Dr. Daniels: Geri, I just wanted to make you aware that I've asked Ann Wagner from NIMH to be on the call to talk about RDoC, and she told me that she has to be off by 11:00 a.m. So you may want –

Dr. Dawson: Oh, okay. Well, we can skip around. Ann, are you on?

Dr. Daniels: She might just be calling in. So give her a few minutes.

Dr. Dawson: Okay. Well, when she calls in, because it's – you know, we've only got about 20 minutes right now before she'd have to leave. When she calls in, let's just move right to that, and then we can kind of come back.

Dr. Daniels: Okay. So Ann, once you join into the speaker line, please let us know you're on.

Dr. Dawson: So that was a really good point. So reliable methods of assessment of the sensory and looking at mechanism prevalence and so forth.

Are there other research topics that we didn't include last time that people think are important?

I think, Scott and John, do you think we addressed – you know, incorporated enough of the issues or that need to be addressed related to how the *DSM-5* might influence, you know, adult diagnosis and access to treatment?

Mr. Robison: I – you know, I guess I

feel okay with research questions, but I still would reiterate my – my question about taking a position vis-à-vis the ICD billing code assignments for the revised ASD and for social communication. And if indeed – if indeed it is – it's still going to be billed according to the existing *ICD* codes, I guess I'll wonder, you know, will it really have a negative effect because the billing codes stand unchanged.

Dr. Dawson: Mm-hmm.

Dr. Swedo: So I can speak to that now. It's Sue Swedo.

From about midpoint of the *DSM-5* development, so three and a half years ago, we started meeting with representatives of *ICD-11*, as that is the only version that is not yet in concrete and making sure that the *DSM-5* would be harmonized with the *ICD-11* so that the diagnostic system wouldn't have to change substantially.

And it's primarily, actually, for the research criteria that *ICD-9* and *ICD-10* have the clinical criteria, which are just basically a name of a disorder and then the research criteria are amplified slightly. For all of the mental disorders, they actually have the equivalent of "see *DSM-IV*." So it was to make sure that the research criteria didn't change that these groups met.

Mike Rutter at the time was in charge of the *ICD-11* childhood psychiatric disorders section, and he and I and a number of other people met by phone a couple of times to discuss the criteria, concluded that *ICD-11* would retain autistic disorder as a separate diagnosis, and merged the rest into autism spectrum disorder. So that – but the criteria for the two overlap enough that there really isn't a problem in using *DSM-5* to make the diagnosis and *ICD-9*, *-10*, or *-11* to make the codes.

In the *DSM-5* textbook and the online version, the codes that appear are actually the *ICD-9* codes for the most part. And for intellectual developmental disorder, intellectual disability is the one that's the most problematic for the neurodevelopmental disorders, because we went from four subtypes of mental retardation – mild, moderate, severe, and profound – down to a single class, intellectual disability, (IDD), and specifiers for the severity.

So that meant the codes couldn't translate from *ICD* – from the *DSM-5* into *ICD-10*. And consequently, there is a note in the right below the criteria in the *ICD* how those should specifically be coded and how the codes will transfer over.

But John is exactly right. As far as practitioners are concerned, services reimbursement and all the rest, the *DSM-5* is an interesting footnote but really doesn't have an impact on the day-to-day management of patients' care and delivery of services. And it's --

Mr. Robison: Sue, there's one thing, though, I'd want to ask, because you and I, I think we talked about this a little bit in Stockholm?

Dr. Swedo: Yes.

Mr. Robison: That the – if – if social

communication disorder is coded as a communication disorder –

Dr. Swedo: Yes.

Mr. Robison: And it's not coded as a pervasive developmental disorder in the existing *ICD* code set that we use?

Dr. Swedo: Yes.

Mr. Robison: It seems to me that there is a potential problem –

Dr. Swedo: Right.

Mr. Robison: – where the service is based on that. And I – so that's actually what I wonder. Should we – should we on the IACC take a position –

Dr. Swedo: No.

Mr. Robison: – re: how that would be coded, or is it set in stone?

Dr. Swedo: I would say that it is essential that it be left separate and left within the communication disorders. We can share the literature and the notes of our discussions, but this was a point of discussion for two and a half years not just with the Neurodevelopmental Workgroup, but with our advisers as well.

And the concern was that PDD-NOS, because it included that sub-threshold symptomatology and atypical autism, which could have only social skills deficits and nothing else, that some of the children in the PDD-NOS group were better served by a social communication disorder diagnosis because it would deliver specific services to them.

Now if we do it for delivery of services, it's a little bit like, you know, calling the kid a zebra to get them what they need. We would need to keep them clean and separate, and that's why the notes are so clear that you should not be giving a diagnosis of SCD to a child in whom you could better make a diagnosis of ASD. And similarly, a child shouldn't get a diagnosis of autism spectrum disorder or intellectual disability when their better diagnosis is social communication disorder or a specific learning disorder.

So it really comes down to diagnostic validity, which is something that's harder to test. But that's the purpose of some of the papers that have been coming out really looking at these separations.

Dr. Dawson: But Sue, could not one argue that – just arguing along the line of, say, what Helen Tager-Flusberg described in her article on the SFARI Web site that we really don't have good validity data for social communication disorder yet?

Dr. Swedo: No, we don't because it hasn't been –

Dr. Dawson: So that – right. So I wonder whether, you know, one could argue that until we have that data that suggests, for example, that a child that only has one repetitive behavior is better served as a –

Dr. Swedo: But, Geri, the child you described was 2, and at that point, they should have –

Dr. Dawson: Pardon me?

Dr. Swedo: In the age of 1 to 2, you can certainly err on the side of moving toward the more inclusive diagnosis. But at the point that the CDC is going to go into 8-year-olds, if we include social communication disorder, we have already seen what happened in the field trials.

Dr. Dawson: No, I'm actually just thinking about the issue of how this translates into billing code, right? And so, I just – I guess one could argue that until we have good validity data that it might be, you know, in terms of –

Dr. Swedo: Well, the billing – yeah, the billing codes for *ICD-9* and *-10*, which will be around until 2015 – now I just heard 2016. So for the next four and a half years, our billing codes are PDD.

Dr. Dawson: Right. So that – so the child who – if you evaluate the child and the child gets a diagnosis of social communication disorder, and if that is then translated into an *ICD* code, then you are saying that should be a PDD-NOS?

Dr. Swedo: The clinician will have to decide whether they put the child into the PDD-NOS diagnostic code or into the generic code.

Dr. Dawson: Right. So IACC could choose to make a statement that until there's good validity data around the social communication disorder diagnosis, that for young children, that one should err on the side of using a code, *ICD* code of PDD-NOS?

Dr. Swedo: I would temper that the way Amy had described earlier and say that since SCD is not deemed appropriate for children less than age 5, 4 to 5, that if you have a young child with social communication deficits that you would not be able to use that – that code.

Mr. Robison: If I could raise another issue here, if we go back to –

Dr. Daniels: John? This is Susan Daniels. I just wanted to remind people that Ann Wagner is on the line.

Dr. Dawson: Oh, good.

Dr. Daniels: I don't know if this would be a good moment to talk about RDoC before she has to go?

Dr. Dawson: Yeah, excellent. Let's do that, John, and then we'll come right back to you.

Mr. Robison: Okay.

Dr. Dawson: Welcome, Ann. We're all –

Dr. Ann Wagner: Hi.

Dr. Dawson: – very interested in RDoC and, you know, the whole – the program, but specifically, too, how it relates to our charge around *DSM-5*.

Dr. Wagner: Okay. I'm sorry to get on late, and thank you for accommodating me.

I think the most important thing – so the RDoC is the Research Domain Criteria. This is an NIMH-specific initiative. And it's – I mean, it's a new way of thinking about and classifying psychopathology, mental disorders for research, and it's based on dimensions of observable behavior and the neurobiology underlying them.

So it's not meant to be a diagnostic schematic, and so it should not conflict with the *DSM-5* or *ICD-10*. Those will continue to be the formats for making diagnoses. So what NIMH is trying to do is to have people who are doing research look beyond the categories and look at the specific kind of dimensions or constructs within those categories as the basis for understanding how things develop, what maintains them, what's the best way to intervene.

So it's – hopefully, it will inform in the future how we think about diagnoses, but that's kind of a long ways away. So Tom Insel talks about this as being sort of a decades-long project that's just beginning. And my view is that NIMH will be encouraging people who are submitting applications for research to be looking within – looking beyond just categorical diagnoses, but say for thinking about research on autism spectrum disorders, defining what aspect of that you are looking at.

So is it the social cognition? Is it the repetitive behavior? And we’ll be encouraging people to measure those more neural constructs both in terms of behavioral measures and neurobiological measures that underlie those things.

So – so it shouldn't be contradictory to the *DSM* or to the *ICD*. And it really is meant to be a way to encourage research to kind of look beyond the behavior and at the neurobiology underlying the behavior.

So I'm happy to answer questions if that was not clear or if I can look at something else.

Dr. Rice: Hi, Ann. This is Cathy Rice.

Dr. Wagner: Hi.

Dr. Rice: Just so then the implications for the IACC would be in the next iteration of the Strategic Plan to be thinking about how to incorporate the Research Domain Criteria into some of the existing questions or whether there are new questions? Does that seem –

Dr. Wagner: –Well I don't know that you need to, actually. I mean, for one thing, this is an NIMH-specific initiative. So this is not something necessarily that all institutes or agencies have adopted.

But I think this is a way to get answers to some of these questions. So, and I think it's important to be aware of it. I'm not sure you need to have specific questions around it.

Dr. Rice: Okay. So more of a conceptual framework in that way that might guide some of the specific proposals that go after the existing questions.

Dr. Wagner: Right. And specifically ones that come to NIMH. So again, I want to emphasize this is an NIMH initiative, not an NIH-wide initiative.

Dr. Rice: Okay. And then, so for implications for, say, someone is applying to NIMH for an autism-related grant and traditionally defining cases by – typically done by ADOS, ADI, clinical judgment together. Will that still – will there be a different standard, or will it be that is still expected, but in addition being very specific about the specific domain that is being investigated?

Does that make any sense? I'm just trying to wrap my head around what that means for researchers.

Dr. Wagner: Sure. Right. So I think there are two ways that this could apply to autism research.

So yes, you could do the original gold standard. You could select patients with ASD based on the gold standard, but you would be looking at something specific.

So for instance, if you're testing an intervention, you would be encouraged to say what it is – what the mechanism of that intervention effect would be. So is it on social attention? Is it on language skills? You know, so is it on flexibility? So drilling down.

So you might – within that group of ASD – might choose people who have a deficit in the area that you're paying attention to, for instance.

Dr. Rice: Okay.

Dr. Wagner: Then you would measure that behaviorally, lab measures, maybe imaging, or something like that, whatever made sense scientifically.

The other way that one could think about it is that you could pick people who have, say, social communication deficits. And you could pick them regardless of what the diagnosis is. So you know, so you could look across diagnoses at a certain construct or domain of functioning.

Dr. Rice: Thank you. Very helpful.

Dr. Wagner: Okay.

Dr. Daniels: Unless there are more questions from the Group?

(No response.)

Dr. Daniels: We really appreciate your time.

Dr. Dawson: Thank you, Ann. Very helpful.

Dr. Wagner: You're welcome. Bye-bye.

Mr. Robison: Could I return to my point on the SCD and ASD. This is John Robison here.

Dr. Dawson: Yes, please.

Mr. Robison: So here is my concern about what we've just – what we talked about. Back in, I think, May or June of last year, when Sue Swedo made the preliminary presentation of the validation studies for *DSM-5* to us at IACC, one of the points of her presentation was that the new criteria captured more people with ASD, not less, as compared to *DSM-IV*.

So we subsequently learned that the more people included those people who were captured by the social communication diagnosis. And then we learned after that that the social communication diagnosis in the eyes of the *DSM-5* Workgroup was not actually an autism spectrum condition. So it was a little – it's a little misleading to say that the new diagnostics captures more people with autism because it actually captures more people with those two distinct diagnoses.

Dr. Swedo: No, it actually captures more people with autism, as well as capturing a new group of individuals who meet criteria for social communication deficit. And I –

Mr. Robison: If that's – if that's true, I thank you for correcting that.

Dr. Swedo: Yeah. I'm sorry that wasn't clear before.

Mr. Robison: So that's what I – that's what I wanted to understand. Can you explain that to me, please, so I get those – that right now?

Dr. Swedo: Yes. So in the field trials – and I think that more work needs to be done and I believe that's already a goal of this Planning Group is making sure that we do look at prevalence and impact of these criteria -- but in the field trials that were done, in the changes from *DSM-IV* to *DSM-5* brought in an additional 2 to 3 percent at one site – sorry, 3 percent at one site and almost 5 percent at the other site.

Then there was an additional 8 percent of kids who hadn't had any kind of PDD-NOS, any kind of autistic diagnosis in *DSM-IV* that met criteria for social communication disorder. We looked at those videos, and for the most part, those kids were exactly who we thought this diagnosis would be capturing, and that is children who have ADHD or other learning – and/or learning disabilities and also have significant social skills deficits.

Mr. Robison: See, I didn't fully understand that when you said it to me in conversation. So if I could rephrase what you just said to see if I'm right? The straight comparison of the autism spectrum in *DSM-IV* to the ASD diagnosis in *DSM-5*, if *DSM-IV* captured 100 people, *DSM-5* captures between 102 and 105.

And in addition to that number, eight more people would be captured by SCD. Am I hear – is that right?

Dr. Swedo: That is what I just said, and I don't want to be quoted on those numbers, although I recognize –

Mr. Robison: But it's something like that. It is definitely then –

Dr. Swedo: It is definitely the fact that the new criteria, because they do not specify an age at onset by age 3 and allow that, you know, sort of social skills are insufficient to meet the demands of different contexts and some of the other changes, including the lack of double counting of symptoms. People might think that that actually should have worked against it. It actually increases the sensitivity of the new criteria because when kids didn't have that one symptom, then they missed out on two opportunities to get counted in *DSM-IV*.

So there were new patients brought in under the *DSM-5* that had not been diagnosed under *DSM-IV* for autism spectrum disorder, as well as a group of children with SCD that had not had a diagnosis before.

Mr. Robison: So thank you. And there's one more thing I want to ask.

When you and I spoke in person, you – you said SCD should capture some children with the attention deficit issues that were incorrectly classified PDD-NOS before.

Dr. Swedo: Yes.

Mr. Robison: So in – in what we're looking at now, those kids are some of the 8 percent that are captured by SCD, and the improved definition essentially replaces the numbers of those kids who would have been in ASD with other people who are captured with ASD in the population, to make the total pool diagnosed with autism still 103, or 4 or 5 percent of what – for that 100?

Dr. Swedo: Yeah, and I – and the reason it's making me a little nervous to confirm that, John, isn't because you don't have the – the context right. It's the specific numbers are making me nervous.

Mr. Robison: Okay, the specific numbers –

Dr. Dawson: So I actually have the article open in front of me.

Mr. Robison: Yeah.

Dr. Dawson: And so this is the field trial article, and it's a bit confusing because – and in this quote from the discussion, it says, "As can be seen from Table 4, there was no significant change in the prevalence of autism spectrum disorders at one site, but there was somewhat of a decrease in the *DSM-5* autism spectrum rates at the second site. A careful review of data from both sites showed that the decrease at the Stanford site was offset by a movement into a new *DSM-5* diagnosis called social or pragmatic communication disorder."

So that seems to suggest that, in fact, there was a decrease, but that the decrease was accounted for by kids shifting from ASD into the social communication disorder.

Dr. Swedo: Yeah, and I apologize for not having pulled up that article before our call today because I'm talking about sort of the in-person analysis of the data with – with Diane Clark, and there were children who had had a PDD-NOS diagnosis that moved over to SCD. But the reason that I'm comfortable saying that it was ADHD with social skills deficits is we specifically looked at those videotapes. They videotaped all of the interviews.

Initially, we were going to publish a study on validity. It became very clear that that wasn't going to be possible because of the way the studies had been done. It had been done to look at reliability of diagnosis over time.

But the coded diagnosis that they were brought in for versus the diagnosis that the clinicians were assigning on *DSM-IV* criteria, because they then rated each patient with both, that's what I'm saying we didn't lose cases that any of us would have called ASD and did bring in additional children. And that's why I was also very concerned about John's statistics because it is. It's only one or two kids in each site.

Mr. Robison: Yeah. So the number of kids making this 103 and 4 percent is fairly small, right? So one kid, more or less, could significantly move those percentages.

Dr. Swedo: That's right.

Mr. Robison: Yeah.

Dr. Swedo: So that's why we need more data, and as Geri has just pointed out, when you look at the data in aggregate, there were children who had a PDD-NOS diagnosis who moved over to SCD. My contention is that they didn't have what most people would have identified as a *DSM-IV* diagnosis of an autism disorder because of the fluke in *DSM-IV* where a copy editor had taken out the "and" and substituted an "or" so that you could have only social skills deficits and get a *DSM-5* diagnosis of PDD to begin with.

Mr. Robison: I see. So if I might ask another question then on diagnosis? How is – how is the use of our ADOS – how is ADOS scoring changed with the advent of *DSM-5*, if at all?

Dr. Swedo: It shouldn't have changed at all, as the ADOS and ADI-R both were based – actually were developed under *DSM-III*, if not *DSM-II*, and go at the core symptoms of autism rather than meeting the *DSM* criteria. And, in fact, maybe Cathy wants to talk to that point about how diagnoses were –

Dr. Wetherby: Well, this is Amy. There are new algorithms that have been published on the ADOS, and they're in the ADOS-2, which do reflect the two domains. So they are consistent with the *DSM-5*. And data from both the ADOS and ADI were used to inform the decisions about the criteria, particularly the two of the four, well, all three in social communication, but the two of the four in order to get the best sensitivity and specificity.

Dr. Swedo: Yes, but it didn't – that was ADOS and ADI-R informing *DSM-5*, not *DSM-5* impacting back onto ADOS.

Dr. Wetherby: Right. But the ADOS algorithms have changed based on research and accumulated data, and the new algorithm has two domains, which is like the *DSM-5*. So it's – it informed it, and it's compatible with it.

Mr. Robison: So is A – now does ADOS pick up a larger percentage of the general population on the autism spectrum using the new criteria than it did using the old criteria, or is the number the same or unknown?

Dr. Wetherby: The ADOS – first of all, the ADOS is a tool, which is used to inform diagnosis. But diagnosis is based on the *DSM*. The ADOS has an algorithm with cut scores based on the best data they have when each, you know, revision has been updated based on research.

So the criteria – the current criteria algorithm has two domains. The previous criteria had three, which corresponded with the *DSM-IV*. So the DS – the ADOS algorithm domains changed and informed the decision of the change that we made in the *DSM-5*.

Dr. Dawson: But I think a lot of people do not understand that the – that a diagnosis is – and Cathy, you know, makes a very strong point of this – that I think some people, you know, don't use the ADI and ADOS this way.

But, so the ADOS and the ADI are two sources of important information. You also have, you know, everything else you have learned about this individual, and the diagnosis is made on the basis of integrating all of that information.

Dr. Wetherby: That's a really important point, Geri. And the hope is that the *DSM-5* criteria will guide that decision-making, but it's a clinical decision.

Dr. Dawson: So this has been, I think, a great discussion, and I don't want to cut it off. I just want to make sure that we're really thinking about these three areas. And we've talked about some of the research areas. We keep moving into the policy and practice areas, you know, particularly this issue of how – the implications of the social communication disorder for making recommendations for clinical treatment and so forth.

But are there other issues in the research before we move on to talking about policy and practice that we should make sure to get on the table?

Mr. Robison: How soon will we have a larger study of the effect of the *DSM-5* change, Geri? How soon will we have larger study results?

Dr. Dawson: I think that there are a number of studies that are ongoing right now, and even at the last IMFAR – and I haven't studied all of them -- but I noticed just looking at all the titles that there were a number of studies that were even presented at IMFAR. I know that there is a – two studies – that Autism Speaks has funded.

One was going back to the South Korean population, which was a population-based study where children were screened – all children in a very large community were screened – for autism and then diagnosed with the *DSM-IV*. We paid for them to go back and diagnose those children also with the *DSM-5*. That paper is now under review with some very interesting, I think, and important findings there.

And then we also are – Autism Speaks is funding a study at the South Carolina site of the ADDM Network that is comparing the *DSM*, *DSM-IV*, and *DSM-5*. And I wonder, Laura, if you could just take a moment to describe that study, because I think it's going to be really important.

Dr. Carpenter: Sure. So the original study we were looking at was a prevalence study, where we're doing population-based screening on a population of about 8,500 kids. And then, you know, we're doing direct assessment on a proportion of those children.

And then Autism Speaks was generous enough to fund us to do an additional study where all the kids that come into the clinics for that second phase of direct assessment are being diagnosed according both *DSM-IV* and *DSM-5*. And as part of the *DSM-5* assessment, we're doing a differential diagnosis with social communication disorder.

Dr. Dawson: So have you, just out of curiosity in terms of implementing it – were there, Laura, just some clear issues that came up right away? You already mentioned the sensory sensitivities, but other issues that struck you as, wow, you know, in order to really understand this, we need more research?

Dr. Carpenter: Yeah. The social

communication disorder has been a real challenge for us. I'm not sure that we've been assessing communication as indepth as is needed for – you know – to answer that question. And by "we," I mean just clinicians diagnosing autism in general.

Because really, for *DSM-IV*, you're just looking for speech – you know, do they have problems with – do they have delayed speech, or do they have conversational impairments? But with SCD, the criteria are much more specific. So we are looking at using some additional parent checklists, and I think, ultimately, there is a need for more direct child assessment and, hopefully, tool development in that area. So that's been a challenge.

Dr. Dawson: So I guess that raises – and I'd be curious, Amy, your thoughts on this – but are there some good clinical recommendations – or maybe now from ASHA – about the tools to use to assess a social communication disorder?

Dr. Wetherby: I think that there are a set of tools that has been developed over the past decade or two that has provided a lot of good information about a variety of disorders that we hope the social communication disorder will capture better or broader. So we have disorders that have been referred in the research literature like pragmatic language disorder, semantic pragmatic disorder. And often parents can get confused if their child is diagnosed with that to think then they don't have autism.

So what we wanted to try to improve with the *DSM-5* is that to measure the social communication piece, but we also specifically say autism must be ruled out. And I think that the research literature now that's out there – and there are a number of standardized tests that are out there – it's still messy because autism was not required to be ruled out. And I think that's the case with specific language disorder research as well.

So keep in mind that about 10 percent of the population has communication disorders, and that might be a speech, a language, or a social communication problem. Autism is– what

– the 1 to 2 percent.

So I think our hope with the *DSM-5* was specifying social – that's not a good word – including a classification of social communication disorder in there; it will actually help alert practitioners to the pragmatic aspect of the problem, alert them that they need to rule out autism spectrum disorder, and this may in the end lead to more diagnoses, more appropriate and more diagnoses of autism spectrum disorder.

And then help the children who have language problems get the appropriate treatment, whether it's on specific language impairment, which is more grammar, word, vocabulary, or social communication problems. So there are a set of tests out there.

I think that ASHA – we're working on a number of papers, the Workgroup members – and we're working with ASHA, with Diane Paul, on getting papers out. And we'll make some recommendations, and I – and Diane – may add what ASHA may do as well.

But I don't think it's just simply one test because tests are – newer and better tests will come along, but there are about six or eight different standardized tests either based on parent report or direct observation that are out there now.

Dr. Dawson: That, I think, will be very, very useful information when that gets published, and it's great to hear that that's underway.

I did want to raise one issue that I had thought that we didn't talk about last time that I'd like the Working Group to weigh in on whether or not we want to take this on. We probably don't because this is maybe, you know, more challenging in some ways than what we've already addressed, which is big.

But I was reading through the papers that were – or the interviews, I should say – that were posted on the SFARI Web site in preparation for this call. I was struck by the interview that talked about the new criteria for intellectual disability, which are not necessarily based on IQ, that just they're more based on functional skills.

And you know, I don't know whether – so that's going to be – that's going to have, I think, really significant implications for people with autism in terms of whether they get an intellectual disability diagnosis or not because there will be many people who score in what previously was considered the nonintellectual disability range before who now, because of more adaptive behavior and functional impairments, will be considered as having intellectual disability.

So this will have implications perhaps for, you know, services, educational placement. It could – it certainly will change as the CDC does its surveillance over time. And one of the things that's always been informative in those reports is looking at, you know, the changes in the proportion of individuals with intellectual disability. That will also, I think, be affected.

So I just wanted to kind of throw that out there and see whether people feel like we should just steer clear of that issue, or is it something we want to think about?

Dr. Swedo: This is Sue Swedo again. And I'm sorry that the criteria looked like that because the first criterion is still intellectual abilities, cognitive capacity. And the reason it's not specific in that criterion that it has to be 70 or less is because of some very awful forensic issues, which allow people to be eligible for the death penalty if their IQ is 71 and not if it's 69.

Because, apparently, the courts do not understand measurement error and to have 70 plus or minus 5 or 2 standard deviations of plus or minus X percent was not something they could handle. So the Committee spent a very long time working on that.

Criterion one is still cognitive capacity, and it's indicated that generally two standard deviations below the mean, using individually administered psychometrically sound measures. And the second one is the adaptive functioning. So you actually have to have both, and it shouldn't change the prevalence there because the text very much clarifies the issues of it's generally going to be 70.

So check the – not that far down in the text, but certainly accessible to courts is the fact that these standard deviations are well known and generally hover around 70 on most of the instruments.

Dr. Dawson: Well, I think I read that and must have read that interview incorrectly.

Dr. Swedo: No, the interview may have been right, and I've spent – it's interesting that I used to spend all my time clarifying ASD, what we meant to say versus what was actually there. And now it's moved on to intellectual disability and specific learning disorders.

So maybe things are –

Dr. Wetherby: Yeah, and Geri – this is Amy – I just think it's great that you raised the question. I think there's a lot of confusion, and I think there was some change from draft to final criteria, and part of that was based on all the public input.

So it's very important that people realize what the final criteria state. Clearly, it says the following three criteria must be met.

Dr. Swedo: Right.

Dr. Wetherby: And as Sue said, A is intellectual, and B is adaptive, and C is onset during the developmental period.

Dr. Dawson: So did you, by any chance, read the interview? And I'm sorry, I don't have it up in front of me to remember the person's name, but that wrote that, and were they just misinformed because they were operating on previous versions of the criteria?

Dr. Swedo: I think they were misinformed, and that one probably couldn't even be explained on previous versions, but just differences in interpretation.

Dr. Dawson: Oh, well, that's –

Dr. Swedo: And I just actually had the same question from a child psychiatrist this morning that said why did you take IQ out? And I said read criterion one and see what – tell me what it says, and they went, "Oh, okay."

Dr. Dawson: So you might want to actually talk to the Simons Foundation because that's probably going to get out there and be confusing a lot of people.

Dr. Swedo: Yeah, we definitely will, and one of the things that the autism community should actually be grateful to us for was that adaptive functioning was brought back in, but only under the consideration that it needed to be adaptive functioning related to the intellectual disability and not related to the autism.

So, hopefully, we'll be able to hammer some of that out –

Dr. Dawson: Well, I'm glad – I'm glad I asked. That was very helpful.

Mr. Robison: Yes, I thank you, Sue, too, for clarifying the points I questioned.

Dr. Swedo: Sure, and as I said to Geri when she reminded me what the article says, we have still a lot of work to do. And I'm very, very glad to hear that folks are already really looking at these criteria. I'm part of the *DSM-5*-point-whatever Planning Group, and we've already met to discuss what changes need to be made.

A couple of changes that need to be made to the autism spectrum disorder chapter or section of our chapter are the fact that after our page proofs, after the Committee's input was completely over, some editor decided to add a specifier "with catatonia," which I think creates tremendous problems for clinicians trying to distinguish childhood onset schizophrenia with an autistic prodrome from true ASD. So we're working to get that one removed.

They also left out the age and pattern of onset because, apparently, it didn't use the right words for specifier. But that means the childhood disintegrative disorder can't be captured with that specifier.

But, and that reminds me to talk about the fact – somebody had asked very early in the conversation about specifiers and what the impact would be on coding.

Dr. Swedo: And specifiers are a completely optional function for clinicians, and they don't have any impact on coding. And that's why we actually moved away from subtypes in intellectual disability just to specifying levels of severity. Because just as the IQ of 70 versus 71 was quite arbitrary, so were the subtype divisions between mild, moderate, severe, and profound.

And so, we don't have any subtypes in autism because the overwhelming literature shows that you really can't make crystal-clear distinctions between, for example, Asperger's and autism or PDD-NOS and Asperger's. So moving away from subtypes to specifiers should, hopefully, make that a little easier.

Dr. Rice: Sue, this is Cathy. A follow-up to that – In your discussions with the *ICD-11* Committee, was there any talk about whether they would consider coding for specifiers in the future, or will that remain under the guise of the clinical modification that if there are some sort of specifiers that rise to the point of needing to be coded for clinical purposes, that that may be considered under the ICD-CM?

Dr. Swedo: Yes. The answer to your question is yes. That currently they wouldn't code for specifiers, but if some of the specifiers looked like they could be reliably distinguishable subtypes, the coding system allows that, particularly within autism and within intellectual disability, because we just add another digit, and we have the digits available, whereas in some of the diagnoses, they don't.

Dr. Rice: Okay. And that even doesn't necessarily have to be a subtype as much as a clinical symptom that needs to be called out for specific intervention sometimes as well?

Dr. Swedo: Yes. Absolutely.

Dr. Rice. Yes. Thanks.

Dr. Dawson: So I'm aware that we have 10 minutes left, and I want to make sure that we leave with some pretty clear next steps, and I think we've done a great job of talking about and fleshing out each of these three areas.

We've touched on training around things like the document that's going to come out that discusses assessment of social communication disorder, and I'm sure there are other issues as well. We've touched on policy and practice and research.

If there are other issues that we haven't, you know, discussed you want to make sure that are on the radar of the Group, you know, please email these to Susan so we can – want to make sure to capture those.

What I wanted to see is whether – and I'm just going to throw this out as a proposal and see how the Planning Group feels about it. But I'm wondering if we want to break into three, kind of Workgroups, to drill down on each of these three areas. And Susan, I haven't discussed this with you. So there may be problems with this from a, you know, Government point of view. So please just tell me if I'm going in the wrong direction here.

But I thought, you know, since we do have, you know, three deliverables, so to speak, you know, the list of recommendations around research, a policy and practice statement, and a list of recommendations related to training and clinician. And it may be that policy and practice and training, you know, are pretty closely related so we could also kind of consider combining those into one – one Group.

But I thought maybe to actually create those deliverables that we might want to break into two Groups. Or you know, the other possibility is maybe we're supposed to go back to the other Group and talk to the bigger Group first before we start working on actual deliverables. So Susan, maybe you can advise me here and let the group weigh in?

Dr. Daniels: I think that structurally – I don’t think formally – we would want to break into Groups. What we can do is organize further calls, and if you want to assign lead people for certain tasks, it would be essentially similar to having a Group, but I didn't want to set up formal separate Groups that were going to have a different mailing list, et cetera, et cetera.

So, because that just will be more confusing. I think it's already a little bit confusing with the Planning Groups under the Subcommittees. So if that would be okay, if there are certain people who want to volunteer to work on a particular task, and we could either have devoted phone calls that are just for one task. Or we could have a phone call and divide it into two sections, and the first half of the phone call is on one task, and the second half is on another task.

I know that people's schedules are a little bit hectic over the summer. I don't know how many different phone calls we'll be able to schedule.

Dr. Dawson: Mm-hmm.

Dr. Daniels: So we may want – we may want to just split the time and have people participate in whatever they want. But that way, everyone also would have a chance, if they happened to want to participate in both activities, that they could.

Dr. Dawson: Right.

Dr. Daniels: And, of course, any products that you all come up with would have to be approved by the full Committee before it could become an official product with the IACC.

Dr. Dawson: So let me – so let me modify the suggestion then. So what if – what if we perhaps had 2-hour calls, and we spent 1 hour on really drilling down and developing, you know, the list of recommendations for research and the second one perhaps combining policy, practice, and training into, you know, one statement.

And that, you know, we have leads for each of those, people who are willing to take the lead in, you know, drafting these things and then circulating them back for feedback.

Dr. Daniels: This is Susan. From my point of view, that would be fine, and we could try to identify times for those calls.

Dr. Dawson: How do other people feel about that as a process, or do you have other ideas?

Dr. Rice: This is Cathy. That makes sense. My one question is, are they really separate processes in that, say, the research goals. Presumably, before that actually gets integrated into the IACC Plan, that will be part of the next iteration, and that's quite a while for that to come out.

So if the full Committee approves, what if we included research recommendations in the policy and practice statement as well, as a way for those to get out circulating and people could give them thought before the actual Plan is updated? Again, with the full

Committee's approval.

And then the statement really becomes a research, policy, and practice statement. Because a lot of it is – the policy and practice issues are really hinging on needing more information in many cases, and so I don't know that we could separate those.

Dr. Dawson: Yeah, I mean, I like that suggestion. How do other people feel about making it even though we would have two parts of an overall document, that this would be one document that would have policy and practice, training issues, and then followed by research recommendations that really are then, to some extent, tied into the questions that were raised as we sorted through the issues around policy and practice?

Dr. Wetherby: I really like that suggestion.

Mr. Robison: I think it's good.

Dr. Wexler: I can go with that. This is Wexler.

Dr. Daniels: Geri, this is Susan. There is – you know – one possibility is the way, if you come up with a statement or a larger document that lays out the issues for the research areas, if you have kind of more general and overarching language, you could come up with more specific language that would be parallel to the type of language we have in the Strategic Plan objectives and save those for insertion in the Strategic Plan when it's updated later this year.

But you could still cover it with the same maybe broader and more detailed language in your statement. I don't know if that would be kind of similar to what Cathy was bringing up, but then you would be bringing out those recommendations earlier in that document, but in terms of the very specific three-line, two-line type of recommendations, they would go into the Strategic Plan.

Dr. Dawson: That sounds very efficient.

Dr. Rice: Yeah, and also I think starting the Strategic Plan Question 1, there was a lot of work put into that to make a succinct summary of where we were at the time, and so that's certainly a good starting point. And through these discussions, we've come up with a lot more issues in certainly the policy and practice side of it.

But there is some of that broad language in there already that we could build on.

Dr. Dawson: So I'm wondering if there's a person who would be willing to kind of go through the documents, the minutes of the two phone calls that we've had, as well as, you know, other information that's relevant, you know, on the SFARI Web site and other -- perhaps other places – and begin to just bullet what some opening – you know, research questions so that we can start with something to react to and to begin to build from.

And then, if there's also a person who would be willing to do the same thing in the policy, practice, and training domain?

Dr. Rice: Geri, this is Cathy. I'll be happy to do that for the research.

Dr. Dawson: Great. Thank you. Is there anybody who'd be interested in doing it for the policy, practice, and training? Okay, well, I will be willing to do that if people would find that acceptable.

So I'll just – I'll go through and just start to catalog, you know, the issues and try to organize them, and then Cathy can do the same. And then perhaps we can circulate that, you know, before our next call. And that way, we can, you know, have something to react to.

Dr. Daniels: This is Susan. On the calls, of the people who are here, does anyone have a general sense of whether July or August are going to be good times for a call? And if you'd like a 2-hour, or do you want even longer than that, a 3-hour? Any thoughts about timing?

I know that people's schedules are kind of difficult over the summer. So we can just do this by Doodle and see what we come up with. But of course, if several people spoke up and said, "Oh, July is out, I'm out," I would just move to August immediately.

Dr. Dawson: Yeah, I actually am out in July.

Dr. Daniels: Okay.

Dr. Dawson: But August is fine for me. And I know that's a time when a lot of people do go on vacation, but I'm just saying for myself.

Dr. Daniels: Maybe – I know that I'm out of the Office for the first part of August for a few days, and then I know some of my staff are as well. So maybe we'll try for something between August 15th and the end of August or something like that.

Dr. Dawson: And what do folks feel, should we do a 2- or a 3-hour? I mean, since these calls are so hard, do you think we should shoot for a 3-hour, or would that be too much for people?

Mr. Robison: I think it's too much. I'd vote for 2. John Robison here.

Dr. Wexler: I vote for 2.

(Laughter.)

Dr. Dawson: All right. That sounds good.

Dr. Daniels: Great. That's good.

Dr. Dawson: All right. So a 2-hour meeting. We'll do it in the last 2 weeks of August, and before that, Cathy and I will have something that everyone can look at and, hopefully, get us started.

Dr. Daniels: Great. And then Geri will give a brief update of the upcoming IACC meeting on July 9th. So that's so the

Committee can hear about the progress the Group has made.

Dr. Dawson: Right. Well, thank you, everyone. And in the meantime, enjoy your summer, and we'll look forward to reconvening in August.

Mr. Robison: Very good. We'll talk then.

Dr. Daniels: Thank you very much. And OARC will be putting more information up on our Web site about *DSM-5*, et cetera. So please keep an eye open for that or an email that talks about the new Web page when we get it up. Thanks.

(Whereupon, at 11:27 a.m., the DSM-5 Planning Group adjourned.)