U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR BASIC AND TRANSLATIONAL RESEARCH

DSM-5 PLANNING GROUP

CONFERENCE CALL

WEDNESDAY, AUGUST 21, 2013

The meeting convened via conference call from 11:06 a.m. to 1:30 p.m., Geraldine Dawson, *Chair*, presiding.

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PROCEEDINGS:

Dr. Susan Daniels: Thank you. Well, I'd like to welcome all our phone listeners and the members of this planning group to the call.

This is a meeting of the DSM-5 Planning Group of the IACC Subcommittee for Basic and Translational Research, which is a group that is working on issues related to changes in the *DSM-5* that happened this past year.

We have on the call a number of people. I'd like to go through and do a roll call so that everyone will know who's here.

So Geri Dawson, Chair of the group, are you here?

Dr. Geraldine Dawson: Yes, I'm here.

Dr. Daniels: Thank you. Jan Crandy?

Ms. Jan Crandy: Present.

Dr. Daniels: I believe Laura Kavanagh will be joining us late. John O'Brien? Cathy Rice?

Dr. Catherine Rice: Here.

Dr. Daniels: Thank you. Scott?

Mr. Scott Robertson: Here.

Dr. Daniels: Thanks. John Elder Robison? Larry Wexler? Laura Carpenter?

Dr. Laura Carpenter: Here.

Dr. Daniels: Diane Paul, I believe, was not going to be able to join. Sue Swedo?

Dr. Susan Swedo: Here.

Dr. Daniels: And I believe Amy Wetherby will be joining us a little bit later.

So anyone who may be on listen only that's going to be joining the speaking line, please speak up and let us know or send me an email to let me know that you're on the call.

So we will be moving into our program in just a minute. I'd like to quickly ask those who are on the phone if you had any comments about the draft minutes that I sent around from the last call.

I didn't hear any comments by email, but I just wanted to double-check that no one had any corrections or changes.

All right. So we will go ahead, and I will assume that that is approval to go ahead and publish these minutes as they are. So we will be getting those up on the Web site for everyone as soon as possible.

I'd like to remind everyone to please speak your name before you give comments on this call because we are having a transcriptionist listen to the call, and it assists them in identifying who is speaking.

Mr. John Robison: John Robison checking in. I might have missed the roll call. I'm 5 minutes late.

Dr. Daniels: Oh hi, John. Thank you for letting us know that you're here. Well, great.

Well, I would – I also have passed out some materials. We have those materials up on the Web site as well for anyone who's listening in and wants to look.

You will see a draft statement that was prepared by Geri Dawson and Cathy Rice. That will be something that can be proposed to the IACC but will be a matter of discussion today. It is just a draft, so it's not a final document, and the agenda is posted online as well.

So with that, I'd like to turn this over to Geri Dawson, Chair of the group.

Dr. Dawson: Hi, everyone. So as Susan just pointed out, what Cathy and I did was to try to draft the statement really in order to have a document that we could all just react to and begin to refine.

So as Susan said, it is not at all a final document or probably even close to final. But we did want to offer something that we could begin to work with and refine, and then, of course, it'll need to go to the full IACC, and I'm sure there will be changes and input at that level as well.

But as you may recall, we decided to have the document, have two pieces to it – one focusing on research implications of the changes in the *DSM* and the other focused on practicing – practice and policy.

So Cathy was responsible for drafting the research section. She also got input from some other folks, and Susan looked over and provided input as well, and then I drafted the practice and policy again with Susan and Cathy looking it over and providing input.

So I think what might be helpful now is if we spent time discussing each of these sections, and we could start with the research as it comes first and perhaps, Cathy, you could just give us a brief kind of summary of the key points that you included, and then we could open it for discussion, and then we'll move on to the practice and policy, and I'll provide an overview of that, and then we can open that for discussion.

And then, based on your verbal feedback, you know, we can create a new draft, and then we could also, of course, send things around if people want to actually write on the document as well.

But let's start with a discussion of the document. So I'll turn it over to Cathy to talk about the research part of it.

Dr. Daniels: Just before we do that –

this is Susan – I heard from somebody who's a listener on this call that there's a lot of ambient noise.

And so they'd appreciate everyone putting their phones on mute if they're not speaking. Thanks so much. Go ahead, Cathy.

Dr. Rice: Thank you, Geri and Susan. So this is Cathy. In the research section, as Geri mentioned, we're focusing on two different aspects – research and then policy and practice.

So for the research questions, these are mainly things that we've discussed on these calls over the last several months that we've been having them in terms of impact on who's identified, when are they identified, what the impact may be on those individuals for service provision as well as for basic research as well.

So starting on page 2 of the draft, there's just a general description in terms of the implications for research and the types of questions we may want to put out there that need to be addressed.

And then we divided them up into three main questions, basically trying to better understand who is being identified and how this may or may not change with the new criteria, the second group of questions about how are people identified with an ASD, and then the third set of questions, what does it mean to be identified with an ASD.

So the who, the how, and the what does it mean are the major conceptual breakdowns of how these questions were added.

Then within each category, there are a variety of questions that go in to support that general concept.

So, first, in terms of the ‘who is identified,’ some of the basic questions about the reliability and the validity of the *DSM-5* ASD diagnosis compared to experienced clinician judgment, trying to get a sense of how the criteria have changed in comparison to experienced clinicians' concept of what ASD may be.

Also, this has been a topic of a lot of discussion, and there have been some studies – but further studies in terms of – are the same individuals who were diagnosed with a PDD under *DSM-IV*, are those same individuals also diagnosed with an ASD under *DSM-5*, and are there certain groups – whether they're toddlers, females, those with fewer symptoms – that are less likely to be diagnosed.

Also, what is the symptom profile of those that meet one set of diagnostic criteria but not the other, what are the general profiles in terms of functioning cognitive demographic – who are the individuals that may or may not be meeting one set of criteria versus the other.

And then we're looking a little bit more about the number and characteristics of individuals identified.

So there's been some suggestion in published papers about looking at fewer symptoms – does the requiring of three social symptoms and two restrictive and repetitive behaviors – does that have an impact on who is and is not classified as an ASD compared to a PDD. In particular, that's been raised with toddlers as an issue.

And then some of the questions about who is identified – is about the reliability and validity of the severity ratings in the two domains and some of the implications to the severity ratings and how they correspond to adaptive functioning.

There are some additional questions about the removal of the age of 3 years for symptom onset, which was present in the *DSM-IV* under autistic disorder, and now it is more broad in terms of early childhood. So does that have an impact on the early identification of children with ASD.

Also, other questions that are important in terms of prevalence estimates – how will we evaluate trends in current autism prevalence estimates based on – that are based – on the *DSM-IV* standards – how do we move forward in terms of looking at what is our estimate of prevalence based on *DSM-5*.

And then some other basic questions about the reliability and validity of social pragmatic communication disorder, how is SCD distinct from ASD and as well as questions about overlap with pragmatic language disorder.

And then more qualitative-type research in terms of the *DSM-5* criteria, how are they understood and utilized among typically underrepresented subgroups – children from racial ethnic minorities, females and adults in particular.

So those are the primary "who" questions.

Dr. Swedo: Can we talk about those before moving on to the next?

Dr. Rice: Sounds good to me, yeah.

Dr. Swedo: And I'd also like – I'm sorry, this is Sue Swedo – I'd also like to go back to actually the introduction – the changes in the *DSM* criteria.

But we could do that later since Cathy's just introduced these questions.

Dr. Rice: Yes. Geri, I'm assuming that at the end – how do we want to do this? Go back and talk about specific changes in each section at the end or –

Dr. Dawson: Yes. I think we could do it as we go along, and certainly that'll make it a little easier than trying to keep all these things in our head.

The only thing we'll have to just – and Susan, maybe you can help me with this – is monitor time and make sure that we don't end up, you know, spending too much time on one section, you know, and get through the whole thing.

But let's – I think it's a great idea to go ahead and open it up. Maybe we can come back to the introduction and just talk about the research part that's been presented thus far.

Dr. Swedo: Sue Swedo again. I would request that the questions be asked in a less judgmental way, for example, Are certain groups less likely to be diagnosed using *DSM-5* criteria?

That goes along actually to my comment on the introduction, which states “the goal of the revisions was to improve specificity of ASD diagnosis – i.e., to reduce false-positive cases.

However, concerns exist that this increased specificity may have gone too far in reducing the sensitivity to ASD diagnosis – i.e., false-negative cases.”

I actually don't believe that that is true, and I think we've had that debate in the media as well as in the scientific literature a number of times, and it's been fairly well demonstrated that that charge was not well founded.

So to ask are certain groups less likely to be diagnosed suggests that we sacrificed sensitivity for specificity and a simple – are certain groups less or more likely to be diagnosed, or you could just say do the new criteria change diagnostic prevalences for these specific groups because preliminary data including a paper published last month shows that the new criteria actually are better for toddlers and early-onset patients.

Then the second issue was about the – do the *DSM-5* criteria identify the same individuals who are diagnosed with the *DSM-IV* PDD? That question is a bit complex, and I guess with the subquestions underneath, it does make it more clear.

But the intention was never to diagnose all of the patients within – with PDDs – within the ASD criteria for *DSM-5* because of the errors that had been introduced in *DSM-IV* in PDD-NOS.

The word "or" was substituted for the "and," which made it possible to make criteria for PDD-NOS on the basis of restrictive repetitive behaviors alone as well as sub-threshold symptoms.

And then on the next page, “does the removal of the age of 3 years for symptom onset alter the early identification patterns of children with an ASD;” again, that's a bit of a complex question because it sounds like 3 years was the time symptoms had to onset.

But in actuality, the *DSM-IV* specified that they had to be before age 3, and the new criteria just say early childhood and include symptoms manifest during adolescence or adults.

So I'm not sure if that question could be reworded to make it more clear. And then my final point is on the issue of how is SCD distinct from ASD in pragmatic language disorder.

While that's an interesting research question, pragmatic language disorder is actually not a defined disorder, even in the speech and hearing literature, and so I would just leave that part off and just leave it at how – what is the reliability and validity and how is SCD distinct from ASD.

Dr. Rice: So in terms of moving forward, should we – do other people want to discuss any of those requests?

Mr. Robison: John Robison here. I certainly – I would agree with Sue that for us to raise the question through the IACC about whether the new diagnostic criteria will capture less people, I do think that's been discussed at great length in the – you know – in the media especially and in the community, and I would agree with Sue about that.

One thing that I think is a point of difference between what I've heard from Sue and what is written here, we – in drafting this IACC document, we say for billing purposes ICD codes are used and clinicians will decide whether to use the ICD PDD-NOS code for people with ASD or SCD diagnoses.

Now I heard from Sue, and I forgot where we were when I heard this, whether it was on the phone or it was in person, but Sue, I heard you to say to me that you felt that there were some number of PDD diagnoses that should more properly be an OCD diagnosis, and you said in your thing just a moment ago –

you talked about some incorrect diagnoses as a result of the definition error of PDD-NOS in the *DSM-IV*.

I guess I think if we're going to take a position in the IACC that the billing – the billing decision – that a clinician has to make is which PDD code to use for a person with SCD, that to me implies that the IACC is taking the position that SCD is an autism spectrum disorder, because the *ICD* includes PDD in the greater autism spectrum, and are we therefore going to say that the position of the IACC is that SCD is primarily “autism light,” if you will. Is that our intention?

Dr. Rice: So this is Cathy, and I don't – I think, John, you make some good points there, and we jumped ahead a little bit to some of the policy and implementation questions, and you know, certainly Geri can speak better to this.

But, you know, my thought was that our intention was not to take that stance but to have that as an empirical question about what is SCD and how does it and does it not overlap with conditions that were diagnosed based on past criteria and conditions that are diagnosed based on near criteria.

Mr. Robison: Well, if that's how – if that's how we feel about it, then I would suggest that we should accommodate what Sue had said, and we should maybe add a paragraph to what you have here to suggest that some people who are – who were formally diagnosed with PDD might more properly be diagnosed with another condition entirely.

Would you agree with that, Sue, or would you think that that's not what you had meant when we talked?

Dr. Swedo: Yes. Actually, you've captured it quite well, and I think that the differential diagnosis both actually in *DSM* – *DSM-IV* – as well as in *DSM-5* made that very clear.

It was just unfortunate that in *DSM-IV* the editors took out the "and" and stuck in an "or" because they thought it made a better sentence structure, and it had a tremendous impact on the sort of – the threshold for diagnostic criteria for PDD-NOS.

Mr. Robison: So that's a really – it's a legitimate point, and I think if we're going to say that in the IACC, one thing that I would suggest, because the public is going to read this and they're not necessarily familiar with this, I would stress that in the – in the tree branch construction of *ICD*, *ICD* recognizes that the compulsive disorders and the autism spectrum are neurologically first cousins, if you will.

So this is not particularly, you know, a judgmental thing, which is something Sue said we want to avoid and I agree with. But I do think it absolutely is a valid point, and it should be a part of our document.

Dr. Dawson: So let me just speak also – this is Geri – to the issue, Sue, that you bring up about the *DSM-IV* era when it said or, you know, versus and with regard to the PDD diagnosis, and I think that the question of how does the change, you know, actually impact who is identified still has to be addressed because whether it was, you know, an error – you know, even though it was an error – rather than, you know, an intentional difference in diagnosis, it still was during that point of history affecting who got put into research projects and how prevalence estimates were made and so forth, and it's still important to understand how – as these systems evolve – how it impacts who's being identified with an ASD disorder.

And you know, it's not in a judgmental way but just in an empirical way. And so I think it's still an important question that needs to be addressed, and I don't think that there's enough research to really – for us at this point, particularly with minority populations and older populations and so forth – that we can just say, well, that's already been addressed or that was just because it was an error so, you know, we shouldn't be addressing it.

Dr. Swedo: No, I actually agree completely, Geri, and – sorry, Sue Swedo – and I think that the point I was trying to make was that – because the introduction is written as if *DSM-IV* was the correct diagnosis and *DSM-5* has now changed to something different and by the wording of the questions in the introductory sentences, the implication is it's a failure – I think if we can get rid of that and then make it very clear, perhaps not maybe defining PDD because its implications for research – the changes to *DSM* potentially impact those individuals who are considered to have a PDD in the past and now an ASD in the present.

The problem with trying to draw a direct and complete parallel between PDD and ASD is that the *DSM-5* was very careful to identify those diagnostic categories which would be moved forward into ASD and those which weren't and the reasons for them.

So if we can somehow just communicate that, and perhaps the best way to do it is just a footnote describing what PDD was in *DSM-IV*, because it isn't entirely clear from the document as it's written that the two things are actually supposed to be distinct.

Dr. Dawson: So, well – you know, I guess one of the things I'm going to suggest at the end of this call is that, you know, for people who have strong feelings about changing in wording that it – you know, we should have a Word version of this rather than just a PDF that people can provide suggested, you know, changes, and that then Cathy and I are going to, you know, have to grapple with how to incorporate those and then send back another document until we all feel pretty comfortable with it, because I – you know, I think that it's a fair criticism or, you know, feedback, I should say, to make sure that there's not a judgmental tone, right, to it.

And so to the extent at which we can go through and change wording to make sure it sounds more – less – judgmental I think that's a – that's a great idea.

Dr. Rice: This is Cathy. I certainly agree, because the intent is to have empirical questions about what was the standard and what is the standard and how are they different and how are they the same.

Dr. Dawson: And, you know, it's kind of interesting a little bit the lens, you know, we read it through, because I don't think, you know, neither Cathy nor I felt like we were trying to be judgmental.

In other words, I like the *DSM-5* myself, right. So it's interesting that, you know, you would read it and feel that, you know, it was judgmental and it wasn't intentional.

So, but I do think that there are probably words in there that, you know, we just weren't aware of, but I don't think there was an intention for it to be judgmental.

Dr. Rice: This is Cathy. I think the addition of more clearly defining PDD in *DSM-IV* is a really helpful suggestion to make that more clear and making sure that any questions include more or less or the same. You know, not one-directional hypotheses, I think is important.

One thing I would say in terms of the issue of pragmatic language disorder is that I think it's worth keeping that in there just because the only research literature that is referred to really related to social communication disorder is about pragmatic language disorder.

And although that has not been defined as a specific communication disorder or a neurodevelopmental disorder, it has been research defined in some degrees, and it's the only referential literature for SCD.

So I think we have to maintain some reference to it, and it could be clarified to say that it's not truly diagnosis but how it is referred to in the literature.

Dr. Swedo: I think that might be reasonable. I guess one of the issues there would be if we're going to do that – how is

SCD distinct from ASD – then we need to be asking exactly the same questions about all of the rest of the disorders.

So, again, if it's just pulled out of that question where you're comparing *DSM-IV* to *DSM-5*, it might be more clear.

Dr. Rice: Sue, could you explain that a little bit more exactly what you mean?

Dr. Swedo: Well, the question is what's the reliability and validity of the SCD diagnosis and how is it distinct from ASD and then in pragmatic language disorder – within all of that you've been talking *DSM-5* or *DSM* diagnoses, and since pragmatic language disorder isn't included in that and actually one wouldn't expect a great deal of differences between social communication disorder and pragmatic language disorder as they were pulled together by some of the experts in pragmatic language disorder.

Dr. Rice: Okay. So just to separate those a little bit more clearly.

Dr. Swedo: Yes.

Dr. Rice: Okay. Gotcha.

Mr. Robison: It's John speaking again. One thing I would be concerned with is that – is that when we say that SCD, that some of those people with a new SCD diagnosis, would get ICD PDD codes and we, by implication, suggest that that is part of the autism spectrum, I actually think that that would be an important statement to make on behalf of the many children who are the recipients of services today with PDD and Asperger’s diagnoses, because I think one thing we lose sight of when we talk about pragmatic language and many of these medical diagnoses is that a very large fraction of the services that are provided come through the educational system, and they really clearly distinguish Asperger’s, PDD, and autism therapies, and I think that our statement should take that into account.

Dr. Dawson: So, John, I think that's an excellent point. I'm thinking that perhaps we should table that until we get into the practice and policy part of the discussion.

But I think it's a very important point, and I hope we can circle back to it when we get down into that section.

Mr. Robison: You know, I apologize, but I actually have to drop off the call because I hurt my back, and I've got to chase that down.

So but I wanted to throw my ideas out anyway even if I'm not going to be there for the end part of the call.

Dr. Dawson: All right. That makes sense. So feel free to mix it up then as far as the order. It's not a big deal.

We can – we can talk about some of the policy and practice things early to accommodate, you know, your schedule and things, too. So that's fine.

Mr. Robison: I feel like we're kind of monopolizing this and nobody else has spoken up. Are there other thoughts on this?

Mr. Robertson: Yes, I had a couple thoughts. It's Scott Robertson. We're still on the research section, right?

Dr. Dawson: Right.

Mr. Robertson: Okay. One of the things, and I don't know whether this can be changed or not – I mean, maybe this is the kind of thing I know that maybe gets fixed in the – in the Word document – but my understanding is that when you're referring to men and women in a nonclinical setting – in the sense of, like, the statement is going to go out for the general public to read – that it might be better to refer to individuals instead of as “females” as a noun but as “women,” which would cover both, you know, girls and adults.

So that's kind of a – like a – language suggestion there. But the other thing related partly to what John said – he mentioned specifically – on children who have a PDD-NOS diagnosis, what about adults as well, and I see – and it kind of – it's across the rest of the document too that I was going to bring up is that the word “adult” I think is only mentioned once, I think, in the whole document unless I missed something in there.

And I would suggest that adults should be moved up farther so that the onus is kind of on there, where it talks about are certain groups less likely to be diagnosed, that adults should, you know, be right in there because we don't know whether or not that's true yet and it doesn't bring up adults until one of the last questions in the research section on underrepresented groups.

And I don't know whether adults necessarily belong in the same area as gender and ethnicity, especially since we don't necessarily know, you know, the prevalence rates around adults.

We just haven't had a lot of research that actually has looked at what prevalence looks like across the whole age span where – versus we have a lot more research showing, you know, the disparities around female to male and around – it's starting to happen around ethnicity.

Mr. Robison: Scott, I would just say that the reason that I specified children actually had nothing to do with adults being diagnosed or not diagnosed.

It was simply a recognition that a very large percentage of the autism services provided in the United States are provided to children through school systems and not through –

Mr. Robertson: Oh. Oh, okay.

Mr. Robison: – not through the medical insurance system – the medical system. That's all.

Mr. Robertson: Oh, okay. Okay. Good point.

Dr. Rice: Yes. And Scott, this is Cathy. I think just the point taken of us as we read through making sure that we're reflecting across the lifespan as much as possible, and if that needs to be clarified throughout the document, suggestions on how to do that would be very helpful.

Mr. Robertson: Yes, because I – you

know, one other thing just to add -- again, it's Scott – is that to add on that point also is that it's been a large challenge for many, many years – as many folks know in the whole community – is that there are a lot of autistic adults that have trouble sometimes as adults getting diagnosis because they were left out as children or whatever the case was.

And many people see the *DSM-5* as some promise in that area because of the fact there's going to be a new onus on kind of revising diagnostic instruments, updating things to fit along the new criteria.

And so that I think it opens a window of opportunity that it could potentially be helpful to recognize some of these challenges that have existed historically and folks making sure that they can get diagnosis as adults and making sure that it's properly captured across the lifespan.

Dr. Rice: Scott, that's a great – this is Cathy again – a great suggestion in terms of the next section about how are people identified with an ASD and making sure that we include the point you just made about the consideration of adult diagnoses and tools, how they may need to be updated or developed to appropriately capture the criteria and the co-occurring conditions – and applying the specifiers and all of the things that apply across the lifespan – but making sure that we do have a particular eye in terms of the application, across range of functioning as well as across age.

So that's a, I think, a good lens to read this next section. Should I go ahead and do a brief – a very brief – overview of what's in the how are people identified with ASD?

Dr. Dawson: That would be great, Cathy.

Dr. Rice: Okay. So as I mentioned, this next section is really much more focused on the mechanics and the screening and diagnostic instruments and how they may need to be modified. But I think we should add, may be even developed to conform to the *DSM-5* criteria, to make sure that it's appropriately looking at the historical and current symptoms that should be captured in a reliable way, how assessment tools may need to be adapted to capture a range of strengths and weaknesses, ages, and cultural backgrounds.

So we kind of touched on the lifespan issue and that in terms of making sure that we are looking across a whole range of functioning and age wise as well, how will the severity ratings and specifiers be assessed and documented reliably, how do the *DSM-5* criteria – do they change the way clinicians, other health and educational professionals, and community members conceptualize and identify ASD?

And we drew the parallel to the way there was such a sea change in the way we see autism after the *DSM-IV* in the inclusion of Asperger’s, and we really began to think about the spectrum of autism and a very different conceptualization of autism than we had had prior to the *DSM-IV*. Are we going to have any sort of change in that kind of conceptual way based on the *DSM-5* criteria?

And that's much more qualitative research and sort of reflecting that that's something that we didn't really do as it was happening with the change from the *DSM-III-R* to the *DSM-IV*.

We didn't really get a pulse among clinicians and people in the community and teachers about how they are seeing what autism is and how that's changing over time – and then another basic question about what tools are used to assess social communication disorder.

Mr. Robison: Cathy, is there anyone on the Committee who can actually tell us exactly where we stand with updating or evaluating the ADOS and the ADI-R specifically in light of the *DSM-5*?

Dr. Rice: Yes, this is Cathy. I can speak to the ADOS. The ADOS-2 that was released last year actually corresponds to the *DSM-5* criteria.

Mr. Robison: So that then means – would that mean that we should be making a little bit different statement in this section because we have an answer to how it affects the primary screening tool? Would it be fair to say that?

Dr. Rice: Well, that is one, and it's a very useful and important and well used – particularly in research – less used clinically tool, the ADOS.

But it really doesn't stand alone as a diagnostic instrument. You really do need to complement it with other assessment tools.

And so I think it's – so we have one tool that is available, but we really don't have diagnostic interviews that correspond in the same way.

We haven't really looked as far as I know – and I'm not sure, others may be able to speak better to it – how screening tools are going to be adapted or not adapted.

Given that they're screening tools and that they're meant to be very sensitive and over-inclusive, a lot of screening tools tend to include a range of criteria that even if you kind of mix up – so how we call the combination in the specific criteria for diagnostic purposes screening tools tends to still be pretty sensitive. So it may be that there has to be less or no changes to screening tools. But I think it's an empirical question.

Mr. Robison: By an interview tool, do you mean the ADI-R, and has that not been updated?

Dr. Rice: That – yes – ADI-R. There are other interview tools as well that are less used, and again, others can speak to this as well.

The current ADI-R algorithm is based on *DSM-IV* autistic disorder, and in research purposes there have been alterations of the criteria to say how does it correspond with PDD diagnosis.

But I don't know that that's really been looked at in terms of the *DSM-5* ASD diagnosis.

Mr. Robison: And does ADOS have any provision for assessing SCD in the new version?

Dr. Rice: No.

Mr. Robison: So it's just not a part of it at all?

Dr. Rice: So some of the behaviors that you're looking at in terms of social communication may be important things that you would want to assess for SCD, first ruling out that ASD is present and then considering SCD.

It could be helpful for that. And the ADOS looks at certain things about reciprocity during conversation, for instance.

That could be helpful in the assessment of SCD, but as far as I know, nobody has really sized that up and said how can the ADOS be used or not be used to help inform an

SCD diagnosis.

Mr. Robison: So would it be correct to say that you're not aware of any validated tool to assess SCD at this point or at this moment?

Dr. Rice: There are tools that look at social communication.

Mr. Robison: Yes, but not at the specific disorder as defined now?

Dr. Rice: Yes. As far as I know, no. And others may verify if that's true if you know of anything. But there are pragmatic language disorder assessments, but they don't really line up with SCD criteria specifically.

Mr. Robertson: So this is Scott Robertson. I have a comment related particularly to ADOS on how – and again, maybe this is the spot where there's an opportunity around *DSM-5* is that in the past with *DSM-IV* there have been some problems.

I mean, I know it's mostly supposed to be used as a screening instrument, but sometimes it's been used as the “gold standard” of diagnosis and has tended to leave out individuals, particularly individuals who are, for instance, adults who have learned adaptive or other kind of coping kind of mechanisms for challenges have tended to sometimes to be left out from the ADOS when they really are autistic, but it doesn't really show up through that screening instrument maybe because they make eye contact and can have a reciprocal conversation, and so it doesn't appear as well in there.

And the *DSM-5*, from my understanding – if I remember right on the criteria – has at least something a little bit newer in there that's almost along the lines of: If you were a child and you were autistic, you're still autistic as, you know, as you get – as you get older and that – and that you should consider the impact of the fact of how individuals have learned ways to kind of mitigate challenges and difficulties.

So I'm thinking that that's also going

to come up, particularly with the ADOS and some widely used instruments right now when they adjust for *DSM-5*.

Dr. Rice: This is Cathy. I think you bring up some good points in that the ADOS is really meant to assess present-during-that-assessment – how is that person communicating, interacting, behaving in a way that is assessed similar to anyone else who's given that assessment.

And so it's really not meant to evaluate historical – you know – the history of how that person has been functioning and adapting, and that's where I think it's really important that we see that the ADOS is really – it is a diagnostic tool but it is one diagnostic tool.

It's not just a screener. It does go deeper, but it has to be used in conjunction with getting historical information and other assessments that look at that person outside of that one setting.

So in the questions that we have in the

document about how are people identified, we tried to capture that by pointing out that we need to capture both historical and current symptoms as well as a reliable way of establishing the presence of restrictive and repetitive behaviors, and that could be based on history, could be based on observation.

But we just need to have a better understanding of what is the current gold standard of how we should be assessing this – how do the tools line up – how should we be using them to complement each other – do they capture across the lifespan and the whole range of functioning that the people who are being assessed may be showing in different domains, and that's quite a challenge.

And one of the things with the ADOS in particular is the ADOS-2, the version that does correspond with *DSM-5*, that actually is primarily for the modules – the toddler module up through module three, and the module four, which is for older individuals who are very – who are more functionally verbal, there have not been corresponding new criteria that have been put together.

And so that really is an empirical question that needs to be assessed of how to best use that tool within that particular group as well.

Mr. Robertson: Wow. That's – this is Scott again just briefly – that's kind of interesting. I hope that they – that is eventually the long-term plan to update, you know, module four being used for teens with more sets of verbal skills and adults, because I think that's kind of problematic if it's not on the line.

And I just wanted to, just one other point I wanted to add on the fact that the ADOS being used in part of the screening is that my understanding on past cases where there's a disagreement between the ADI finding kind of past history that the ADOS, you know, not necessarily showing the person's current difficulties because of the kind of confines around the setting and the individual learning to compensate and mask kind of difficulties that others who know that person really well and see in them, you know, more than, you know, in a 20- or 30-minute observation can, you know, know of specific difficulties they have.

If there's a mismatch between those two, the ADI and the ADOS in terms of one finding and one not finding, that you tend to – at least from what I've seen in the past – there's a tendency to say there's not a – there's no autism here.

Dr. Swedo: They're actually not following the directions of the instruments then, because Cathy Lord has made it quite clear, as did Michael Rutter originally, that both are, as Cathy's been saying, they are tools and that the gold standard is actually the clinical judgment based on information from not just those tools but from multiple sources over multiple contexts, and that is emphasized again in the diagnostic criteria for *DSM-5*.

Cathy, I wondered if in that – this section is lovely because I think you really did do a nice job of getting together all of the many, many things that we need information about.

The comment would be on the presence of restricted and repetitive behaviors – does imply current, whereas you start the question appropriately by asking about historical, so I may suggest some changes in those words.

And then the other comment that I had was actually on the second bullet – “how do the *DSM-5* criteria change the way clinicians” blah, blah, blah, and the parentheses is actually not correct.

When you explained it, it made much more – much better sense, but the impact of *DSM-IV* was not actually to broaden the concept of autism to a spectrum including Asperger’s. It was very much about making distinct diagnoses that had supposedly clear distinctions between them, and Asperger's was actually in the *DSM-IV* criteria defined to be more severe impairments in social reciprocity than autism itself was.

So the scientific literature has definitely broadened the concept of autism to a spectrum, but it wasn't actually in relationship to *DSM-IV*. It was independent of that, and I – we – have data for that because we had to look at that as a part of developing the recommendations for *DSM-5*.

Dr. Rice: Yeah. This is Cathy. That's a good distinction, because what it’s meant to be is that it's the unintended consequence to some degree – not necessarily what the criteria specifically stated but then how it was conceptualized, used, and spread throughout the community to some – the increased awareness and the broadening of the concept of autism.

Dr. Swedo: Yeah. So it may be that even in – I'll suggest some changes there because if that was the intent, probably the biggest *DSM-IV* impact was actually in that very broad criteria included under PDD-NOS.

Dr. Rice: Right. Okay. Yeah, if you could suggest some changes to make that more clear, that would be really helpful.

Mr. Robertson: Can I – yeah, just to add one other thing – this is Scott Robertson again – that the, I think, maybe one way to make that clear would be the social-cultural kind of implications that went from there because it was more of a social-cultural shift.

It wasn't – as was pointed out – it wasn't necessarily an intentionality on, you know – done in the, you know, in the research sphere and on the *DSM-IV* development.

But that was the impact that, you know, happened in social-cultural in terms of the shift among people in society. It wasn't intended, but it happened.

I mean, you can look between, you know, 1994 and now, and I think it would be kind of – you know, I think one could, you know, say that there wasn't a connection between the fact that *DSM-IV* changed and the world views of people and society changed – maybe not necessarily in the way that it was intended but like –

Dr. Swedo: Right. So it's almost as if DSM-5 better captures the community and clinician's view of autism as a spectrum disorder, because I think that is a valid question to be asked about the recommendations for *DSM-5*.

The intent was that the entire spectrum of severity would be represented, and as one of these questions asked, did we set the threshold in the right place to separate those individuals who have impairment and therefore have a disorder from those who don't?

Ms. Crandy: This is Jan Crandy. I want to bring up a point about – because I think this might need to be included in research – the delay or the timeframe or the implications of practice, how that's going to – because especially for states, for them to change using different diagnostic tools once they're even made, that could take years for them to actually be implementing everything.

Is there going to be that kind of research? I don't know that if we're looking at that that we're going to have these dual diagnoses out there and how we're counting that, and I don't know if I'm articulating that correctly, but hopefully some people –

Dr. Rice: This is Cathy. I think – I'm just puzzling over what a research question would be there, or is that more an implication for practice and policy in terms of the uptake, the development of tools, the training required, those types of things that might be better captured in the practice and policy piece unless someone has a suggestion of a research question.

Dr. Dawson: Yeah. So I guess the research question, if I understand what Jan is saying, it would be, you know, how should studies that are looking at, you know, state-implemented programs handle the differential rates of uptake, right, of the use of the new system on the data that's going to be derived, you know, in those studies – something like that. That was awfully wordy, but you get the idea.

Dr. Rice: Right. So –

Dr. Dawson: Is that what you're saying, Jan, that you're going to have different states that some of which as they're collecting that data at the state level you're going to have varying systems being used for a while as some states quickly adopt new criteria and others are slow to do so and you have to –

Ms. Crandy: And they're even slow to change tools that –

Dr. Dawson: – take that into account if you're looking at aggregating data across states, for example?

Ms. Crandy: Correct. Thank you for that.

Dr. Rice: Okay. That's very helpful. All right. Anything else on the how question?

Dr. Carpenter: So this is Laura Carpenter. First of all, Cathy, I think that you've done such an amazing job on this, and the questions are so comprehensive. I really like it.

One thought that I had – I don't know if this would be appropriate for this document – but there's nowhere where we talk about what we think the implications are in terms of characterization of participants for research studies going forward.

I mean, do we want to make any recommendations? And this is all kind of in the vein of what we've been talking about with what the challenges are.

But do we want to make any recommendations or statements about how this might affect – it's not so much a research question but more how it might affect the design of future research?

Dr. Rice: Yeah. So I'm trying to think about – we could add a question about the comparability in describing them – make sure when we're talking about who is being identified that we're also talking about within research protocols how that has changed.

But I think, Laura, what you're saying is do we want –

Dr. Carpenter: I'm not sure it's so much – what you've done here has really nicely laid out sort of a research agenda of what needs to happen going forward.

But do we have any guidance for researchers now who are designing studies and how to handle the changes? I mean, we've already talked about that there are so many – there are so many challenges with, you know, having no official sort of diagnostic instrument for SCD and no official interview for *DSM-5* ASD, but do we have – do we want to say anything about what sort of minimum criteria are needed to characterize participants in, let's say, a critical trial with *DSM-5* ASD?

Dr. Dawson: Yeah, I think a related issue, Laura, too, might be in, say, patient registries or in longitudinal studies recommendations for how to handle, you know, these changes in order to allow some integration of information either over time or with – you know – with existing data sets, right?

Because that is going to be an issue. I mean, I don't know if it is the role of our group to do that, but I do think that, you know, the field is going to have to grapple with that.

Dr. Carpenter: If you read what our mission, you know, sort of the introduction – it sounds like that's where we're going to be going.

Like, if you talk about, like, implications for research, but then sort of the approach we've taken has been more just to sort of lay out a research agenda, which is awesome and very well written and very comprehensive.

So this would be taking the document maybe a little farther than – I don't know if some folks want to go that far.

I do think it would be useful, you know, for researchers designing studies right now.

Dr. Dawson: Well, I do think that at minimum we should probably have a statement that says something to the effect that, you know, researchers, you know, will need to be very thoughtful about how to handle, you know, the changes in diagnostic criteria in situations where they're either integrating it with information, you know, collected previously using the other system or in, you know, longitudinal studies and are encouraged to have at least some analysis that allows some understanding of what the impact of the change is because there would be different ways of doing that, right?

So you might have a certain number of people where you do both systems, and then, you know, that's what – that's what the CDC is doing, right, is they're trying to really study, okay, now we're going to be shifting – how is that changing and they're going to do a study or they're doing a study where they compare.

So, you know, that might be worth spelling out. It might be too hard because I don't think we really know yet to say okay, how should researchers, you know, implement the *DSM-5* now, you know, especially when there are not tools for some of the, you know, the criteria.

Dr. Rice: Yes, this is Cathy. I wonder if at a minimum we should say that there needs to be a current and a historical assessment of all relevant *DSM-5*-defined criteria, that you should carefully document the basics for the – an ASD diagnosis and then when possible evaluate *DSM-IV* and *DSM-5* criteria, something –

Dr. Dawson: Well, particularly if there are studies in which both systems are going to be used, you know, in combination.

So, you know, the ATN registry – you know, you've got 5,000 kids with *DSM-IV*, and now prospectively they're going to shift to *DSM-5*.

Should we just say, okay, well, that's that, or should there be some, at least, attempt to say, okay, you know, are we capturing the same population so when we start making, you know, doing studies we know that we're really talking about the same thing or, you know, or for example with the CDC, you know, how is that impacting how you think about the prevalent statements

I don't know. Sue, do you have any thoughts on this?

Dr. Swedo: Sorry. No.

Dr. Dawson: Okay. I mean, I think just a section that talks about this as an issue and the need to be, you know, coming up with a plan to thoughtfully address these issues would be sort of the minimum. But I'm not sure we can develop what people's plan should be.

Dr. Carpenter: Absolutely. I mean, we can't be prescripting what, you know, people – how they design their studies and how they characterize their participants.

I do have a fear that, you know, we might get – start, I don't know – one response that someone could make would be to throw up their hands and say, you know, there's no standardized instruments for *DSM-5* ASD, so we're just going to use clinician judgment, and we want to continue to encourage people to characterize their participants according to using standardized information so that we can compare across studies.

So you know, even if a particular checklist or a particular assessment isn't necessarily normed, I mean, I think that would improve research.

I don't know. Maybe my – maybe my concerns are unfounded, but that's one thought I had.

Dr. Rice: This is Cathy. I think those are really important things – that we don't just throw out tools and say that they're not useful anymore because the reality is that the *DSM-5* criteria didn't necessarily make up new criteria or behaviors.

They are just arranged in a different way, and so the individual features or symptoms or characteristics that may be assessed using old tools are still going to be relevant.

It's just then, how do they ultimately line up with the intensity, the description, the combination of criteria that are now meant to be the threshold and considering both the historical and the present profile?

So at some point – I think that was well said, Laura, about that we need to continue to use tools and to be able to compare across studies.

The tools may still need to be in development. But however you are documenting or however you are arriving at the ASD diagnosis, that you carefully document what the basis for that diagnosis is.

Mr. Robison: Cathy, it's John again. When you were talking about tools, do you have any awareness of whether the newly created severity scores in *DSM-5* are accommodated in any current screening tool? Do we have any tool which purports to establish a real standard by which one would assign a severity score?

Dr. Rice: Based on my knowledge, the only thing that may correspond somewhat is in the ADOS again. There is a severity score now, but that is an overall severity score where the *DSM-5* breaks it out by domain – so for social communication and interaction severity and restrictive and repetitive behavior severity. So I don't know of anything that looks at it in those two separate domains.

Mr. Robison: Do you think we should express concern about that? Because I think that the severity scoring is going to become one of the – I think it's going to become a battleground in education where schools are going to say, well, a score of this does not really qualify for any services where this does, and I also think that school systems may endeavor to use severity scoring to say that the kids at the one end are Asperger’s kids, kids at the other end are autism kids. Should we take a position on that?

Dr. Swedo: So I think we've moved on down into, “what does it mean to be identified?”

Dr. Rice: Exactly. Perfect segue, John, and thank you, Sue, for pointing that out.

So the next section on what does it mean to be identified is an attempt to think of what are the empirical questions there based on those concerns.

So one of the questions is how will the severity levels be used and how will they impact service provision although – and then maybe we should point this out – I think it is stated and has been stated very clearly that they should not be used to access or deny services – that for a diagnosis, a person should meet at least severity level one for both social and restrictive repetitive behaviors but that it should not be used as you were concerned about, John.

But I do think it's still an empirical question about what will happen in actual practice and that we do need to be able to follow that and have some data that shows how these severity levels are being used and do they actually impact service or not.

So I don't know if that – these bullets are stated that way that makes that clear or if we need to make some revisions to be a little bit more clear about what the main questions are.

Mr. Robison: Well, I think it's fine to say that they shouldn't be used to deny services. But I think it would be naive to think that that won't happen, and I think that it would be beneficial to the community for us to – even if we do nothing else – just to restate that position that someone who is diagnosed at any level of severity with an ASD is a person who, by definition, would potentially benefit from some kind of service.

So we should be clear that anyone with an ASD should be receiving service, especially if they're a child and it's in a school system.

And again, I want to – I don't want to, you know, dismiss adults, but I just want to – be conscious of the educational situation and what this is going to mean to them.

Dr. Carpenter: That seems like something appropriate for our implications for practice and policy section.

Dr. Dawson: Yeah, I agree, and I don't think it's really been captured probably well enough yet.

I do wonder, though -–the way that it's worded in the research section implies that, you know, if someone just read this, they might think that it implies that it's an okay thing to do, and I wonder if – and maybe this is too strong – but if it were worded something like will the severity, you know, to what extent will the recommendation that severity levels not be used to prescribe specific services, you know, be followed versus, you know, will systems in fact use this in a way that it wasn't intended.

In other words, if it really incorporated some language that made it clear that this is not supposed to happen.

Dr. Rice: Right. That's a good addition, I think.

Mr. Robertson: So a couple of comments I had – this is Scott Robertson again – one of which is on that – “What does it mean to be identified with ASD?” is I think the section we're in right now if I'm correct –

Dr. Rice: Correct.

Mr. Robertson: – is that it almost feels along those lines that when we have the parenthetical on the second bullet, for example, will level one become mild ASD or Asperger’s and will services take this into account – level one, two or three programs.

That parenthetical is almost leading in that sense that it almost causes someone to say oh, level one equals, you know, mild. It almost promotes, you know, that more normative kind of, you know, way of equating those two together, and it almost produces kind of an acceptability of those two connections.

So I'm wondering if that can be reworded, either taken out in that parenthetical or reworded in a sense that it doesn't, you know, almost provide a normative connection in someone's head where they read this – they read the statement - and make that connection.

Maybe they haven't made that connection before and would almost kind of cause, you know, something to happen they didn't necessarily, you know, that you weren't necessarily intending in the way that we just wanted to know, you know, is there a connection without, you know, sort of implying that in the reader's mind.

Dr. Swedo: I want to second that. This is Sue Swedo. And I also – the parenthetical, I think, just needs to be stricken because it does exactly what the text, the criteria, every instruction in the manual asks not happen, and that is that you collapse the severity level for social communication and the severity level for RRB into a single severity level for the ASD.

That is not permitted, and in fact the specifiers were specifically put after each of the criteria to make sure that clinicians hopefully can understand that.

Dr. Rice: Yeah. I think – this is Cathy – going back to what Geri had suggested about making the statement – include what is recommended, that there are two separate severity levels, and that they are not utilized to access or not access services.

And I think, John, you had a nice comment, too, that to achieve a diagnosis of ASD that you are meeting the severity level – a threshold there and that indicates that you are a person that would likely benefit from services by getting that diagnosis.

So if there's a way we can incorporate the recommendations versus the fears of what will be – how it will be implemented – I think that would be a better way to phrase this one.

Dr. Carpenter: So maybe, Sue, you could just clarify for me – this is Laura Carpenter – in the – right now we don't want people using those severity ratings to sort of assign services or level of services partly because of concerns about the utility and the reliability of that – of those ratings.

But over time, if they're shown to be reliable, would that be one possible implication that the Committee would have felt comfortable with?

Dr. Swedo: In theory, yes, but the note actually makes it quite clear that we shared exactly the same concerns as this note, and that's actually why it's level one, two, and three, and it started out to match the rest of the *DSM* as mild, moderate, severe.

And every single one of us was very uncomfortable with anybody ever thinking there was such a thing as mild autism spectrum disorder within the framework of life, right? If they meet criteria, then you have a disorder.

It may be less severe than other individuals but not – and consequently we did not want it tied – and in one of these calls the representative from education had actually said that some of these concerns may not be warranted because service provision is done on an individual basis rather than on group diagnostics.

And the second thing is that the specifiers are not diagnostically coded. So they don't immediately transfer from a clinician's diagnosis into anything that the Education Department would get.

Dr. Carpenter: Right. Yeah, I was just thinking like long term. I mean, is the hope that, if they are shown to be reliably assigned by clinicians, would that be what they would be used for? Otherwise, what's the point of assigning them?

Dr. Swedo: The point of assigning them

was to try and individualize diagnoses just like the rest of the specifiers so that when a clinician was talking to another clinician and said this person is a level one on RRBs but a level three on social communication, you would immediately have a sense that that person's greatest challenge right now was in social communication.

And, again, these are current severity ratings, and that hopefully is clear in the instructions that, you know, they're going to change over time and that clinicians are encouraged to look at what people would be functioning at without supports in place, assuming that those supports may be bringing them into an apparent less severe category.

Dr. Carpenter: Okay. Thank you. That's helpful, and yes, it is clear in the instructions.

Dr. Rice: This is Cathy. But I think it does raise an important research question that is very tricky to formulate, because by formulating the question we don't want people to jump toward using the severity levels within each domain to inform treatment.

But ultimately we need to have some well-done research that helps us know whether the current severity levels in each domain does inform intervention.

So I think we do need to add something that is stated in a careful way, encouraging research about the utility of the severity level in terms of does it actually provide useful information for what the next step is for supporting that.

Dr. Swedo: Right. So we already had that up under who is being identified. The question is, What is the reliability and validity of the severity ratings for the two domains?, and then the next one is, Does the inclusion of severity ratings correspond to impairment that help distinguish those – the disorder – from those in the broader phenotype?

And I'm going to suggest – I'll send my comments so you can see it in writing – but if we just change this bullet to “What are the ways that severity levels are used for social communication and RRBs, and is there a relationship between the severity ratings and service provision?”

Dr. Rice: That would be great, yeah.

Mr. Robison: It's John here. I actually have to drop off now, but I just want to say that I'm in agreement with the direction that the conversation is going right now, and I just want to thank, you know, you, Geri, and Cathy for putting together this outlined document and also you, Sue, for your contributions to it here. So I will talk to all you folks later on.

Dr. Dawson: Good luck with your back, John.

Mr. Robison: Yeah, I hope –

Mr. Robertson: And good luck with getting that managed.

Mr. Robison: Yeah. I sure do hope I don't end up crippled with that thing, but we'll see. So I'll talk to you later. Bye-

bye.

Dr. Daniels: Thanks, John. This is Susan. Just wanted to give you all a reminder that we are about 30 minutes out from kind of starting to wrap up. So we want to make sure there's enough time for the next section.

Ms. Crandy: This is Jan Crandy. On that last comment when she gave the language for the bullet, you meant ASD on that bullet, not SCD, correct?

Dr. Rice: Actually, we did mean SCD.

Ms. Crandy: Okay.

Dr. Rice: Just in terms of looking at what is the – what does it mean to be diagnosed with SCD is really the question – how does that inform the treatment techniques that are used as well as eligibility for services. Does that seem appropriate for –

Ms. Crandy: Well, I think that we do need to address the severity levels, as John had said, about ASD, too, and I do have concerns about the SCD.

On the last bullet: “How does the

inclusion impact treatment and techniques and service eligibility,” can we also add the current insurance mandates – autism mandates?

Because I am concerned that those SCD kids are not going to have – a lot of the insurance mandates say specific and do not include that diagnosis, so those kids are not going to have access to ABA, not that we decided that's what's the best treatment for them, but at this point that is what's being utilized for that group of kids that were under the spectrum.

Dr. Rice: Or maybe keeping it broad.

Ms. Crandy: I want them to be able to have access to that until we decide – until it is determined what's the best treatment for those kids.

Dr. Rice: Yeah. So maybe it's service eligibility, coverage, and access.

Ms. Crandy: I like that. Thank you very much.

Dr. Amy Wetherby: This is Amy Wetherby. Can you hear me?

Dr. Rice: Uh-huh.

Dr. Wetherby: I joined a little bit late. I apologize; I had a conflict. So under SCD also there's a bullet where you talk about how is SCD distinct from ASD and pragmatic language disorder.

I would ask that you strike “pragmatic language disorder” because our intention is that it's a broader – it would include that and I think, again, it's sort of like what you were talking about with the severity – it's suggesting that they're distinct, which was not our intention.

Dr. Rice: Uh-huh. Hi, Amy. This is Cathy. We had some discussion about this and went around trying to – definitely we'll address that –

Dr. Wetherby: Okay. Thank you.

Dr. Rice: – to make sure that that's more clear, and I did suggest though that we keep some reference to pragmatic language disorder in a sense of referring to the literature.

Dr. Wetherby: Yeah. That would be great.

Dr. Rice: But not as a specific diagnosis.

Dr. Wetherby: Or distinguishing it, yes.

Dr. Rice: Right, right.

Dr. Wetherby: Okay. That would be great.

Dr. Dawson: All right. Well, I think we should, with Sue's suggestion, move on to the second section on practice and policy. So we have enough time to discuss that as well.

But keep in mind that we will provide everyone, and in fact it's already been provided to – Sue pointed that out to – us a Word version of this. And so if things – issues – don't get discussed on the call, people can certainly bring those up and incorporate track changes, and we'll talk at the end about how a process for incorporating that kind of feedback.

But moving on now to practice and policy, so where a few broad issues that are raised here. One, I think the first bullet, is to capture the idea that clinicians should just be cautious, you know, how they're using the new criteria as it relates to making recommendations around services because the – there's not a lot of prospective data.

There's a lot of retrospective data on how these work – the criteria work but there's – the prospective data in terms of the field trials is on a pretty small sample of kids from a pretty higher income kind of background with not a very diverse background and certainly does not include young children and adults.

So you know, we still have a lot to learn about the *DSM-5* and how it's going to work in the real world, and so people just need to be cautious, I think.

And then I sort of provided the example of that, for example, if you had a toddler who clearly had impairments in social communication and exhibited one – you know, perhaps even very severe repetitive behavior but didn't happen to have sensory sensitivities – and I did see a case like this so I know they exist – and a child like that may benefit from autism early intervention services but may not qualify from a diagnostic point of view.

And so the basic recommendation that I wanted to make in this section, that I would like people's feedback on, is the idea that really when we make recommendations around services, that it should be based on the specific needs and the match of that child's needs to the available programs rather than a diagnosis per se.

Now, of course, when we get into insurance payments and things like that, that's not how the real world necessarily works, but in any case – or even in school systems it doesn't necessarily work that way.

But anyway, so that was a concept that I'm trying to capture there. One is that for people to be cautious, realizing there are still more research that needs to be done to – on the reliability and validity of the criteria – and second, that, you know, we shouldn't use very strict cutoffs in terms of diagnosis when we think about services but rather really think about the child's individual needs or the adult's individual needs and how they match the available services in that community. I'll open that for feedback.

Dr. Wetherby: This is Amy Wetherby. I just want to comment on that. I think that you're raising a really important point, but it – I think the way this is worded it – suggests that the *DSM-5* is worse than the *DSM-IV*, and I think that this problem is – has been there all along – and that the *DSM-5* may improve it in some ways.

But it's really a system problem. So if we think about early intervention within the Part C system, whether that's education or health depending on the state, it's more uncommon that actually a diagnosis of PDD or autism would be used, but instead they're going to be referred to as “developmental delay.”

So I wonder if we could try to address the systemic needs to have more clarity on an early diagnosis and perhaps even suggest a provisional diagnosis of ASD, because – as we talked last time – a child like you were describing would not meet the criteria for SCD.

And so that child – we need to be on the lookout as that child gets a little bit older for the potential autism but they're showing the risk for autism and need the services early. That's the – you know – that often is not happening now.

So could this be an opportunity to improve what's happening now? I don't think the *DSM-IV* helps that problem.

Ms. Crandy: I would – this is Jan Crandy – I would definitely support some language to support a provisional diagnosis because you are correct.

These kids are having developmental delay as their diagnosis, and they are not getting pushed toward autism treatment.

Dr. Dawson: So what exactly are you suggesting there in terms of – are you saying that a child who has social communication impairments with or without two repetitive behaviors or, you know, in that category should be given a provisional diagnosis? Or what are you saying?

Dr. Wetherby: So I'm talking about, really, children under 4 because we – as we talked last time – the *DSM-5* specifies or indicates – specify is not the right word – indicates that you're not going to give an SCD diagnosis until a child is 4 to 5 years of age, and part of that reason is because you can't really accurately sort these out yet because there's not enough language development to sort these out and because we know the repetitive restrictive behaviors in sensory may unfold over time so you can't rule out ASD.

So it's these children, particularly the birth to 3 – even if we stick with the birth to 3 – because that's a separate system within the IDEA, and urge the use of some terminology whether it's provisional or at risk for – and that's a little bit of a dicey word within the Part C system –showing signs of autism spectrum disorder – you can't yet rule it out.

I think just that approach to make sure they get connected with early intervention services that address the autism symptoms.

And right now the DD is so overused that children end up getting very generic treatment and very little treatment. There are many factors contributing to that – or they're not even picked up at all.

Dr. Dawson: Yeah, I'm just trying to figure out how to, you know, make that a – to really word that in a way that is clear.

Are you suggesting, for example, that we say, well, first of all, do people like the idea of saying that services should be based on need rather than diagnosis?

Dr. Wetherby: Yeah, as long as that doesn't lead to this generic DD diagnosis and then –

Ms. Crandy: This is Jan, and I'll tell you in practice they're telling you that they're treating the need and not the diagnosis and what you see is that kids continue to have that DD label and do not get treatment specific to address autism.

Dr. Dawson: Right. But it – and it seems to me that if, in fact, you know, the evidence suggests that the repetitive behaviors could unfold over the early years that this – that the *DSM* – it may not make it worse, but it's certainly – it won't make it better, right, to be able to, you know, pick up on these kids and diagnose them early because they aren't going to be showing enough repetitive behaviors or sensory sensitivities to meet a diagnosis.

Dr. Wetherby: So this is Amy. I'm not sure that that last part of what you said is accurate yet. I don't –

Dr. Dawson: No, I agree. There's not enough data one way or the other. But there are kids – now, whether it's true across the board, obviously there are questions and there are many kids who show early onset of repetitive behaviors or sensory sensitivities, but there are also kids who end up with an autism diagnosis who could clearly benefit from early intervention –

Dr. Wetherby: Well, right.

Dr. Dawson: – where these don't – the second piece doesn't manifest fully until, you know, maybe 3 or 4.

Dr. Wetherby: Right.

Dr. Dawson: And so for those kids, they're not going to get – they're going to have even a harder time getting early intervention if they have to show two things rather than just one.

Dr. Carpenter: So is the direction our discussion is taking that we just want to, you know, to enlighten people that they have the option to use the provisional qualifier in cases like that where there is a strong presumption that the child has autism – but doesn't meet full criteria – they can do 299.00 and then just put “comma provisional”?

Dr. Wetherby: Yes. I think that would –

Dr. Carpenter: And it's not going to – from a coding standpoint like a, you know, an ICD coding standpoint – it's not going to make any difference. It's still 299.00.

Dr. Wetherby: Particularly children in the birth to 4 age range – I think that would be very helpful to encourage.

Dr. Carpenter: I mean, to me, I would even be happy if we just said even younger than that, you know, birth to 3.

Dr. Wetherby: If we just do birth to 3, right?

Dr. Carpenter: Yeah. I think that's – it's the kids – primarily, it's the kids under 2 that are, you know, that really present the problems where from a clinical standpoint you know they have autism.

They meet criteria on the ADOS, and you just simply cannot check off all those boxes on the *DSM*, but there's a very strong presumption that the child's going to end up ASD. You absolutely want them to get services, and I think if we just –

Dr. Swedo: Excuse me, but what boxes can't you check off on the *DSM*, because the experience – published experience – to date shows it's actually more sensitive in that early infant toddler range.

Dr. Dawson: I don't think we have enough data yet. I mean, I know there's been one study, but I think it's still – and the other thing is that it's more individual – also individual cases, right?

So it may be on the whole it's more sensitive, but you still have these cases, and it may be the minority of cases, but where that second category evolves and --

Dr. Swedo: Is it because they don't yet have RRBs, sensory sensitivity or can't meet the two of four on the second criterion?

Dr. Dawson: Yeah, exactly. Exactly.

Dr. Wetherby: Well, I would also argue – we see cases where the RRB drives down the social communication. I think with very young children, it can go either direction.

They are developing, and the signs of autism can, you know, it can really interfere with development and learning, and so then you end up with autism, you know – a much more clear case of autism, and I think we want to try to pick it up as early as possible, and as you do that, the cognitive delay is less and the symptoms may be less.

Dr. Carpenter: This might be going too far afield, but I've also had –

Dr. Dawson: You know the developmental research has – and clinical observations – have shown that there are cases, particularly in the birth to 3 period, where children will go on to develop autism but do not fully manifest all the symptoms, you know, early on and that those children can be given – if you see the signs of autism whether it's repetitive behaviors or social communication – that a provisional diagnosis is appropriate and could then allow access to early intervention services for those children.

Dr. Wetherby: I think that would be great, because I think truly even by 24 months, you can't rule out autism yet or ASD if you're seeing some of the signs.

Until that child really is at least closer to 36 months, you can't rule it out. The whole point is to get the services.

Dr. Carpenter: can I just address the comments from earlier where someone asked about which criteria you couldn't check off? I think the A-3 criteria can also be a challenge in kids under 24 months.

You know, if they – if they're the kind of kid that makes a lot of social approaches and is interested in other kids but still has, you know, very clear deficits in joint attention and everything, it's hard to document social relationships in a child that young.

And this – and we're talking about very rare cases – I mean, this is not the – I don't think this is a systematic problem, but

I do think there are cases where, you know, the child just needs to be a little bit older to show the deficits in the formation of social relationships.

Dr. Dawson: Well, I'll give a stab at rewriting that section and then – and send it around to people, and then, you know, we can continue to refine it.

Dr. Wetherby: That sounds great.

Mr. Robertson: So I had a couple of comments related. I know we're talking mostly right now about the younger age ranges, but I wanted to also make sure to emphasize the implications for the school-age individuals and older.

Is it one – and I don't know whether this can go on as a separate bullet or maybe incorporate it more strongly in the rest – existing text – is the fact that the -–I know it was mentioned earlier – that in the conversation on this call that the – educationally individuals – there's supposed to be individualization of assessment for diagnosis, but the reality is that each state from my understanding has their own operational criteria for what autism looks like that are not – they don't use the *DSM*.

They kind of have what's created in each individual state for what they consider under an autism category that is under a special education law, you know, mandated federally and then operates at the state level.

But I'm guessing in many states, and I think this – I think this was the case with *DSM-IV* – is that the states kind of use that to inform how they go about creating their operational definition.

So I'm wondering if *DSM-5* may have an impact on what it looks like in terms of how they classify individuals with autism as far as, for educational purposes, how *DSM-5* is going to change that as well as how it's going to change how the systems look like for developmental disability service systems in the 50 states, which, again, also look very different, you know, across the different states because they're not using strict *DSM-5* criteria.

They have really, really different ways of grouping individuals into different parts of the – of the system and deciding whether they're in the system or not, and I'm wondering if this could be spun out a little bit – a little bit more in the implications.

Dr. Dawson: So, Scott, do you see that as an implication issue or more of a kind of a research issue in terms of needing to understand how states are using these?

Or do you feel there's an implication that should be clarified in terms of making a recommendation about how they should be used?

Mr. Robertson: Well, I guess it could go in either in terms of how you – how you word it. I mean, it's an implication of the criteria itself, as that's going to happen. It's going to inform the changes at the state level in terms of what their definitions look like.

Is it implication that we should say,

you know, how are state is looking at it? Yeah, I think that would belong in there, I think. But maybe if you think it's more appropriate to address that in the research section, I mean, I'd be – I'd be fine with that.

I just want to make sure it's addressed because I think it's going to be a – it's going to be a really big phenomenon is how the 50 states are looking at – they're probably looking at *DSM-5* right now and maybe changing their definitions of how folks are – how students in K-12 are receiving, you know, special education services and what their services look like and what the – you know, it's also into the level one, two, three is the same problem on the service systems world that you could see clinically you might end up having that educational wide, too.

I think John had kind of had brought that up basically before, is that, you know, is there going to be any situation right there where that's all clear?

So I don't – maybe this is more appropriate on the research section. I just want to make sure to address more strongly in this document that, you know, specific elements of the – of the K-12 system and how they're going to be – the effect the *DSM-5* changes are going to have on that.

You know, and then some cases, its existing problems as was mentioned that are already – are out there that we have these disparities across different space – that we don't really have any unified standards and in some ways *DSM-5*, you know, may help that or may – you know – may hurt that in terms of causing even more chaos in terms of how people, you know, think about autism, you know, nationally.

Dr. Rice: Scott, this is Cathy. So on the research we did, we added something about the differential potential uptake in different programs and across the states to address that.

So I think we have that with the

additions in research.

Mr. Robertson: Do we have that as far as – as far as the states themselves, or you don't want to get into that specific of the state – the specific educational definitions for classification?

Dr. Rice: I think we could say across different programs and states and –

Mr. Robertson: Okay.

Dr. Rice: – somehow make that broad enough to cover a range of issues. But, you know, it is a question about will the federal eligibility criteria change at all or do they need to change.

They are pretty broad, and they're meant to show educational impairment. So I've heard some in the educational world indicate that there really shouldn't be much of an impact on *DSM-5* related to educational eligibility of criteria for autism. But it's important that we study that and understand what's happening.

Dr. Wetherby: This is Amy. The problem

is – I think that Scott's making a very, very important point – the problem is it's defined federally.

If you look in the IDEA the way they define autism, it really fits with what we're saying with the *DSM-5*.

The problem is each state has their own eligibility criteria, and so I would love to see the IACC make recommendations on what – I mean, I look at this and it seems like, again, that *DSM-5* is creating a new problem, and I think the problem has been there and the *DSM-5* could improve it and could the IACC at least make recommendations to help improve the problem.

The State of Florida, as an example, did finally change their state eligibility criteria, and it lined up with the *DSM-IV*. We're working to try to get it to line up with the *DSM-5*. But for the adult services, they have restricted it to autistic disorder in the past.

So the hope is that *DSM-5* will help

prevent that problem. It may not. But could you recommend that the states – you know, provide services to the broader autism spectrum, and I think that's the problem that's been there which we were trying to fix.

Mr. Robertson: Yeah, and obviously I concur on that – is that I think you put it – I think you put it even much better than I – than I put it as that – is that maybe having a recommendation on there that, you know, that it probably would behoove states to do what Florida has done and align things, you know, with the *DSM*, you know, as feasible, although not just for the educational system but also for the DD systems as well.

Dr. Wetherby: The DD system is in need of help, yeah.

Dr. Dawson: So why don't I try to draft a separate bullet on that for people to react to – that the issue of, you know, a recommendation that states, you know, implement the *DSM-5* and that – and recognize that qualifying for an ASD diagnosis according to the *DSM-5* implies the need for services.

So let's move on to the next one because I know we're kind of running out of time here. The next one is – fourth bullet – has to do with this idea that a lot of people think that because the *DSM-5* is out that one needs to go and requalify for a diagnosis of autism, or schools may feel like, okay, we have to rediagnose everyone to see if they can still get into the autism classroom or whatever.

And my understanding from Sue's, you know, various presentations – and she's on the call so she can clarify this – is that it was the intention of the workgroup that, you know, if people have a current diagnosis that they should retain a diagnosis and remain eligible for the services that they're currently receiving. Is that correct, and could we make that statement? Because that could have a pretty big impact if we could.

Dr. Swedo: I think that would be very helpful.

Dr. Dawson: So do you feel comfortable –

Dr. Swedo: Anything that's – yeah. Anything that the IACC can do to reiterate what the workgroup and the *DSM* actually says and that that is the–- these things are supposed to be independent of it – a service provision would be very helpful.

Dr. Dawson: So do you feel comfortable with the way the bullet is written then? It says it's important for families, individuals on the spectrum, and practitioners to know that individuals who currently have a diagnosis of ASD based on the *DSM-IV* system – or it could say PDD, I guess – retain an ASD diagnosis for the purpose of qualifying for clinical and educational services.

It's not appropriate for an individual currently receiving ASD services to be denied those services because of the change in the *DSM* criteria.

Dr. Swedo: All right. The only place

that I would have to quibble some is in the – those PDD-NOS people who should never have had it.

But I think that the risk-benefit ratio is there. Maybe I'll work – can I work on that one a little bit and see if I can reword it so it maybe –

Dr. Dawson: Yeah. Tweak it.

Dr. Swedo: – says the same thing without arguing with the criteria, and the note that's in there makes it very clear that if you had autism, Asperger’s, absolutely no question PDD, the question needs to be do you have threshold symptoms because, again, it wasn't just social communication; it was the inclusion of sub-threshold a.k.a. broader phenotype individuals.

Dr. Dawson: Right. But we have to be careful because we said earlier in the document that you base these services on need, you know, and so if an individual was receiving services in a classroom and doing well and it turned out they got in there because of the, you know, historical period where they had the – or, you know, they qualified because of “or” rather than “and.”

Dr. Swedo: Yeah, that's why I think I'm going to rewrite it to make it say the same thing without being untrue.

Dr. Dawson: Okay. All right.

Dr. Swedo: I understand what it needs to say, and I will work on it –

Dr. Dawson: All right. Got it.

Dr. Swedo: – and then maybe get back to you.

Dr. Dawson: So that's good. Okay. So the next one, unless anybody else has concerns about the previous bullet, has to do with the social communication disorder, just recognizing that this is very new.

We don't yet know what interventions are most effective, that it's possible that children with a diagnosis of social communication could benefit from some of the same services that are designed for – currently designed for – children with ASD, and so we need to just evaluate the needs of each individual child and match those to the services that are available and to include ASD-specific services such as early intervention if appropriate.

So in other words, what we don't want people to say is, okay, you have – you have – social communication disorder – you may now not, you know, go into this classroom that we called our autism classroom even though that would be the absolute best place for you to be helped with your social communication disorder.

Dr. Wetherby: So Geri, this is Amy. I would love to see you remove the "virtually nothing is known" because I don't think we could have gotten it approved without – there is 20 years of research that we did refer to – some information.

Dr. Dawson: Okay.

Dr. Wetherby: We certainly need more information.

Dr. Dawson: Well, yeah. All right. But I meant the specific new diagnosis.

Dr. Wetherby: Yeah.

Dr. Dawson: Yeah. So why don't – could you help me reword that?

Dr. Wetherby: Yeah. Just tone it down a drop. And then I think – I mean, I don't think we want to suggest that all children with SCD should go into an autistic classroom, either. So we just need to be careful.

So I think what – the way you're wording it, "based on need," is great, and I do think there's some – a little bit of – treatment research that many of these individuals we're really talking about weren't getting the right targeted services because the social part of their communication disorder was missed. But, again, I think just the positive spin –

Dr. Dawson: Do you want to help – Dr. Wetherby: Yeah. I will help you with it.

Dr. Dawson: – on working on that one?

Dr. Wetherby: Yeah.

Dr. Dawson: And sending me feedback? Okay. Great. Any other input on that one?

Ms. Crandy: This is Jan Crandy. I really appreciate that you have this bullet in there and that we're addressing it. So I look forward to have the language revision will work. Thank you.

Dr. Dawson: Okay. The next bullet is – has to do with the *ICD* codes, and too bad John isn't on because I know this is important to him, but he can always weigh in later.

But so it's just clinicians will have to decide whether to use the – and by the way, I took this right out of our notes – will have to decide whether to use the ICD PDD-NOS code or the broader ICD PDD code for individuals with a *DSM-5* ASD or SCD diagnosis.

And then I just – since, you know, I didn't really know what the recommendation should be – I made it kind of a very general statement of it's important for clinicians to develop a rationale and consistent approach to their use of *ICD* codes for children with an SCD diagnosis until there are more data on the validity.

But, you know, if others have ways that you feel we should comment on the issue of the *ICD* codes, I'm open.

Dr. Wetherby: And this is Amy. I don't know my *ICD* codes as well as I should, but I think that some SCDs are coming from language disorder. So I don't think they're all going to be tied to PDD-NOS. So we may want to add just maybe another option.

Dr. Swedo: Right, because actually what – that's what the field trials showed was – that the SCD was bringing in additional individuals, and I think one of the concerns about the bullet before and this billing purposes bullet is that it is very strongly implying that SCD is “ASD light,” and it's actually quite clear that ASD is a rule out and that children with SCD don't have “autism light.”

So I'm a little uncomfortable. I think

this is what John was talking about before he left the call. I understand the need to make sure that children are going to continue receiving appropriate services, but I think that we're not doing the field a favor by implying that SCD is a new way to diagnose autism because that's absolutely not the case.

Dr. Dawson: Right. So we could try to make that stronger, but you know, for me – in terms of what I was trying to apply here or imply – was not that SCD was “autism light” but the idea that and I – because I'm just thinking about the real world and how, you know – when I see kids and, I mean, there could be a child who has both pragmatic language disorder, social communication disorder, and what you do is you – and let's say it's a 10-year-old child, all right, and you're working with his family to find the right classroom, and it may be that in that school the autism classroom is the perfect place for that child because they're really focusing. It's a high-functioning group -- they're focusing on social communication.

And so what you don't want to do is to say, you know, that they should be denied services because of that that might have been designed for kids with autism if that is appropriate for that child.

Dr. Wetherby: But the *ICD* code would not dictate the placement, at least within the IDEA.

Dr. Dawson: Right. Well, I was talking about the – she said both of these.

Dr. Wetherby: Yeah.

Dr. Dawson: So now, for the *ICD* code, I think I was just trying to be pretty neutral that they need to develop a rational and consistent approach –

Dr. Wetherby: Yeah.

Dr. Dawson: – you know, that people have to think it through. In other words, we don't really know how people are going to use this yet, so it's important to be thoughtful and rational about it. I didn't know what else more to say.

Dr. Swedo: So actually, if you take out then the sentence "clinicians will have to decide whether to use" this or that, I think just “important for clinicians to develop a rational and consistent approach” makes great sense, and I don't think you need that sentence that actually confuses PDD with SCD.

Dr. Rice: This is Cathy. In the *DSM-5* after each diagnosis, there is the corresponding *ICD* code listed – and I don't have my manual in front of me right now.

So I was thinking for ASD, it is recommended to use a certain code already in there. So that may be something we want to look at and to think about, again, back to what is recommended in the manual, and do we support that or have recognition or recommendations about implementing that in a certain way?

I don't remember what is suggested for SCD, but I think there is an *ICD* code that was mapped and encouraged to be used in the manual.

Dr. Wetherby: Is that what's in the little parentheses in gray?

Dr. Rice: Yeah, like F-84 for autism.

Dr. Wetherby: Yeah. So I happen to conveniently have my manual.

Dr. Swedo: Right. So for social pragmatic communication disorder the code is F80.89, and for autism it's F84.

So there actually is a code, and to indicate that plus the level of services required – might address both concerns here.

Dr. Dawson: So do you think we even need this bullet? I mean, I incorporated it because it was brought up a lot in our discussions, but I wasn't actually sure what to do with it, which is why I have sort of a low-key recommendation of just develop a rational – but it sounds like there's already recommendations in the manual, too.

Dr. Swedo: Yeah. So we could just substitute that sentence "clinicians will have to decide" blah, blah, blah and just put what the codes are.

Dr. Rice: Yeah. I think that would make sense.

Dr. Dawson: Okay.

Dr. Wetherby: Now, there were some errors in that original publication on the – on the – communication disorders, the actual code. So we just need to make sure – Dr. Swedo: Yeah, I think it was under the expressive. We just fixed that one –

Dr. Wetherby: Yeah.

Dr. Swedo: – so we'll make sure that we get the right one.

Dr. Wetherby: But in the hard copies that people got first round would be wrong. Yeah.

Dr. Dawson: Okay. Great. All right. So I will do that and then – let's see, we just have I think one more bullet and – oh no, we have two.

Okay. So this next bullet has to do with Asperger’s syndrome, which came up in our conversations quite a bit, and Sue has made this point in her talks, I think. So you'll have to tell me whether you feel comfortable with it.

But it's the idea that, you know, people who want to continue to use that label certainly are able to do so and that, if they met *DSM-IV* criteria, could even be put into their medical record as part of the specifiers.

What do you think about this, everyone, in terms of feedback on this bullet?

Ms. Crandy: I think – this is Jan Crandy – I think it's very important that we keep this because I think it's important to that group of folks that are proud of that label and want to carry that label.

Dr. Wetherby: This is Amy. The problem is – the reason that in the *DSM-5* it was removed is because there's not a reliable valid tool to make the diagnosis.

The other issue is that in some states, like in Florida, it may then restrict you from getting services. So we were trying to solve that problem.

So I'm just afraid we're going to lose those two reasons why it was removed. And certainly anyone has the right to have the diagnosis in their medical record if a professional is going to give it to them, but I'm not sure – I don't really understand. It wouldn't be a list of specifiers in the *DSM-5,* so that's not clear to me what you're recommending.

Ms. Crandy: This is Jan Crandy. I'm not talking about people going forward. I'm talking about people that already have that diagnosis. A lot of them do not want to be under the autism umbrella.

Dr. Swedo: Right, and – sorry, Sue Swedo – and I think that for the bullet the issue is that it's – can be – indicated in their medical education record as part of the list of the specifiers.

That's just not correct, and as Amy pointed out, there were a number of problems, including the fact that those who are currently self-identifying as Asperger's or “Aspies” in particular didn't actually meet the criteria for Asperger disorder in *DSM-IV*.

So it's a colloquial term that's being used that's completely separate from the *DSM*, and maybe that bullet could just be changed. Although Asperger’s syndrome will no longer be considered a formal *DSM* diagnosis, the specifiers, which indicate verbal abilities and intellectual impairment will permit identification of these individuals going forward, and then that could facilitate continuing research.

And then the last part is completely true. People who wish to continue to use the label are encouraged to do so.

Dr. Dawson: Do you think that we should just strike out the "it is possible" part of the first – first – part of this bullet and just say –

Dr. Swedo: Yes, because – yes.

Dr. Dawson: – and just go, you know, it won't be a formal diagnosis, but people who wish to continue to use it are encouraged to do so, recognizing this is no longer –

Dr. Swedo: Yeah, and then you wouldn't even need that second part again.

Dr. Wetherby: Do you – but do you want to encourage them to do so because it may restrict them from services?

Dr. Swedo: Maybe that sentence should be in there: "However, in some states this would limit access to services."

Mr. Robertson: And one thing to add is that I think to make that more neutral than encourages if they wish to do so they can.

But I'm not sure if we want to necessarily, you know – “encourage” kind of sounds more of a – we're motivating folks to be using a diagnosis that for practical purposes no longer exists because of the shift to autism spectrum disorder. So I think the word "encourage" is problematic.

Dr. Dawson: Yeah. Yeah, I agree. Okay. So I'll work on this one, and we'll – I'll improve that.

And then the last one is “need more information on the use of specifiers and severity ratings. They have enormous potential.

However, more systematic and valid methods for determining severity are needed before they can be reliably integrated into clinical diagnostic practice.”

That might be a little too strong. But what do people think about this? This is – again, I'm kind of bringing this up because it came up in conversation.

Dr. Swedo: I think that maybe – I agreed with everything there except “before that can be reliably integrated into clinical diagnostic practice" because until that – until we get the research to show that – what we proposed isn't actually a pretty good approximation for severity. We don't know that.

So maybe, “However more systematic and validated methods for determining severity are needed.”

Dr. Dawson: Great. Yeah. We'll delete the last part. So I can do that.

So Susan, can you quickly tell us our process for, you know, providing this input onto the Word document and how we'll try to integrate that?

Dr. Daniels: Yes. I think that – Geri, would you like for us to have everyone send their track changes, if they want to do specific edits, to you and me and Cathy –

Dr. Dawson: Yes. That would be great.

Dr. Daniels: – and then for you and Cathy to put them in the way you think that they go, and if they want to just email a suggestion and not provide actual track changes and just say, can you please address this issue, just to send that our way?

So if you could send them to Geri, Cathy, and then copy me on it that would be appreciated, and we'll make sure that everything gets addressed in this next iteration, and then we can pass it around again by email, and if everyone is happy with it, then it can be ready for the Committee meeting that will be taking place on October 9th, which is a date that we set because the Committee at the last meeting told us that they wanted to use the October 29th meeting date as a workshop rather than as an IACC meeting. So we set October 9th as the new IACC meeting.

I have one other item. I sent around a link to a *DSM-5* resource page that OARC put together in response to the requests by this group, and so when you all have a chance to look at it, if you have any suggestions about what you'd like to see on that page, feel free.

I'd like to thank the APA for giving us permission to reprint the criteria for ASD and SCD on our page, which we thought would be useful to this Planning Group and as well as to the public, who may be interested in reading those particular diagnostic criteria.

So those are all available. We tried to put in all the items that were mentioned by members of the Planning Group, but if there are other items that you think would be useful to the general public, please let us know, and we'll see if they can be incorporated.

Dr. Swedo: Hi, Susan. This is Sue Swedo. I have finally succeeded in getting the APA to correct the specifiers, so I will send you as soon as it's known what the correct list is, and it actually goes back to what we had all thought it was going to be – specify agent pattern of onset fitting with this document rather than what's actually printed in the first printing of the book.

Dr. Daniels: That would be terrific, so please send that my way when you have it available. Thank you.

Dr. Dawson: Well, thank you, everyone, for all your hard work on this. I think it's going – it's shaping up nicely, and you know, after some back and forth, then we'll – we can present it to the broader group. But I think it's going to be hopefully a helpful document.

Dr. Daniels: Right. This is Susan. I just wanted to add something for the – especially for the external experts that are helping out the Planning Group.

Our next step will be: Once we've gotten a document together that the Planning Group is happy with, that can be passed along to the chairs of the Basic and Translational Research Subcommittee to look at.

Geri is one of those and then Tom Insel, and then it'll go to the full Committee, and if the full Committee adopts it they would – they would publish the statement as theirs but credit would be given to external experts for their help with this effort.

So sorry. Thank you so much for being with us, and thank you, Geri, for leading the call, and we appreciate all the assistance and the time and effort you all put in about this in putting together this document. So we will be in touch by email. Thank you.

Dr. Wetherby: Thank you.

Mr. Robertson: Thanks to everyone. Bye.

Dr. Daniels: Bye.

(Whereupon, at 1:03 p.m., the DSM-5 Planning Group adjourned.)