

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
INTERAGENCY AUTISM COORDINATING COMMITTEE  
SUBCOMMITTEE FOR BASIC AND TRANSLATIONAL  
RESEARCH

DSM-5 PLANNING GROUP

CONFERENCE CALL

THURSDAY, APRIL 11, 2013

The meeting was convened via teleconference at 11:00 a.m., Geraldine Dawson, Ph.D., *Chair*, presiding.

PARTICIPANTS:

GERALDINE DAWSON, Ph.D., *Chair*, Subcommittee for Basic and Translational Research, Autism Speaks

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

COLEEN BOYLE, Ph.D., M.S.Hyg., Centers for Disease Control and Prevention (CDC)

JAN CRANDY, Nevada State Autism Treatment Assistance Program

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

JOHN O'BRIEN, M.A., Centers for Medicare & Medicaid Services (CMS)

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

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

TABLE OF CONTENTS:

<u>Roll Call and Opening Remarks</u>	
<u>Susan Daniels .....</u>	<u>3</u>
<u>Discussion of Issues Related to <i>DSM-5</i></u>	
<u>Geraldine Dawson .....</u>	<u>4</u>
<u>Wrap-Up and Next Steps .....</u>	<u>58</u>

PROCEEDINGS

11:00 a.m.

Dr. Daniels: Good morning. I'd like to welcome everyone to this conference call of the IACC's DSM-5 Planning Group, under the Subcommittee for Basic and Translational Research of the IACC.

Welcome to all of our listeners on the phone and to IACC members who are on this call, as well as our guest Dr. Susan Swedo. We're going to be discussing some of the issues related to *DSM-5*. But before I turn it over to the Chair of this group, Geraldine Dawson, I'd like to go ahead and do a roll call to see who's on the line from the IACC and our guest.

Geraldine Dawson?

Dr. Dawson: Yes, I'm here.

Dr. Daniels: Coleen Boyle?

Dr. Boyle: I am here, thanks.

Dr. Daniels: Laura Kavanagh?

Ms. Kavanagh: Here.

Dr. Daniels: John O'Brien?

He said that he may be joining us a little later.

Scott Michael Robertson, I believe was not going to be able to attend, due to a schedule conflict.

John Elder Robison?

He may be joining us later.

Larry Wexler?

He may be joining us later.

And Jan Crandy.

Ms. Crandy: Here.

Dr. Daniels: And then we have our guest, Dr. Susan Swedo, who is also on the line.

Dr. Swedo: Present.

Dr. Daniels: Thank you.

So I'll turn this over to Geri to introduce the call and the topic for the day.

Dr. Dawson: Great; thank you, Susan.

So, welcome everyone. The purpose of this planning group is to consider issues related to the new changes in the diagnostic criteria for autism, autism spectrum disorder. And, as most of you know, we are

anticipating that in May, the American Psychiatric Association will be publishing its new revised criteria for diagnosis of autism spectrum disorder. And this is the result of a lot of work that has been ongoing over the last couple of years by a Neurodevelopmental Disorders Working Group.

And, we are very fortunate to have on the call Sue Swedo, who actually chaired that work group, [DSM-5 neurodevelopmental] and so we can—we have the opportunity to discuss with her and ask questions, and really have her expertise as part of this process.

We've tried to form a planning group that represents a lot of different perspectives, including the CDC, where, you know, there are questions about how this change might impact prevalence; HRSA, the part of the Federal Government that has to do with practice and services and training; the Centers for Medicare & Medicaid Services; the Department of Education; self-advocates—we have two self-advocates on the Planning

Group; and then myself from Autism Speaks.

And so, what we would like to do, I think, today, and I'm certainly open to hearing from the rest of the Planning Group members about their thoughts on this, but my thoughts are that what we want to achieve is to, first of all, define the issues or questions that this group would like to consider or address, in terms of the potential impact of the *DSM* changes on issues related to families out in the community, how this might impact things like services or other issues that are really important to families and people with autism, and also how it might impact science, which ultimately can impact the community—so questions, for example, about how it might impact estimates of prevalence of autism.

So, I think that we can define what we think are the important issues that we want to discuss and then to begin to consider a plan for, well, what is the IACC's role in considering those issues? You know, is it to

develop a policy statement? Is it to consider the kind of research that needs to be done? You know, what could be the role of the IACC in ensuring that these changes, as they roll out, don't have any negative impact either on the science or on services?

And then, I think if we can come up with a plan, then as part of that we would try to define, you know, what the product is of this exercise, you know, whether it's a letter, or a recommendation for research that might become part of the new Strategic Plan; so there's a variety of products or deliverables that this Committee might have. And then who would do what, in terms of actually carrying out that plan.

And then, what we would like to do—and this may take, of course, more than just one phone call, which is fine, because there's at least one person that's not here, that couldn't be on the phone call today, more than that maybe, and so we want to make sure to have everybody have a chance to weigh in.

But, ultimately, we'd like to be able to report back to the next IACC full meeting from this Committee and give them a sense of what we are trying to achieve and where we stand in terms of achieving it.

So, I thought what I might do is just open it up with just raising a couple of issues that made me motivated to want to develop this Working Group, and then open it up for discussion among the people on the call about what they feel are the important issues that we might want to address.

Before I do that, are there any comments or questions, input about what I said so far, from the folks on the phone?

Dr. Swedo: No, thank you, Geri; that was very clear.

Dr. Dawson: Okay. Well, for me, I think, as a Chief Science Officer at Autism Speaks and representing families—and I have been following the *DSM-5*, and Autism Speaks has been following the developments on the *DSM-5* over the past year or so—and we've been



posting a series of letters that I've written on our Website, where at each stage we've tried to outline kind of the progress and the issues that we saw, and we've also submitted comments to the American Psychiatric Association, so we've been very actively involved.

And, in that process, I've tried to listen very carefully to what the concerns of the community are. And, I should say that I think my own personal point of view as a scientist and clinician and Chief Science Officer of Autism Speaks is I think that the changes on the whole are very rational and could have a very positive impact. There are lots of positive things about these changes.

So, in no way raising these issues should not convey that we feel that the changes are negative. We think it reflects the advances in science, and they were really carefully considered. And so, what we just want to do is to really consider now, okay, what is the impact now that these changes

have been made?

The two issues I would say that I hear from the community that have been raised, that seem to be most important in our minds, one is, how will the changes in the diagnostic criteria affect access to services? And, particularly, there's concern about the new diagnosis of social communication disorder. And since this is a brand-new diagnosis, and it does represent, you know, the end of the continuum of the autism spectrum disorder is one way to look at it, and that's a question in and of itself; but, you know, would we want clinicians, for example, to recommend interventions that are appropriate for kids with autism spectrum disorder, or would the idea be that they would get completely different kinds of interventions?

And, you know, this, of course, affects things like insurance coverage and access to special programs or special treatments that are designed for kids with autism spectrum

disorder. So, that's one issue.

And then, the second issue has to do with impact on estimates of prevalence. So, that is maybe more of a scientific issue, but I think it's certainly one that comes up in terms of what I hear from the community—that they are wondering, you know, how will we, how will the CDC deal with this in terms of trying to understand, you know, over time how estimates of prevalence change.

So, there are a lot of sub-questions and I think Coleen sent an email, she did a very nice job outlining many other questions, so I'll let her present those. But those are the two big ones that I hear about most in my role.

So, why don't I open it now to others on the Committee, in terms of trying to first to sort of define what we think are the most important issues that we need to consider.

Dr. Boyle: Geri, this is Coleen, and I sent these questions, at least to our thoughts—quickly whenever it was, last

Friday—and I actually think the way you summarized it into the two big bundles—those are, to me, the major headings in terms of what we should be considering—you know, from a program policy perspective, what are the impacts, and from a science research perspective, what are the impacts? So, I think that, you know, overall structure is very appropriate, in terms of thinking this.

I feel like some of the stuff that I sent forward is much more of the drill-down, maybe not as relevant as those two big bundles. And, I did send them to everybody, so, I mean, I can just say them quickly for those folks that are listening to the conversation who wouldn't have been privy to this.

So, maybe just from the prevalence perspective, you know, you were right on the mark in terms of trying to understand the impact on prevalence, and how this, you know, relates to monitoring trends over time, and, you know, evaluating trends with,

essentially, two different systems or two different ways of characterizing the condition under *DSM-IV* versus *DSM-5*.

And then also, how to track maybe the social communication disorder. Should that be part of that umbrella? And I know that our program folks are, obviously, in our ADDM network is giving that considerable thought.

So, that was the one bundle under the prevalence that I had set forward.

And then, under maybe more of a diagnostic heading, you know, I guess some of the questions that we had were, well, how will existing diagnostic instruments change, you know, and how to track the possible changes, and how the community and clinicians conceptualize ASD, so, you know, how to get more of a real-time feel about how this is impacting community practice. I guess that's one thought there.

There's a severity component that's part of *DSM-5*, and again, how will that roll out, both from a qualitative and maybe a

quantitative perspective? And then again, how would that sort of, thinking how it intersects with science, how does that relate to maybe evaluating the autism phenotype from a research perspective?

And then I think the final bundle, actually, had to do with the social communication piece. And, I think you talked about that already, but, you know, how will it be operationalized, and do we have—and again, both from a diagnostic and from a science perspective, you know—do we have reliable measures of this from a diagnostic perspective that can be translated into research? And what you said in terms of how it might impact services.

So, those were the questions that I had sent forward to the group last Friday.

Dr. Dawson: That's great, and it's very, I think, well fleshed out and well-articulated.

How about others, in terms of are there other issues that we need to be considering

here? We don't have our self-advocates on the line, which is really too bad, because I think one thing we haven't heard yet is, you know, the issues around the diagnosis of Asperger's syndrome, and, you know, how that might—how people think about that from the point of view of identity, and being involved in groups that are "Aspie" focused, and also even the programs that were developed for Asperger's syndrome in schools, for example.

I remember in Seattle there were, you know, a couple of high school programs that you have to have a diagnosis of Asperger's syndrome to qualify for that program. So, you know, we could also see some changes there, I suppose.

Are there other issues?

Ms. Kavanagh: This is Laura from HRSA. I wouldn't—I don't have additional issues. I just want to reiterate some of the same things that we're hearing from our interdisciplinary training programs, leadership education, neurodevelopmental

disabilities and developmental behavioral pediatrics—both from a provider perspective and as educators, clarity about the expectations of the new diagnosis, particularly, concerns about the severity and how that is going to be used clinically.

From the epi perspective, similar to the concerns expressed, Geri, both by you and by Coleen, we have the National Survey of Children's Health, and how might those changes impact the prevalence rates that we're reporting as well.

And then, from our state demonstration grants, really, families are concerned about what's the potential impact on access to services for families. So, nothing new, but just to reiterate we are hearing the same themes.

Dr. Dawson: Thank you.

Other issues, and I think the other thing, Laura, that was really helpful hearing from you is, it's good also to be considering the different stakeholders, and so you are



representing some very important stakeholders, you know, from a HRSA perspective, you know—clinicians, and training and education, and prevalence estimates using a different methodology, and services.

So, you really touch on, I think, all aspects of, you know, issues that are raised by the changes.

Any other thoughts about the issues that we should get on the table?

Dr. Boyle: Larry Wexler was supposed to be part of our group, both him and John O'Brien, cause it would be really great to have a sense, from both a CMS and Education perspective, what their concerns are.

Dr. Dawson: Yes.

Dr. Boyle: And thinking of the policy lane.

Operator: Dr. Wexler has joined; his line is open.

Ms. Kavanagh: Okay, great.

Dr. Dawson: Well, Larry, welcome. I

don't know if you just heard the statement that was made. We were just saying, oh, we wished you were on the phone, because we would love to have the CMS perspective—

Dr. Boyle: Education.

Dr. Dawson:—sorry, Education. Did you just join this moment, because I could do a quick recap?

Dr. Daniels: Larry, do you have the call-in information? I sent it out this morning, but I'll reforward it to you.

Operator: Mr. Wexler, please check your mute button. Mr. Wexler?

Dr. Dawson: So Larry, we can't hear you.

Dr. Wexler: Can you hear me?

Dr. Dawson: Yes, we can now hear you.

Dr. Wexler: Okay. I'm really sorry. I'm sitting literally in the chair in the ophthalmologist's examining room. So I may have to get off. I told Susan Daniels that that was my situation. It's a longstanding appointment. Just from an Education standpoint, we're definitely interested. We

don't know if we're concerned yet about the change, because we're not sure what it will result in. We don't require a medical diagnosis for services under IDEA, so it would mostly be school psychs who are making most of the diagnoses of children with autism. Honestly, we just don't know what effect this would have. I can tell you our numbers as percentage of the population have doubled in the last 6 or 7 years, in terms of our rates of reported children.

Dr. Dawson: Well, Larry, I'm curious, among your colleagues in the Department of Education have they been started to discuss how the school systems are—

Dr. Wexler: Okay, I have to get off. I'll get back on in a little bit; my doctor is here.

Dr. Dawson: We'll look forward to your input at a later time. So, we'll make sure to have another call, and recap everything and give everyone that is not represented on this call a chance to weigh in on everything we've

talked about.

So, you know, this will just be sort of the beginnings of this process. Those other perspectives are absolutely essential.

So, anyone else, before we move on to—okay, well you know, I would love to at this time, you know, and as we go through this process, to hear Sue's reflections thus far. And, I guess one of my first questions, Sue Swedo, for you is, I know that as the working group made, you know, those recommendations, that there was a lot of emphasis on the science and the research.

But did the Committee also consider some of these more policy-oriented questions, and did the Committee make recommendations about these things, or how did the Committee feel its role was, or the APA's role is, in terms of making a recommendation about how—what kind of services should be provided for a child with social communication disorder?

Dr. Swedo: Thank you, Geri. I'll start sort of at the beginning of all of that, and,

hopefully, be able to circle back to the question, specifically, about services for social communication disorder.

Dr. Dawson: Okay.

Dr. Swedo: But I want to reiterate what I presented at one of the IACC meetings, and that is to remind folks that the *DSM-5* is a clinical manual. As Larry had just said, it is psychologists, psychiatric social workers, and others who were making the diagnoses of autism spectrum disorder or determining services in the schools.

And, they use the *DSM*, but in actual fact, the medical codes for autism and related disorders come out of the *ICD-9*, and the *ICD* codes here in the States haven't changed. Internationally, they are already working on *ICD-11*, and our work group [DSM-5 neurodevelopmental] and the *ICD-11* Neurodevelopmental Work Group, started working closely together as soon as that work group [DSM-5 neurodevelopmental] was formed 2 years ago and we will continue to move

forward with them. In fact, we have two members that are on both Committees.

So, *ICD-11* will have diagnostic criteria that have also changed somewhat for the disorders, but in the *ICD* codes they didn't ever have separate diagnostic codes for PPD-NOS and some of the others.

So, in that way, I think the coding changes will be less than some people have worried that they might be.

In terms of services delivery, we worked really hard on that and are very, very grateful that *DSM* moved from *DSM-IV* as a Roman numeral to *DSM-5* as an Arabic numeral, with the understanding that it was actually *DSM-5.0* and 5.1 or 5.2 could come as soon as data were sufficient to justify changes and that going forward is to be a much more responsive volume.

One of the things that Bryan King, a work group member, had discovered for us was that in the past decade there have been only 14 publications that used "Asperger

disorder," "PPD-NOS," or "autism." The other thousands have used "autism spectrum disorder." So, in some ways our recommended changes are an attempt to catch up with the field.

Certainly, the epidemiologic surveys have not separated diagnostic categories and, in fact, have included PPD-NOS in the *DSM-IV* format, which has atypical autism that includes sub-threshold symptoms and clinically significant symptoms on only one of the domains.

So that, PDD-NOS, in which individuals had only social communication or social reciprocity, or communication deficits, or restrictive repetitive behaviors—those who had symptoms above threshold for social communication deficits will likely be covered under the new social communication disorder. But, it was always envisioned as a separate disorder, not part of the autism spectrum. And that's why we worked very, very hard to make sure that the early childhood history

could count for that second domain of restrictive repetitive behaviors, because the data available to date show that when individuals who otherwise meet criteria for autism and autism spectrum disorder in its fullest extent—including Asperger and PPD-NOS—fail to meet currently, they still have that early history of repetitive behaviors, restricted interests. And if you include its the broadest sense of fixated interest and restricted behaviors, that most individuals will continue to meet that criteria throughout lifetime.

So, the field trial data—I'm sorry I'm talking so fast, there's too many things going through my head—but, from the field trials that were done for autism spectrum disorder at two sites, we were able to get a sense of how *DSM-IV* diagnoses were going to map onto *DSM-5*. We need additional studies on that, because that was only a few hundred patients. We would, obviously, like to know more information about that.



Cathy Lord published a paper in the *American Journal of Psychiatry* recently, where she took the START [Statewide Autism Resources and Training]), CPEA [Collaborative Programs of Excellence in Autism], and Simons collection of several thousand individuals, but there we don't have the contrast group of those who have other diagnoses, such as ADHD with some social skills deficits. How they are going to sort out going forward?

In the *DSM-IV*, it's quite likely that their records would look like PPD-NOS, particularly when you are looking at services delivery. So, that's one question -- how do children with a dual diagnosis of ADHD and social skills deficits sort?

But, for the larger group, the children initially identified in *DSM-IV* as autism, Asperger, or PDD-NOS, they, 95 percent of them continue to meet criteria for autism spectrum disorder using *DSM-5* criteria.

We also picked up a few additional cases, who had not met *DSM-IV*, but now meet

*DSM-5* criteria. And, if you add in the number of children who now meet social communication disorder criteria, that was an additional 5 percent of that clinic population.

So, I think it's going to be really important—in one of Coleen's questions, it was how is SCD to be compared to ASD? They need to remain completely separate, but it may make some methodologic limitations on assigning diagnoses out of school records, if the school records are only documenting what the current symptomatology is, because it's that early history is so important for diagnosis of ASD.

The question about clinical use of severity scales and access to services, we have highlighted it in the—immediately below the criteria, as well as several places in the text that any individual who meets criteria for autism spectrum disorder should receive appropriate services— that the Level 1, Level 2, and Level 3, do not translate into mild, moderate, and severe. There are a

lot of reasons why we had to choose three levels rather than a sliding scale, but within the three levels, the lowest of them is 'requires support in order to function optimally'. So, they are not to be used as treatment, you know, targets or treatment guidelines, and certainly not as a means of denying services to an individual, but rather to help clinicians get a sense of the impairments of that individual patient.

And, I think one of the big advantages going forward with *DSM-5* is going to be the fact that, even though we have this very broad spectrum of individuals defined as autism spectrum disorder, within it you have the capacity to add specifiers that give you a very precise, individualized picture of that person's impairments, but also their strengths in specific areas, such as IQ, verbal abilities, and additional burdens, such as co-occurring medical conditions or other psychiatric disorders.

Dr. Dawson: That's really helpful. I'd

like just to make a couple of comments; this is Geri.

So, going back to the issue of PDD-NOS versus social communication disorder, so, you know, a person could have just one restricted or repetitive behavior and not two, and then, miss a diagnosis of autism spectrum disorder. Isn't that right?

Dr. Swedo: That is correct, but because restrictive or repetitive behaviors are only one of the four criteria. Which also includes sensory issues and excessive adherence to routines and rituals, and fixated interests. The historical data suggests that it will not happen that a person would have that and yet have the sense be that they met the rest of the criteria for autism spectrum disorder.

Dr. Dawson: Right, but I do think that that's kind of important because that does mean that there would be individuals who have social communication impairments and one—you know, theoretically anyway—one either sensory or repetitive behavior and still not, within

this scheme, be considered part of the autism spectrum disorder—autism spectrum—is that right?

Dr. Swedo: Yes, unless we can demonstrate that in the past that they did have them. So, that's where I think the instruments, actually, have to be developed, that more rapidly and accurately define that early history to get the repetitive behaviors, which either have been trained out of the person or that have just become less obvious over time.

Dr. Dawson: So, you know, and then two other points, and then I'll just pass it—you know—let other folks weigh in. But, one thing I think is really important when we consider the discussion of this Planning Group, is that, I think it's great that 95 percent of the people will continue to have a diagnosis on the autism spectrum continuum. That's very, very reassuring.

And, in my mind this Committee is really concerned about the 5 percent, or it's the 1

percent, right? So, to me, it's that small population of, you know, real people, because if it happens to be your kid, you don't care if it's just 5 percent, it's your kid, who now is being affected. So, I think I want to be careful that we don't use that as kind of a, you know, feeling like, oh, well, you know, then we don't need to—

Dr. Swedo: Only 5 percent.

Dr. Dawson: —work around this.

But the other thing I wanted to mention is that, if there were data, let's say in the future, published—because a lot of the work that has been done, even Cathy Lord's large study using the Simons and the CPEA data sets, still were retrospective analyses of existing data—but, you know, and all the problems we could talk about that—but in the future, if we have data that is prospectively gathered in the sense of, you know, looking at how the *DSM-IV* and the *DSM-5* compare, and if it were found that children who previously were diagnosed with PDD-NOS—and, actually, I

think the field trials show this—now often will get—not often, but sometimes—will get a diagnosis of social communication disorder.

And, what that would mean is that, in the past way that we conceptualized autism spectrum disorder, we were considering those children as part of the autism spectrum, and now what we are doing is lopping them off and saying, you know, they are no longer a part of the autism spectrum.

Dr. Swedo: Right.

Dr. Dawson: And my concern there is that a lot of the work, for example, on early intervention has included those kids, right, who previously would have gotten a diagnosis of PPD-NOS, and, in fact, if you look at the RCT published, I think, in 2000 by Tris Smith on the Lovaas Model, it was those kids with PPD-NOS who actually made the most gains and did the best, you know, in response to early intensive behavioral intervention.

So, I guess one question that I think I'd like this Committee to grapple with is,

you know, if the DSM Work Group is going to be making a hard point that kids with social communication disorder no longer are part of the autism spectrum, then it has pretty big implications for people, I think, in saying, well, should they receive early interventions that are designed for kids with autism spectrum disorder?

Dr. Swedo: Right, so, Geri, can I respond to that before we open it up to the rest of the group?

Dr. Dawson: Yes, absolutely.

Dr. Swedo: I agree completely with your concerns, and I just want to reassure those on the phone, as well as the rest of the community, that we did pay very, very close attention to that 5 percent. And actually, my work group viewed videotapes of the interviews of these patients, and that 5 percent that did not meet the *DSM-5* but had had a diagnosis of something in *DSM-IV*—those that we were able to view—the reason, it's that group that I just talked about, the ADHD



with some social skills deficits, where the decision had been made that a PDD-NOS diagnosis would be more helpful to that child, not that they were actually ever part of the true autism spectrum.

But the most important piece of this is the fact that coming out of OCD, and chairing this group, I have taken the chair's prerogative of sort of saying, do we really need these RRBs as a major part of autism? Isn't it all about the social communication?

And we had a workshop back in 2007 where we examined that question very, very carefully, and I was quite surprised to find that the RRBs are a core and defining feature of autism spectrum disorder.

The PDD-NOS children, not just in the field trial, but in the case descriptions that have been presented, who will no longer meet criteria for ASD are that sub-threshold group that I spoke about. And, I suspect that most people don't know the current PDD criteria to understand just how broad that

sub-threshold was, but it would include all individuals that we talk about as sort of the broader autism phenotype.

And, therefore, I think we do need to study that question, but I just want to make sure that we going forward don't use terms like have now been excluded from the autism spectrum, because it isn't clear that they were ever on the autism spectrum.

Dr. Dawson: Well, but I don't think we have definitive data to say that they weren't in the past included, at least when they did the diagnosis, not from the point of view of, you know, would a clinician, if they looked at this case, you know, maybe reconceptualize it, but really before clinicians were giving that diagnosis and, therefore, kids were getting access to the services, one could say they're a broader phenotype, but what if those are the kids who, you know, very quickly respond to early intervention, and their life trajectory is so much better, right? And they don't end up with, you know,

social impairments and other kinds of things that affect, you know, their ability to use, you know, their skills.

So, I still think it's a very delicate issue. But, let me open it up to others. I don't want to dominate the conversation here.

Dr. Boyle: This is Coleen, and this is a great discussion. Obviously, it's a complex issue. You know, I guess one of the recommendations that I had made is that, you know, I don't know how to do this, but how to track possible changes.

Geri, you were talking about sort of prospectively collecting data to get a better sense of what's really happening real time. You know, so how do we do something like that? How do we get a better sense of how this is rolled out, and, you know, what impact is happening?

You know, we do have some ongoing systems, you know. One we heard about on Tuesday that HRSA has; it's a bit more real time. You know, we have an ongoing study, or

you have an ongoing study in South Carolina, that's trying to get a pulse on that, but that's obviously only one location. But I do feel like it's important to, you know, get more of a sense, and, you know, have some kind of measures or systems in place to capture this.

Dr. Wexler: This is Larry Wexler. Can you all hear me?

Dr. Dawson: Yes.

Dr. Wexler: Thanks. Sorry about having to depart before; the doctor called.

Just from an Education perspective, in terms of any prevalence rates, we'll be very challenged to be able to contribute a whole lot to that. And I say that because when you are talking about catching kids really early, our first—essentially, our Part C program, birth to 3, you know—most of those kids are labeled as developmentally delayed. I mean, the states have a lot of flexibility in terms of who they serve.

A lot of parents don't want their child

labeled anything, quite frankly, from birth to 3. And then from 3 to 5, our 619 code—there's a similar situation. An awful lot of children are labeled developmentally delayed, as opposed to a specific disability category. We have 13 disability categories, autism being one of them.

So, that's just some info for you to be aware of.

Dr. Dawson: So, Larry, I'm curious from an educational perspective, and also reflecting on what you just said. So in the birth to 3 period, which, by the way, we know very, very little about the *DSM* in that period, because even the field trials were, you know, with kids between 6 and 15, and Sue can correct me on that one. But, I know it wasn't preschool kids, or birth to 3.

So, the question I would have, too, is that if people are less—if they are somewhat reluctant to give an autism spectrum disorder diagnosis during that phase, would you, perhaps, anticipate that clinicians might be

inclined to use the term social communication disorder, because maybe it's easier for parents to hear?

And, you know, whether or not it's for that purpose, or because, for other reasons they get that diagnosis, how will, you know—from an educational point of view—how might that impact a child's ability to participate in a classroom that's designed for kids with autism spectrum disorder? Do you think that they're going to be included or excluded? Or what kind of educational recommendations will your psychologists make for a child with social communication disorder?

Dr. Wexler: You know, it's very—I mean, things vary greatly from birth to 3 and then 3 to 5. From birth to 3, services are not an entitlement, and some cities have very narrow definitions of eligibility for Part C services. Some include at-risk as a category.

You know in the at-risk department, when you have that diagnosis available, I would think that social communication disorder

would not make a difference in terms of kids getting served, whether they are essentially coded as that or autism or on the spectrum.

In states that are a little more, you know, looking at specific diagnoses under our categories, it would be a big problem, in the sense that there is no category "social communication disorder."

So, unless—I mean, we don't—we don't serve kids who are just ADHD; we only serve kids who are ADHD who qualify under "other health impaired." And there's quite a few of them, I might add. But, if a child that's labeled as a social communication disorder can also be, you know, accepted as having autism, then they would qualify.

So, it's very hard to predict, and things go from state to state. We define the disability, but the eligibility is determined, you know, by state procedures. I'm not sure if that was helpful.

Dr. Dawson: That was very helpful. And, in fact, one of the things that I think you

raised which is really important, which is that—so a higher functioning child who did not get qualification because of, say, a delay in language or cognitive ability, who had a social communication disorder would not get served in the birth to 3 system.

Dr. Wexler: Except our number one service area, you know if you look at the graph of the age of when our kids get eligible—the largest group is between 2 and 3, and that's mainly based on language delays.

So, a child with a language delay, or a speech/language disorder, is, in fact, eligible under all of our—whether it's Part C or Part B, or 619, that's very common. There are an awful lot of kids with autism who, in fact, are, you know, labeled under that language, speech/language problem.

Dr. Dawson: Sue, can you remind me, in the social communication disorder criteria, because I don't have it in front of me, a child can get that diagnosis without a



language delay, or do they need a language delay?

Dr. Swedo: No, they do not need to have a language delay, but it does not preclude the diagnosis. So, the only thing that—the only provision is that you have to have ruled out autism, and it provides very clear directive for that issue we had spoken about earlier, RRBs.

But, if a child had specific language impairment, they could also have social communication disorder, or they could have social communication disorder as a stand-alone diagnosis.

Dr. Dawson: So, this would be something like a pragmatic language disorder.

Dr. Swedo: That's exactly right, pragmatic language impairment, yes.

Dr. Dawson: Right. So, Larry, would a child with pragmatic language impairment, without a delay, for example, in vocabulary and syntax and the other aspects of language, would they qualify for birth to 3 services?

Dr. Wexler: More than likely, if it's a speech language disorder, it does not have to be a delay. I mean, we serve just a huge number of kids, essentially, who have articulation problems. You know, they may not be delayed, but they have some type of articulation problem.

It kind of depends again on the state. For instance, Florida, to serve kids in speech/language, they have a very narrow definition of, I believe and please don't quote me on this, but I believe they require pretty close to a 2-year delay. And, as a result, they eliminate a huge number of kids, certainly kids at the age of 3, who—you know, what language are you supposed to have at age 1? So, it makes it very challenging.

But, the fact that they are not delayed, if they have, you know, an articulation problem, in general they would qualify. So it doesn't have to be a delay.

Dr. Dawson: So, this might be a recommendation that we could make if we end

up making recommendations, because I think this is an important point. If we can capture it, which is to make a recommendation that social communication impairment—which is, basically, the pragmatic aspect of language—it's not articulation. It's not syntax; it's not semantics; it's not, you know, vocabulary. It really is the social use of language and the other aspects that go along with that, you know, back and forth, and picking up on the nuances of reciprocity, et cetera, that that be considered through the birth to 3 system as, you know, as a condition that like articulation without language delay that would qualify for services, that we could make that.

Now, of course, they can decide not to do it, but it is a recommendation that we could make.

Dr. Wexler: Certainly, my suggestion would be is check with ASHA, in terms of what they would consider, because in most instances the kind of description you're

making would probably be a language disorder, and then they would almost everywhere qualify.

You know, it's—the problem is the variability across the states. But I would start with ASHA in this area, because they're kind of a standard, and they set standards for their speech language folks nationally.

Dr. Dawson: Yes, that's really helpful. And so, it may be as simple as making sure that ASHA and, perhaps, in our recommendation, that we, if pragmatic language disorder, for example, is, you know, at least by ASHA would be a language disorder, therefore, and most states would qualify a child. Then the clarification would be to make sure that people understand that social communication disorder is a pragmatic language disorder.

Dr. Wexler: Exactly. I mean, I would say, you are right on target, but I think your key is ASHA, because with states and, frankly, we talk to ASHA when it's a

technical kind of determination like that.

Dr. Dawson: Yes, that's helpful.

So, how about, you know, going up into the elementary school and adolescent age now and then how do you think your psychologists will be making recommendations based on social communication versus ASD? Do you think kids with social communication disorder will be served in a classroom of children with autism, or do you think they would be treated as a kid with language disorder?

Dr. Wexler: You know the law is that, regardless of disability, the child needs the services to address his or her needs. So, I mean, that is the law.

If you are talking about your focus is on where they're served, that's a very different question. And, you know, the bias in education is, in fact, not to serve kids, you know, by disability in separate classrooms but to, you know obviously, include them in more of a general education environment.

But, I can't say where they would be served. You know, I mean, you know, there's a lot of variables there. Number one, does-a-squeaky-wheel-get-greased kind of reality that, I mean that's the reality, that if a parent really pushes, they tend to be able to get what they want for their child. You know, that is a fact.

Another issue is what services, you know, what's available, you know, how severe the child's disability is. You know, the schools are they're obligated to provide a free appropriate public education. Appropriate is defined as the child gets educational benefit from the program. It is a—I mean, we say it's a Chevrolet, it is not a Mercedes. And that that's—you know, so, different districts have very different resources, yet still meet the requirements of the law.

I'm not saying it's right. I'm just saying that's what the law says.

Dr. Dawson: So, well, this has, I think,

been really—at least helpful for me. It's kind of edifying around some of the issues around social communication disorder. I guess my one last question for Sue, before maybe we move on to some of Coleen's issues that she's raised. So, Sue, why didn't you guys just call it pragmatic language disorder?

Dr. Swedo: Because pragmatic language disorder didn't include the nonverbal communication piece that's so crucial to this, and, actually, even within autism spectrum disorder, the *DSM-5* criteria, we worked very hard to make sure that the integration of nonverbal and verbal communication was part of the diagnostic criteria to, actually, broaden that criterion beyond what had previously been described.

So, if you have a minimally verbal or a low-functioning individual who has more profound impairments in communicating in social situations, we had hoped that the SCD would pick up that group of children.

Dr. Dawson: And, what did the Committee

think in terms of what kind of services would be appropriate for this kind of child?

Dr. Swedo: I think it totally depends on the impairments for that individual. As I said, it was an attempt to go beyond Dorothy Bishop's PLI, and the way it's been described for others is pragmatic language impairment, to include this unknown group of individuals who have primary deficits in social communication. They may or may not have been picked up as PDD-NOS in the past, and I think as you already said, Geri, we really just need a lot more data to know going forward how these people are the same or different.

Dr. Dawson: But what you're saying does suggest that the simple solution of making sure people know that this is what, you know, previously was called "pragmatic disorder," "language disorder," that, actually, is not right. That you are saying that it isn't exactly what—

Dr. Swedo: It encompasses that, and the text talks about the relationship of PLI to



SCD. And in the actual title of the disorder it's "social (pragmatic) communication disorder." And the criteria focus as much on the nonverbal communication as on the verbal abilities.

Dr. Dawson: But, it is technically a new diagnosis.

Dr. Swedo: It is, yes.

Dr. Dawson: So, the question of what services those kids would receive, that sort of has to be made up as we go along? How do clinicians figure that out?

Dr. Swedo: Well, I think Larry said it best. I think people have already been doing that. One reason that we use PDD-NOS so frequently is that, with the sub-threshold criteria, it allowed you to use that diagnosis to get services for a child who needed them for, perhaps, other reasons.

Again, let's go back to the fact that services—nobody has used *DSM-5* or *IV* before for direct delivery of services. They had to be able to translate it into an ICD code or

to an IPA [independent practice association] service delivery code.

Dr. Dawson: Well, that's actually not true. I've used it, you know, myself as a clinician in a lot of different contexts, two point—you know, 2.900.

Dr. Wexler: Hey, folks, I'm about to descend into the bowels of Metro, so I'm going to have to sign off. But, you know, if you have any questions related to the sort of educational benefit and the educational requirements, please give me a holler or send me an email. I'll be happy to help in any way I can.

Dr. Dawson: So Laura and Coleen, I just want to make sure—and Jan—I want to make sure that you have a chance to express some of your concerns and questions and, especially, with Sue. You know, being part of the work group, it really helps to get her perspective.

So, why don't I open it up so that we can talk about some of the other issues, like

the use of the severity ratings and others that were raised?

Dr. Boyle: I guess I--this is Coleen--I guess I flagged a few things while Sue was talking, in terms of thinking about what the Committee could do.

So, one was that, Sue, you mentioned that instruments have to be developed to capture the historical information, that critical information you talked about, in terms of the repetitive behaviors in early childhood. So, you know, maybe getting a sense from you of what the state of the art is around that would be very helpful.

And then, I guess maybe a little bit more, for me personally, a little bit more explanation around the severity level, in terms of the impairment level. You said it shouldn't be translated in terms of, you know, service, I mean obviously, just like Larry said, in terms of, you know, the ideal state, obviously, services should be appropriate to a child's need and their

disability and their functioning level. So, I'm assuming it's not meant from a service perspective, but it is, again, and maybe it can be equivalent to the adaptive behavior of the child? I guess I'm trying to wrap my head around this a bit.

And then, that's more, just me for my edification, but then I'm just thinking of it in terms of how it translates into, you know, some of our science and research-related questions.

Dr. Swedo: So, for the first piece, the instrument development, the status of that is that there will be an open call for instrument development.

One of the frustrations has been that the most widely used research measures, the ADOS and ADI-R are not easily available or translatable to clinicians because of the copyright protections. And, at the NIH, our attempts to sort of move around those—it's a very long history, but it has to do with the original ADOS, ADI, and its protections

moving forward.

So, I think that a system that really translated into the clinic much more accurately and specifically could be useful. But, as we all know, the gold standard remains sort of the expert clinician.

I think the instrument development needs to be—as I said—include that historical piece, but even if we can just use the new broader criteria that we attempted—because in the text there is, actually, the course of illness described, the differences in symptom presentation from early toddlerhood, the targets of the early intervention that Geri mentioned, all the way through adolescence and adulthood. And, it's those individuals who may have been missed, because somebody thought, oh, they are making eye gaze fine, and that had been the only criterion spelled out within the old *DSM-IV* criteria.

So, I think instrument development is crucial, and the IACC can, hopefully, play a role in making sure that it's coordinated

across the various disciplines that interact with individuals with autism, including the question of severity. And, I think there the [DSM-5 neurodevelopmental] Committee worked really hard to not only use words that would make it clear that if you meet diagnostic criteria for an autism spectrum disorder that you have an impairing condition, and that if the symptom severity is at the lower end, it's still above the clinical threshold. So, that's the first and most important thing. We just need to make sure it never gets lost, because everyone on the [DSM-5 neurodevelopmental] Committee felt very, very strongly that we didn't want this to turn into, 'oh, he has mild communication deficit and only mild RRBs, therefore, he doesn't need X, Y or Z— that's not the situation at all.

How that translates into the actual practice, I think, is again something that this Work Group can start, but it's going to take the entire IACC, as well as the larger

community, to address this question.

The specifier is not for severity of autism spectrum disorder, but for severity of each of the two separate domains; and again, that was done on purpose to try and make it more difficult for people to misuse the three levels.

Dr. Boyle: That's helpful. Again, I'm just trying to—I'm going back to data that was presented by Stephen Blumberg and Michael Kogan, which—I don't remember if they actually had it in the presentation on Tuesday, or if they presented it in the larger report. But, obviously, they were looking at changes over time relative to parents' report of severity. And, I guess, it would be great to be able to—not to negate the parent report, because, obviously, that's how families are experiencing the condition. But also to have a sense of, and again I'm assuming this is a qualitative versus a quantitative assessment—at least right now—but it would be nice to be able to kind of

have a second—like we have a diagnosis of ADHD, where we have, you know, a parent perspective and a clinician perspective, or another rater perspective about severity levels.

Dr. Swedo: Yes. And, I think at least from our clinical practice here, one of the limitations that Dr. Blumberg didn't talk so much about is the question is ever had a clinician make the diagnosis, and it isn't uncommon for somebody to use that diagnostic term, and then as we saw in the earlier report, one-third of the families didn't feel that the child currently had the diagnosis, which seems unlikely.

Dr. Boyle: Yes, Well I know they are investigating that, so, hopefully, we'll have a little bit more of a—be able to wrap our hands around that one a little bit more.

Dr. Dawson: So, Laura or Jan, would you— are there some issues you'd like to get on the table, or have a chance to ask Sue some questions, from the perspective of the



Working Group?

Ms. Kavanagh: This is Laura. I don't have any additional questions. This was extremely helpful. Thank you so much for providing this additional information.

Actually, I take that back, the one question I would have is, what are the plans for how clinicians will hear or learn more about the severity scores, in particular—is what I was hearing from -- this was a meeting of fellows of developmental behavioral pediatrics, and how—what that's going to be—how that's going to be implemented in the clinical setting, beyond the clarity and the definition itself.

Dr. Swedo: It was, specifically, decided that the severity levels would be specifiers rather than subtypes. I'm sure you're all familiar with the subtypes of mental retardation, where mild mental retardation actually has a different diagnostic code than moderate, severe, or profound.

Ms. Kavanagh: Right.

Dr. Swedo: And, actually, in intellectual disabilities, we moved in the same direction to get away from that artificial separation.

In these severity levels, as a specifier, it's up to the clinician to use them or not. And I'm hoping that we can use the initial roll-out to be a call for folks to start playing with them, in particular, obviously clinical investigators who are going to need to decide, does that help us to interpret research reports.

Ms. Kavanagh: Thank you.

Dr. Boyle: This is Coleen. That was very helpful. And, Geri, I'm thinking from an IACC perspective, and maybe we can add a research target or a research question, to understand, you know, the reproducibility, the reliability, in the context of, you know, applying the diagnosis of these severity levels. So we could get a better sense there.

Dr. Dawson: Right. You know, I know we only have about 15 minutes, and I would like

to spend the last piece on kind of clarifying what we think, you know, the purpose of this group will be. What would be the actual plan and product that we would produce?

I did want to quickly follow up on the question, though, that Laura asked Sue, which is, so is the APA going to be providing online and in other training for clinicians on the *DSM-5*? And will there be a way that people can, you know, get trained, and see cases, and all of that?

And then, how do you think it might impact any kind of diagnostic tool?

Dr. Swedo: I don't know what the APA has planned. Our [DSM-5 neurodevelopmental] work group was disbanded in December after we submitted our final draft. And everything has been under embargo since then.

I can tell you, when our [DSM-5 neurodevelopmental] work group was still functioning, and working together, that we had indicated our interest in being part of such an effort and training. And they'd

actually talked about having workshops at all of the major meetings on using the criteria.

There's a master's course at the APA meeting in May that will be the first step in that. And I think we just need to make sure that we get presentations. And, I like the idea of an online course, since the move for *DSM*, in general, would be an online interactive document.

Dr. Dawson: And, do you think it will change any of the diagnostic instruments? I guess the algorithms—have you heard whether there will be other changes?

Dr. Swedo: I think that the algorithms will change, but the sense was that the new criteria were fully encompassed under the current diagnostic instruments.

Dr. Dawson: Okay. So, the ADOS could still be used—

Dr. Swedo: The ADOS could be used very easily with a different scoring algorithm, and I think that may already be underway. The ADI-R was a little trickier, but the elements

were there; it was just a question of whether the waiting would be appropriate.

Dr. Dawson: Right, okay.

So, going back now to this issue of, what do we think this group should do. Coleen has already mentioned the idea of, as we, you know, update the Strategic Plan, or even if we end up making some kind of general document out of this Working Group, specific to the *DSM-5*—

Dr. Boyle: Geri, this is Coleen. Can I ask a clarification of Sue on that last point?

Dr. Dawson: Yes.

Dr. Boyle: So, on the algorithms—so, Sue, could the ADOS then be used to make the diagnosis of the social communication disorder?

Dr. Swedo: I don't know. We didn't, actually, talk about that. That's a good question. Again, remembering that SCD in our Committee's view is not part of the autism spectrum.

Dr. Boyle: Okay.

Dr. Dawson: That's a good question, Coleen. Yes, wow, okay. That's interesting.

So, anyway, one of the things that we could do out of this Group is to come back with some specific recommendations about research that needs to be conducted. I mean, I'm sure there are many questions. But, essentially, it's sort of a new objective on the *DSM-5*, with some questions that would address a number of issues, some of which we've had a chance to talk about today.

So, how do folks feel about that, as being one product that would come out of this Group. And, of course, we would have to have everything discussed and approved by the full IACC, but, you know, we would come back to the full IACC at some point with a draft of a set of research recommendations.

Dr. Kavanagh: That seems like a very reasonable course of action for this Work Group.

Dr. Boyle: Oh, definitely, so now we'll

have 71 objectives, right, Geri?

Dr. Daniels: 79.

Dr. Boyle: Just teasing.

Dr. Dawson: I know. So, Susan, your role right now is to brace, to get Tom braced for another objective. I know he always look forward to adding them.

Dr. Daniels: Yes, and, you might want to think about, too, whether you would want to separate it into much multiple objectives—because in terms of the tracking, and the type of tracking the Committee seems to want to do—which would be very granular—it's kind of hard when the objective has many different things lumped into it, to clearly define which things have done and not done.

Dr. Dawson: Yes. Yes. Okay.

So, a set of research objectives specific to the *DSM-5*.

Dr. Daniels: Maybe you are shooting for 100 objectives.

Dr. Dawson: Well, hopefully, we don't have that many, but anyway—

And then, the second thing, I guess, the second area of policy and practice—what do you folks feel would be the best, you know, product, so to speak, or the best course of action, that this Committee could take to address the policy and practice?

Dr. Boyle: So perhaps, saying some of the needs that are required for implementation. We just talked about the training for clinicians online.

Dr. Dawson: Right, good. Okay, so the needs would be one thing—and are we imagining a kind of a little white paper, or it's just—Susan, help me here. Do you think of these as kind of IACC policy statements, or what is this?

Dr. Daniels: You can make a statement if you feel that there's a value in making a statement from the IACC about this. Or you could write up a one-pager, or two-pager, and make that a statement from the Committee.

Dr. Dawson: Okay. How do people feel about that, sort of a policy and practice



statement?

Dr. Boyle: I think that sounds very reasonable. I'm wondering from Sue Swenson, if they had already given some of this—if the [DSM-5 neurodevelopmental] Committee or work group, had already given this thought, in terms of what we'd need for implementation?

Dr. Swedo: We have given it thought, but we haven't moved toward implementation.

Dr. Boyle: But if you had given it thought, rather than reinventing the wheel here.

Dr. Swedo: Yes, and I think similar to other disorders, there are some models that are already in place. So, I think it could be—I don't want it to be a brand new initiative by itself, but we certainly could pay attention to it within the larger framework of trying to look at impact.

Coleen, one of the things you had said earlier is so crucial. And that was to sort of—maybe it was Geri, the two of you together—thinking about the *DSM-IV* to -5

transition is going to be best done by just getting some more clinical data about how the two are related or not.

Dr. Boyle: Yes. The other one, Sue, that you brought up that I forgot—and maybe that was part of the discussion earlier and I just didn't quite understand all of it—was, I guess, children with dual diagnoses, with social skills deficits, like with ADHD, and what the impact there is.

Dr. Swedo: Right.

Dr. Boyle: I don't know if that's a research question, but I guess maybe I'm going beyond the policy and practice piece. Or maybe it has implications for policy and practice, and we just don't know what they are yet.

Dr. Dawson: Well, I do think it relates to—what I've written down so far under the policy and practice statement is that, one thing would be needs around training and other potential needs.

And, I think, Laura, you know, in

particular, was really concerned about this, with the LEND Program and so forth.

But the second one might be some recommendations around, you know, kind of implementation and interpretation. And, we may not feel comfortable going that far, but, you know, I think that at least—we should have a discussion about whether we want to make any statements to the effect of, you know, in light of the lack of knowledge about, you know, how these will impact practice—the Committee suggests, you know, X, Y and Z.

And, I actually have some thoughts along this line, but the idea would be to make some general recommendations that would, essentially, make sure that you do no harm, right? Or clarifications, right? So we might want to make some clarifications around the interpretation of some of these, that are just—like, for example, that, I heard Sue say that severity ratings should not be used to make recommendations about whether, you know,

a child—or, should not be used for excluding, you know, from services, right? So the mild child doesn't mean that they don't need services.

And, even though that may be said in the *DSM*, and certainly implied, those kinds of things might be helpful to, you know, state in this letter, so that people make sure that they understand some of those things.

Do you think that's going beyond our purview?

Dr. Daniels: Are you asking me, Susan?

Dr. Dawson: Yes; Susan would be great, or anyone, but Susan, particularly, you would know.

Dr. Daniels: You can make those kinds of statements in your statement or recommendations. I think that that would be within your purview.

Dr. Dawson: So, how do folks feel about us taking on a few of those kinds of recommendations, if we can agree upon them?

Dr. Boyle: I think it's very reasonable.

I mean, it's a pulse check, and I think it's something to revisit as data comes in, and implementation happens.

So, yes, I think it's very reasonable.

Dr. Kavanagh: I think it's the greatest concern on the part of practitioners and families, too, so to include something like that in a policy and practice statement I think would be important.

Dr. Dawson: Are there other things that should be included in the policy and practice statement?

Dr. Boyle: Training right now, implementation and interpretation-related issues beyond—I'm just writing down what you were saying, Geri—I guess I think of the services world here. And obviously, we are saying—the only piece we've talked about is the fact that severity ratings should not be in any way, or not in any way, but should not be used to qualify or disqualify a child for particular services, but that services should be appropriate to that child's disability and

need, as Larry stated.

I guess I'm wondering, you know, are there training—when we talk about training for providers, are there training aspects for the service provider world—early intervention, or others? I mean, I'm just trying to think of what the implications would be for that world.

Dr. Kavanagh: Right. Dr. Dawson:

Well, I guess, you know, one—well, first of all, one thought that crossed my mind earlier, you know, that we might want to make a recommendation on—if we can agree on it, and it'll take quite a bit of discussion—but would be the idea of saying that, sort of reminding people that are going to be using this system that—and I think Larry was the one that made this comment—which is that, ultimately, the recommendation should be individualized, and not, you know—and that these diagnoses should not be used to include or exclude, necessarily, but rather, you know, that it really is up to the clinician

to make a recommendation.

So that, for example, there may be some children with social communication disorder for whom early intervention, behavioral intervention, you know, even intensive, would be perfectly appropriate. Whereas, for others, you know, it would not be. And that, sort of separating out when you get into these other areas, I guess the slippery slope there is that, if we worked really hard for kids who have autism diagnosis, to always have early intervention, if you use that same logic, you could exclude them. But, in fact, you know, the way that it works in practice is that you do make recommendations that are, you know, mostly based on just the individual needs of the child.

So, I don't know. That was the one thing I was kind of grappling with, just because I do think there's some kids with social communication disorder that probably could benefit from early intensive behavioral intervention. And they could be pretty

severely affected, and have one repetitive behavior, and, you know, be incredibly helped by early behavioral intervention.

And other kids who might have a mild pragmatic language disorder, with a nonverbal component, and, you know, basically, should be seeing a speech therapist.

So anyway, I guess I'd like to spend a little more time with the Committee just thinking all that through a little bit.

So, you know, I think we are coming to the end. I guess one last question I'd like to just finish with today is, are there other people outside the IACC and Sue that we think would really add a lot to this Planning Group, that could help us?

Dr. Boyle: I guess I think maybe Laura Carpenter, you know, Cathy Lord, Amy Wetherby. I mean, I don't know, I'm just thinking of people that I know.

Dr. Dawson: Right. I thought maybe someone from ASHA.

Dr. Boyle: Yes, that's a great idea.



Dr. Swedo: Stacy Shumway had worked with us on the social communication disorder piece, but Amy Wetherby also could represent that.

Dr. Boyle: Okay.

Dr. Dawson: So, Sue, this is a funny question, but how much—I mean, do you feel like you can pretty much represent Cathy Lord's perspective, or do you feel like that there's, you know, some very important kind of extra knowledge that she would bring in?

Dr. Swedo: I think I can represent it, as long as we can work the way we have here, where we—Coleen's outline was very helpful. And as we are moving forward, if we could just have opportunities to get the input from folks. There were many members of the Committee that argued different of these points.

As we were talking today, I was having different voices in my head. So, I'm happy to reach out to Cathy in that regard, as well as Bryan King and Joe Piven and all the other

folks.

Dr. Dawson: So, you can really consult them as needed. So, it sounds like maybe having Amy and someone from ASHA on?

Dr. Boyle: Geri, my thoughts about Laura Carpenter, she's the PNI that's working on that translation for the ADDM/Autism Speaks project in South Carolina, so, you know, around this issue she might be, particularly, helpful.

Dr. Dawson: When don't we, unless people have other suggestions—and we can always add later—but maybe consider asking those three folks. Would that be okay, Susan? Can we do that?

Dr. Daniels: Yes. It will be little challenging, of course, getting all of those people to have the same time on their schedules free. So we'll have to work on finding a time that works.

Dr. Dawson: Yes, and, you know, it may be that we just have to have—we have to just kind of go on with, you know, 80 percent of

the people at any given time, you know, because I just think sometimes it becomes impossible.

But, you know, Laura Carpenter, Amy Wetherby, and then maybe I can ask Larry whom he would recommend from ASHA.

Dr. Daniels: Right.

Dr. Kavanagh: Geri, did you say that somebody from CMS is already part of the work group but just wasn't able to make it today?

Dr. Daniels: John O'Brien

Mr. O'Brien: I'm on the line. Sorry, I joined a little bit late.

Dr. Dawson: Oh, John, hi.

Dr. Kavanagh: Oh, great.

Dr. Dawson: Glad you're here. If we had known you were here, we would have been picking your brain.

Mr. O'Brien: Well, you know, I'm not a clinician by trade, so that could be dangerous. (laughter)

Dr. Dawson: Well, anyway, next time we'll look forward to getting your input.

All right, folks, well, it's 12:30. I think this is a good start. And so, Susan, you'll organize our next call for us?

Dr. Daniels: Yes, I'll be in touch about a call and trying to find a time that works for at least a good portion of the group. There were some people who couldn't be on today's call, and we'd like to, hopefully, get them back in on the next call.

Dr. Boyle: This is Coleen. I just want to make one suggestion, that the next time that we make sure that at least one of the self advocates—the time works for at least one of the self advocates, since we haven't heard that piece at all in this conversation.

Dr. Daniels: Right. Originally, John Robison was going to be on this call.

Dr. Boyle: That's right, that's right, I apologize, yes.

Dr. Dawson: He may have had a conflict that came up at the last minute.

Dr. Boyle: Okay.

Dr. Daniels: Okay, well, then thanks so

much, and we are adjourned.

(The call was closed at 12:30 p.m.)