

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

TUESDAY, NOVEMBER 27, 2012

The Subcommittee met via webinar at 11:00 a.m., Eastern Standard Time, Denise Dougherty and David Mandell, Co-Chairs, presiding.

PRESENT:

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PRESENT (continued):

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JOHN P. O'BRIEN, M.A., Centers for
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LYN REDWOOD, R.N., M.S.N., Coalition for
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In many cases throughout the transcript, two or more speakers began to speak at one time, causing interruptions. When this occurred, it was denoted by dashed lines.

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PROCEEDINGS

11:06 a.m.

Dr. Daniels: Hi. This is Susan Daniels from the Office of Autism Research Coordination. Welcome to everyone in the public and to our Subcommittee members.

We are looking forward to having this call today to talk about the 2012 update to the strategic plan. Dr. Tom Insel, Dr. David Mandell, and Denise Dougherty will be leading this call. And we'll be discussing chapters 5 and 6 of the strategic plan.

I have a couple of quick announcements to make. There will be an IACC Full Committee meeting on December 18th by teleconference. And we will be holding an in-person public comment period here at NIH. All the details will be posted on the web. So it will be mostly by phone, but there will be an in-person public comment period for those who may wish to give oral public comment. And that public comment period will be webcast

live, so that all of our Committee members and members of the public can watch it on their computers.

We will also be having a meeting on Tuesday, January 29th. And that will be a Full Committee meeting in person here in Bethesda. And more information about that meeting will also be posted soon. I just wanted to let you know about that so you could make note of it in your calendars.

At this time, I would like to turn things over to Drs. Insel, Mandell, and Dougherty.

Dr. Insel: Okay. Do we need to do a roster of who is on the phone?

Dr. Daniels: Yes. We do need to do roll call. The other item I would like to mention is as people are speaking on the phone today, please identify yourselves so the transcriptionist knows who is speaking.

Let me quickly go through the list to do a roll call. Tom Insel is here. Denise

Dougherty?

Dr. Dougherty: Yes. I'm here.

Dr. Daniels: Thank you. David

Mandell?

Dr. Mandell: I'm here.

Dr. Daniels: Laura Kavanagh?

Ms. Kavanagh: I'm here.

Dr. Daniels: John O'Brien?

Mr. O'Brien: I'm here.

Dr. Daniels: Larry Wexler?

(No response.)

Dr. Daniels: Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: Idil Abdull?

Ms. Abdull: Here.

Dr. Daniels: Jim Ball?

(No response.)

Dr. Daniels: Not here. Anshu

Batra?

(No response.)

Dr. Daniels: Not here. Sally

Burton-Hoyle?

Dr. Burton-Hoyle: Here.

Dr. Daniels: Jose Cordero?

(No response.)

Dr. Daniels: Not here. Jan Crandy?

(No response.)

Dr. Daniels: Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Scott Michael

Robertson?

Mr. Robertson: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: I'm here.

Dr. Daniels: Great. So we do
have a quorum. And so we can begin.

Dr. Insel: Thank you, Susan.

This is Tom. Let me just quickly
welcome everybody. And I will turn this over
to David and Denise in just a moment, but I
wanted to make some introductory comments.

We had a parallel meeting
yesterday for questions 1, 2, 3, 4, and 7.
And so today it is to finish up with 5 and 6.

In that meeting, similar to this one, we were trying to make up in some ways for lost time because we lost the discussion we were hoping to have during the days that Hurricane Sandy hit the East Coast.

So much of what we will have to get through today we had hoped to do in a face-to-face meeting. And this is not ideal, but at least it's one way of trying to get to the end game. And the end game is really to have an update of the plan that will be completed by our next meeting in December 18th of the full IACC. And we can vote on the full update and then to have that ready to go to Congress before the end of December. So what we want to do today is to look at questions 5 and 6, in the draft form that they're in now -- and I know a lot of work has gone into this and I've seen these in various iterations and I can tell you that these have changed probably more than any other part of the plan. But what we need from you is a really careful

look at this to make sure that we're capturing what you want as a Subcommittee to take to the full Committee in December. We will, in fact, ask you to vote on each of these and get a sense from the group about whether there is consensus and if there isn't, where the areas are that we'll want the full Committee to discuss further in December.

Let me say also by way of introduction as we did for the other questions yesterday that we want to the extent possible to really keep this update focused on what are the major breakthroughs in research or very high impact changes in policy, reminding all of you that this is for the research strategic plan.

So what we're really talking about are the issues that impact the science of autism. There will be a whole other effort around the services agenda. And some of that has a lot to do, obviously, with policy.

But here it is really asking what

has changed in the last 18 months. We want to keep this at a very high level. One might argue that these could be very, very short chapters as a result. And I think they have become rather short.

We don't want to reiterate what is in the plan. There is no need to restate what is already there. We don't want to rewrite the plan. There may be interest in doing that next year. But this is simply to ask what is new since January 2011 and what are the new gaps that that new science has opened up for us.

One other point about this that became clear as we were talking about, especially about the biology yesterday, was that some of the most important innovations or most important breakthroughs of the last 18 months are not directly about autism but about other changes that are happening in this case in biomedical research, new tools that have been developed, new insights based on the way

that a field like genomics or microbiomics or proteomics has evolved.

And although these are not yet being applied to autism, they certainly suggest new opportunities. And so some of those have ended up being inserted into the gaps sections for questions 1 through 4 especially, and to some extent in question 7.

I'm not sure that will come up today for questions 5 and 6, but I thought I should put it on the table because the way this has happened, I think understandably, is that people look at what has been published in the autism literature and want to capture that as what is new.

I just want to encourage you to think beyond the autism literature to recognize what is happening broadly that might be relevant and could become even more relevant in the next year or so if we encourage people to go there in the gap section.

Now, those are the framing comments I wanted to make. Let me, before turning this over to David and Denise, ask if there are any general questions about the goal of today's meeting or the process that we're undertaking.

Dr. Ball: This is Jim Ball. I have joined the call.

Dr. Daniels: Thank you.

Dr. Insel: Okay. Welcome.

(No response.)

Dr. Insel: All right. Hearing none, David, Denise, it's all yours. And we'll want to walk through these fairly quickly, just to make sure that people understand what has now been included and get a sense of what areas may need a little more clarity or whether there are missing pieces here that need to be reconsidered.

So I'll turn this over to both of you. And I don't know how you want to divide it up between questions 5 and 6, but I'm sure

you will have a good way of doing that.

Dr. Dougherty: David, you should go, right, because you took the lead on putting these together --

Dr. Mandell: Sure. So I want to --

Dr. Dougherty: -- with all the input of the experts and others.

Dr. Mandell: Right. To build on what Tom had said, I think that when we started this as a group, a lot of people expressed frustration with the scope and priorities of the way the chapters 5 and 6 have been written to date. And, really, I think we all took this as an opportunity to rethink what those chapters and what the services research agenda and the research agenda around adults with autism should look like.

And I want to assure everyone that that work will still be incorporated when we go to develop the next strategic plan. And

Tom and I have talked about this a lot.

In the interim, our task at hand is much more narrow, which is to look at what the research updates should be based on what has come out since the last update was done.

And so to do that, I took all of the hard work that people had done and took what had been done really in the last 18 months and tried to do it in a way that would fit within the organization of chapters 5 and 6 and the organization of the way the updates have been done to date.

So what you see -- and hopefully you have all had a chance to read it -- are two drafts, one for chapter 5 and one for chapter 6, that try to incorporate those new findings into a way that both is consistent with the previous chapter but also begins to hint at some of the things we might like to see expanded or changed in the next version of the strategic plan.

So I think probably the best way

to do this is to do it chapter by chapter. So to go through the draft for chapter 5, to have some discussion, think about whether there are changes that we want to make, and then to vote on that as a Subcommittee and then to move to chapter 6.

Susan, is that the right process?

Dr. Daniels: Yes. That sounds good.

Dr. Mandell: Okay. So for the draft for chapter 5, Denise and I tried to break it into, as you can see the heading, issues related to access and payment, translating research into practice, disparities, wandering and elopement, seclusion and restraint, mortality and family support, which I lined up not exactly with the smaller workgroups that we had come up with, but I think incorporates the work that each of them had done.

I am hoping that everyone has read it. So, rather than go into detail and read

sections to you, what I would rather do is open it up and ask if there are any questions or comments, things that people feel are missing or things that people feel are redundant, either with each other or with the previous updates.

Dr. Insel: David, this is Tom. There is a comment in here. Since it is mine, I guess I will just start with that one. It's in the first paragraph under "Access and Payment."

Can we provide a number that goes with the 45 percent of children with ASD received Medicaid-reimbursed services? Beyond the percentage, is there an actual absolute number that could give the reader a sense of what that looks like?

Dr. Mandell: Absolutely, absolutely. I can add that number in. Sorry.

I didn't realize that that's what you meant by "number." It's kind of evident now, but --

Ms. Abdull: Hi. This is Idil. I

was wondering if it's possible to -- and I don't know. Maybe that number that Dr. Insel was talking about would cover it. So we know how many states had state-regulated private insurance paying for access to services for autism. But do we know how many states also have for Medicaid, whereby Medicaid pays for it, and what they are, because it varies state by state?

Dr. Mandell: What are you referring to when you say, "pays for"? Do you mean that they --

Ms. Abdull: For early intervention. Some states, from what I found out, is that some states have -- they pay for early intervention services such as ABA or floor time. And most don't pay, but there are about 12 or 13 states that pay for it, either by having the 1915(i) Medicaid waiver or an autism-specific waiver, like Wisconsin and Pennsylvania have it, sort of like the way it lists 30-plus states that have private

insurance. I wonder if there is a way to list how many states whereby Medicaid has the same thing that the private insurances are paying for in terms of early intervention services.

Dr. Mandell: Sure. There are nine states with autism-specific waivers. There are many more states that have waivers that are not specific to autism but cover autism as a target group. To try and figure out in those waivers, I don't know that there has been any published research that looks at whether there are behavioral interventions specific to autism that are covered in those not autism-specific waivers with autism as a target group.

Ms. Abdull: Right, right. Yes. There isn't. So that would be like -- I don't know -- maybe a gap.

Dr. Mandell: Sure.

Mr. O'Brien: David and Idil, this is John. I wanted to remind folks that we do have a document in progress that is really

looking at some of what states are covering. And I can go back and look at the level of detail that we're getting from the contractor.

Some of it is exactly what David is saying, which is: here are the various Medicaid authorities that are using specific for individuals with autism and even provide details of the extent to which it's focusing across the lifespan or on specific ages.

I'll also look to see whether or not they have done some review of some of those other 1915(c) waivers, in particular, that are focusing on larger populations, of which autism is one of them, to see whether or not they are teasing that out as well.

But, again, that is something that we are working on, should be available sometime next year.

Ms. Abdull: Okay. Thanks, John.

Dr. Insel: David, another question. There are several manuscripts in press, including at least one of yours. Are

those out by this point or -- can we cite? I know I think the Perrin one may be out, but I'm just hoping that since we are going to take this to -- we want to finalize this by the end of December. Do we know whether those will be out in 2012 or --

Dr. Mandell: I will call the journals to find out. And if they're not, I will remove them from the report.

Dr. Insel: Well, I mean, I am not sure you have to remove them, but it would be great to have a final reference if they're available.

I wouldn't take it out if it's not in 2012. I just know noticed that we had the same thing happening yesterday on some of the questions. And, amazingly, a bunch of the papers were -- three papers came out yesterday in the Archives of General Psychiatry that we had to revise. And several of us worked last night to capture all of those.

So I just wanted to encourage

anybody who knows about something that is in press or that is going to be out, a) we get a final citation if it's out in December and b) if not, make sure that we know that we can still include it as in press.

Dr. Mandell: Okay.

Ms. Redwood: Hey, David, this is Lyn Redwood. I have a comment about the very last paragraph regarding the findings of wandering and elopement. And it has that it suggests "the urgent need to develop and test specific interventions to improve safety for individuals with autism, either by directly intervening with the individual or indirectly through training the first responders." And I was wondering if that "or" could be changed to an "and."

Dr. Mandell: Sure. Absolutely.

Ms. Redwood: Because I really think that needs to be both.

Dr. Mandell: Okay.

Ms. Redwood: And thank you for

including that in there. I think it's very important.

Ms. Singer: So this is Alison. I want to make another comment on that same paragraph. I agree with Lyn about the "and."

And I am also hoping since there were three suggestions that fell out of that study, I was hoping at the end of the sentence, we could add "through training of first responders, and the broader community" so that that would speak to the efforts to establish the AMBER Alert.

Dr. Mandell: Good. Sure.

Dr. Rice: This is Cathy. To add onto that, that language that you just suggested, Alison, also could be wider in terms of health care providers than educators as well, that that could encompass that also.

Ms. Singer: Great catch.

Ms. Redwood: That's a good point because I think pediatricians should be trained too to ask those types of questions

when they're making the diagnosis of autism or seeing a child with autism.

Dr. Mandell: So how about if the clause were to add "either by directly intervening with the individual and indirectly through training the first responders, health care professionals, educators, and the broader community?"

Ms. Singer: Great.

Ms. Redwood: That sounds good. Was there any reference to the new diagnostic code for wandering and elopement that was established? That might be something else to put in there as well.

Dr. Mandell: So how would it fit within the framework of a research agenda?

Ms. Redwood: Well, it is an update, too, on services, right?

Dr. Mandell: Well, so I think what Tom had said earlier, and I think what was sort of in the general theme here, is that these updates are really supposed to be about

factors that relate to research findings or indicate the need for additional research and that there will be a separate initiative about services.

Dr. Rice: Yes. This is Cathy.

One of the reasons that the code was approved, in terms of the utility of the code, was not only the service potential benefits but also for data collection, in that if it is a diagnosable -- or not diagnosable but a recordable code that goes along with wandering, it would hopefully improve our ability to collect some data on how prevalent it is, even though it would be an under-count but at least it would be a start. That is one potential connection to research, is that it be having the code lay that very initial foundation to be able to use that code for future research.

Dr. Burton-Hoyle: This is Sally, Sally Burton-Hoyle. I have a comment. And I don't know quite how it could be worked in.

It could be worked in I think with just a word or two regarding the gaps in regard to family support.

Dr. Insel: Before we go there, Sally, can we just finish up on the wandering/elopement issue, because I think --

Dr. Burton-Hoyle: Oh, sure, sure. Sorry.

Dr. Insel: What I am hearing is some interest in the first part of this; that is, in what is new, including a mention of the new code because of its value in collecting data on wandering and elopement. Am I capturing that right?

Dr. Mandell: I think that's right. And Cathy's point was examining its utility for surveillance.

Dr. Insel: Okay. Any other concerns about that or if there are -- is there any reason not to include it since it does provide us -- it's something new. And it is actually something the IACC has been

invested in. And it does provide a data source that wasn't there before.

Dr. Mandell: Well, it actually may not be as much a new data source as a new data element within existing sources.

Dr. Insel: Okay. Maybe that's an important distinction, too. I was about to ask somebody to craft a sentence under wandering/elopement to capture this. Who wants to volunteer to do that?

Ms. Singer: I'll do it.

Dr. Insel: Okay. Thank you.

Ms. Singer: I just want to understand that we would not include -- is my mute on?

Ms. Redwood: I am sorry. Who volunteered to do that? We couldn't tell on the phone.

Ms. Singer: Oh, it's Alison. I think my mute was on.

Ms. Redwood: Oh, Alison. Okay.

Ms. Singer: I have another

question. So we would not want to include the fact that the ICD-9 code was a direct result of research that came out of an IACC meeting?

I mean, to me, that's a great example of the power and value of the IACC. It is a direct result of research. I think to me and hopefully to the broader readership, it would indicate a practical value of research, which is often a criticism that parents bring to the table.

Why would we not want to include that?

Dr. Insel: I think we are including it, right? I haven't heard anybody who's suggesting we not include it at this point.

Ms. Singer: Okay. So when I write that paragraph, I'm going to write those two points, that "as a result of the wandering study, a new ICD-9 code was created and that the ICD-9 code will enable us to track and determine prevalence of wandering."

Dr. Rice: This is Cathy. I think just in terms of the specifics of the timing, that the code was actually established first as the result of the community concerns as well as the informal data that was brought to bear at the IACC meeting, which then led to both the code and the study.

Ms. Singer: So, Cathy, we are going to write this paragraph together, I think.

Dr. Rice: Sure, sure. No problem.

Dr. Insel: And it may not need to be a paragraph. It sounds like two sentences will capture what --

Ms. Singer: Or one. We can do it in one sentence.

Dr. Insel: One sentence is even better. Okay.

Ms. Singer: I can name that tune.

Dr. Rice: Sounds good.

Dr. Insel: These are great

suggestions. Anything else to add or delete or edit on this?

Ms. Abdull: Hi. This is Idil.
Oh, go ahead.

Dr. Mandell: No. Just someone had brought up before, I think, something about family support that got tabled.

Dr. Insel: Right, right. We were just going down that. So let's go back to that comment about family support.

Ms. Abdull: Can I add something or ask a question about the wandering one? So, for example, -- unless we are not in the gap area yet, but -- who pays for these children to make sure they are safe?

I mean, how do we -- in Minnesota, we have this with a tracking system, but it's county by county or you have to pay extra and make sure that police in that district is trained. Is that part of a gap that we want to make sure that we not only just do the surveillance, but then we also want to make

sure that they are safe and that these children be prevented from wandering. Is that part of the gap or are we not there yet?

Dr. Mandell: So, Idil, how are you sort of thinking about that within the context of either research findings or implications or call for new research?

Ms. Abdull: Well, I mean, the research indicates that a lot of children with autism wander, right? They have no fear of safety, including mine. But to have the ICD code, it's good to do the surveillance, like Cathy said, and make sure that we know how many of these kids are actually doing this, but in terms of making -- how do we prevent that?

I'm just wondering if there is a way to say what do we have in place now, the same thing, that Life Project that we have in Minnesota. Only the other states have something else. How can we put something in the gap or in the future so that we're not

just counting them, but we're preventing these children from wandering or at least, if they do, a way to catch them safely?

Dr. Rice: Yes. I think this speaks -- this is Cathy -- to the need for additional intervention and prevention research on this issue and what is effective, what keeps children safe, what also certainly addresses concerns about the individuals' rights, and what can actually be feasibly implemented to keep kids safe.

So I think that a general statement about the need for research in terms of effective prevention and intervention.

Ms. Abdull: Right. That's it. Intervention, how do we -- what research has been done for intervention? That's good. Thank you, Cathy.

Dr. Dougherty: This is Denise. So the words in the what gaps have emerged, "findings regarding wandering/elopement suggests the urgent need to develop and test

specific interventions to improve safety for individuals with autism."

Ms. Kavanagh: This is Laura. Can we add "test-specific prevention strategies and interventions to improve safety"? Will that capture both aspects?

Dr. Mandell: Yes, sure. Okay. All right. Anything else on the wandering/elopement before we move to the family support?

Dr. Burton-Hoyle: Okay. This is Sally. Again, one point that was emphasized and reemphasized with the experts for the family support committee was getting materials in easily accessible, readable sorts of materials, to parents and other individuals, non-peer-reviewed journal sorts of things.

Is there something in that sentence in that section that would talk about that any of the information from all of the different things in this chapter could be made more accessible to parents and other people in

the community, meaning --

Dr. Dougherty: I think we meant to include that under "Additional research on effective models for supporting families."

Dr. Burton-Hoyle: Okay.

Dr. Dougherty: So you can do research on how to create user-friendly documents, right?

Dr. Burton-Hoyle: Okay.

Dr. Mandell: That was the hope, I think.

Dr. Dougherty: Yes.

Dr. Burton-Hoyle: Okay. That's good. Okay.

Dr. Dougherty: Thank you. We are trying to stick within a word limit.

Dr. Burton-Hoyle: I know. I know.

Dr. Mandell: Okay. Other questions, concerns, or comments about other parts of this update?

Mr. Robertson: Well, David, this

is Scott Robertson. I just had a comment also on the family support area.

Dr. Mandell: Yes?

Mr. Robertson: The sentence, one sentence, in there says British researchers found that the level of unmet need for young persons with ASD was associated with excessive caregiver burden.

Dr. Mandell: Right.

Mr. Robertson: Is there any way you could provide a little more specifics in terms of what is excessive caregiver burden standardized terminology in the health care literature in terms of does that refer to something more specifically or is there something, you know, in terms of the current state of what that -- you know, that seems very fuzzy to me what excessive caregiver burden refers to.

Dr. Mandell: I think that's a good point. I don't have that paper in front of me right now, but I will go back to it and

clarify that.

Mr. Robertson: Okay. Great.

Dr. Insel: This is Tom. That's a great point. I think we should look at that language. Even if that's the language that's used in the paper, we may want to think about finding a different way to describe this.

Dr. Mandell: Sure.

Dr. Insel: Anything else in this chapter?

Ms. Abdull: Hi, David. This is Idil.

Ms. Redwood: Go ahead, Idil.

Ms. Abdull: Oh, no. You go ahead.

Ms. Redwood: I just had a question in the gap because the paragraph that starts with "The recent findings regarding lack of quality in positive outcomes for community-based care." And then it goes down to say that there's a recommendation that quality measures can be developed. I'm just

wondering if we should use a little bit stronger language, instead of "can be," like "should be" developed --

Dr. Mandell: Sure.

Ms. Redwood: -- or do people feel that that is too prescriptive?

Dr. Mandell: I think we should be prescriptive.

Ms. Redwood: I agree. That was all.

Dr. Mandell: Okay.

Ms. Abdull: Thanks. That's what I was going to say except I was also going to ask about -- I'm sorry. This is Idil. I was going to ask about the -- when we talked in the other group before the full Committee, we talked about the cost and the burden, the financial burden or maybe even the emotional burden of families that are caring for children with autism and the little research that has been done says that it costs millions and millions of dollars.

I just wonder if we think that's enough research done or if we can -- if that would be also part of the gap because it doesn't just affect even just the mom and the dad. It really does affect the whole family.

And it takes a toll financially and emotionally on families.

Dr. Mandell: So as someone who has done a bit of that economic research, I would argue that where the research needs to move is towards understanding the extent to which specific interventions and support reduce overall family system and societal costs, rather than --

Ms. Abdull: Okay. Rather than tell us how much it costs to reduce it because, at least in some in our community, not just the financial but some of these parents are getting heart attacks or themselves mental health conditions or strokes because of the stress of these children.

So to reduce that for the family

and then to have some steps, you know, to have some -- what needs to be done to reduce it, do we need more family support? Do we need more waivers? I mean, we need to be more specific and do research in how do we reduce family burden and increase family support.

Dr. Insel: Idil, this is Tom. I hear you. It's actually in the plan already, in the 2011 version, quoted "an initial part of this process is the assessment of needs and costs." And it goes through to spell out what those might look like. So I am not sure we need to repeat it if it is already in the plan.

Ms. Abdull: Right, right. You're right. You said let's not repeat what is already in the plan, but it hasn't gotten better, right, Dr. Insel? So I guess my question is, what can we do now to make sure it gets better and that families are not being stressed out continuously?

What is missing in the research

gap? If we know the problem exists, what do we need to do to enhance that and get rid of that problem, at least decrease it, if that makes sense?

Dr. Rice: Yes. This is Cathy. I don't know if this is a place where research on how systems of care could be better coordinated and research into coordinated systems of care fit in here and somewhat address Idil's point.

It doesn't speak specifically to stress but whether that actually eases some of the caregiving challenges that families are facing. And that could be a research-oriented type question and something that reflects work that's going on.

Ms. Abdull: Yes. No. That's good. I think coordination is good, but I just wonder also do we even know what helps. I have yet to see anyone that tells me "This is what is going to help."

So I just think if we know the

problem exists, we need to come up or do research on what could help, what interventions do we need to start or come up with or change the systems that would help these families so they themselves are not having secondary chronic conditions because then that only adds to the financial burden.

Dr. Mandell: Well, I --

Ms. Abdull: I am sure I not articulating this well, but I think those that are parents get this thing.

Dr. Mandell: I think that what you're talking about certainly fits in with -- I mean, part of it is it sounds like when you say, "what helps," you are specifically referring to family well-being.

And certainly we have one sentence, "Additional research on effective models for supporting families is sorely needed." And perhaps we're doing that section a disservice and need to expand that a little bit.

I would want to try and be it. If we were going to be prescriptive, then we should also be specific.

Ms. Abdull: Right.

Dr. Mandell: And so I would want to figure out how to do that in a specific way that builds on existing research.

Ms. Singer: This is Alison. And I think, Idil, what I am hearing you say is great evidence for why the IACC needs to take on writing a service delivery plan in parallel to the services research plan. I think that's something that as a full Committee, we have to decide that we are going to invest energy and effort towards because I think it comes up constantly. And I think it is the logical next step from updating the research to provide a road map for what we have learned from the research that can instruct service delivery.

Ms. Abdull: Well said. Thank you for being in my mind.

Dr. Insel: Alison, this is Tom. Can I ask you to bring that up in December at the full IACC meeting? I think this is a conversation we need to have with the full Committee about how we want to proceed next year. We won't be able to do it in this venue, but it's really a good topic for us to think about collectively.

Ms. Singer: Yes. I would be happy to as long as Denise and David won't hate me forever.

Dr. Dougherty: Not at all.

Dr. Insel: You don't have to name names. That would be fine. That would be great.

Dr. Mandell: It would be pretty unlikely that we will hate you forever.

Dr. Dougherty: Yes.

Dr. Mandell: Yes. All right. I am going to suggest that we vote as a Subcommittee on this update for chapter 5.

Dr. Insel: Before we do that,

let's have Susan review what the changes are so people will know what is in the hopper here and they can hear. If you could just review for us what we have heard so far, in the way of suggestions?

Dr. Daniels: Sure. So the changes that I heard were in the second paragraph on the first page that David is going to add in a number to go along with the 45 percent. Towards the bottom of that page, that last paragraph, we're just going to check all of those in-press articles and see if any of them have been published yet and update as needed, but we'll leave in press there if they have not been published yet.

On the second page, in the wandering and elopement section, Cathy and Alison are going to work on some language about the ICD-9.

On that same page, in the family support section, David will clarify the language about excessive caregiver burden.

On the third page, in the second paragraph, there is a language change.

"Quality measures can be developed" will be changed to "Quality measures should be developed."

And in the second to last paragraph, findings regarding wandering/elopement suggests the urgent need to develop and test specific prevention strategies is going to be added and interventions, to improve safety for individuals with autism. I would suggest striking "either" because there is not an either/or anymore "by directly intervening with the individuals and indirectly through training of first responders, health care professionals, educators, and the broader community."

So those are the changes I heard.

If there is anything else that I missed, let me know.

Ms. Redwood: Hey, Susan, there

was just one other one that I didn't get a chance to mention, but it's in that same paragraph where the "can" is going to be changed. It says, "may be required." And that's in the very last sentence of that paragraph. And I'm wondering if that could also be changed to "will be required" from "may be required."

Dr. Daniels: The Subcommittee, how do they feel about that?

Dr. Mandell: I like that in our --

Dr. Daniels: Okay.

Dr. Mandell: -- in our new, more assertive --

Ms. Redwood: Thank you.

Dr. Daniels: Those are the changes. So then you can go ahead and --

Dr. Insel: So you need a --

Dr. Daniels: -- vote on it.

Well, if they're fairly unanimous, we don't need to go name by name, but if they aren't,

then we'll have to go down the list.

Dr. Insel: So can I make a motion that this be accepted?

Ms. Singer: Second.

Dr. Insel: Any seconds?

Ms. Singer: Second.

Dr. Daniels: All in favor?

(Whereupon, there was a chorus of "Ayes.")

Dr. Daniels: Any opposed?

(No response.)

Dr. Daniels: Any abstaining?

(No response.)

Dr. Daniels: The motion carries to accept this chapter with the changes described for submission to the full Committee on December 18th.

Dr. Insel: Great. Let's go on to question 6. Denise, are you going to take us through this one?

Dr. Dougherty: No. I think David is.

Dr. Insel: You're on a roll,
David.

Dr. Dougherty: He's the first
author, senior author.

Dr. Mandell: I have been put on a
role.

Dr. Dougherty: I mean, I am glad
to if he wants me to, but -

Dr. Mandell: No. That's fine.

Dr. Dougherty: Okay.

Dr. Mandell: So the same thing
holds for this chapter as the previous one.
We attempted to take what people in the small
workgroups have done that is relevant for
adults, which was, frankly, most of it, and
put it in the context of an update,
understanding that we were building from what
is in the chapter already and what the addenda
were already, divided into the categories of
diagnosis, epidemiology, quality of life and
functional outcomes, and service use, and then
try to develop to highlight gaps that related

to those areas.

You'll notice that the gap section is not that long. And, frankly, that's because in the chapter, a lot of the gaps that relate to these areas have already been highlighted. It's just that there was some new research in those areas that we thought was worth noting.

So, with that, I'll open it for questions and comments.

Dr. Ball: Hi. This is Jim. Just a real quick typo fix. Under "Diagnosis of ASD in Adults," right after the Ritvo citation, I think it should only be "but only one instrument."

Dr. Mandell: Thank you.

Dr. Burton-Hoyle: I have two other minor editorial changes at the top of page 2, "Notably, a randomized trial conducted by Gantman, et al., found that," strike "which."

Dr. Mandell: I am sorry. Tell me

again where that was.

Dr. Burton-Hoyle: I'm sorry. The top of page 2, the sentence starting, "Notably, a randomized trial," under "Quality of Life, Functional Outcomes" --

Dr. Mandell: Okay.

Dr. Burton-Hoyle: -- but on the second page. Just strike "which." "The study found that their."

Dr. Mandell: Thank you.

Dr. Burton-Hoyle: And then under "Service Use," the second or the last sentence, I think it should be "The study also highlights the critical importance of Medicaid entitlement."

Dr. Mandell: Yes. This one was very late at night.

Dr. Dougherty: This is Denise. Actually, under "Service Use," the third line down, I wasn't clear what functional therapies are. And I just did a Google search. And in the U.K., they include specialist massage and

pilates techniques to release stiff, tired, aching muscles, which appeals to me. So I'm headed over there after this call.

Dr. Mandell: I guess sometimes they are referred to as neurodevelopmental therapies also. I was thinking about speech therapy, occupational therapy, and physical therapy.

Dr. Dougherty: Maybe spell that out.

Dr. Mandell: Okay.

Ms. Singer: Can we say habilitative? Is that correct?

Dr. Mandell: In this context, it certainly would be, I think.

Dr. Rice: This is Cathy. I have a question under the "Diagnosis of ASD in Adults" and the second sentence saying, "But only one instrument was tested in an unselected community sample." The reference -- it would be good to have the reference of which one of these represented the one that

was tested.

I imagine the Brugha -- is that about the validity or does that just refer to the instrument?

Dr. Insel: Brugha refers to the unselected community sample.

Dr. Rice: Yes. That's what I thought. But just adding the reference of which of the four referenced above was the one tested in the community sample.

Dr. Mandell: Yes. That is very confusing. Thank you.

Dr. Dougherty: This is Denise again. I'm sorry to add this, but I see that we really don't mention and maybe it should be a gap. We don't mention disparities. So maybe a gap that needs to be investigated is disparities in the adult population.

Dr. Mandell: So mention it specifically under the gaps?

Dr. Dougherty: Yes.

Dr. Mandell: Okay.

Mr. O'Brien: And, David, this is John O'Brien. Along that same line, I didn't know if there was anything in the epidemiology of the section. You had mentioned that the study that found that individuals with ASD were considerably socially disadvantaged, but whether or not there was either a few more words or a sentence that actually could highlight what that meant or if there was anything specific around race or ethnicity that was available to highlight in that section?

Dr. Mandell: The epidemiology one?

Mr. O'Brien: Yes.

Dr. Mandell: It was really -- so the differences there were really about social and economic capital, which those are the social disadvantages, not that they came from traditionally disadvantaged groups.

Mr. O'Brien: Okay.

Dr. Mandell: But I can clarify

that.

Mr. O'Brien: That might be helpful to clarify it.

Dr. Mandell: Sure.

Dr. Insel: And, David, that was the Brugha study. So that's a U.K. sample, right?

Dr. Mandell: Yes. Right. And I can add that, too.

Dr. Insel: Can you go back to the previous comment? I'm not sure I quite understood the issue about putting something in the gap related to the health disparities.

This is covered nicely under "Service Use."

In terms of the gaps, what specifically -- some of that is covered in the previous chapter, of course, where we talked about, just talked about, gaps that have emerged. Is there something relevant to adults that we should put into the gap section here? How do you want to --

Dr. Dougherty: This is Denise. I

suggest it just seems as if when we are doing -- since there are so many gaps in the adult research literature, that when that research takes place, that we be sure to identify any disparities. And sometimes if that is not said explicitly, it gets lost.

There may not be any disparities.
I would be surprised.

Dr. Insel: Can I just suggest -- again, this is Tom.

Dr. Dougherty: Yes, sure.

Dr. Insel: I agree it's important to know about them. I guess I would rather see the gap focused on how to close those disparity gaps, that the research need is to figure out how to fix it, not so much how to define or simply to describe it.

Dr. Mandell: The sentence I was starting to craft as people were talking about it was "More recent community studies have highlighted disparities in service use and outcomes among adults, similar to what has

been found in children, highlighting the need or suggesting the need for interventions to reduce disparities in this age group as well."

Dr. Insel: I like that. That's great.

Ms. Abdull: I like that, too, actually. This is Idil. You are right, all of you, Tom, David, and Denise, that we know disparity exists, but what we don't know, whether it is early intervention or adults, is how to reduce it, what interventions should we take, whether it's national level or statewide, to reduce it or even which agency should do it. So I like that.

And then I also have a question about on the adults, the quality of life. I know it says ASD, which should cover across the spectrum, but I feel as though people who are nonverbal or are on the severe end of the spectrum are not doing as well as people on the other side of the spectrum.

And I wonder if there is a way to

put that as the gap. And we need to figure out how to help them while they are part of the ASD. They're not able to talk for themselves. So they often get left out

Dr. Mandell: So do you want me -- so how would you like me to highlight that under --

Ms. Abdull: So on the gaps on nonverbal autism or people with -- I don't like the word "low-functioning" because just because someone is not talking doesn't mean they're not intelligent, but just have a better way for them to have a better quality of life.

A lot of times text or the augmentative communication devices are only used for children. And I think it's important to teach those, even adults, the iPad. A lot of times a lot of people don't use, you know, try to teach these adults how to communicate through the iPad or through text or through something. And I think not enough research

has been done to make sure their functional outcome meets their best outcome.

And so I'm not sure exactly how to articulate this. I can send that to you. But we need research that would enhance their quality of life by making sure that they have the whole thing, whether it's the communication or whether it's just the quality of life, whether it's just even safety things.

Dr. Mandell: Sure. So one of the things we can do is point out that much of the research that has been done among adults has been done among those who are --

Ms. Abdull: High-functioning.

Dr. Mandell: Well, I wouldn't use that term.

Ms. Abdull: Right, right.

Dr. Mandell: We may need specific research on strategies to improve functional outcomes among nonverbal adults as well.

Ms. Singer: I don't know if I'd use the term "nonverbal." We've been using

"severely challenged."

Dr. Mandell: Okay.

Mr. O'Brien: Or more challenged.

Ms. Abdull: Or more challenged,
yes, just something, yes -

Mr. Robertson: This is Scott
Robertson. One clarification that I wanted to
put, particularly on communication, is the
term "nonspeaking" or individuals with
significant, say, communication challenges are
terms, phrases like that, are more preferred
to nonverbal, but "nonverbal" is kind of
outdated.

Dr. Burton-Hoyle: Right.

Mr. Robertson: But I don't think
that the other ways it was mentioned as
specific to -- I mean, we're planning the
communication. So it should be specific to
communication if you're talking about someone
who uses, for instance, augmentative or
alternative communications.

Ms Abdull: Right, right. And so

--

Dr. Burton-Hoyle: The term "nontraditional communication" is something I use a lot myself.

Ms. Abdull: Which one of those do you like, David?

Dr. Mandell: I don't like "nonverbal" because I think that there are people who do very well without speaking.

Ms. Abdull: Right, right, right. But just communication. You're right. My son is one of them. He can communicate very well with iPad, but it's important that we give them the tools to communicate, even if they're adults. And I think that's important. That improves their quality of life.

Dr. Mandell: All right. So how about do we want to make it specifically about communication? I mean, that is one domain, but --

Ms. Abdull: I think if we put "communication." I also like Alison's that

people that are challenged because they could have other -- they could also be severely challenged in many areas of the spectrum.

Dr. Mandell: I would be comfortable with more challenged. I don't know. Are other people comfortable with that?

I don't want to be the arbiter of this.

Mr. Robertson: This is Scott Robertson. I would be more comfortable if it's in the sense of support needs, the individuals who do need the more extensive support needs, rather than -- because to me the phrase, you know, "more challenged" is basically just another way of saying, you know -- high and low-functioning language. And that's really more terminology that doesn't really necessarily relate to the practicality that individuals are challenged in the sense that they require more supports for difficulties they experience.

Dr. Mandell: So you are suggesting among adults with greater support

needs?

Mr. Robertson: Yes, yes. I would think that would be a better way to describe it.

Dr. Mandell: All right. That's what I've got.

Dr. Daniels: David, where are you going to add that language? Was that going to be somewhere in "Quality of Life"?

Dr. Mandell: I was going to add it under the gaps and talk about the fact that much of the research that had been done was on individuals who were functioning in more conclusive environments and that not as much research had been done among transitioning adults and adults with greater support needs.

Ms. Redwood: Hey, David, this is Lyn. I had a question. I haven't read the Lerner study that you cite that talks about the criminal justice system and ASD. Was it mentioned anywhere in the updates, since it's a 2012 publication, with what's new? I was

just wondering whether or not it should be mentioned there.

And then also the reference to that study -- and I don't know if this is true or not, but from the things that I've read in an online forum, many times when adults or children even with ASD run into problems with the criminal justice system. It's because the actual police officers are not trained to recognize symptoms of autism.

So when they see somebody that is exhibiting bizarre behavior and they ask them a question and they don't respond verbally and they run off, then they get tasered and drug in. And so I think part of it is just a lack of training as well.

So I don't know if that could somehow be reflected there or if that was anything that was addressed in the Lerner article itself because I have not read it.

Dr. Mandell: The Lerner article was in -- I don't have it in front of me, but

it was in the Journal of Psychiatry and Law. And it was more -- it wasn't really presenting data on the intersection between the two. It was really saying -- the Journal of the American Academy of Psychiatry and Law. And so it was really looking at the intersection of some of the behaviors that may be criminalized in certain contexts.

And so I didn't feel comfortable putting it in the new research side because I didn't really see it as research as much as sort of a review and opinion, which is why I used it to justify the gap.

Ms. Redwood: Were there any specific recommendations that came out of that that could be acknowledged in a sentence too from that article?

Dr. Mandell: I can go back to it and look. I mean, for the next update, I do know that there are like three or four articles currently under review that have not been accepted for publication that are about

this intersection of the criminal justice system and people with autism that do present data. And so I think that soon we will have data here, but I will look at the recommendations in that article and see if there are some that are germane.

Dr. Rice: David, this is Cathy. There is one paper published on children from South Carolina on the intersection of people with autism and the criminal justice section.

I can send that to you.

Dr. Mandell: That was the one that was out of the ADDM site that did that?

Dr. Rice: Yes.

Dr. Mandell: Right. Yes. Okay.

I would appreciate it if you would send it to me. But yes, it was about kids.

Mr. Robertson: David, this is Scott Robertson. I did have one comment related to that, the criminal justice mention there. Is there any way to put more balance on there that we don't have great research,

both on autistic people within the criminal justice system but also in terms of, you know, who are victims of crime as well, not just criminals but victims of crime, that there should be balance, because it's almost -- the way it's phrased there almost implies an association between -- you know, that we are looking at association between the two. And the reality is that we don't really understand, you know, on both sides of the ends, you know, the extent of which autistic people as well can be victims of crime, too.

Dr. Mandell: Sure. That's a very good point. I added it in.

All right. Other comments or suggestions?

Mr. Robertson: Yes. This is Scott Robertson again. I also had a comment on the quality of life. Is there any way to phrase significantly differently the sentence about sheltered workshops? It says that Cimera and colleagues in 2012 found that

sheltered workshops' most common strategy to enhance employment outcomes for adults with ASD do not increase the probability of employment, despite the considerable greater expense than other vocational strategies.

There are many things I find problematic with that sentence, including the fact that I wouldn't consider a sheltered workshop a strategy. I'd say it is non-recommended by government reports, et cetera, non-recommended and recent research studies, non-recommended setting for employment in the segregated nature in terms of the problems with abuse and neglect and pain and not able to transition to competitive employment, but I wouldn't call it a strategy and related to that also that the phrase "to enhance employment outcomes," you know, it almost suggests that there were thoughts in terms of a benefit around there when the research has been showing for a while that the sheltered workshops are disadvantaging

autistic adults in comparison to integrated employment.

Dr. Mandell: So what you just said was -- actually, the point that I was trying to get across and I think that this article tries to get across, although obviously I didn't do as good a job as I thought, I mean, so it is --

Mr. Robertson: Yes.

Dr. Mandell: When I say, "strategy," I certainly don't mean to imply any value or judgment about whether it is good or bad. It is just when you look at the U.S. Rehabilitation Services Administration and you look at people with autism who are served through that system, it is the most common way that they are served.

Mr. Robertson: Well, is there a way to put that so that it does reflect that it's commonly in use but there wasn't necessarily good -- you know, there wasn't any research data to support it; now that research

data is coming out showing that the integrative employment -- I mean, is there a way to rephrase the sentence kind of to reflect that it is widespread but, you know, not recommended in terms of what is coming out of research related to integrated types of employment?

Dr. Mandell: I am open to ideas about -- do other people have ideas about how to change it? I guess I am not sure what --

Ms. Singer: I am not sure what's unclear about this. I understand what Scott is saying, but I am not sure how to rewrite that sentence to make it more clear. I think it's actually reflecting exactly what Scott is saying.

Mr. Robertson: Okay. Because this sentence seems like it's not reflecting that to me. I mean, if I'm a lay person reading that, you know, the first part, you know, there's a linkage, direct linkage, between sheltered workshops and enhanced

employment outcomes. So I don't know. At the least, I think the word "enhance" perhaps could be replaced with another word, but, you know --

Ms. Singer: I think if you want to, David tried to write it very scientifically without any judgment. If you wanted to add some judgment, if the Committee agreed that this was the right judgment, one way you could consider doing it would be "After Cimera and colleagues found that sheltered workshops (unfortunately, the most common strategy to enhance employment outcomes for adults with ASD) do not increase the probability of employment." When you are adding --

Dr. Ball: This is Jim Ball. Or just get rid of --

Ms. Singer: I don't know if it's appropriate for this Committee to do that.

Mr. Robertson: What I am saying is it's not a judgment thing. I mean, the

research literature base in this area for the last three years has already shown that there are more favorable outcomes in terms of wages, in terms of length, cost, and service uses for integrated employment. I mean, that's not a judgment thing. That's actually objective from the research literature.

Dr. Mandell: Great. And that's what I thought with this sentence.

Ms. Singer: But that's what it says there.

Mr. Robertson: Okay.

Dr. Mandell: That is what I'm saying. If it doesn't enhance employment outcomes --

Mr. Robertson: Okay.

Dr. Mandell: -- and it's more expensive --

Mr. Robertson: Okay. How about the most currently used strategy?

Dr. Burton-Hoyle: This is Sally. The word "strategy" implies it's maybe kind

of more of a best practice thing. So it's an approach that has not been successful.

Dr. Mandell: Do you want me to say "approach," instead of "strategy"?

Dr. Burton-Hoyle: Well, I don't know. I'm suggesting maybe.

Dr. Mandell: Yes.

Dr. Burton-Hoyle: The word "strategy" is bothersome.

Dr. Mandell: Well, I'd be happy to do that. I do think that I agree with your assessment of the literature, although I think there just hasn't been that much and this is I think the best study to date on this issue.

Yes. I'm a little stumped. I guess I thought the sentence was getting across exactly the point that you're making.

Dr. Ball: This is Jim Ball. The most currently used approach probably would fit better because as I read it also, in the very first glance at it without going deep into it, it does come across as though that is

the common strategy. People see that as a common strategy where here we're not defending it, but it does come across in a way I think -- you know, I agree.

So if you just did the approach piece and then just made it the most currently used one because that's what everybody uses at this point in time, especially the brick and mortar, you know, where the money goes with some of the agencies that provide services for individuals with autism? That way it will differentiate it so that it doesn't come across as though it's what people want to use.

Mr. Robertson: It would read like something like "Cimera and colleagues found that sheltered workshops were the most commonly used approach for employment for adults with ASD do not increase the probability of employment," you know, et cetera, et cetera.

Dr. Mandell: Okay. Okay. I can do that.

All right. Other concerns?

Ms. Abdull: Hi. This is Idil.

And I know we're limited with how many words we can use here, but on the David and Denise subgroup, we talked about education, higher education for adults with ASD and making sure that they are able to transition from high school into maybe even college. And I don't see that mentioned here at all. In fact, the word "higher ed" is not mentioned. Is that because we're going to mention it another place or --

Dr. Mandell: No, we don't mention that. In part, I don't mention -- well, the only place that it is mentioned is under the epidemiology of autism, there was a study of the prevalence of ASD among college students.

Ms. Abdull: Right.

Dr. Mandell: As far as I know, you know, the working group, the work group, on this didn't find anything. Nor did I when I did a second search of any articles over the

last two years find anything else related to higher education and autism. We certainly can mention in the gaps that given the prevalence is high --

Ms. Abdull: Right.

Dr. Mandell: -- in universities, that we need to develop ways of supporting those students or to see how --

Ms. Abdull: Yes. I would like that, if possible, to at least put it in the gap because a lot of times there isn't a lot of help from high school to college. A lot of parents don't even think that far ahead, but I think we need to support families whose children are able to go to college.

Dr. Insel: You know, I hear the need. This is Tom. But this really sounds like it's not a research or scientific question. It's a question of providing much needed services. So this goes back to Alison's urging us to do a different document that gets into these very specific needs. I

am not sure that it belongs in the research strategic plan.

Ms. Abdull: Do you think, Dr. Insel, that it belongs in the gap maybe? Do we know enough? David said there hasn't been any research study found. But could it be maybe we could do research and find out that yes, the gap does exist and then here is what we think or here is what could be suggested to --

Dr. Insel: You know, I have to say if we had ten million dollars for this, I'd much rather spend it on fixing the problem than studying it or just trying to categorize it. I think it would be better just -- unless somebody felt that it's something we shouldn't do, I wouldn't bother to study it as much as figure out how to fix it. So it does feel much more like a service need, not a scientific question.

Dr. Dougherty: Do we know how to do it? This is Denise.

Dr. Insel: Well, there may be an issue about the best way to implement, but I just want us to keep focused on this being a research strategic plan. This is really trying to figure out where to put the research funds to get the most impact on the needs of the community and on answering the questions that we don't have answers to at this point.

It sounds like a need, but it does feel that it's one that should be really featured in a document on how to provide better services and supports.

Dr. Mandell: I am wondering if, Tom, do you see that as different than, say, when we talk about the research on strategies to improve functional outcomes among adults with greater support needs or other places where we have talked about intervention, you know, the need for sort of community-based intervention research in a particular area? Does this one strike you as different than that?

Dr. Insel: Well, I think that those are worth including here. I guess I worry when we start to get into a smaller grain size to say we need to focus on A, B, C, or D. At this point I'm not sure that's where we want to be.

You know, as soon as you begin to say let's look at college completion, then you have to wonder about housing. It's just that there are so many needs here and --

Dr. Mandell: I see what you're saying.

Dr. Insel: I guess I would like to keep this kind of at the level of the boulders and not the rocks and talk about the general area without getting much more specific. Once you start to get specific, you're going to leave something out that you wanted to include. And then pretty quickly you are rewriting this entire plan.

Dr. Burton-Hoyle: This is Sally.
And why I support that so strongly is that it

goes back to the general community and training and training of doctors and all of that sort of education and training because the more the community at large understands what the spectrum is, the more encouragement there will be for people to entertain the thought of college.

Dr. Mandell: So were you using that as supporting Tom's argument about keeping --

Dr. Burton-Hoyle: Yes, yes. I'm sorry. Yes, I was.

Dr. Mandell: Okay. Anyone else interested in weighing in on that or are we --

(No response.)

Dr. Mandell: So then we'll keep that sort of specific population out.

Any other comments or questions about the report for adults?

(No response.)

Dr. Mandell: Susan, is it worth going over the changes we have suggested and

then asking for a vote?

Dr. Daniels: Yes, we should unless there's more discussion that needs to be had about these sections.

Mr. Robertson: There was one other thing, David, that I forgot to mention. This is Scott Robertson. In the gaps emerging in the past 18 months, I think there was a sentence like "Again, this review points to the critical lack of tested interventions for adolescents, young adults, address core symptom or functional domains." I'm not sure. By "core symptom or functional domains," I mean, is that pointing to the core challenges that autistic adults face or talking about just daily living skill, kind of functional things? I mean, I'm not sure what that phrase is hinting at with "core symptom or functional domains."

Dr. Mandell: The "core symptom/domain" specifically refers to communication, social ability, and repetitive

behaviors. The "functional domains" refers to the extent, the areas in which problems in those areas then affect functioning.

So I could elaborate on that a little. I again was sort of, you know --

Mr. Robertson: You had the word count problem --

Dr. Mandell: Exactly, right.

Mr. Robertson: Okay.

Dr. Daniels: It would be fine for you to be able to elaborate on that. You can add that in.

Dr. Mandell: Okay. All right. Any other things before we go over the changes?

(No response.)

Dr. Insel: Susan, do you want to review?

Dr. Daniels: Okay. Starting with the second paragraph, "Diagnosis of ASD in Adults," we have a couple of typo fixes. We have asked for clarification of language.

Let's see. We're adding something about the U.K. and the Brugha study. So those are the changes there.

In the "Epidemiology" section, a clarification of what "socially disadvantaged" means.

Did somebody have a comment?

(No response.)

Dr. Daniels: In the third paragraph, "Quality of Life," "functional outcomes," the last sentence on this page is to be revised, "Cimera and colleagues found that sheltered workshops were the most commonly used approach for employment of adults with ASD do not increase the probability of employment."

On the next page, a couple of typos, a comma to be removed. In the "Service Use" paragraph for the top of the page, more elaboration on functional therapies. There was a little bit of a discussion of whether the words might be "habilitative speech,

occupational, physical therapy." So that can be revised by David or David and some other colleagues. There's a typo, "importance of Medicaid," in that paragraph.

And in the gap section, there were a number of changes. One, the one that we just discussed, there can be some further definition of what the core symptoms and functional domains are that are described there.

Adding something, more description about criminal justice issues and victims of crime, the addition of additional language on improving functional outcomes in adults with greater support needs, and adding some language on disparities.

So those are the changes I had. Is there anything else that was missed?

Ms. Abdull: Hi, Dr. Daniels. This is Idil. I was wondering when we said, "the greatest support needs, including" or is there a way to put communication just so --

because if I'm reading that, I'm not always just thinking of communication? That's one of the biggest challenges for people who are not able to communicate verbally.

Dr. Daniels: So, David, is that something you can just make note of when you're --

Dr. Mandell: I am sorry. One more time? I wasn't sure I understood.

Ms. Abdull: Oh, yes. Sorry. When we were talking, we were trying to say, rather than saying, "nonverbal," we wanted to make sure that we put a language that emphasizes the need to communicate, not necessarily verbally but ability and having the ability to communicate. And I am just wondering if we could put that word in there, greater support or people who need greater support, including communication. If there is a way to put the word "communication" just so when people are reading and they were not part of this conversation, they would understand

that is a need?

Dr. Mandell: How about if we listed it as a need, rather than as defining the population? So "research" --

Ms. Abdull: And the need, yes.

Dr. Mandell: -- "to improve functional outcomes and communication among adults with greater support needs."

Ms. Abdull: Yes.

Dr. Mandell: Okay.

Dr. Daniels: So that can all be worked. So most of these things are suggestions that have been discussed. And then David and/or other Subcommittee members can craft exact language that would be used to achieve these changes.

So if there are no other comments, then we're ready to take this to a vote. Do you have a motion on the floor to accept this chapter?

Dr. Insel: I move to accept.

Dr. Daniels: Second?

Ms. Redwood: Second.

Dr. Daniels: All in favor?

(Whereupon, there was a chorus of
"Ayes.")

Dr. Daniels: Any opposed?

(No response.)

Dr. Daniels: Any abstaining?

(No response.)

Dr. Daniels: The motion carries
unanimously to accept question 6 with the
aforementioned changes for submission to the
full Committee on December 18th.

Dr. Insel: Okay. Susan, what
else do we need to cover in today's meeting?

Dr. Daniels: So the next step
would be that we would ask that you would all
-- so, David and Denise, if you would kind of
oversee the completion of the changes that
have been requested by Monday, which is
December 3rd as well?

Dr. Dougherty: Yes. Monday is
December 3rd.

Dr. Daniels: December 3rd to turn it in to OARC, to send it to me by December 3rd. What we will do in the office is we will send you an annotated copy of these two chapters showing the spots where changes were requested. So we kept track of everything. And we will give that back to you as a guide.

And you can start working on it beforehand if you'd like. You don't have to wait for us. But we'll give you that to help you with that. And if you need any additional help with references or other things to speed the process, let us know.

And we will be meeting again as a full Committee on December 18th by teleconference, as I mentioned at the beginning of this call. So we will be in touch about that.

Are there any questions that anyone has?

Ms. Redwood: Do you know what --

Ms. Singer: Do you have the date?

Ms. Redwood: Sorry. That is the same thing I was going to ask, the time of the call on the 18th.

Dr. Daniels: So tentatively it's scheduled for 10:00 a.m. to 5:00 p.m. It may be shorter if we end up not needing the time because the agenda hasn't been planned yet. But currently we reserved 10:00 a.m. to 5:00 p.m. Eastern time.

Dr. Mandell: On the 18th? Okay.

Dr. Daniels: On the 18th.

Dr. Mandell: All right.

Dr. Daniels: And public comments.

Ms. Abdull: And, then, did you say the other one is January 29th?

Dr. Daniels: Yes. January 29th will be an in-person full Committee meeting with all of the usual things that we have at our meetings. The December meeting is kind of a special meeting just to get this document finished.

Ms. Abdull: And did I hear you

say that meeting, that in-person meeting, will be in Miami or -- no? If you were on vacation, maybe I could trick you.

Dr. Daniels: We kind of wish it were going to be in Miami, but it is really going to be in Bethesda unless another nor'easter comes along and hits us, in which case we might have to postpone.

Dr. Insel: Should we entertain a motion about the Miami idea?

Ms. Abdull: If you guys get another hurricane, I vote for Miami.

Dr. Daniels: So hopefully if the weather holds up, we will be meeting on January 29th in person.

Dr. Mandell: Sounds good.

Dr. Daniels: We will be in touch by email. And if there are any questions or, like I said, if there is any help that you need, please feel free to contact us. And we'll try to provide whatever you need.

Dr. Insel: Okay. Anything else

from the Subcommittee?

Ms. Singer: Yes. This is Alison.

And before we go, I just want to thank the Subcommittee chairs. The writing on these two sections was very, very clear. And not to impose judgment, but it was, you know, really beautifully done and very comprehensive compared to some of the impenetrable stuff we saw yesterday. So I just want to say thank you for writing with the stakeholder audience in mind.

Ms. Abdull: Yes. Thank you very much.

Dr. Insel: Let me second that. I know that what we have is a product at the end here that is very different from where we started. So I also wanted to thank especially David and Denise but everybody on the Subcommittee for getting us here. This is so important.

And I know that at one point, there was a lot of frustration and especially

from many of the experts who felt that they wanted to do something very different than what was in the current plan. But, unfortunately, this isn't the time or place. There will be a time or place, and place, to do this, hopefully in 2013.

But I really appreciate everybody focusing down and getting this job done so nicely. I think that the writing, as Alison said, is excellent. And what we have here is very solid, very rigorous. I think it will stand us in good stead.

Susan?

Dr. Daniels: I have one other comment to make. Just to let you know what the process is after OARC receives things next Monday is that our staff will begin doing some editing and formatting of the document. So the document you see on November 18th will all be integrated with what the other Subcommittee did.

And we will try to smooth out the

language, make sure that everything flows properly and is formatted correctly. And you'll have a chance to, of course, look at it again and make any comments you need to on December 18th. Just wanted to let you know that that was the way that we would be handling the document between now and then.

Dr. Mandell: Thank you.

And, Susan, officially welcome back.

Dr. Daniels: Thank you. Thank you very much.

Dr. Insel: Okay. Unless there are any other issues, we are adjourned. Thanks, everybody.

(Whereupon, the above-entitled matter was adjourned at 12:31 p.m.)