U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE CONFERENCE CALL

TUESDAY, MARCH 19, 2013

The meeting convened via conference call at 10:00 a.m., Thomas Insel, *Chair*, presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, IACC, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), (NIMH)

IDIL ABDULL, Somali American Autism Foundation

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

SALLY BURTON-HOYLE, Ed.D., Eastern Michigan University

MATTHEW CAREY, Ph.D., Left Brain Right Brain Blog

JAN CRANDY, Nevada State Autism Treatment Assistance Program

GERALDINE DAWSON, Ph.D., Autism Speaks

DENISE DOUGHERTY, Ph.D., Agency for Healthcare Research and Quality (AHRQ)

TIFFANY FARCHIONE, M.D., U.S. Food and Drug Administration (FDA)

PARTICIPANTS (continued):

ALAN GUTTMACHER, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

DONNA KIMBARK, Ph.D., U.S. Department of Defense (DoD)

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

CINDY LAWLER, Ph.D., National Institute of Environmental Health Sciences (NIEHS)
(representing Linda Birnbaum, Ph.D.)

SHARON LEWIS, Administration for Community Living (ACL)

DAVID MANDELL, Sc.D., University of Pennsylvania

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

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

ROBYN SCHULHOF, M.A., Health Resources and Services Administration (HRSA)
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ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF)

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PROCEEDINGS:

Dr. Daniels: Thank you. Welcome to all the IACC members and listeners on the phone. We're glad to have you all with us today for this phone call of the Interagency Autism Coordinating Committee.

We are going to be talking about public comments today and other IACC business items. I would like to get started by taking a roll call of who's on the phone.

So, Tom Insel will be here in just a minute. James Battey or Judith Cooper? Linda Birnbaum or Cindy Lawler?

Ms. Lawler: Cindy, I'm here.

Ms. Birnbaum: And Linda.

Dr. Daniels: Okay, thank you. Coleen Boyle?

Dr. Boyle: I'm here.

Dr. Daniels: Josie Briggs? Denise Dougherty?

Dr. Dougherty: I'm here.

Dr. Daniels: Tiffany Farchione?

Alan Guttmacher?

Dr. Guttmacher: I'm here but will have to sign off shortly before 11:00.

Dr. Daniels: Okay, will Alice Kau be joining us when you leave?

Dr. Guttmacher: I think so, but I don't know for sure whether Alice is on this speaking line.

Dr. Daniels: Okay. All right, thanks. Laura Kavanagh?

Ms. Schulhof: Hi, this is Robyn Schulhof sitting in for Laura Kavanagh.

Dr. Daniels: Thank you. Donna Kimbark?

Dr. Kimbark: I'm here.

Dr. Daniels: Walter Koroshetz?

Dr. Koroshetz: Yes, I'm here, but I also have a meeting for 11:00.

Dr. Daniels: Will somebody else from NINDS be stepping in?

Dr. Koroshetz: My assistant Kate Saylor is on the line, yes.

Dr. Daniels: Okay. Sharon Lewis? Or anybody else from ACL? John O'Brien? Or anyone else from CMS? Larry Wexler? Or Michael Yudin from Department of Education? Okay, for the public members, Idil Abdull?

Ms. Abdull: Here.

Dr. Daniels: Jim Ball? Anshu Batra? I think she's not going to be able to join us. Noah Britton? Sally Burton-Hoyle?

Dr. Burton-Hoyle: Here.

Dr. Daniels: Matthew Carey?

Dr. Carey: Here.

Dr. Daniels: Dennis Choi? Jose Cordero? Jan Crandy?

Ms. Crandy: Here.

Dr. Daniels: Geri Dawson?

Dr. Dawson: I'm here.

Dr. Daniels: David Mandell?

Dr. Mandell: I'm here and will have to get off the phone a few minutes before 11:30.

Dr. Daniels: Thank you. Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Scott Robertson?

Mr. Robertson: Here.

Dr. Daniels: John Elder Robison? Alison Singer?

Ms. Singer: I'm here.

Dr. Daniels: So I believe we have a quorum. And anyone else, any other IACC members who join late, or if you're having trouble with your speaking line, just speak up later in the call, or send me an email to let me know that you're on the phone.

Thank you. And, okay, why don't I take you through the approval of the minutes?

Ms. Lewis: This is Sharon Lewis. I just joined. Sorry I missed roll call.

Dr. Daniels: Oh, thanks. Okay, anyone else? I hear something, but it's garbled. Who is that?

Dr. Koroshetz: I think it is just background noise.

Dr. Daniels: Okay. All right, so let's talk about the draft minutes for January 29th, 2013.

I did receive a note from Lyn Redwood, but I haven't had a chance to read it yet about a correction. I don't know if you want to say anything about that, Lyn, right now or if we can just take care of it offline.

Are there any other comments about the minutes, any corrections or changes that need to be made?

Dr. Boyle: This is Coleen. I have a minor one, as well –

Dr. Daniels: Sure.

Dr. Boyle: – on the bottom of Page 10. But I can send that to you as well, okay?

Dr. Daniels: Okay. That's fine. Is there anything else that anyone feels needs to be changed? Okay. Not hearing any, do we have a motion on the floor to accept the minutes?

Dr. Koroshetz: So moved.

Dr. Daniels: Second?

Dr. Boyle: I second.

Dr. Daniels: All in favor?

[Chorus of ayes]

Dr. Daniels: Any opposed? Any abstaining? The motion carries to accept the minutes with the changes that Coleen and Lyn mentioned.

And so OARC will go ahead and make those changes and post these minutes to the website. Thank you. And then I will turn it over to Dr. Insel.

Dr. Insel: Okay. Thanks very much, Susan. And welcome everybody. This is a somewhat impromptu meeting that we've set up to finish some of the business that didn't get finished when we met on January 29th.

The issue at the time was that, while we had a period for public comments and we had received a great number of written public comments, what we lost in our agenda because of all the discussion at the end of the day was a chance to discuss those.

And so the agenda for today's meeting is to take some time to review what we've heard, reflect on it, discuss it as needed. And in addition, we would like, around 11 o'clock, to focus your attention on a letter which is coming from the Services Subcommittee as a potential action item for the IACC.

You should have received copies of both the written public comments for January 29th as well as the oral public comments. And then again, we had received additional comments written since that meeting, which were also sent to you as written public comments for March 19th. There are a large number of those, as well.

So, that said, let me simply put that on the floor for discussion and invite anybody on the Committee to reflect on what we've received and to suggest anything that you think that the IACC needs to consider with that in mind.

Ms. Singer: This is Alison. I wanted to focus on the comments from Amy Lutz which are on Page 3 of the packet. I want to thank and commend Ms. Lutz for her participation.

And for those who might not remember, Amy has started a group to try to focus on ending aggression and self-injury among individuals with autism and other developmental disabilities.

First, I want to say that it is not so easy to stand up there the way she did and talk about your child, the challenging self-injurious behaviors and to show photos the way she did.

That takes real courage and a real sense of wanting to improve the lives, not only of your own child, but of all of the children who are most seriously affected by autism. And it's really important to do what she did and to shine a bright spotlight on this population, which has really been in the dark.

This is definitely an underserved population with unique needs, and they have not had a voice at the table. And because, unfortunately, many of them are in inpatient facilities or residential placement and because their parents are physically and emotionally exhausted.

And these kids and adults need to be represented in the strategic plan in the new iteration. In the current version, I don't think that their needs are at all addressed in terms of treatment or services or quality of life.

This is the population for whom the focus remains on safety, on preventing injury to themselves, and injury to others. And for many of them, the world is getting smaller and smaller every day.

And we need to learn more about this population and why there is a lack of appropriate placement opportunities for kids with the most severe needs.

Honestly, the only thing I can think of that is more heartbreaking than being told that your child needs to be checked into a psychiatric inpatient treatment center is to be told that there's a waiting list for that placement, which I learned subsequently from Amy is, in fact, the case.

So I would like us to invite someone from one of these psychiatric behavioral clinics to address the IACC at our July meeting so that we can learn more about this population and understand the treatment options that are available to meet their needs.

I'm told that Kennedy Krieger Institute's Neurobehavioral Center in Baltimore is one of the best centers for this type of treatment, and that the person who leads that center as its medical director is Dr. Lee Wachtel.

So I would like us to talk about inviting Dr. Wachtel to address our group at our July meeting.

Mr. Robertson: Okay, and I wanted to just add something to that. And I –

Dr. Insel: We need to make sure we identify ourselves so people who listen I –

Mr. Robertson: Oh sorry. Sorry, this is Scott Robertson. I just wanted to add something to that, is that I think that maybe also that could open the conversation about educating the entire mental health, you know, we can educate the psychiatric and mental health community about autism and developmental disabilities, because I've had, especially sometimes particularly in private facilities, sometimes the public and state-run and community facilities that are connected to government have been educated, say, for instance here where I live in Pennsylvania, our state autism agency has been educating folks in the mental health areas who are in public places and public, like, state-run centers, and in other states that's also true.

But particularly, I think, often in private psychiatric inpatient facilities, there's not really good understanding about the communication needs, social needs, a lot of other things that kind of were mentioned and sensory, et cetera.

And so I think that that's one of the problems that, you know, should be addressed on kind of a broader topic there is educating folks in the autism community about psychiatric kind of related and mental health related challenges and folks in mental health and psychiatric communities about autism and developmental disabilities.

Ms. Redwood: Tom, this is Lyn Redwood. I wanted to also comment about Mrs. Lutz' presentation. And I support everything that Alison said, along with the recommendation to have someone come and address the Committee regarding these self-injurious behaviors.

But I also want to point out that I think it is really important, especially since many of these children are non-verbal, that we also investigate the potential for medical comorbidities being the underlying culprit behind a lot of these self-injurious behaviors.

I've been to conferences before where gastroenterologists have put up pictures of children that were, you know, clawing at their skin and had all these tremendous self-injurious behaviors where they had to be restrained, only for them to later find out that they had severe esophagitis and gastroenteritis and ulcerative colitis. And with appropriate medical treatment, those self-injurious behaviors went completely away.

So I think we really need to look at that, as well. There was a document that I think Susan Daniels sent around to the entire Committee that spoke to that issue and how children with sinus infections were exhibiting head-banging behavior.

And once they were appropriately treated, then those symptoms went away.

So I think we shouldn't overlook that. And I think we also need to look closely at the use of electroconvulsive therapy. I'm very concerned about some of the long term sequelae to brain development secondary to the use of electroconvulsive therapy, which my understanding is one of the reasons why they discontinued this practice years ago.

So I would like more information about that, as well. I know that's something that Amy Lutz has sort of suggested in her presentation.

But I think we also need to look real closely before we jump to something like ECT therapies in terms of what might be the underlying pathology behind these behaviors, versus just treating the behavior, try better to understand what's causing it.

So I would like to ask that we also have somebody come and present to the Committee on these medical comorbidities and autism.

And that would also address several of the other public comments that we received from Dawn

Loughborough and also M.L. Ferreira, I believe, that also spoke about the urgent need to look at these medical comorbidities and ASD and how, by doing so, we can help to improve the lives of individuals with autism now.

Dr. Insel: Thank you, Lyn. This is Tom. One of the people who has talked a lot about this, someone we could bring to the IACC meeting, is Tim Buie at Mass General, who tells a very compelling story from the videos of children with esophagitis who are non-verbal and then the effects of treating the esophagitis on self-injurious behavior.

So that may be one possibility for the July meeting.

Ms. Redwood: Arthur Krigsman is also a physician, a gastroenterologist, I believe he's in the New York City area, who has a lot of experience in treating individuals with ASD for GI disorders.

And there's also several physicians that also address a lot of these underlying comorbidities, whether they be metabolic or immune, that could also offer some insights.

Dr. Dawson: This is Geri Dawson. I was just going to say, it sounds like that this is, perhaps, an IACC meeting that could have as a broad theme more severely affected children, which includes issues around self-injury and aggression, but also these medical comorbidities, so that we can look at the links and the different kinds of treatment approaches and issues that come up in trying to help these children and adults.

You know, one of the things that might also be helpful on this panel, if we do have a panel of speakers to come in, is to have someone from the Autism Speaks Autism Treatment Network, because this was really the sole, you know, driver of forming that network was to begin to develop guidelines on these medical comorbidities.

And folks like Tim Buie were very much part of the inception of that in the beginning where those videos, you know, inspired the development of the network.

Ms. Redwood: Tom, this is Lyn. I also wanted to point out that that's actually one of the cross-cutting themes in our strategic plan that states that we need to develop and have multi-disciplinary health assessments and effective treatment guidelines.

So that was one of our cross-cutting themes, and something that we really haven't addressed as a Committee.

Dr. Insel: This is Tom. The other perspective to put into this mix, because it's beginning to sound like we have a panel that's developing for the next meeting, besides someone from the ATN, perhaps Jim Perrin, who would be really terrific for this, would be someone from the Lewin Study Group who could share with the IACC the results of the Health Outcomes Study looking at health outcomes in 33,000 children with autism and give us a picture of what those results look like.

So, because I don't think any of that is published yet, but that might be of interest also to the group. So maybe, you know, we could begin to think about this as a topic for deeper dive.

First, just to get all of us, as a Committee, informed about the issues, both comorbidities and the issues about how people are managing self-injurious behavior, which is what Amy Lutz was really focused on.

Ms. Lewis: Tom, this is Sharon Lewis. I completely agree with your comments, Lyn, around both being concerned about ECT as an option.

And, you know, given what we know in terms of the research base, in terms of long term impact, and also frankly the one major residential center that's using ECT as an aversive behavior modification technique is currently under investigation for human rights and civil rights violations by the Department of Justice. So I think we need to be aware of that perspective in all of this when we talk about ECT. So I think that's an important piece.

The other piece that I guess I would love to see if we're going to bring in folks to talk about this, is consistent with this, in particular, for people who are non-verbal and who end up with self-injurious behavior as a form of communication, whether it be because of a co-occurring condition that's medical in its base or due to other reasons in terms of their inability to communicate.

There are a lot of folks out in the UCEDD

Network that have done a lot of work on this. There's also actually an individual here in Virginia named David Pitonyak who has really done a tremendous amount of work around individuals with extremely difficult behaviors and non-verbal, and finding ways to stop self-injurious behaviors.

So I would throw that into the mix and I'm happy to forward the information about David.

Dr. Insel: That would be great.

Ms. Abdull: Hi, this is Idil. I agree with you, Sharon, 100 percent that I think a lot of times self-injuries, not maybe all the time but often, comes from non-verbal children or people with autism.

And I would say it's their inability to express what they want and what they need. So even in our community, most of our kids are non-verbal and they also have self-injury behaviors.

But what we found is that when you give them an ability to communicate, whether it be sign language or a device, the behaviors go down and the self-injury goes down, and the child all of a sudden appears.

And so if there is a way to see if there's a correlation or invite people that could talk about the non-verbal population, which is 25 percent, is what I understand, of autism people are non-verbal.

And if there's a way to make sure that, because a lot of times a lot of these early interventions, they don't want to do augmented devices or sign language because they say, well, if you give the child those, including my own son, they would say that if we give him a machine to tell us what he wants, he's not going to talk.

And they would say I – and there is a study that said that. There is a study that said if we give him the DynaVox or some augmented device, he won't initiate the communication.

So he had lots of self-injuries and he had a lot of behaviors. But then the minute we gave him the iPad and he was able to tell us what he wants, that all went away.

And I just wonder if, I mean, I would hit myself if nobody understood me and I couldn't get my needs and wants across but I knew what I wanted.

So I just wonder if there's a correlation, if we can get people to talk about non-verbal, if we can take the stigma out of non-verbal and that giving these people and these individuals or children the ability to communicate, and that communication is not only verbal.

Mr. Robertson: Tom, this is Scott Robertson and I agree completely that communication issues are a major part of that, and I hope that that would come up in discussion on a panel and make sure to have folks that are kind of experts and really knowledgeable on the augmented communication and alternative communication issues for devices and pictures, et cetera, because that does make a big difference.

Because I agree, if I wasn't able to, and many of us would, if we were in that same boat where we were placed in a situation where we were not able to communicate our needs and wants across, of course we would maybe be communicating in other means and sometimes that leads to folks communicating, you know, through the way they act.

But then there's also things like sensory issues, et cetera, that should also be mentioned on this. I know that there was a study – I can't remember when it came out. But there was a study that found that a lot of things around aggression were related to sensory and to sleep, actually, was a large part of it too, is that I think that that's, you know, part of the medical stuff should also be looking at what we can be doing to help folks with getting better rest, whether that's things that are looked at, you know, physical activity during the day or otherwise.

And that can feed into often the, you know, something that may try to mimic, you know, things that started and led to more aggressive kind of forms of actions were related to simply not having good sleep or maybe not having good means to manage sensory issues and have communication access.

Dr. Burton-Hoyle: This is Sally Burton-Hoyle, and I want to support what some of you have been saying. And it is that Kennedy Krieger is the place where those individuals with the most severe behaviors are hopefully being brought in.

But there's such a waiting list and there's such constraints on how you get in that the opposite end of the continuum would be David Pitonyak, whose teaching and practices anyone can do.

There are so many things that people are restricted by, either, waiting lists, eligibility, or finances. So if we, and I love the idea of a panel so that we can each bring information from and then to the experts that would be on this. But, please, let's include various sorts of things in this panel.

Dr. Insel: So this is Tom. What I'm hearing, then, is really harking back to the comments from Amy Lutz, that the Committee would like to have at its next in-person meeting a panel on non-verbal people on the spectrum, whether that is related, and the relationship to self-injury where the self-injury is a reflection of a medical comorbidity and pain or reflection of just the frustration of not being able to communicate or not having people understand what the wants and needs are.

But you'd also like to have someone within the panel who can talk about what's been helpful, so what the potential approaches to this are that might be better than what is generally being done.

That's a bit of a difference from where we've been in the past, but it is something that, as Lyn pointed out, is in the strategic plan and an area of priority and maybe not something we've talked enough about as a Committee.

Dr. Carey: Tom, this is Matt Carey. I think in the beginning of the year, we started talking about having panels. I think we didn't quite get to that last meeting, and I think that this would be good.

I mean, we shouldn't lose track. I think Alison, you know, brought up this and I think we really should be expanding on what she said and we shouldn't lose track of the self-injurious part as we expand it.

But, yes, I mean, I think one of the proposals I put out was really looking at this population, not just self-injurious but really the population kind of more intellectual disability, self-injurious behaviors, all the -- I – a lot of more additional disabilities than just autism.

But the other one was, also, I think I was proposing that we look at just medical delivery for this population. I mean, when I talked to some doctors, they say they get about 75, 80 percent of their information from communicating with their patients.

If you've got a patient who either has trouble communicating or has sensory issues, that gets very much limited. And I think, you know, looking at just medical delivery in general would be a great thing to include.

And there is one person up here at UC San Francisco who's been very much focused on that, and that's Clarissa Kripke. It would be great if we could possibly bring her in to talk, as well.

Dr. Insel: So can I ask from members of the Committee to send suggestions to Susan and we'll begin to put this group together.

I'm also mindful of the comments we had at the last meeting that we want to be a little better about time management at our meetings so we don't run out of time, don't have to have a special meeting for the discussion of public comments.

So as we put a panel together, we'll try to limit the number of people so that we cover the main issues, but it may not cover every issue to everyone's satisfaction just because we want to make sure that we get the entire agenda done when we meet in July and not run out of time like we did last time.

Mr. Robertson: Tom, are we able to bring up the other - I don't know if we still need to be focused on that comment because there was another public comment that I wanted to mention that particularly struck me from the previously --with Dena Gassner's presentation.

Dr. Insel: Okay that's great, Scott. Before we go there, let me just make sure. Is there any other comment about Amy Lutz's comment to us, or should we move on?

Dr. Kimbark: Tom, this is Donna Kimbark. I just wanted to ask, are we planning on having people come to the July meeting to just give presentations, or can we have them sit in a panel and do it, have a discussion rather than have presentations?

Dr. Insel: You know, I think what has worked best in the past is a mix of the two, so brief presentations followed by a panel discussion with a lot more interaction with the Committee.

So that's what we'll plan for, unless anyone has a better idea. We want to make sure that there's plenty of time for interaction, so we're not just being talked at, but we have a chance to really have a dialogue with experts in this area.

Dr. Kimbark: I'll send a name, as well. I heard a presentation about a year and a half ago at the AHRQ over at Frederick, Maryland. And it was very interesting.

It was from a pediatric neurologist over at Kennedy Krieger as well. And I'll send Susan the names and all of that.

Dr. Insel: That's great. So we may not be able to invite everybody, but we would like to get everybody's input about who to invite. And it would be helpful to get not just names, but also a little bit about the person, if you can. So let's go back to Scott's question. I'll turn this back to you, Scott.

Mr. Robertson: Yes, it's Scott Robertson again. And I was starting to say Dena Gassner's presentation, I believe she's a social worker and she had presented about a lot of the issues particularly facing autistic women in adult life.

And I guess it would also extend to issues for girls during childhood that have not really been addressed that well in the research literature. There's not really much literature at all, to my knowledge.

And it's certainly an area that needs to be covered better. And maybe it would give you something to mention in the strategic plan as this is a major disparity issue that there's not really much about, you know, unique issues to women, anything that are kind of different in terms of, you know, health-related kind of issues, anything on access and healthcare.

I mean, there's so many things that are different already that we know generally between men and women, you know, just in the broad population.

So that's why I think this particularly struck me in terms of a lot of the things that she mentioned that she's seen in her clinical practice, whether or not, you know, you don't really see it being studied in the research literature.

And what can be done about that to kind of increase our focus and, you know, maybe even spur at least a little bit of interest to get at least some data collected on the differences that autistic people experience both in adult life and in childhood between females and males just to find, you know, a little bit better in terms of richer data on there that would be helpful for folks in practice and healthcare settings to know about where the differences lie.

Dr. Insel: Other thoughts or comments about public comments, either the oral or the written comments from last meeting or the ones leading up to today?

Dr. Farchione: Tom, before you move on, I just wanted to let everybody know that I joined the call about 10 minutes ago, and I've been waiting for a chance to jump in. But this is Tiffany Farchione from FDA.

Dr. Insel: Oh, hi. Welcome.

Dr. Farchione: Thanks.

Ms. Redwood: Tom, this is Lyn Redwood. I had also mentioned the comments by Dawn Loughborough, if I'm pronouncing her name right, and M.L. Ferreira who also talked about the medical comorbidities. And I wasn't certain since that was tied into the discussion with Amy Lutz if that was going to be part of the panel, as well?

Dr. Insel: Lyn, maybe you could just say a little bit more about, specifically if we were to put this into the same panel on self-injury and non-verbal autism, how would you like it to be represented?

What do you think would be the key issue? And for instance, would someone from the Autism Treatment Network be able to cover this?

Ms. Redwood: Well, you had actually suggested Tim Buie, Tom, as somebody who could speak to some of the medical comorbidities with regard to gastrointestinal.

I mean, maybe Tim could also include some of the other things from other practitioners in his presentation on the panel discussion.

But I think it's important to have somebody there that also looks at treating some of these underlying medical conditions. I mean, how many times have you had a severe headache, or somebody on the Committee, that felt like, you know, banging your head or squeezing your head?

I just think it's really important to not lose the perspective of how some of these underlying disorders can be driving this behavior.

And even with what Idil was saying in terms of communication, you know, that same frustration to not be able to communicate pain is very important. And these individuals may not know how to specifically communicate pain.

So I think it's something that we need to do as a Committee to raise awareness of general practitioners or healthcare providers treating children with autism to consider those things when they see these behaviors, and to provide some type of guidelines regarding what's appropriate for medical evaluation, especially a child who's non-verbal.

And I think that was also something that Dr. Dawson was supporting with ATN.

Dr. Kimbark: Lyn, this is Donna Kimbark. I just wanted to ask you, are you advocating for someone to be on that panel that we're discussing, but also I – because this is what I would also like to see. I would also like to see the Committee address it separately, as well, the comorbid conditions because I think it's an important enough issue that it shouldn't just be part of another thing. It should be as its own stand-alone issue to discuss. And I'm sorry if I'm not communicating that well.

Ms. Redwood: I agree with that, too. The more focus we can get, I think that the faster we can help to actually improve some of these behaviors and the health of the children or individuals with autism. So I would support, also, a stand-alone panel or even a workshop.

Ms. Abdull: Hi, this is Idil. I was wondering what Scott had said about girls. And we know that autism hits boys more than it does girls. But I just wonder, I always hear that when it hits a girl, it's more severe and that the, you know, what they go through is different.

So I just wonder if there is a way to talk about that a little bit, or to see what exactly the difference is and if it's more severe and if we can have some education or some information for professionals or providers, and even families, just so they know how to deal with, because I think raising a boy and a girl is different in itself, but then when the disability is on your daughter, it probably is different.

And then I also wanted to see about the sensory issues and how we can make the autism community in general, that autism is not just a behavior where you need ABA and that's it. A lot of these children also have sensory problems. And what I found is that a lot of providers, if they do ABA, they don't want to do anything else and they think whatever the child is having is ABA can fix it.

And a lot of times if you mix the developmental approaches, such as sensory processing disorder, children that have that, it helps.

But I don't know where they get this idea. They keep telling me that research says, you know, Idil, that we can't mix the two because they'll cancel.

And I think a lot of times they're looking maybe some direction from IACC. And if we can talk a little bit about that, how putting therapies together helps children rather than one at a time.

Mr. Robertson: Can I mention just a quick thing on that? And I agree wholeheartedly with the mention on the sensory issues. And I think that's one of the reasons why sensory was added, you know, to my understanding, to the DSM-5. I mean, it actually is in there now in the diagnostic criteria.

Yes, sometimes people don't really take it as seriously in part because there's not as great research literature, and because people continually only often study, you know, most of the research literature is simply just on the communication social issue.

So I think that's something that has to be, you know, focused on long term. And I do agree that, you know, educating folks about the need that there's nothing wrong with having people from multiple different professional backgrounds kind of work together rather than pursuing it from any one thing, whether it's behavior or just speech.

You know, having those things kind of be complementary because my understanding, and you know, I think we could have better data to support this, my understanding from what I've seen in terms of outcomes myself is that folks who have had support from a wide range of things including, you know, speech, OT, et cetera, have better outcomes.

So for instance, like on sensory things, that's an area where occupational therapists should be assisting with that, for instance, because that's part of their area in terms of expertise is sensory and motor issues are something that they have a lot of knowledge and understanding in practice around and should be assisting autistic individuals in childhood and adulthood, you know, with developing coping strategies and compensatory mechanisms, uses of technology, et cetera, to assist in those sensory issues.

Dr. Insel: So on this issue, again this is Tom, can I get a feeling from the group about what you would like the IACC to do with respect to sensory issues?

Is this a place where you would like to hear about recent research, a place you would like to hear about therapeutics, you want to raise awareness about this?

I think for the issues around non-verbal autism and self-injury, we heard a panel formulated where people clearly wanted to scope out the nature of the problem so that there would be a deeper understanding of it.

On the sensory side, maybe somebody on the Committee who's interested in this could help us to know what you would like the Committee to do.

Mr. Robertson: Tom, I think, you know, it would be nice maybe at this meeting or another meeting to maybe even have just a brief maybe a presentation or a short discussion on, if you will, the state of the state in the research around sensory issues.

What do we know right now and what do we not know? And what should we be looking at as far as sensory issues and as far as things in formal practice to how we help individuals with developing coping strategies and dealing with sensory issues, you know, that can cause a lot of difficulties in terms of life with other kinds of things, in terms of other facets of quality of life that can be affected if sensory issues, you know, do not have strategies and supports for managing?

So maybe even just finding out, you know, what is the current status in terms of things in the literature right now and then what folks are studying and emerging research that's being done right now and coming out soon, and what could be done that's not being done right now in the research literature.

I mean, is it possible just to have that as an update on things?

Dr. Insel: That sounds great, and something we could put on the agenda. We may need to turn to some of the experts on the Committee about who they would recommend for this or we can also check in the research portfolio and see who's in this field that would be able to help us get a broad picture of it. But that's a good recommendation. So we'll put it on the list.

On the question that was raised relating to the letter we received about autism in girls, just to mention that one of the new ACE centers has that as a specific focus.

So, people, we will hear much more about that going forward, but it may be a little early to expect results. But that's just recently funded.

Mr. Robertson: That's great.

Dr. Insel: Other comments about the comments?

Ms. Abdull: Hi, this is Idil. There was one comment about the letter that we're going to talk about and that health parity should apply to both private and public.

But we can defer that because that's all about what we're going to talk about next half an hour, hopefully.

Dr. Insel: Right, okay. Unless there's anything else on these comments, do you want to go ahead and move into the discussion about the Committee business, which starts with the letter?

Ms. Abdull: Yes, I vote yes.

Dr. Insel: Okay. Alright. So you should have received a copy of a draft of a letter on coverage for behavioral treatment. It's the one that begins "Dear Madam Secretary."

Dr. Daniels: And it's on our website, too, for anybody who's listening.

Dr. Insel: So this is, again, just in draft. It's something that the Services Subcommittee has taken a look at and has put together.

And maybe we can ask at this point David and Denise to take us through this. David, can I turn this over to you and Denise, both of you, to give us an overview of what this is and why now and what you need from the Committee?

Dr. Mandell: Sure.

Dr. Dougherty: I'm here, but go for it, David.

Dr. Mandell: Okay, thanks Denise.

Dr. Dougherty: I think you revised this after our Services Committee call?

Dr. Mandell: I did.

Dr. Dougherty: Okay.

Dr. Mandell: So a letter was originally discussed at our last full IACC meeting as a way to provide the IACC recommendations regarding what benefits states should cover in their essential health benefits package as we move towards the Affordable Care Act.

And so this letter is, at this point, given where states are, it really has the potential to be used at a state-by-state level rather than at the federal level for states to make decisions about what their benefits should be.

So in this letter, we describe what we mean by behavioral treatment and the urgency in covering behavioral treatments for children with autism.

We recognize that there are many other services that children with autism need and that adults with autism need, but that the purpose of this letter was to be highly focused on these behavioral health treatments that have the most evidence to support them and have the potential to be included specifically in these state benefit packages.

We drafted the letter. We discussed it as a Subcommittee. There were some concerns that people wanted to be addressed, including making it clear that for most people with autism, this is a lifelong condition that will require supports across the lifespan, and to make it clear that we are advocating for these benefits both in the public and private system, because as some of us thought, but Idil fortunately contradicted us, accurately contradicted us, we thought that the essentials health benefit plans would be set for both private insurance and public insurance. But states don't necessarily have to adopt them for both.

So that's the letter in a nutshell and the changes that we went through. I think I would rather leave most of the time for any discussion or questions people have about the specifics of the letter.

And what we need now in order to be able to release this letter from the IACC is a vote approving it or not approving it. And when I say now, I mean not this minute Susan, so don't worry about calling/not calling for a vote.

[Laughter]

Dr. Insel: Denise, anything you would like to add?

Dr. Dougherty: No, I think the revision is good and is clearer about the evidence base. Tom, you were the spokesperson for the evidence base, for the most part, on the Services call. So are you comfortable with it?

Dr. Insel: I am. You know, I think this has been driven by two issues, as far as I can understand. One is the sense that policies are about to be set in states across the country over the next very few months.

So the feeling that we had when we met back in January, and this came up at the meeting and then was discussed very briefly in the kind of rushed period at the end of the January 29th meeting, was that the clock was ticking and if the IACC is going to have any impact on either the essential health benefits or on coverage, we need to act very quickly.

And the second piece that provided the timeliness were these two very recent reports that were meta-analyses or reviews. One from the HRSA-funded project and another one was a Cochrane analysis looking at early intervention.

And both of them were strong enough we thought, although neither of them were perfect and they both had sort of caveats built into them.

But together, we thought maybe this was the time to at least bring to the Secretary's attention that there was new information in the literature that might influence decisions being made about coverage or about essential health benefits.

So that was the timeliness factor and why this is coming in front of the whole IACC because we have from both January 29th, some of the comments we heard then, and from the services Subcommittee was that time is of the essence and we need to do something about this in the short order if we're going to do anything at all.

So let me leave it at that and open this up to the Committee for a broader discussion.

Ms. Abdull: Hi, this is Idil. So David, I have just a question or maybe a comment because I like this. The letter's sort of still the same, but we've added the things that we wanted at the end.

And so at the beginning page and a half or two, it explains, you know, what ACA is doing, what private insurance is, which states are paying, which states are not paying. It explains, you know, eloquently and in detail, which is good.

And then towards the end, the last page it has just one sentence that it's critically important that this medical coverage should be available to privately and public insured children so a two tiered system for autism care is not created.

I think if I was reading this letter and I would pick up that ABA is so important and early intervention is so important for the private insurance market.

I don't know if I would pick up on the public because it doesn't say Medicaid, it doesn't say CMS, it doesn't describe how many states pay early intervention through Medicaid or CMS.

And then it also doesn't say what I think is important which is that early intervention such as ABA is not part of the EPSDT. And sad to say, a lot of people even within CMS don't even know this. Not John, of course.

But I just, I don't know if there's a way to just explain it so that if the Secretary is skimming through this or reading, she can catch it that we need to make sure that children that are low income, that are particularly, you know, disproportionately minorities, we want to make sure that they also get the services and that right now, I think we said in our last report, nine states have autism specific waivers where we've used early intervention as opposed to 32 states.

So right there and then, disparity's already there because the starting point is not even for the haves and the have-nots.

And I don't know, maybe I'm just looking at it wrong. But if I was just reading this letter, I wouldn't pick up the need to help low income children that have Medicaid as an insurance.

Dr. Mandell: How about if after that sentence about the two tiered system for autism care is not created, we added a sentence or two specifically about Medicaid, the lack of coverage for these treatments in Medicaid as well as in private insurance, and the known disparities in receipt of this care by income?

Ms. Abdull: Right. And then we can, I don't know if it's possible, but is it possible to say that the currency in this guidelines for EPSDT do not cover early intervention, such as ABA, because we clearly are saying that the private insurances don't cover it. The states have to choose, and only half of the states have chosen so far.

So if there is a way to make clear that this is important for both private and public. And for public, we mean by Medicaid, CMS guidelines, which currently doesn't cover. And so far 9, or I've heard 11 now, states are covering early intervention.

You know, something like that just so the Secretary, in her head can think if we're going to decrease disparity, we're going to have to have policies that actually decrease it.

And unless we recommend policies that decrease it, unless we send letters that face awareness in her mind that the starting point is already not even for children that are low income that are disproportionately minorities, I think, you know, we got to keep hitting this brick that in order to eradicate disparity in autism, we have got to change policies. Does that make sense?

Dr. Mandell: Certainly, I agree with everything you said, Idil. And I share your concern. My challenge in figuring out how to do this was to keep it concise and to figure out where to put it so that I –

Ms. Abdull: Right.

Dr. Mandell: It made sense with the flow of the letter.

Ms. Abdull: We can start at the beginning. So at the beginning, David, you know how you say that you talk about the ACA and you talk about how many states.

So when you say how many states have that have taken behavior therapy under ACA, right next to it we can say and then for Medicaid, public insurance, this many states have done it.

And then at the end where you say let's make sure that we don't have two tiered system, we can put exactly the sentence that you just said before now. You know what I mean? Just so we're hitting the message for both kids.

Dr. Mandell: So the other place I was considering putting it was in the paragraph that starts “roughly half of the states.”

The problem is that the roughly half the states will offer plans that provide autism specific behavioral intervention. That's not about the autism mandate which is sort of the parallel to the autism waivers.

That's about states that have made the decision to include it in their essential health benefits. So if we were going to put a sentence in there that related to the public system, it would really be it's not known how many states will make or will require these interventions to be available through their Medicaid plans as well as through private insurance.

Ms. Abdull: Right. We can put that in there. I mean, there is 11 now is what I'm hearing. We had 9 a few months ago, now there's 11 states.

But still, we're not even close to the private insurance and that's how disparity happens, when the equal access to care is not even, that's disparity.

Dr. Mandell: But do you mean 11 states with autism waivers or 11 states who have said this benefit will be covered under our Medicaid plans as well as be required to be covered by private insurance?

Ms. Abdull: No, no, no, I don’t know about the private. The private insurance, I mean, everybody fights for them. What I understand is 32 or so. Only my lens is always look at for the low income, the underdog kid.

And there are 11 states that now are paying early intervention through their Medicaid, through the 1915(c). No one has applied the 1915 (i).

So through autism waivers, but they cover, like Wisconsin and Pennsylvania, they cover early intervention.

Dr. Mandell: Right, but Idil, we don't know what those states are going to do with their Medicaid plans under the Affordable Care Act. We don't know if they're going to include those waiver services in the Medicaid plan.

Ms. Abdull: Oh no, they're not.

Dr. Mandell: Right, and so I –

Ms. Abdull: You mean ACA law, no one is. Yes.

Dr. Mandell: So the issue is not that currently only 11 states have waivers because we're not talking about how many states have private insurance mandates.

We're talking about the states that have made a decision to include this coverage under their essential health benefits.

Ms. Abdull: Right.

Dr. Mandell: And so I don't want to talk about waivers and mandates, but because I don't think that's the relevant thing here.

But I think we can say we don't know how many states are going to include this in their Medicaid plans in that third paragraph.

And then later, I think, we can talk about how important it is that they do it and expand that sentence about not creating, you know, that part about not creating a two tiered system.

Ms. Abdull: Right. And then so in that sentence, not create a two tiered system, would you add the EPSDT and that early intervention is not part of it because as John always tells us, that was created 40 years ago before ABA or even autism was a hot topic. I mean, you don't have to I –

Dr. Mandell: Yes, let me play with the language. I'm not sure I want to start getting into mentioning specific service types.

And I mean, it may be more useful to say something like Medicaid, currently there is no service type within Medicaid that explicitly covers these types of interventions for children with autism.

Ms. Abdull: I will be okay with that because then I – go ahead.

Dr. Insel: Yes, this is Tom. I would agree that we should keep this focused, but I wouldn't get into too much detail about specific programs.

But Idil's point about clarifying the distinction between public and private is still probably useful. I have to confess that that first sentence in the third paragraph, roughly half of the states will offer plans, I had misunderstood that.

So it would be useful to add the clause in "within their, essential health benefits plans" or something like that so that the reader would know that there is a distinction that even this deals with the private insurance.

And that there's a remaining question about how much would be done through public coverage.

Dr. Mandell: That makes a lot of sense.

Dr. Insel: Yes you know, I thought I actually understood this. But I didn't until that distinction was made. So I think other people may misread this, as well.

Dr. Mandell: Okay. Thanks, I will I –

Ms. Abdull: That makes sense. Thank you.

Dr. Insel: Other thoughts or comments about the letter, or questions about its focus?

Dr. Dawson: So this is Geri. First of all, I want to commend the group that has been working on this and I think it's a great letter. And I just very much appreciate all the work that's been done.

So the only minor thing that one might consider including, and I don't know how you feel about this, but since we know that the efficacy of these early interventions for improving cognitive ability, IQ in particular, is one of the stronger outcomes or consistent outcomes that have been found.

And given the recent cost of autism analysis that was carried out by David, in fact, that showed the differential cost of caring for an individual with a higher and lower IQ, and that in the context of our understanding that now autism costs about $137 billion annually in care.

I just feel like that perhaps weaving in the point that, you know, I know that we did make reference to the Netherlands study and the cost effectiveness of early intervention.

But I think this issue of that when we help to increase cognitive ability, we also really provide a trajectory to more independence and end up with a longer term cost savings, that that could potentially be woven in, especially at a time when cost is so important.

[Pause]

Dr. Mandell: So I think that the issue of cost is a great one, Geri. I was wondering how to weave it in. There is certainly the potential for cost savings, but not great empirical data on doing it. Did you have some specific recommendations that sort of how and where we would do that?

Dr. Dawson: Right. So in the point where we, I think it's at the end of the paragraph that says “autism effects at least 1 in 88”.

Dr. Mandell: Yes.

Dr. Dawson: So after including 1 in 54 boys, we could say that recent, you know, economic analyses indicate that the annual cost of caring for individuals with autism is approximately $137 billion.

And then at the end of that paragraph, there could be a sentence that says something to the effect of providing early interventions that can improve cognitive functioning, you know, will help to mitigate costs of caring for individuals with autism.

And then you could include the data that suggests that individuals with intellectual disability, I think it's what, 2.4 or is it 2.3 million a year and then it's, I think, 1.4 for an individual without intellectual disability.

Dr. Mandell: Okay.

Mr. Robertson: So I had a comment, David, on the adding, more things around specifics on costs. My concern about adding dollar values is it's not like we have, say, you know, full studies or so on this.

There's only a few studies and a lot of the studies that are out there right now that have those specific amounts that were mentioned have some confounds and flaws to those studies.

I mean, it's not like you can necessarily take the quantitative things mentioned on there and say oh, that's definitively the cost for support for folks.

There's a lot of assumptions and problems with some of the existing research literature on lifelong cost for services for autistic people.

And so that's a major concern of mine of adding a dollar value into there, into a letter like this is it doesn't really show context in a lot of these studies that there's more to them than just a dollar values they have.

That there's really complex issues when the studies have looked at cost. And it’s not something that I think is as straightforward as just putting, you know, $500 billion or whatever and saying that's a definitively cost of services for folks. I think that would be misleading to put that in there.

[Simultaneous speaking]

Dr. Koroshetz: This is Walter Koroshetz. Can you hear me?

Dr. Insel: Yes, go ahead.

Dr. Koroshetz: I just wanted to comment, I think it's somewhat similar, and it'll come back to it in a second. But I was thinking that what's missing from the letter which I can understand why it might be missing and that would be fine.

But it's the idea that we talked about that no one feels confident, as I heard it, that the delivery of these services is being evaluated and to know exactly what therapy works for which population in terms of developing better therapies.

It seems to me that we should include some mention of the fact that research is going to be needed to kind of -- as these things are happening, to really evaluate them and hold the providers accountable for getting the outcomes we expect.

And also for getting the research on, you know, the effectiveness and the value that they add which comes into the economics as well, that this is the kind of data that you would want to collect as these things roll out.

And in talking to medics, the CMS folks on other projects, this issue of getting the best care for the right cost is clearly right up front.

But I think I agree, we don't have the data now. But I would say we should include something like that in this letter that further research is needed to get at what works best for which people and which populations and what the cost effectiveness is.

[Several speakers]

Ms. Crandy: I would hope that would be a different letter.

Dr. Burton-Hoyle: This is Sally Burton-Hoyle. And I think that it depends on the state you're in what emphasis there is on self-determination.

And I think that there are many people that have difficulty with a number which self-advocates feel engenders pity. And I don't think it's necessarily right.

You know, when I see figures like that, like how much per year or it costs or billions it costs over a lifetime, you know, self-determination studies, and I know there's one in Michigan that found very different results.

So I think until there is something that talks about the range of costs that a person may and their family may have, I don't think an amount of money would be at all a positive thing to put in.

Dr. Insel: This is Tom. We had a lot of discussion about this in working on the letter through the Subcommittee. And at one point, we did have more information about the annual costs and lifetime costs.

And that dropped out for two reasons. One was there was a bit of sticker shock and we were actually concerned that someone who was a payer looking at this letter would see that number and say this is not something I want to get involved with.

But the bigger reason was that as we looked at the literature, we just couldn't find the evidence base that said that these interventions would reduce costs by X amount.

We had the Netherlands project, which is now cited in here, and David has the reference. I think it's reference number four, and that we've included.

But decided that rather than going any deeper into this issue, we would bring it back to the IACC to say guys, we really need a lot more information.

And as we begin doing or recommending clinical trials to the research community, we need to make sure that trials have built into them some kind of a study to look at cost offsets or cost effectiveness so that people know what is worth paying for because, you know, that is a question that keeps coming up over and over again.

As Walter mentioned from CMS, they really want to know that this is the right investment to make.

So at the end of the day, what you see is kind of the result of a lot of discussion we had about just this point, and decided that it was better not to put a lot of emphasis on the things we don't know to say a little bit about what we do know.

But not to put a lot of emphasis on the enormous cost of this disorder except to say that our best sense was that early intervention would reduce, or I think the term we have is mitigate the lifetime cost of disability.

Dr. Dawson: So Tom, this is Geri. Since I brought up the issue, I am absolutely fine with that and I understand your logic and the various comments. And I'm completely comfortable with leaving it as it is.

I think just two quick points. I mean, one is the idea that, you know, if we can provide these cost savings, the idea is that we could use that money to provide a lot of other kinds of services for people with autism.

And so the idea isn't necessarily that we would pull money away, but that if we could distribute it and use it to help people to be more successful in their work environments and so forth, you know, that would be a great thing.

The second thing is, you know, Autism Speaks is currently funding two sets of cost effectiveness analyses. One looking at the cost benefit of providing early intervention.

The second one that we're working on is looking at the cost effectiveness of providing transition services from adolescence to adulthood because, you know, that's a very, very important point in development and providing those services helps to establish a more successful adult trajectory.

And so we're hoping that these kinds of arguments can be used to really advocate for those kinds of services.

Ms. Abdull: Hi, this is Idil. Dr. Dawson, I don't think you were on the services call, but I think the reason we took off the cost, as Dr. Insel said, is it was Anshu I think who said that we don't want to shoot ourselves in the foot because if we put a lot of money in there, then people might just get shocked and say oh my God, that's too much. Let's just kill the whole thing.

Dr. Dawson: Yes, I'm fine with that. I don't have any big problem with that and I understand the logic and also the other concerns that were raised.

Dr. Insel: Other thoughts or comments about the letter? We want to take this to a vote in this meeting, if possible. And David, you have to get off the line in a minute, so I want to make sure we cover this while you're still on.

Dr. Mandell: I appreciate that.

Ms. Abdull: I'm sorry, this is Idil again.

David, is it possible to just read what that change that one sentence or two sentence that you were going to put in. Could you read that out loud just so I have it in my mind before we vote?

Dr. Mandell: Well, in order for me to read it, I would have had to have written it.

Ms. Abdull: You are not psychic, come on.

Dr. Mandell: But for the paragraph that begins, so the two changes based on, I think, your really perceptive comments, Idil, the first one would be in the paragraph beginning roughly half the states.

So in or at the end of that paragraph, I will add something about this being for private insurance. This is what we know about what's happening for private insurance.

And that there's little information about what will be included in Medicaid plans. And also a sentence saying that currently there is no explicit service line in Medicaid that is used to cover these kinds of early interventions for children with autism.

And then at the end where I have the sentence about the two tiered system, I will add something more about the known disparities in access to care between these two systems.

Ms. Abdull: Okay. And then when you cite one of your studies or disparity study, or it doesn't matter if you don't.

Dr. Mandell: Always happy to cite my own research, Idil.

Ms. Abdull: That will be awesome. Thank you very much.

Dr. Insel: Alright, so are those the only two revisions to the letter as we have it in front of us? If so, do people feel comfortable voting on this with those two revisions that David will put in subsequent to the vote?

Dr. Koroshetz: Yes.

Ms. Abdull: Yes, yes.

Dr. Insel: Okay, Susan can I turn this over to you for a vote?

Dr. Daniels: Okay, let's clarify what the two items are that I - can we vote?

Dr. Insel: So David just read them. In the third paragraph, it'll include some reference to this half the states being for private and that there's still no clear picture of what the public system will do.

And at the end of the letter, we'll also clarify, he will clarify that the two tiered system for autism care should not be created in both Medicaid and in private insurance.

So those are actually simply clarifications. It's not adding anything beyond that. And it just goes back to the issues that Idil helped us to understand and we actually got John to verify this at the services Subcommittee level that what we're talking about with essential health benefits is around private coverage, and it's not yet the case that public coverage, that Medicaid coverage will follow the same policies or guidelines that will be in the essential health benefits, which was unknown to almost everybody on the call at that time, except John who was very helpful from CMS letting us understand that.

Given that, can we go ahead and take this to a vote?

Dr. Daniels: All right, do we have a motion on the floor?

Dr. Mandell: So moved.

Dr. Daniels: To accept this letter with the two changes that were just stated. A second?

Dr. Dawson: Second.

Dr. Daniels: All in favor?

[Chorus of ayes]

Dr. Daniels: Are there any opposed? Are there any who will be abstaining? Do we feel that we need an accurate count? It sounds like it's unanimous I –

Dr. Insel: It does.

Dr. Daniels: I – and we have a quorum. So we're not going to take a count because we are at quorum and it sounds like a unanimous vote.

We'll say that this was a unanimous vote in favor to accept this letter with the two changes. So David, you'll go ahead and make those changes and get the letter to me. And then our office will prepare it for transmittal to the secretary.

Dr. Insel: And it will be posted on the IACC website.

Dr. Daniels: Yes, as soon as it has been sent to the secretary, it will be posted on the website.

However, just for those who are listening, just be aware that there is, as with all government things, some paperwork that we will have to do in the office to get the letter prepared, forms that we'll need to fill out, et cetera.

So it won't be within a day, it'll take us a little bit to get everything ready. But as soon as it is up on the website, we will let you know.

Dr. Dawson: So Susan, is there any way that you could give us a, you know, 24 hour heads up of when you plan to send it?

Dr. Daniels: Yes.

Dr. Dawson: That would be, or even more, but you know, if we could have some anticipation of when it will be posted and sent, that would be really helpful.

Dr. Daniels: Sure, we can do that. We can let you all know what the status is. You always receive notification from me anyway.

So yes, we will let you know before we release it. And we'll release it, of course, as soon as possible because I know people want to be able to access it.

Dr. Dawson: Great, thank you.

Ms. Crandy: Susan, this is Jan Crandy. Do you think it's, like, next week because I really need that letter.

Dr. Daniels: It may be. It depends on when David's getting me these changes and so forth, and then we'll get it formatted and send it off as soon as possible.

Dr. Mandell: I can make the changes tonight.

Dr. Daniels: Okay.

Ms. Crandy: Thank you, David.

Dr. Daniels: It shouldn't take that long then.

Dr. Insel: We'll do it as quickly as possible, Jan.

Dr. Daniels: And Jan, if you can write me an email and just let me know when you need it. That would be helpful.

Ms. Crandy: Thank you.

Dr. Insel: Okay, good work, team. And thanks to David and Denise and the services Subcommittee for getting us this action item. Any other business for the IACC?

Ms. Redwood: Hey Tom, this is Lyn Redwood again. I hate to keep bringing it up, but I really didn't feel as though there was an answer to the question that I asked earlier about addressing comorbidities and also the suggestion that was made to have that discussion be sort of a broader topic in a workshop. So I would love to get some feedback on that.

Dr. Insel: Lyn, I heard two things, that in the upcoming meeting when there's a panel to deal with self-injury and non-verbal people with autism, that there will be some discussion there about the medical comorbidities.

But in addition to that, you and others have asked for a deeper dive on medical comorbidities and the possibility of doing this at either that meeting or another meeting where we have a much more in depth discussion about this.

There are now some really interesting data to bring to this discussion as well, with Lewin Group's report that will be out fairly soon, as well as the work of the ATN.

So it sounded to me like that was actually a separate discussion from self-injuries. So it would be something about medical comorbidity there.

Mr. Robertson: Tom, I have a question related to that, just a quick, and by medical comorbidities, we're including not just physical kinds of things, but some mental health and psychiatric as well, right?

Dr. Insel: Let me turn that question around to Lyn and others who have brought this up. How wide do you want the spectrum to be?

Ms. Redwood: I mean, I think that would be fine, Tom. But I sort of feel like those issues are oftentimes addressed already in the medical community, whereas, some of these other issues are not being adequately addressed. So that's why, you know, I had suggested the focus on looking at the metabolic, immune, GI, those types of things.

And I think it was – was it Donna Kimbark also that had supported the idea of having a workshop. So that was the question that I had – was whether or not this would be something that would move into a workshop.

Dr. Burton-Hoyle: This is Sally. I strongly support that. I think that there are too many families confused and are turned away by their medical doctors. I think more information on the physical aspects that people with autism experience.

Dr. Insel: I think I had mentioned, this is Tom, Lyn in an earlier conversation that NICHD and NIMH and the Special Olympics are putting together an event in September on precisely this issue, but for developmental disabilities broadly looking at how to increase awareness of medical problems in this population so that not everything is just attributed to their developmental disability.

And we have really good evidence that everything from dental care to mental health care is not optimal for this population. But that's a somewhat broader focus, that's not just autism that's going to be looking across the board.

And I think what you and others have suggested is that there may be some more unique issues within autism that deserve some special attention.

Ms. Redwood: Right. Well I don't know if this needs to be in terms of a motion that would be made to have a workshop on this issue. I'm just wanting to get direction in terms of trying to move this issue forward where it's not dropped.

Ms. Singer: Well maybe it makes sense to first have the panel discussion, and then see which issues really emerge as topics on which we need to take a deeper dive.

I mean, we haven't really looked at this issue at all, I think, is the reason why we want to have the panel. So maybe we should wait for the outcome of the panel and then move forward with deciding where we want to invest our energy for a workshop.

Dr. Insel: Alison, when you say panel, you mean the panel on self-injury, or I –

Ms. Singer: Yes.

Dr. Insel: I – a different panel? Okay. The other thought I have is that since there's a major event being planned on this topic, even though it's for a broader population, could we leverage that to do some part of that event specifically around autism and have half a day or something like that, because that will bring a lot of the most significant players in this field together at one time.

Ms. Singer: What's the date on that event?

[Several speakers]

Dr. Insel: - separate workshop or a separate meeting.

Ms. Singer: What's the date of that event? Is there a date already?

Dr. Insel: We haven't set the event. There's a team that's planning it at this point. And it will be, again, cosponsored by Tim Shriver and the Special Olympics along with NIH.

And the reason I bring it up is it's driven by exactly the same issues that Lyn brought up. It turns out that those are concerns not limited to the autism community.

The one addition I think we would want to put into this, which may not be so much a focus for the event that's currently planned, is to also bring adults into the conversation so there's a focus on the needs of adults, many of whom may not have been diagnosed and for whom the diagnosis is missed because people don't often associate autism and adulthood.

Dr. Daniels: Tom, this is Susan. Does it make sense for us to reach out to this group that's planning this conference and find out how we might be able to integrate something from the IACC's priorities in whether it would be to have something beforehand or I'm sure that they have a full agenda of what they want to do.

Dr. Insel: Well if we're going to do that, this is the time. They're just now planning. And so it's still early days. But I think we're talking September, October.

Dr. Daniels: So we could be in touch with them and find out what they're doing?

Dr. Insel: Yes, if that's what people want to do. But I don't want to railroad the discussion here. I just bring it up because that's already happening. And it just seemed like an easy way to leverage a project that's already on the books.

Dr. Koroshetz: I think it's a good idea. This is Walter. I think we could learn a lot from, you know, areas, conditions that are facing the same problems and trying to leverage the next piece that comes into the bigger meeting. But then to really have an autism focus as a satellite, I think, would be good.

Ms. Abdull: I agree.

Ms. Singer: I would be happy to handle that.

Dr. Insel: Lyn, how do you feel about that? Is that – did that missed the point?

Ms. Redwood: You and I had emailed about this previously. I was trying to pull up that particular email. I guess I see some overlaps in terms of medical comorbidities within those two groups, predominantly seizures.

But a lot of the other medical comorbidities, I don't know that they are really an issue in the developmental disability classification, like GI, gastrointestinal problems, immune system, metabolic, those types of things that I think are specific to the autism community.

So although there is some overlap there, I think that there's enough uniqueness in terms of trying to develop effective guidelines for really investigating and treating some of these medical comorbidities that the workshop that you're talking about really would be somewhat inadequate.

I also have some concerns about it not taking place until the fall if we have a sense of urgency. So those were the concerns that I voiced with you previously with that approach.

Dr. Daniels: Lyn, this is Susan. If we were planning a workshop now, it would probably be in the fall anyway because we can't put together a workshop in the matter of just a few weeks.

It takes a lot of effort to be able to put together all the logistics for a workshop. So if we were going to do a standalone workshop, it would probably be around the same time.

Dr. Insel: But to Lyn's point, I wonder, could we do something in July? I would really love for the IACC to hear from the Lewin Group about the comorbidities that the largest study ever done with 33,000 children with autism.

It's claimant data, so it's not ideal in that sense. But the results are pretty impressive. That and the ATN has, putting the two of those together, I think, begins to give us a different picture than where most people are coming from.

And I agree with Lyn, there's some urgency to getting that information out there because most pediatricians don't know about this.

Dr. Koroshetz: We could set a panel up now to try to develop, you know, something for our next meeting and then also to plan a meeting in concert with the bigger one in the fall?

Dr. Insel: Yes, let's think about that. If we can do something, that would be kind of an intro, you know, just to maybe hear some of the data.

And then use the fall meeting for a longer conversation about what some of the solutions might be and how to pull this together with, especially the primary care community.

Ms. Singer: So this is Alison. I thought that working with the Special Olympics conference was in addition to doing the panel at the July meeting?

Dr. Insel: Yes.

Ms. Singer: I thought that we had discussed the idea of having the panel which included the topic that Lyn had brought up about medical comorbidity as one of the panel topics.

It also included the representative from the ATN and the then representatives talking about self-injurious behavior and psychiatric inpatient and the treatment options that are available or not available for that population and doing a broader panel.

And then, as one of the valued outcomes of that panel, maybe figuring out where we want to take a deeper dive after the Special Olympics.

So you know, I see this as different steps that will speak to the urgency.

Ms. Redwood: And Alison, I thought that, too.

Ms. Singer: – can do these things in parallel.

Ms. Redwood: And Alison, I agree. I thought that, too. But then I heard Dr. Insel say that the focus was going to be more on the non-verbal and self-injurious. So that's why I brought it up and asked the question.

Ms. Singer: But I thought we had agreed, I mean it was my understanding that we had agreed for that panel, that one of the particular likely causes of self-injuries were these undiagnosed medical comorbidities.

And then that would be one panelist we would want to include on the panel, maybe one of, I heard four topics that came out. So maybe we want to have four speakers on that panel.

Dr. Insel: Yes, I think that would work. So let's do that. And we'll plan to build the July meeting to make sure this topic gets sufficient discussion and focus.

But in addition to that, look at the way we can interact with this bigger meeting, which may be a multi-day meeting, I actually haven't seen the agenda, that's being planned for the fall and build something into that specifically around autism.

Ms. Singer: And I'm happy to help with both of those activities.

Dr. Insel: Okay, good.

Ms. Redwood: And me, too, Tom.

Dr. Insel: Terrific.

Ms. Abdull: Hi, this is Idil. So then just to make sure I understand it, for the July meeting, we'll have more in depth discussion for the self-injurious, the non-verbal and the comorbidity, right?

Dr. Insel: That's right. There'll be a panel on that. General topic, it will include not only medical comorbidity as a cause, because as people here brought up, issues around communication.

Ms. Singer: And also that's where we put the person from the Lewin Group?

Dr. Insel: Yes.

Ms. Abdull: So maybe I, yes, okay. Sounds good.

Ms. Singer: Medical outcomes?

Dr. Insel: Right. Okay, we're at the end of our assigned time. Are there any other issues that need to be brought to the table for IACC business?

All right, hearing none, I want to thank everybody for their attendance today, and their participation. We got actually quite a bit done in the 90 minutes.

Thanks those who listened in from the public that is not on the Committee. We will be meeting again, Susan, our next I –

Dr. Daniels: Our next meeting is April 9th for the full Committee. And we also have some different Planning Groups from the Subcommittees that may be having other meetings in between.

And we will keep you posted on the development of those meetings. And we will get an update from the Subcommittees at the full Committee meeting on

April 9th.

Dr. Insel: Great. And we'll turn around this letter as quickly as possible. Thanks again to David and Denise and the services group for putting this in front of us.

Thanks everybody, and we'll see you in April.

[Chorus of thank yous]

(Whereupon, the Full Committee conference call adjourned at 11:33 a.m.)