U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR SERVICES RESEARCH AND POLICY

FRIDAY, MARCH 8, 2013

The Subcommittee for Services Research and Policy (SRP) convened via conference call from 2:00 p.m. until 5:05 p.m., Denise Dougherty and David Mandell, SRP Subcommittee Co-Chairs, presiding.

PARTICIPANTS:

DENISE DOUGHERTY, Ph.D., *Co-Chair*, SRP Subcommittee, Agency for Health care Research and Quality (AHRQ)

DAVID MANDELL, Sc.D., *Co-Chair*, SRP Subcommittee, University of Pennsylvania

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

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

IDIL ABDULL, Somali American Autism Foundation

ANSHU BATRA, M.D., Our Special Kids

JOSE CORDERO, M.D., M.P.H., University of Puerto Rico

JAN CRANDY, Nevada State Autism Treatment Assistance, Program and Nevada Commission on Autism Spectrum Disorders

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

PARTICIPANTS (continued):

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

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

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

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

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

LARRY WEXLER, Ed.D., U.S. Department of Education (ED) (representing Michael Yudin)

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PROCEEDINGS:

Dr. Susan Daniels: Thank you. Welcome to everyone on the Subcommittee, other members of the Committee, and members of the public who may be listening in. Actually, there is no question-and-answer session on this call. So, I just wanted to clarify that.

We welcome all of you to this conference call. We are glad that you could join us. We are going to be talking about issues that the Subcommittee for Services Research and Policy will be handling for today.

I would like to let Dr. David Mandell and Dr. Denise Dougherty welcome you all, also, onto the call.

Dr. David Mandell: Hi. This is David Mandell. Welcome. Thank you all for making it.

Denise, I don't know if you want to say a few words. And, Susan, I don't know when we should start to go over the agenda.

Dr. Daniels: So, we will do roll call after you have a moment to welcome the

Subcommittee.

Dr. Mandell: Well, I don't think I need any more moment than that.

Dr. Daniels: Okay. Denise, do you have any comments?

Dr. Denise Dougherty: No, I don't have any additional comments. Welcome, everybody, and thanks for joining.

Dr. Daniels: Great. I will go ahead. This is Susan Daniels. I will do the roll call.

So, Denise Dougherty and David Mandell are on the call.

Idil Abdull?

(No response)

James Ball?

(No response)

Anshu Batra?

I couldn't make that out. Who was that?

(No response)

Anshu Batra?

(No response)

Jose Cordero?

Dr. Jose Cordero: Here.

Dr. Daniels: Jan Crandy?

Ms. Jan Crandy: Present.

Dr. Daniels: And Sally Burton-Hoyle was not going to be able to join today due to a family emergency.

Laura Kavanagh?

(No response)

And I heard Laura earlier on the preconference. So, I am going to check her off as here.

John O'Brien?

Ms. Laura Kavanagh: I'm here.

Dr. Daniels: Okay. Thanks.

John O'Brien?

(No response)

Lyn Redwood?

Ms. Lyn Redwood: Here.

Dr. Daniels: Thanks.

Cathy Rice?

Dr. Catherine Rice: Here.

Dr. Daniels: Scott Michael Robertson?

Mr. Scott Robertson: Here.

Dr. Daniels: And Alison Singer?

(No response)

And I would like to remind everyone on this phone call, please say your name before you speak because it makes it easier for the transcriptionist to keep track of who is speaking, and makes for an accurate transcript for the meeting.

And I would also like to take you through review and approval of the November 27th, 2012 minutes. Those were sent out – the draft was sent out prior to the meeting.

Does anyone have any comments on those minutes, any concerns, or things that need to be changed?

(No response)

Hearing no comments, is there a motion on the floor to accept the minutes?

Dr. Mandell: So moved.

Dr. Daniels: Second?

Dr. Cordero: Second.

Dr. Daniels: All in favor?

(Chorus of ayes)

Any opposed?

(No response)

Any abstaining?

(No response)

So, motion carries to accept the minutes as written, and they will be posted to the website as soon as possible. Thank you.

And now I will turn it over to David Mandell and – oh, you know, I apologize, I need to also just check to see who might be on the call who is not a member of the Subcommittee. There may be some Committee members who are also present. I apologize. I should have done that earlier as well.

So, can you please just let me know if you are on the call and you are not a part of the Subcommittee?

Dr. Thomas Insel: I'm here. Tom Insel.

Dr. Daniels: Thank you.

Anyone else?

(No response)

Okay. I don't hear any others. If anyone else joins later or if you are currently on mute or having trouble being able to connect, please just say something during the call or send me an email to let me know that you are on the call. Thanks.

And so, now, David and Denise, I will turn it over to you.

Dr. Mandell: All right. So, we have really two major tasks for this call, I think. And, Denise and Susan, please join in if I am missing anything.

But the first is to go over the letter which was drafted to the Secretary regarding the Affordable Care Act and the essential health benefits and to decide whether this is something that we think is acceptable coming from our Committee that we want to present to the full Committee for vote, or whether there are changes that need to be made.

And the second thing we need to do is to discuss what we want the activities of our Subcommittee to be for this coming year, understanding both the limitations that are imposed by staffing at OARC, and also our timeframe, since the IACC is set to sunset in

2014. I don't remember the exact month, though.

Dr. Daniels: September.

Dr. Mandell: In September.

Denise or Susan, did you want to add anything to that?

Dr. Daniels: This is Susan. I would just add that, also, just the limitations on the Committee's time because I know that all of you are very busy. And so you might want to be mindful of how many different tasks you take on, and possibly making them serial, so that you are not attempting to do too many tasks all at the same time, but prioritizing the tasks so you can get them each accomplished in order.

Dr. Mandell: Thank you.

Dr. Dougherty: Yes, this is Denise. I just wanted to remind people – actually, it was news to me - it shouldn't have been – but that this particular IACC expires in September 2014. So, that gives us, basically, what, 15 to 16 months to get some focused work done.

Nothing like a deadline to focus the mind, I think.

(Laughter)

Dr. Mandell: So, I want to give people some context for the letter. Hopefully, everyone received it. I know that Susan had emailed it out.

If you recall, at the full IACC meeting we talked about the idea of providing some advice to the Secretary regarding issues related to policy and services for autism, and that the implementation of the Affordable Care Act offers a particularly important opportunity to do that.

We talked about it there, and also in further discussions in crafting this letter, the idea that any letter we might want to put out should be very targeted, and that we could think about a series of statements like this addressing multiple issues, but perhaps with each only addressing one. I think it provides more strength for the arguments and more focus to the arguments within the letter. It keeps them within the attention span of people who we hope will use them.

And then the second thing is that, regardless of what the Secretary chooses to do with this information, these letters also can serve an important purpose for other groups to inform their decisions about services and policy for people with autism, knowing that this is the official position of this body.

So, that being said, we thought of this letter as perhaps the first in a series, assuming that this process works out, and it specifically addresses the need for essential health benefits to cover behavioral health treatment for children with autism.

So, I think that is probably enough preface. I think we would be very eager for feedback on the letter and perhaps also more generally on that process for more statements from the IACC.

Dr. Anshu Batra: Susan, this is Anshu. Can you hear me now?

Dr. Daniels: Yes, we can hear you.

And, David, do you want to say something about who was involved in drafting the letter, just for anybody who might have missed all of that from the last meeting?

Dr. Mandell: Sure. So, John Robison, Tom, Denise, and I all worked on the text of the letter, as did Susan and her staff, who were really instrumental in fact-checking and making sure that what we said was accurate.

Did I miss anyone there? I think that was it.

Dr. Daniels: I think that was it.

Dr. Mandell: All right.

Dr. Daniels: Thank you.

Ms. Crandy: This is Jan Crandy. In reviewing the letter, I think it is very thorough. The research there is very supportive. My question is – and I heard a little bit of it before preconference — I am wondering, why aren't we having a sentence at the end that says something like, "It is with urgency that we recommend and request Madam Secretary to issue a directive to states requiring this coverage at research level and of intensity within the central benchmark framework, as Congress intended"? Can you address why we can't have a comment like that where we are actually asking her to do something, instead of just providing her with information?

Dr. Mandell: Susan and Tom, I would appreciate your input on this. I guess there was some fuzziness about where the line regarding lobbying is.

Dr. Insel: Right. So, this is Tom. You know, I think it's a good question. We are an advisory committee. We are not an advocacy committee. So, as much as we might want to advocate for her to do any specific thing, the best way we can serve is through providing advice, and the advice needs to be based on the strongest science or evidence that we've got.

I think in this case, as David said at the beginning, I am not sure, in all honesty, how much a letter to her will result in any given action by her. I think the hope is, if the Committee can make a statement that is clear about the scientific evidence, that letter could be used by others who might want to be advocating for this. But the pure advocacy is really outside our role.

Dr. Mandell: I did want to bring up two things that other people on the Committee brought up who are not here, but I would like them entered into the record.

The first was Idil, who was concerned that we make it clear – she didn't want us just to be focusing on private insurance. And she wanted the letter to include some content related to Medicaid.

And the second was John Robison who, although he was involved with the drafting of the letter and initially agreed with this tack, was concerned about the lack of mention of adults, et al.

And so, I did want to put those two issues on the table and make sure that they were at least on the record and, hopefully, discussed as well.

Dr. Insel: There was another issue as well. The letter doesn't really discuss the AHRQ evaluation, which was less positive than the two that are mentioned.

Dr. Daniels: There is a fourth issue as well. This is Susan. Matt Carey sent me something to share with you, that he said that he would like to see an inclusion of speech and occupational therapy. And if you need more information, I could read you the entire text that he sent me.

Ms. Abdull: Hi. This is Idil. Can you guys hear me?

Dr. Daniels: Who is that?

Ms. Abdull: Oh, sorry, this is Idil. For some reason, you guys couldn't hear me.

Dr. Daniels: Okay. Thanks.

Ms. Abdull: I will go ahead. I don't know who was speaking, but I will, if I can, speak next.

Dr. Mandell: Go ahead, Idil.

Ms. Abdull: Oh, sure. Yes, thank you so

much. So, this is Idil again. And I had sent that email. Maybe I should have just waited for today. But I think sending anything to the Secretary is always a good idea in raising awareness for autism. I just have a little concern about when we say we want to make sure that let's get behavior therapy for the Affordable Care Act, and we don't mention anything about the Medicaid or the CMS guidelines for making sure behavioral therapy is also in place under Medicaid – I am not necessarily saying we need more money or funding for Medicaid.

I think David said it before, that what we have is really good enough. But just sort of changing the policy, so that just like immunization, just like all the other things that children get, behavioral therapy is part of that.

I also do agree with John, who is not here today, that we really have to be careful when we are recommending anything, services that we are recommending across the spectrum, across the lifespan, including adults and also children that have Medicaid as an insurance, not just private insurance.

And so I don't know if there is a way to include that. And I was listening to David saying that we should maybe get a series of letters, but sometimes if you send too many letters, sometimes they might not pay attention to all of them. So I just want to see if there is a way to condense it and just plant the seed in the Secretary's mind that, yes, we need therapy for all people across the spectrum and across the life, including those that have Medicaid.

Thank you.

Mr. Robertson: David, this is Scott Robertson. I would like to make a few comments, too.

I concur with the thoughts that – I had concerns when I read the letter that a multipage letter on autism in terms of expanding supports and care would not be talking about the lifespan and would only be talking – in many cases making reference to just young children in a lot of those studies referenced.

And John also had mentioned this as well, and my understanding is that it only was specific to behavioral therapies and did not include mention of things that we do, you know, have some support and evidence base for on OT and speech therapy and some other forms of supports and services that could be mentioned.

And then I also – and I don't know whether we want to go through the text right now, or whatever – but there are some spots in terms of how the text is phrased in here that I think it could be worded better. In some places, this almost describes – it almost uses kind of, rather than factual, more like alarmist-oriented language and kind of uses language that kind of almost describes autism as a burden thing, rather than saying that supports will increase kind of quality of life, it kind of is more talking about, you know, the problems of individuals who do require supports and services, as if that's kind of the end-of-the-world type thing. And so I think that could be phrased a little bit better, particularly on page 2.

Dr. Mandell: So, Scott, maybe – I appreciate that sort of general concern, and maybe we could first have a discussion about the general concerns because if we don't come to agreement about those then some of the wording issues may be moot. And then we could talk more specifically about wording.

Dr. Cordero: This is Jose Cordero. I would like to make a comment.

Dr. Mandell: Go ahead, Jose.

Dr. Cordero: Oh, I just wanted, in looking at the letter, I think that it's nice that we have something that very clearly shows what evidence there is. But I think that we have to be careful in two areas.

One, at least an experience that we are having in some areas is that healthcare coverage is not even including the process of diagnosis of autism.

The second thing is that I think that we need to be careful in saying that these services that are found to have some benefit, it's all that the child with autism would need in order to thrive and develop. And it is really a combination of management. Really, the point is that it needs to be covered, what the child needs.

Dr. Mandell: So, can I – sorry, go ahead.

Ms. Crandy: This is Jan Crandy. I just want to make a couple of comments. The way that I understand this letter is it is addressing a specific issue that, when Congress intended to have ABA autism treatment included under behavioral health, that it would be included. And now it's not. And without some action happening, we are going to lose that across states, and states are going to have to fight for it individually again, after we had that.

And speech and OT should be covered under habilitative now. So, I don't think that we are going to lose speech and OT. I think we are going to gain speech and OT.

Ms. Abdull: Hi, this - go ahead Larry.

Dr. Larry Wexler: This is Larry Wexler. Oh, thank you. I had a couple of comments also. And I read this, the lens I have on is an educational lens. So, it may be different from you all.

But, you know, this is based on saying the expert panel concluded that children with ASD should have access to at least 25 hours per week. And then it implies that the Affordable Care Act should pay for it.

And the concern that I have is that 25 hours a week can be done in schools. That includes OT, PT, and a variety of other related services.

So, to a certain extent, if the goal is 25 hours, at least, outside of school, you are not saying that. So, there needs to be some clarity here that a child with autism qualifies under the Individuals with Disability Education Act, which is to get a free appropriate public education based on the individualized needs of the child.

And so that is not something that gets covered under the Affordable Care Act necessarily. That gets covered under the child's school district.

So, to some extent, I would read this as saying, well, if they get 25 hours a week in school, then that's it, we've met our obligation. So, I would be cautious that the unintended consequences, you are actually providing less service through this letter than more service.

Thank you.

Ms. Abdull: Hi. This is Idil.

I agree with everyone here, and I especially really agree with what Jose said. We really have to make sure, when we say we are recommending ABA, then we are saying, then, there is nothing else. I mean, autism is a neurodevelopmental disorder. So, if we are leaving the neurodevelopmental therapies, I think we have to be careful. There are a lot of other therapies that work.

And also when this was being added into the affordable healthcare law, it was Senator Menendez and Congressman Doyle who wanted it. And I remember I would vividly probably call them daily saying, if you are going to demand the private insurance pay for this, what are you going to do? How will you make sure the children that have Medicaid, who are financially vulnerable, are going to be able, also, to get the same services?

So, we fought it because we didn't think it was holistic enough. We didn't think it was fair enough. And if our goal this year, I hope, is to decrease disparity, we have to make sure that access is equal from the get-go, not later, and not come back for the low-income, most likely minority kids. But let's help to make sure all children get therapies that are cost-effective, that are based on science, that we have now.

And then, also, that it is fair for all children. Dr. Insel, I loved his blog where he said, regardless of wealth, race, or location. And I just feel like this letter, it just doesn't do that for me. It makes it as though ABA lobbyists wrote it. It just makes it so that we are saying let's just get ABA.

And also what I am finding out from at least in our state is that, because it is not part of the essential benefits right now, if states have to cover it, it would cost a lot more. And we just have to be careful that we are not adding already to a financially straining system.

Dr. Rice: This is Cathy Rice.

I would add two things. I think back with what Larry Wexler said about the importance of also considering educational services, although this is a letter to the Secretary of HHS, I think at least a note of the need to coordinate with education services, and particularly those provided under IDEA.

And it becomes a particularly important issue for early intervention, where many states, the early intervention, zero to 3 or zero to 5, depending on the state programs, although under IDEA, are housed in departments of health. And there is sometimes overlap within the ability to use Medicaid funding to pay for services and at other times use private insurance funds to pay for IDEA services.

So, that is somewhat of the situation that I think needs to be recognized in that vein in terms of the need for at least the coordination of these services.

And then one more point. To what Idil was just saying, in terms of here we have multiple potential funding streams within the insurance realm, whether private, public, as well as educational services, and additional potentially out-of-pocket services.

And then we have the issue of behavioral health treatment versus habilitative treatment, or allied health treatment, being OT, PT, speech. So, some recognition of the need to be efficient and coordinate services for both the family and the payer and provider across these different arms.

And that may be too detailed, but I do think that if we are making recommendations of what the IACC is saying families need, it is not only equitable access to care, but coordinated, clear streams that they can actually access. And so that coordination piece I think we need to make sure we do include as well.

Dr. Mandell: This is David.

Can I try to address some of those issues? Most of them were issues that we attempted, that we thought about while we were crafting the letter.

With regard to speech, occupational therapy, physical therapy, other therapies that are often needed for children with autism and adults with autism, most of those are already covered in state plans. And so we thought that the important thing about this letter was its targeted nature toward a specific evidence-based or set of evidence-based treatments that had strong potential not to be covered, depending on what states did.

And so that is really how we focused the letter. I completely agree, and I don't think this letter in any way implies, or it certainly doesn't mean to imply, that this is all children with autism need with regard to their care, but that this was a critical component of that care that was in danger of being left out of state plans.

With regard to the issue about Medicaid, my understanding – and I could be wrong – is that these are plans, under the Affordable Care Act, these are plans, and benefits that will be required across all payers in the state, including Medicaid. And so that sort of disparity in care between what is available in private insurance and what is available in public insurance, at least in name, will not be there with these essential health benefits.

Ms. Abdull: So, David, are you saying, then, whatever is available under affordable healthcare law would have to be available on the Medicaid side?

Dr. Mandell: So, that's my understanding, that these are the benefits that a state would adopt across all payers within that state.

Unidentified speaker: Yes, I think it is true.

Ms. Abdull: So, at least in Minnesota, that is not what I am hearing. And at least from CMS, that is not what I am hearing. Because, as you know, ABA or any autism therapy, for that matter, whether it's behavioral or neurodevelopmental therapy, is not part of the EPSDT. So, therefore, it is not basic essential benefits under all the states that have some kind of Medicaid services, which means that if a state wants to pay for any kind of autism therapy outside of those, and speech and OT is included under EPSDT, they have to put up the money.

So, for instance, in Minnesota we have been asking consistently, can Minnesota pay for behavior therapy and neurodevelopmental therapy? And so the Governor put in $12 million this year. It has not yet passed the

Legislature.

So, then, the Federal Government, CMS, if we send that application, and if it passes the Legislature, they would match that 50 cents to the dollar, which means, then, just because we have the ACA does not automatically mean it will be covered under Medicaid. Each state has to put up money for it to cover those services.

That is why the disparity part is going to be hard because not every state is going to have vocal parents like us who are going to demand that, whatever we are going to cover for Michael Smith with Blue Cross Blue Shield, that that gets covered for Michael Smith with Medicaid.

Dr. Mandell: And is Minnesota including any kind of behavioral treatment as one of the essential health benefits?

Ms. Abdull: No, it is not. So, the private people are fighting their own battle.

Dr. Mandell: So, I think that that is exactly the issue. If states were to include this as one of the essential health benefits, then that would not be a battle the parents would have to fight in each state, regardless of whether they were insured by Medicaid or by private insurance.

Dr. Insel: Right. So, Idil, I think you have just – this is Tom – I think you have just defined the reason for doing this letter.

Ms. Abdull: So, I understand where you guys are coming from, but I would want to make sure, because that is not what CMS told me. When I had asked John and others in Baltimore and Chicago, they said, even if behavior therapy was part of Minnesota's healthcare, it would not mean that Medicaid would automatically cover it.

So, unless I understood them wrong – I don't know if John is on the call, but he would know better than I.

Dr. Insel: So, the fundamental principle is that there are no decisions about Medicaid coverage made by CMS except the decision to match what each individual state decides to cover.

Ms. Abdull: Right. That is the way I understand it.

Dr. Insel: So, you are always back to doing this state by state. And the Secretary has been very clear that she will not be putting out any guidelines that are either disease specific or that are Federal guidelines for coverage under the ACA. That is still going to be a decision, whether it is cancer or autism, that will be left to each state to decide what they will cover and who they will cover within their own Medicaid guidelines. What CMS meant, then, is the commitment to match that.

Ms. Abdull: Right. But, I mean, what we are saying, though, this letter, the way I understood it, is saying that we want to make sure that ABA is part of the ACA. And what I am saying is that, if that is what we are asking, we also need to ask that behavior therapy is also part of the EPSDT under CMS guidelines.

It is not disease specific, but it is therapy specific. In other words, in order for both Michael Smiths, the Medicaid kid and the Blue Cross Blue Shield kid, to get equal access, because disparity we know happens when services are unequal, right? So, in order to get equal access to services, the services must be equal.

Dr. Mandell: Idil, if we are saying it is under the ACA, it is the same thing as saying it will be under Medicaid state by state. I think it's a different issue, and I don't think it's possible for us to tell CMS, because EPSDT was a congressional requirement but that states have implemented individually. So, CMS isn't telling states what is covered, what has to be covered under their EPSDT benefit, except to say that it is all medically necessary services.

I mean, that would be a very different battle than saying that – on the other hand, if a state includes these behavioral treatments under the Affordable Care Act as one of the essential health benefits, that is the same thing as saying it would be covered under Medicaid in that state.

Ms. Abdull: I am not so sure about that one. I think we should ask John or somebody at CMS. That is not what I am hearing, that it automatically would be covered under Medicaid just because it is in the ACA law. Are you kidding? That would be like a dream come true. We wouldn't have to fight anymore.

Dr. Mandell: Well, I think that that is very worth doing some more research on before we – because that is my understanding. I could be wrong, as I have been about so many other things.

But, yes, that would take care of this issue and, again, would be a very different battle and a very different request than saying that CMS should specify some service within EPSDT, which they don't do now for any services.

Ms. Abdull: Right.

Dr. Rice: David, this is Cathy Rice.

Going back to the points you were making in terms of responding to our variety of comments, you made a statement that was really nice and clear. And in some ways, when reading the letter, I was like, what is this, why are they writing me? And I think it would be nice to put up very soon that the point is to address that critical component of care, that risk of being left out, and here is why.

Dr. Mandell: Okay.

Dr. Rice: That is how you had stated it, and I thought that was really nice and clear.

Dr. Mandell: So, we could certainly put a sentence in the letter that says we are not arguing in any way that this is all the care that children with autism need, but it is an essential component that is at risk of being left out.

Is that what you were referring to, Cathy?

Dr. Rice: Yes. I think, one, that, then, makes us, as a Committee, bring the conversation back to do we agree that that is how the letter has to be – or should be or has to be – and go from there. Because pointing that out up front I think is really helpful for framing the way that the letter is framed, then, in that vein.

Ms. Kavanagh: This is Laura Kavanagh. I agree with that wholeheartedly. I think that provides such clarity about what the expectations are of this letter and answers a lot of the questions.

Dr. Insel: This is Tom again. If I can respond, and I agree, actually. I think having some clarity at the outset will help on this issue.

But I do think that, in defense of some of the language in the letter, the impetus for this was simply to be very clear that there have been a couple of recent reports, metaanalyses essentially, of the evidence base that says that there really is a strong scientific basis for covering this.

All of the other interventions, which many of us may think are meritorious, I don't believe we have got that kind of evidence base behind them. I may be wrong about that.

But even this, the behavioral therapy evidence base, which is probably the strongest card for the hand that we are holding, was questionable. And as we mentioned before, the AHRQ report actually said that the evidence isn't there yet, that it's at best modest, and it's because of the poor quality of many of the research studies that have been done that make it very difficult to support this as an evidence-based intervention.

That came out in, I think it was – I want to say April of 2011. It may have been a little later than that. And that is, I think, what most people are looking at when they think about where are we with respect to behavioral interventions for children with autism.

The point here was that there are two very recent reports that we felt would be useful to put out there that provide a somewhat stronger commentary, although to be fair, the Cochrane Analysis is based on a total of something like four or five reports, only 200 children, and it's pretty thin. And even that report itself is fairly ambivalent about this evidence base.

Remember, we are not comparing this to the evidence base for the treatment of other disabilities. We are talking about what does this evidence base look like with respect to the use of antibiotics for infections, with respect to treatment of diabetes, cancer, heart disease. That is the kind of evidence base people are looking for when we are talking about the implementation of the ACA or essential benefits.

So that is what we are up against, and I think we have got to provide the most rigorous statement possible about why we think this is ready for prime time. But we do need to be careful not to stretch ourselves into territory where someone else could come up and say, "Gosh, you know what? That just doesn't hold water. The number of studies done is not sufficient. The quality of the studies is inadequate. And that does not have the strong evidence that one would need in medicine today."

Mr. Robertson: This is Scott Robertson. I have a comment related to what you just mentioned.

I could be wrong on this, but my interpretation in terms of when I read through the letter does not reflect what you mentioned in terms of that there is, you know, some disagreement, maybe some concerns about the evidence base on behavior things. The letter seems to almost project a much stronger position than that.

I wonder if that is doing somewhat of a disservice, to maybe try to project that things are stronger in the evidence base than maybe some of these reviews have said about it.

Dr. Wexler: Tom, this is Larry Wexler. I will comment again. At least in the Department of Education, when you use the term "strong," you are only referring to randomized controlled trials. And from what I could read in all these studies, there was one very small RCT. And I think we should be very cautious to base public policy on evidence that is not strong. Or don't call it strong; call it mild or moderate evidence.

But I see nothing in what has been sent to us that indicates that there is strong evidence that anything is effective in this, strong from the perspective that it is based on an RCT or based on multiple RCTs. So, I agree with you, Tom, that this is somewhat optimistic. And I am wondering if a letter to the Secretary should be based on optimism rather than on a fair representation of the evidence.

Ms. Abdull: Hi. This is Idil.

I just have one more comment about the age. Because I think what Dr. Insel was saying is that, even though it's at best modest for these ABA therapies, all of them, almost, say early intervention, children that are younger than 6 or 7. But the letter sort of just has unlimited hours for any age, which there isn't any study for that.

So, I am just wondering, even if we write this letter, if we would have to write that it's for early intervention, meaning that a child's early years in life, which is what the little study that we have indicates, right?

Dr. Insel: Just to clarify – this is Tom – there are two reports. The Technical Expert Panel Report that came out in December covered 300 studies, including several RCTs for children broadly.

The second report, which is the Cochrane Analysis, which came out in October, was only for early intervention. So, that was defined as the intervention beginning when the child was under the age of 6. That was a much thinner pool of studies, but there was at least one RCT in that group.

And what we tried to do here was – I don't think we used the term – maybe we did – "strong evidence," but we tried to quote from those reports to simply convey what it was that both the Technical Expert Panel and the Cochrane Analysis recommended, based on the reviews that they had done.

Mr. Robertson: Tom, this is Scott Robertson. I just wanted to clarify. I didn't mean the term "strong evidence" as literal, but just the letter, from a big-picture standpoint kind of conveys almost that standpoint. If I am a layperson kind of reading this, you know, it doesn't seem to connote the fact that there is a little – it just seems so head-on on this thing, almost like we have been doing this for like 50 years kind of thing.

I mean, that is the way it comes across to me, that there is a lot of certainty on how these things are working and the improvements and gains and things like that. And it doesn't convey some of the things that, well, you mentioned in terms of thoughts from the literature about that we don't, you know, have as many well-developed RCTs, et cetera, as was mentioned in the other comments.

Dr. Rice: This is Cathy Rice.

And this gets back to an issue that I struggle with when we're talking about the evidence for interventions more broadly. The gold standard really is these RCTs looking at group effects, impacting core features of the condition. Ideally, does this person move to a level of functioning where they maybe not qualify for that diagnosis? You could get into all kinds of debates about what is outcome.

But, at the same time, when we are talking about autism, and we are talking about such a heterogeneous condition across a whole range of intellectual functioning, all types of functioning, and we haven't even been able to come up with a good way to have solid phenotypic groups. This goal of having big group effects from RCTs, I don't know how appropriate it is.

And at what point do we need to consider evidence that looks at movement among certain domains? So, language functioning, in particular, or really giving some credence to the thousands of single-subject and small-group designs that have been done that show, when you are addressing a specific challenging behavior for a particular individual, that behavioral intervention, and ABA, in particular, is very effective for making those behavioral changes and helping support a person's progress in terms of decreasing aggressive behavior, increasing functional language, a whole host of things.

So, I think one of the things, when we are debating this, the Cochrane Report is less in terms of considering those types of studies. And I need to read it again more carefully, but I think the other report does, although I think it is still limited to studies that had at least 10 subjects involved.

There is another evidence base that hasn't been very well summarized or qualified in a way that really hurts us, I think, in our discussions. I don't know that we can solve this now. But I would like us, as a Committee, if we continue to be talking about how can we build the research base that is going to support the evidence of what works for treatments that we have, a good discussion about what we mean by outcome and what types of outcomes are appropriate for autism.

So, all this to be said is that, I mean, it is actually pretty amazing that we do have some of these RCTs starting that are finding these group differences. And I think in this case we are talking about, again, how David framed it, in that we are talking about a very specific gap that we want to make sure that, if a child with autism, hopefully, and I don't know if we need to put in the qualifier "working with a qualified professional" – I think that is assumed, that we are talking about medical plans and policies that have providers that have gone through the credentialing process and are there, and are able to perform or provide behavioral treatment.

That is not really stated, but I think that that is an important step to remember, that we are talking about qualified plan providers in this option and the ability to provide behavioral intervention as the child needs and based on these principles available as a bottom line. That doesn't mean the child has to have it, nor does it mean that it is the only thing the child needs, but that it is available.

I think that is what we are trying to get to here. And do we agree that that is a minimal thing that is worth pushing for in making that recommendation?

Dr. Mandell: Cathy, I think you just hit it on the head, this idea. Yes, is this some minimal thing that we think, based on the evidence, knowing that it is not the only thing that kids with autism need, and that the evidence is not as strong as we ultimately would want it to be, is this something we feel comfortable pushing should be included in state insurance plans?

Dr. Batra: David, this is Anshu.

I actually was on the Technical Expert Panel. What Cathy just said was exactly one of the reasons why there was actually some moderate support, so to speak, within the group. Because there were so many different opinions from various people because of just the heterogeneity of this disorder, and depending on what area of expertise the person would bring to the table. And I have to tell you, a lot of the time was spent agreeing to disagree about that.

In my mind – I have been listening to everyone, and I actually agree with everyone here – I see this as an opportunity, especially as a major change of policy is coming forth for healthcare, that I think it is important for us, as a Committee, as an advisory Committee, as a Committee that people look toward to obtain some guidance, to at least have a statement to say that, yes, we are aware that we still need more evidence-based research, but at least for what is out there so far, we need this to be included in healthcare plans.

And I, as a consumer for a lot of the services we have been talking about for the last 10 years that I have been paying it either out-of-pocket or have gone through, oh, countless paper and email arguments with insurance companies to pay for it, I think that, again, reading through this letter that has been so eloquently generated, I see this again as at least a start to support the need for intervention, whether it is behavioral intervention or at least habilitative intervention, at least to put it on the table. So we don't miss an opportunity to have a voice in this process.

And again, I absolutely agree with what Larry said about the schools from the education realm. I am very concerned about us saying 25 hours per week is what has been recommended and say, well, okay, and the school districts look at it and say, "Okay, well, we are covering it." And the insurance companies saying, "We're covering 25 hours. It is being covered in the school."

I think that has to be looked at, as well as a statement that has to also say that, clearly, we are focusing on this new evidence that has come out for the young population, but we also need more support and research to apply to the adolescents and the adults.

Again, that is sort of what I see the purpose of this, is really just a statement to say, "This is what we have so far. We clearly are still in the process."

But I wouldn't want to miss this opportunity at least. And after having read this, I am going to use a lot of this language for myself as well as my patients to get some coverage through third-party payers.

Dr. Insel: Anshu, this is Tom.

That is very helpful. I think just to rewind the tape a little bit, we got into this because of the conversation at the last full Committee meeting. Toward the end of that meeting, what we heard in the conversation around the table was that there was an urgency because the states were going to be making decisions about coverage relevant to the ACA, parity, other things that are happening in real time.

And at that point, the essential benefits had actually not even been released. That happened since our meeting.

But it was a real concern from some members of the Committee – and actually, I think there was a comment from Peter Bell as well from the audience from Autism Speaks – that this was this critical moment in time. And the question was whether the IACC could be helpful here by providing information from a body that wouldn't be advocating, but would just be providing the best evidence as we know it in February or March of 2013 to be able to guide the Secretary in the way she thinks about this, and then, to have this used by others in any state or, as you were saying, even by providers or by consumers, as they think about what the states should cover.

So, the spirit of this was really to keep a very narrow focus in a very time-bound way to fill what we heard at the meeting was an urgent need, with the idea that we could turn this around very, very quickly.

It wasn't meant to cover, you know, as other people have asked, all the needs or even all the eventualities that might come up, but just to provide the evidence as we know it at this point in time to inform this set of decisions that people are going to be making.

Dr. Batra: Right, Tom, and I think that we really are tasked on the IACC to, then, consider all these other thoughts that everyone has put forth and use that over this next year to year and a half to really push forth that message or that mission.

But I think for this specific task, it really should be a very short and sweet little document that can easily be read very succinctly saying, "This is what we have right now. This is the evidence we have to support these interventions. Clearly, we need more."

And so, that way, at least it is out there. We are providing a paper trail, so to speak, and a template for the rest of us out here that just are looking for some guidance.

Ms. Abdull: Hi. This is Idil.

I was wondering if I can suggest something. Is it possible to write like a shorter version of this and sort of mention what Dr. Insel and everyone is saying, that this is the best we have got based on science? Because I am one who believes that science and research should drive policy, not lobbyists or not who can speak louder.

But based on the science that we have now, which is for younger children because it is early intervention, if we can put an age or from this age to this age, it is the science that we have, and then, if we can make sure and mention there isn't really anything for adolescents and older people with autism, and so, there is a need to do research to find out what would work for them.

And then, also, by the same token,

mention, if we can find from John or somebody at CMS, what it covers, whether just because it is under the ACA, then does it automatically become coverage benefit under Medicaid? I don't think it is. But if it is, good. If it is not, could we also have a sentence that says, "In the interest of decreasing disparity, that we feel it is important that public insurance also changes its policy or comes up with a way to cover evidence-based autism services and therapies"?

Dr. Insel: Idil, I think John O'Brien will be joining us in the next 5 minutes.

Ms. Abdull: Okay.

Dr. Insel: So, maybe we can table that question. Because I understand your question. I don't think any of us has all the information to answer it, but he probably does. So, let's wait until he joins us. And then, maybe you can put the question directly to him.

Ms. Abdull: Okay. But what about the age one, in terms of age? Because the way this letter says, it just says behavior therapy. And if I am a provider, and as many do here in Minnesota, they would just say, you know, a 20-year-old, we think 40 hours of ABA is medically necessary. I wonder -- all the research is earlier children, younger kids. So, if there is a way to mention the age-wise and what ages has the research been done on --

Dr. Mandell: I agree with you, Idil, but I think _

Ms. Crandy: This is Jan Crandy. Can I make a comment on that?

I caution you about saying the age in there specific. I understand where you guys are going from that. But, even talking to insurance, what could possibly happen is, then, they say, "Only kids 6 and under get this coverage," and that leaves out all those adolescents and older kids that have the possibility of getting ABA to help them. Because there have been states that are only paying for 6 and under.

Ms. Abdull: I know, Jan, but that is the research that we have. I mean, I think research and science should drive policy, though.

Ms. Crandy: But there is research for older kids. There is research.

Dr. Rice: Yes, this is Cathy.

It goes back to what evidence are you looking for. And the reviews have been focused on kids. But, again, there are many, many, many hundreds of studies about using behavioral interventions with the whole age spectrum.

Now is it appropriate for all levels of functioning and for every domain and every issue and every person? Absolutely not. But there is evidence for certain types of behaviors that it can have an impact.

Ms. Crandy: This is Jan again.

There is even research for adults using ABA to change behavior.

Dr. Mandell: I think that, yes, Jan, absolutely and, Cathy, too. There is a tremendous body of single-group and single-subject research for adults and adolescents, school-age kids, using behavioral treatments to change specific behaviors.

I think that, for this particular letter, given the potential cost associated with what we are asking for, we wanted to try to stick with things that had the greatest evidence base to support them at a level of rigor that would be recognized by others making these kinds of decisions as a high bar.

We may want to at some point – one of the things John Robison was saying about issues related to adults is he was suggesting the letter, in a separate letter, really be a call for a particular kind of research in particular areas, so that we could have a level of evidence similar to what we have for kids.

I would be really worried about diluting the message in this letter by thinking about populations in whom these interventions had not been tested with the same level of rigor or calling for interventions that hadn't been tested in the same way.

Dr. Rice: I agree. I was just going to say I think those are all great points, that just a little bit more context of – the focus of this letter is what we have the strongest evidence on, but there are things that we are not addressing. So, it is not the whole picture. And we talked about that a little bit earlier, that, again, this doesn't represent everything for everybody, but it is a minimal standard for a subgroup.

Dr. Batra: Right. This is Anshu.

David, I was going to say that is a really wonderful point you brought up because we don't want to shoot ourselves in the foot here by giving too much information.

Dr. Rice: Right, right.

Dr. Batra: So, again, I just see this as a task. It is an opportunity to provide a short and sweet document that not only is to state what our opinion is collectively as a group, but also, then, to be provided as something of a template for the rest of us to use in whatever capacity, whether it is to access service in school districts, whether it is to access service from third-party payers, or whether it is just to provide as an information, piece of information for the collaborative process.

Dr. Mandell: So, I assume John O'Brien is still not on the call yet.

Or, John, are you there yet?

(No response)

No, I guess not.

But we have other items on the agenda. We have been discussing this letter for an hour. I want to make sure we give it the full attention that it needs, but I want to figure out – and, Susan, maybe you could help us – what do we need to do to bring closure to this conversation?

Dr. Daniels: Well, David, this is Susan.

I think that it sounds like there is still quite a lot of controversy over this letter, and it doesn't sound like we are anywhere near being able to approve the letter or even start addressing some of the changes that would be needed.

So, I would suggest you either continue discussing further or, if you think that the Subcommittee cannot get to any type of a conclusion on this, on March 19th we are having a Committee phone call and we could bring it to the full Committee. But I don't know if that would even be helpful because the Subcommittee really should be doing a lot of the legwork to get this done.

Dr. Mandell: Well, maybe I am a more glass-half-full kind of person, but while I think that there are some concerns about the letter, I wasn't sure I heard – it sounds like we were starting to have some general agreement.

And I guess there seemed to be three areas, or maybe four areas, where there has been some concern or disagreement at the beginning, but that it seemed like we were moving more toward agreement. And maybe if I put them out individually, we could see where we are with the Subcommittee.

And in no particular order, I think they were the issue of whether the letter sticks with a particular age group or is more inclusive of all ages. And maybe I could put that one out there first.

There are sort of two parts of that. One is adults versus children. Do we save issues related to adults for a different letter? And then, if it is children, do we specify preschool-age children or do we keep it broader, like it is now?

Ms. Crandy: This is Jan Crandy.

Since it is covering through age 26, we are addressing ages through 26 in this letter, am I correct? That is how I am reading it.

And I don't think that we should talk about – it says 26 in that one study – I don't think that we should mention age again. So, that way, at least people have the option to have this coverage through age 26.

Mr. Robertson: Well, this is Scott Robertson. I have a comment, then, related to that.

Individuals who are, say, 18 years old and older are not children. If we are talking about something that is related to something that has coverage all the way up to 26, I mean, then we really need to be talking about lifespan of adults and children. And I think we are conflating things around this.

I mean, if it has relevance to adults, then we should be talking/mentioning at least somewhere in here that autism is a disability across the lifespan, and that individuals do eventually age into adult life. I mean, the word "adult" should appear somewhere in here. And that is part of what is a major concern with the current language of the letter.

I guess I think that there are enough concerns that we have out there, that I can't see us – maybe I am wrong on this – but I can't see us agreeing with things as they are right now, just to get a letter going through. There seems to be a lot of concerns about how many parts of the letter are written right now, from what I have seen.

Ms. Abdull: Hi. This is Idil.

I really just think that I agree with Scott because, if we are saying that age 26 for ABA or 40 hours from start to – that is going to have controversy, and the states will fight it. I think Anshu said it best, that we probably shouldn't shoot ourselves in the foot.

Based on the research that we now see, it is for early intervention; it is for younger kids. So, if we are going to write a letter to the Secretary, we should write it based on the findings that we have now for the children, how old they are, and when the research was done, how old were they, from what age to what age. It is not necessary to go into detail into the age, but really make a point that it is for early intervention. Because, otherwise, states will fight it and insurance companies will fight it.

And I know everybody is saying, you know, "Who cares? The blood-sucking insurance companies, they should pay." But I really think we have to be careful because they also have doctorates or also want to make sure that it is evidence-based. And the evidence is not there.

But, then, by the same token, we need to say something about adolescents and youths and adults with autism. What services are there? What should we ask the Secretary, even if we are not asking specifically, but just to plant the seed that there is a need, that these children do grow older and they become adults, and that we need to think about what to do and how to help them.

Dr. Mandell: So, Idil, would you be okay doing that in a separate letter, so as not to dilute the specific message of this one?

Ms. Abdull: And leave this one as having just up to 26?

Dr. Mandell: No, no, no. Saying that this is focused, you know, that we are talking about younger children here –

Ms. Abdull: Right, right.

Dr. Mandell: – but leaving in a separate letter the issue of the need to address, you know, to develop more of an evidence base for older children, adolescents, and adults with autism?

Ms. Abdull: I think so. I think a letter like that would drive perhaps services for adults and adolescents, but, then, it should drive researchers to think about and study more what kind of services might help them.

I will leave that to the adults that are here to speak more eloquently about their issues. But, as even my son gets older and he will get into double digits next year, I think it is important that we have something – we are either doing the research or that we are offering services. We can't just wish. We have to start doing the research on how to help these children as they become adolescents and adults as well.

But probably Scott is the only one here. I would like his comment or addition to that.

Mr. Robertson: Yes, this is Scott

Robertson.

To dovetail into that, I know that one of the concerns – and maybe this fits its way into another letter, I guess – one of the concerns that I have had is that there has been so much emphasis only singularly on childhood things, such that we have this interweaving of states across the country – I think it is maybe 36 states that have these insurance laws, and they are all geared singularly toward childhood. None of them go, as far as I know, none of them really go past I think maybe 18, maybe 21. I mean, none of them really go past that.

And there has been an emphasis in Pennsylvania and some other places to – there was large interest in getting financial coverage and supports for services for individuals in adult life, including needed OT, speech therapy, et cetera, recognizing the fact that challenges do persist into adult life, particularly, say, for executive functioning issues that are probably the most pressing thing often for adults that things like OT could be assisting.

Yet, you don't really see that in terms of what has been done in the healthcare realm when you look at the insurance laws. When you look at some of these other prerogatives out there, you get the impression – and I guess that is also a concern that I have with this letter. I want to make sure that we don't give the impression that early intervention also is this magical kind of thing.

And some of the language where it talks about the worry about what might end up in adult life almost conveys in some ways – you know, the premise is that early intervention is this magical thing that is going to make sure that individuals are kind of set for life. But while early services and supports are really helpful and beneficial, and there is grounding to show that they are, we have to be cautious not to go too far on that because there should be recognition that individuals are still going to continue to have challenges throughout the rest of their lives because that is realistic for this neurological development disability.

You know, it is not realistic to say, because you are having early intervention, that everything kind of goes away. And I worry that that is the kind of impression that is from this letter.

Mr. O'Brien: Hi. This is John O'Brien. I apologize for being tardy.

But I have just caught the last couple of minutes of the conversation. I think it would be helpful to remind folks that a lot of what was being done through the Affordable Care Act was to certainly expand insurance to both children, youth, and young adults. But, frankly, the bulk of the additional people that were going to be covered were going to be adults that didn't have insurance.

And so, I think that we should probably take that into account as you are thinking about anything that you want to put forward to the Secretary around coverage of services.

Dr. Batra: David, this is Anshu.

I strongly feel and I agree with what Idil and Scott have mentioned, but I feel like that should be part of the update for 2013. And we should really be emphasizing the need for research and services and changes in policy for our young adults, our adolescents and young adults, and to really highlight that need.

But, again, I think the purpose of this letter, this document, really should be very, very narrow and should really focus on this opportunity we have to highlight what we do know right now and to, again, provide something for parents and families and individuals with disability to, then, go to a third-party payer, to an organization, to then help them provide access to service.

Dr. Rice: Yes, this is Cathy.

I think that the decision is there is this very small window. This is not going to come along again. So, can we agree on a core-focused target or not?

Dr. Batra: This is Anshu again.

I think, you know, again, the update, I mean the whole purpose of this Committee is to provide Congress, and really the Secretary, with what is new and what is needed. I mean that is the big picture here.

Ms. Abdull: Hi. This is Idil.

Now that John is here, could we ask him – sorry, Anshu, after you are done – the CMS questions?

Dr. Mandell: Sure. John, we want to know if a state, with the Affordable Care Act, if a state has a service covered under its essential health benefits, does that mean that all insurers in that state, including public insurers, need to cover that service?

Mr. O'Brien: Go ahead, David. Was there some additional question there?

Dr. Mandell: No, that is it. I was going to make it more specific, but that is really the question. So, if they include behavioral treatment as an essential health benefit in that state, does that mean that that becomes an essential health benefit or a required coverage service for Medicaid as well, for public insurance?

Mr. O'Brien: Sure. And I hate to speak Federalese, but we are right in the middle of having a final regulation around this. So, I will talk about what we have in the proposed rule.

In the proposed rule, we stated that the alternative benefit plans, which are the plans that are going to cover the expansion population, the Medicaid expansion population, have to offer the 10 essential health benefit categories that are in statute. But those are, again, just categories. Neither in the Marketplace, formerly the Exchange, or in the Medicaid regulations did we specify particular services that were in many of those essential health benefit categories. So, we didn't drill down into the detail of what you are talking about in terms of specific coverage for ABA or other types of treatment in mostly any of those categories.

Dr. Mandell: But, as a general rule –

Mr. O'Brien: But we do have to cover the 10 essential health benefit categories, including mental health, substance abuse, and behavioral treatments.

Dr. Mandell: I think that was the specific question.

Idil, does that answer to your satisfaction or -

Ms. Abdull: So, John – sorry, David.

Dr. Mandell: Go ahead. Sorry.

Ms. Abdull: No, that is okay.

So, I was just going to say, then, John, you said that the 10 essential benefits, one of them is mental health. And then, did you say behavioral health treatment?

Mr. O'Brien: So, it is mental health. It is substance use treatment, and it is behavioral treatment.

I always get confused if it is behavioral health treatment or behavioral treatment, but it is one of those two. Let me pull out my language.

Ms. Abdull: Okay.

Ms. Crandy: It’s behavioral health.

Dr. Insel: Hey, John, while you are doing this – this is Tom – Idil posed a question to us in the following way, and I don't know that any of us have this information except you: If you are in the State of Minnesota, and Minnesota decides that in the essential benefits package ABA gets covered for autism, does that mean that Medicaid in Minnesota will cover ABA for autism?

Mr. O'Brien: So, there is a couple of choices that states make around how they determine what is covered or not covered as part of their essential health benefits.

So, for states that are choosing to set up their Marketplaces – that is for those individuals between 133 and 400 percent of the Federal poverty level – they select from one of the 10 different plans that they have in their state to be able to create their benefit plan that will include all 10 essential health benefit categories.

So, a state could say, for this group of individuals, 133 to the 300 percent, 400 percent, for those individuals, we are going to select the Blue Cross Blue Shield plan as our benchmark plan and offer those services that are in the benchmark plan.

For Medicaid, it could be the same or it could be different. Medicaid, because we had benchmark plan language since 2008, I want to say, or 2010, in our regulations we said, "Here is the starting place for benchmark plans." And we gave four different options for the states to start from.

A state, then, selects from one of those four options, which could include the Medicaid state plan or not, and then, would have to compare their benefits in their starting point with one of the 10 plans that are part of that state's essential health – or state's selection. It is complicated.

So, Tom, it is a long way of saying a state could have different plans for those individuals participating in the Marketplace and different plans for individuals participating in Medicaid, but all of them have to ensure that there are services within those 10 essential health benefit categories. The services could be different, depending on what a state decides between the Medicaid expansion population and the higher income group.

Does that help? Or did I just make it more complicated?

(Laughter)

Dr. Rice: Can you say that again?

Dr. Batra: I didn’t understand a word.

Ms. Abdull: Now I know why I don't work for the government.

(Laughter)

Dr. Rice: Another Federal person here doesn’t understand it either.

Dr. Insel: It sounds like the bottom line is Idil's concern is right. I mean, she had looked at this letter and said, "This is great for private insurance, but what about Medicaid?" And our assumption was, well, Medicaid has always been such a great system in terms of parity and in terms of coverage that we don't even need to raise it here.

But what you are saying, if I get this right, John, is that, actually, going forward, it is possible that Medicaid and the Marketplace could end up with two different schedules for coverage. And somebody might be covered if they are in that expansion population, but not if they are in the core Medicaid population?

Mr. O'Brien: That's right. That's right, Tom.

Dr. Insel: We didn't get that. We didn't know that before.

Mr. O'Brien: For the expansion population, it doesn't necessarily change the coverage in the regular Medicaid program for folks that are currently Medicaid eligible.

Dr. Insel: Wow. Okay, that's news. So, that is important information to have, and it does mean that maybe we should think about providing that insight or at least including some reference to public as well as private insurance or public as well as private coverage.

Dr. Mandell: That makes a lot of sense, yes.

Dr. Insel: Thank you, Idil.

I have to say this completely went by us. I don't think any of us realized this was an issue until you brought it up.

Ms. Abdull: Oh, you're welcome. I think I heard that I get a free lunch next time or something.

(Laughter)

Dr. Mandell: There is no free lunch.

Dr. Insel: After the sequester, we will see about the free lunch.

(Laughter)

Ms. Abdull: So, I think in a nutshell, then, maybe if we write – I agree and I understand everybody's comments and everybody's lenses, and we all have different lenses that we advocate for.

So many people have said, "We don't want this opportunity to pass." But if we can write a letter that is maybe one page or so, if you remember, the Secretary is very busy. And so, something that she would read very fast that would talk about the intervention or the research that we have now for early intervention, but, then, also mention the gaps in the Medicaid, the very-low-income Medicaid children and, then, also adolescents' and adults' lack of actual research, even though we know there are various studies, but the randomized controlled studies. Something to that effect I think might be good. I don't know what others think.

Ms. Crandy: Idil, this is Jan Crandy.

So, you are talking about a different letter, correct, another letter?

Ms. Abdull: No, modifying this one, so that it makes sense. There is a need to do this behavior therapy, based on the evidence that we have now for younger children, but, then, recognizing within the same letter that there will be a gap in Medicaid. And so, maybe, then, people like me who advocate for Medicaid children can use it and say, "Look, there is a gap. We need to change the Medicaid guidelines." This will give me a green light to buck John. Who knows?

Ms. Crandy: Idil, this is Jan again.

Could we have maybe a small sentence in this one that is adding public and private insurance in here, just mention of that? And then, have the other information in a separate letter?

Because I think that we need the research and everything that this says, that this letter has. I would hate to remove any of this research and make the letter shorter. I love the letter how it is. Maybe add the words "public and private insurance" in there. And then, let this letter go as is. And then, have another letter that addresses those other issues.

Dr. Mandell: I think we could write – I am not sold on the need to get it down to a page, but we could certainly put in a sentence that points out that Medicaid is the single largest insurer of children with autism, and that it is important that we not have a two-tiered system with autism benefits only for those in private insurance, or this particular treatment benefit only for those in private insurance.

Ms. Abdull: Okay. That sounds good to me.

Dr. Batra: And, David, this is Anshu.

I would put that right in the first paragraph.

Dr. Mandell: Okay.

Dr. Batra: And then, the other very minor comment I had was to really address the issue with children and adults, et cetera, et cetera. Instead of just focusing on the language for children, saying "individuals with autism". And that way, you know, it sort of goes around that issue that the research is really more targeting the younger set.

Because the healthcare policy is really extending to young adults. So, just go with "the individuals with autism". And that way, you know, it doesn't create any friction or any misunderstanding.

Mr. Robertson: This is Scott Robertson.

I don't think that changing to "individuals" necessarily fixes the problem, I mean, that it is focused singularly on children. I am not sure if that really addresses that problem.

Dr. Batra: Well, I understand, Scott, and I am not saying absolutely. I am just saying, for the focus of this letter – again, narrow focus of this letter— to broaden that term, so that it doesn't just highlight just children.

But, again, clearly, there is this huge disparity and lack of attention and emphasis in the other populations, clearly. But, again, I see that as something we highlight and really bring and emphasize in the update.

Dr. Insel: Yes, I think so. This is Tom again. I think I want to support what you just said, Anshu.

The issue for this particular letter is going where the science is. As far as we could tell in the quick review we did, there just are no robust RCTs with adults looking at behavioral therapy. There is some pretty good evidence, and there are well-designed RCTs for medications, but that is really not a question for adults.

So, it seems to me that the lesson is not so much to write a letter about that, but to make sure that the full IACC, and particularly the other Subcommittee that is dealing with the research, takes this on as a very high priority because it is such an obvious gap.

And rather than sending a letter out saying we don't know anything about that, it would make more sense to me for us to take that on as our responsibility, as a Committee, to say, since we are trying to prioritize research, this is a place that needs to be underlined and done in the near-term.

Mr. Robertson: Well, Tom, this is Scott Robertson again.

I am not sure I understand why the letter can't include at least a sentence in there that mentions something to the effect of, while autism is a disability across the lifespan, or something like that, that the focus of this is limited specifically to guidelines for children, or something like that. I mean, I think that there should be some kind of language construction in there inside the letter itself to emphasize that point.

Ms. Crandy: This is Jan Crandy again.

I would caution to leave it out because, if people are going to use this letter outside for support, putting a flag on not to cover adults because there is no evidence, not to cover adolescents because there is no – it could hurt us more than it helps us.

Dr. Batra: Yes, this is Anshu.

My son is going to be 16 in a couple of months, and I would be very hesitant to take this letter to my insurance company or my school district and try to obtain services that I know will help him. Again, I see it as something that, again, could be used negatively.

Mr. Robertson: Well, this is Scott again.

The concern I have is that it seems like there is almost an emphasis to have it kind of both ways, to have recommendations that are only specifically geared around children, but, then, to use this to inform things for adults. I mean, it doesn't make much sense to me that this could be having discussions around things in adult life and to be for something that is going to have coverage all the way through adult life. It doesn't even use the word "adults" ever anywhere at all in the letter itself.

And so, that was my main worry on that. That is why I think that there should be a statement that says this is focused specifically on children, because it is. The letter brings up things, mentions studies, mentions different aspects of behavioral therapy that only have evidence for children. I mean, that is the specific focus of those studies.

And I think that is only making sure that it clarifies things at the beginning. So, someone understanding the letter knows that that is the case.

Ms. Abdull: Hi. This is Idil.

Scott, I was just wondering, you are looking for – I am trying to see if I can get inside what you are advocating for. So, you want to make sure that the adults, the youth and young adults also are getting services, right? So, what would one sentence be, so that a parent or yourself, you can take it to the insurance, and, hopefully, even to Medicaid, and say, "Look, we want to make sure that we are helping somebody in this age?" What would be to your satisfaction?

Dr. Mandell: Actually, Idil, I don't think that is what Scott is asking for.

Ms. Abdull: Okay. Oh, I see.

Dr. Mandell: I don't think he is saying just cover treatments for adults. Are you, Scott? You are saying that we should be explicit? You want to acknowledge that it is a lifelong condition, even if the specific treatments we are talking about are not geared toward adults?

Mr. Robertson: I want to acknowledge at the forefront that autism is a disability that does go into adult life. But, then, have something more explicit on here to say, while it does go into adult life, the specific things that we are mentioning here, which is true, that the letter is focusing on children, so I think it should clarify that the focus of this and the recommendations reflect studies that were done with the focus on children. That's all.

Because I worry, by not having that, by not even having the word adults used in here, or whatever, that it could lead to some kind of confusion.

Ms. Abdull: Scott, I think that makes sense because you want to make sure that at least people know. And I think it is a good idea what Dr. Insel said, that we should have more research being driven by the lack of research for it.

But you want to make sure that it is mentioned in here that the research that we have in this letter is for early intervention for younger children, and that autism is across the lifespan, and we need to put that in there?

Mr. Robertson: Yes, yes, yes. Just even one sentence in there that –

Ms. Abdull: Is that doable, David or Denise?

Mr. Robertson: – mentions that. It is a multiple-stage letter. I think there is room for that, you know.

Dr. Mandell: I think it is actually a clause. Yes, I don't think it will be difficult to do.

Mr. Robertson: Okay.

Ms. Abdull: So, we have a consensus.

Ms. Crandy: Also, that we don't say, because of this research, exclude different age groups from behavioral health treatment. I think it is a very minimal sentence that says, autism is across the lifespan or that it affects the person for their life.

Dr. Mandell: Yes, I think we can do that.

Ms. Crandy: Okay. I just don't want this letter to hurt us.

Dr. Mandell: I hear you. Of course, it is not going to go out without people's approval. But I think I could craft something that addresses Scott's concern without having unintended negative consequences.

Mr. Robertson: David, this is Scott again.

Can you also, is there a possibility of even something short in there to maybe just clarify or correct a little bit further that, while we are focusing – you know, as you say, maybe the intent has to be on behavioral things because that is the nature of what this is targeting – to have something just more clear also at the outset that says something to the effect of, while this is focused on behavioral things, there are other supports or therapies, or whatever language you want to use, that have effectively or that are used for autistic individuals and families. You know, something on there that mentions that to the effect of a little bit clearer in there I think would be also helpful.

Dr. Mandell: Well, there I might argue with you a little bit about the definition of effectiveness because I think what we are arguing here is the reason we are saying there is a certain urgency around making sure the essential health benefits, and now, of course, the Medicaid plans, now that we know that, cover these is because of the evidence base that supports them, which is stronger, for better or for worse. It is unfortunate that we don't have a stronger evidence base other places, but it is stronger than the evidence base for some of these other supports, that even if the expert consensus says they are important, we still don't have rigorous studies that show that.

Mr. Robertson: Well, okay, maybe effective is the wrong word on that, but it would be nice for something that even addresses the fact that there are other things out there other than behavior things that are used by individuals. I mean, it would just be nice --

Ms. Crandy: What about promising?

Dr. Rice: This is Cathy.

We are talking about a person with autism is often a person, and that is a silly statement, but I think an important one of saying, if you are talking especially about co-occurring conditions, the range of things that happen in life, there may be other treatments that are relevant for anxiety, for depression, for a variety of things that could be helpful.

So, I don't know that we can go in this letter into the whole range of other treatments, except to say that, you know, what about just saying that this does not cover the potential treatments that a person with autism may need, considering their entire, you know – oh, however we want to say it – medical needs.

However, this is a focused discussion about this one area.

Ms. Abdull: I think we should maybe stay focused. Sorry, this is Idil.

I was just thinking, Scott, maybe if we – I understand totally what you are saying, but I think if we put – you know how they say, if you put too many fingers in a pie, it gets ruined. If we sort of stay focused on the evidence that we have now for the early intervention, and then think about other areas and think about other research that we could do to make sure that adolescents, young adults, and older adults with autism do have the necessary support and services they need, and then, also, the research that is needed to make sure they get the necessary support and services they need. I don't know. That is what I was thinking. I don't know what you think.

But maybe if we just focus on this letter, but then, keep in mind and be cognizant that there is so much more that needs to be done for autism across the lifespan.

Dr. Insel: If I can say something here? This is Tom.

I am listening to the conversation pretty carefully. My sense is that the group is coming to some consensus that they want to keep this focused, that the more focused it is, the bigger the impact could be, and that there are lots of other issues that we need to deal with, either with another letter or with a committee. But that what David has put in front of us is pretty close with some tweaking in the language and a few additional comments.

So, I hear, Scott, your concern about the letter in its core, but I think, other than those concerns, is there anybody else who would not want to go ahead with something that looks like what was distributed?

Dr. Cordero: This is Jose. I think that, actually, the real danger is if we don't go ahead and point out about this specific area that we are addressing in the letter. I think that this would be a missed opportunity if we don't.

Mr. Robertson: Well, Tom, I just want to say that I could potentially support something with changes. I just don't want to give my approval to say I agree with everything 100 percent as the letter is currently written. And I gather that is what is being requested in terms of whether there is approval of how it is 100 percent written. I think, with changes, I could potentially support it, but those changes aren't there yet. That's all.

Dr. Insel: Yes, I think for the group here, for the group process, because it could be hours before we all finally just give up, what I think we will need to do is help come to some agreement about whether this needs to go forward with some tweaking that David can do and share with all of you or whether we are just ditching the idea altogether because not everybody can agree to all 100 percent of it.

Ms. Abdull: Hi. This is Idil.

So, I think we should go forward with it based on the tweaks that just came up. I think, Scott, on your first point of having a sentence about the adults, that autism is a spectrum across the lifespan, I think if you would be okay with that, I think that would be good.

And then, Dr. Insel, think about the other stuff that we need. And if we have to write a letter specifically for adults and adolescents, I am for it 100 percent.

But this research is for early intervention, and we would miss the opportunity if we didn't do it now.

Female Participant: Agree.

Ms. Redwood: Tom, should we put this to a vote?

Dr. Daniels: So, this is Susan.

David, can we spell out exactly what types of tweaks need to be made so that the Subcommittee can then vote on it? So, what tweaks are we proposing making?

Dr. Mandell: I have been taking some notes, but I am sure they are not complete.

So, the first tweak is to add something

indicating or acknowledging autism as a lifespan condition with supports needed throughout the lifespan.

The second was to specifically mention the need for Medicaid plans to cover this particular benefit as well as private insurance companies/plans, so as not to create a two-tiered system.

The third tweak, which I am not sure we are in complete agreement about, was having some sentence that says something like, individuals with autism require a lot of different types of care. One particular form of care that has the most evidence to support it is in danger of being left out of the essential health benefits, or out of state plans.

So, those were the three tweaks that I had captured. I may be missing something, though.

Ms. Abdull: So, you said four, right? I didn't understand the last one.

Dr. Mandell: No, no, I think I just said three. The one adding something about it being a lifespan condition; the second, the issue about Medicaid coverage; and the third, some general sentence about individuals with autism requiring a lot of different types of care. The type of care with the most evidence to support it, these behavioral interventions for young children, is in danger of being left out of state plans, of the essential health benefits. Those were the 3tweaks that I had that we had comments about.

Ms. Redwood: David, I just have one comment to make. Would there be a way to sort of quantify when you say that autism is a disorder that lasts across the lifespan? Because, you know, we just heard at our last meeting that some children recover from autism and that they may not need services across the lifespan.

So, I think if you said something like, you know, for the vast majority or for the majority, that it is a lifespan disorder, but it is not always.

Dr. Mandell: Okay.

Mr. Robertson: Well, this is Scott.

I would be careful with the language around that because the optimal outcome, used the term optimal outcome; it did not use the term recovery. But, regardless, I think there is recognition there is definitely strong support in the literature and in practice that people do experience a disability across the lifespan, including the person who is talking to you right now.

Dr. Insel: But just again, the letter currently says that. It says children who are not treated face a lifetime of disability. So, is that acceptable?

Ms. Redwood: I think it is.

Mr. Robertson: Well, I guess my concern, Tom, is that, even with appropriate supports, services, treatments, I mean, you could still face some disability challenges. And that is one of the worries that I had about that statement.

Ms. Redwood: Scott, this is Lyn, and I

have a son right now in college who was diagnosed with autism and he is not receiving any supports or services. So, I sort of have to counter with that, that that’s is not always the case.

Mr. Robertson: Well, Lyn, I am not receiving any supports and services, either, but that doesn't mean that I wouldn't benefit from supports and services and don't have ongoing barriers and challenges, like most autistic adults I know.

So, the belief that disability barriers and challenges go away because people are not getting supports and services as adults, the lack of coverage for adults does not reflect that they don't have difficulties.

Ms. Redwood: Right. I just had some concerns about a statement that implied always.

Mr. Robertson: Well, I don't think I would use the word always. Just the recognition, you know, that it does extend into adults. I never used the word always in the previous language.

Ms. Redwood: It implies in the statement that autism is a lifelong disability. And I think that what is in there now that says, without treatment or without appropriate treatments and supports, it can be a lifelong disability. I want to throw that out there because there is research coming out that, with appropriate treatments – and we don't know why – but some children are making remarkable improvements in their longer-need services and supports.

Dr. Rice: What if we said has typically been? Is that too qualified or –

Dr. Insel: Do we know that there are people who have not been treated who recover or who lose a diagnosis?

The sentence currently says, children who are not treated face a lifetime of disability, increased healthcare, educational and services costs, and in some cases require costly 24-hour services and supports over the whole lifespan. So, that is currently in the letter.

Ms. Redwood: Cathy, what is your experience with CDC in terms of that? Do you see children that do not receive services that recover?

Dr. Rice: Very few, but we only look up through age 8. So, very few to none would be considered out of the spectrum by that age.

But, in terms of adulthood, I think we have to look at the research by Pat Howlin in the UK. It is the best. I am trying to remember. I remember that there was a proportion that she classified as doing well, but I don't necessarily think that is to the level of what you are saying, Tom, of totally.

Dr. Insel: But the assumption is that many of them – and certainly that is true in Debbie Fein's project – that those were kids who received intensive treatment.

The question on the table is whether there is rationale to provide treatment or not. What we were missing in trying to understand this was the kind of cost-effectiveness of treatment. We just don't have those data, except from the Netherlands. We have so much data in other disorders, but not here.

But, absent that, we thought that since this is ultimately a document that could be read by a payer who is trying to make a decision about whether to cover or not cover, we should try to provide what evidence there is that there may be a cost to not treating, to not covering, that there may be increased costs in terms of other kinds of healthcare needs and long-term costs. But we don't have spectacular data about that. We tried to put together what we could from the literature that we have.

But if people are not comfortable with that, or if you think that the literature doesn't support any of that, it is going to be really important. We need to make sure that this reflects the best science we have got.

Mr. Robertson: This is Scott.

I don't disagree that individuals without the right supports that they need can face difficulties across life. I don't disagree with that. I just thought that the statement could be worded better in its language. You know, it seems almost borderline kind of polemical rather than kind of factual-based in terms of what it is looking at. It is almost kind of speaking toward more of we will create a burden on society kind of thing, rather than we will face a large range of adversity that could be averted with the right supports.

Ms. Crandy: This is Jan Crandy.

I will tell you, a lot of the studies that I see, and when we go to legislation and we are testifying, we are using language that says this. We even have said, and I don't know where it is pulled from, that only 2 percent of children that do not receive any type of treatment will have that best outcome. And I know we had to pull that from some study to be able to say that.

Ms. Abdull: This is Idil.

I guess what everybody is saying, in a sense, is that, with treatment, the outlook is better, right? So, this letter is to get treatment paid by the payer, whether it is public or private.

And so, our goal should be, while we don't have the science, I don't know if any of us will be alive to get the correct science for all autism's Four Kingdoms. I love that blog.

But, with treatment, the outlook, and whether it is recovery to some people's eyes or whether it is just maintaining and not being able to need services, or whether it is just needing a little services, with treatment, early intervention treatment, the outlook of that child becoming an adolescent, a youth, a young adult, and then, an adult later on is better, right?

So, therefore, maybe it is best to keep this letter the way it is because, with treatment -- we are asking for treatment from the Secretary. We are saying, could you please make sure early intervention treatment is covered.

So, if we kind of contradict ourselves, we are going to be shooting ourselves again in the foot.

Ms. Redwood: I agree, Idil. And by saying that it is a lifelong disability, but you need to treat it early, it is sort of contradictory. So, I like the statement that Tom had that is already in the letter.

Ms. Abdull: Yes, me, too.

Mr. Robertson: This is Scott.

My concern is that the science speaks about it in terms of lifelong challenges into adult. I worry, how can we go ahead and, then, create a separate letter and talk about ongoing challenges that adults have if, in the letter that we talk about it in childhood, that we don't even make acceptance of the fact that autism can continue into adult life? I mean, those seem to be almost contradictory, if we have a separate letter that talks about the needs for supports and services to be integrated for autistic adults if in our letter on children we are not even recognizing that autism continues into adult life. I mean, they don't seem to fit together.

Ms. Abdull: Would it be better, Scott, then, if it said– is it that you want to make sure that it is a lifespan? So, then, you want to take away that, with treatment, children get better or are you saying that – what is it that you would like on the letter? Because I guess I am getting confused.

Mr. Robertson: I would like better acknowledgment about that lifespan supports are, you know, supports across the lifespan are beneficial for autistic individuals, and that we have recognition of that. And I think many people would not disagree with that.

Dr. Mandell: What in the letter currently contradicts that? Scott, what in the letter currently contradicts that?

Mr. Robertson: I don't know if it necessarily contradicts, but it almost implies that autism can't exist into adulthood by talking about the fact that – it almost is this kind of premise of do early intervention and, then, everything gets better, kind of thing. I mean, that is the impression that I get almost from the letter.

Dr. Mandell: Really? Because that was not my –

Ms. Abdull: Yes, I didn't get that. I wonder if we could – and I am fairly certain it says that – but if we could say autism, when we are describing that autism is a neurodevelopmental disorder that is across the lifespan, but, with treatment, children, their behaviors or their outcomes improves. Not necessarily. I think you are turning away the fact that you lose the diagnosis just because you got behavior therapy early on. And so that, all of a sudden, you are not autistic anymore.

But, if we could say that it improves the person's quality of life – I mean, I don't know. David is the architect here. But something to that effect, that while it is a spectrum, while it is across the lifespan, with early intervention of behavioral therapy, based on the science that we have now, children do make significant improvements. Is that good, Scott?

Mr. Robertson: Yes, that I would support that. I would support the outcome changes that you just mentioned.

Ms. Abdull: Okay.

Ms. Crandy: Tom, this is Jan Crandy.

I propose that we take a vote with the changes that were mentioned by David because we are going to run out of time, and we are going to end up without a letter.

Dr. Insel: You have to propose that to your Chair. I am just listening in with great interest.

So, David, if you want to take a vote –

Ms. Abdull: I'm sorry. This is Idil again.

So, David and Denise, based on what Scott just said, because we want to be sensitive to people if they are having issues and we want to come to some consensus, because if the majority always rules, the minority gets screwed all the time, right?

So, I want to be able to hear Scott's points. I think he finally just said that he agrees with something I said, which I forgot. But, David, maybe if you wrote it, then is that something that we can do, that "autism is across the spectrum or across the lifespan, but, with early intervention, children are able to make significant gains?

Mr. Robertson: Yes, I agree with that. I could concur with that. And I would like to ask to be mentioned, you know, somewhere in that. That gets to the point, yes.

Ms. Abdull: Very good. And Denise?

Dr. Dougherty: My impression is that we need to go back and revise this letter, taking into account what folks have said, and then, send it out again.

But maybe Susan can tell us what the approach is here. Can we get a vote without having another meeting?

Dr. Daniels: We can vote to accept, well, to go ahead and make these four changes, it sounds like. Or we don't actually have to vote on that, if the Subcommittee wants to make those four changes. And then, if the Subcommittee feels like they need to see it again and have yet another call, we can schedule another call. Or you can vote to – I don't know that the Subcommittee sounds like they will be comfortable with voting to accept with changes without seeing the changes first.

Dr. Dougherty: Oh, no, no. That is what I am suggesting, that the changes get made and we circulate it again.

Dr. Daniels: So, then, you will need another phone call most likely. So, then, on the 19th, you won't be able to do anything with it. So, we can try to schedule –

Dr. Mandell: Does that mean we can't vote by email, Susan?

Dr. Daniels: If there is going to be any significant discussion, we need to keep that in the public realm.

Dr. Insel: What about discussing it on the 19th, the whole Committee?

Dr. Daniels: We could do that. If the Subcommittee wants to, we can go ahead and have David make changes and then bring it to the full Committee on the 19th for discussion. And that, basically, would be a lot of the people that are on this call, plus additional people. And then, on the 19th, the full Committee could decide to just accept it.

Dr. Insel: I am concerned that there is some time-sensitive aspects to this because decisions are going to be made in lots of places. If you want this to have any impact, it is probably better not to kick it off to July or August.

Dr. Daniels: What we could do is have you all vote to have David make the changes and, then, bring this to full Committee for further action.

Ms. Crandy: I would support that.

Ms. Abdull: I would support that.

Mr. Robertson: I support that.

Dr. Mandell: Why don't we bring it to a vote then?

Dr. Daniels: Okay. So, David, you have already laid out the four changes. I don't know if you need to repeat those. So, if you would like to take it to a vote and lay out what the vote is about?

Dr. Mandell: Okay. So, the vote, then, is to accept that I will take this letter, make the changes that have just been discussed and distribute it and actually, then, distribute a draft to the full Committee for discussion and vote on the 19th.

Dr. Daniels: That's right. So, then, it would be coming from the Subcommittee as the Subcommittee's version for the full Committee to vote on.

Ms. Abdull: So moved.

Dr. Batra: Wait. David, is there any way you can make these revisions and, then, send it out to us who have been in on this discussion for the last 2 hours, and then, we vote or we give our approval or our changes? And then, with that, we bring it to the full Committee?

Because my concern, again, is that to bring everyone up to speed, again, I am concerned that on March 19th we are going to be in the same place.

Dr. Mandell: It sounds like, from what Susan is saying, if there is going to be any discussion of the changes, then we can't do that without another call. That would be the purpose of bringing it to the full Committee.

Dr. Batra: Can we at least come to some agreement with the language based on our conversation today?

Ms. Abdull: So, maybe, David, could you say what we discussed then or –

Dr. Batra: Because when we meet on the 19th with the full Committee, that we set the conversation where we left off, and it is open to the public to make comments as well. And that way, again, we are not reinventing the wheel.

Dr. Daniels: And this is Susan.

Just please remember the purpose of the call on the 19th was originally to spend an hour talking about public comment, and then, I believe there is a half-hour or so that is supposed to be for other Committee business. And so, if we think that there is going to be an extensive discussion, I mean, I might need to amend the amount of time for that phone call, because we don't want to give short shrift to the public comments. Just a side note.

Dr. Mandell: So, Susan?

Dr. Daniels: Yes?

Dr. Mandell: If it is acceptable, I am happy to send out a draft over the weekend to the members of the Subcommittee. If they just write back with any edits or comments directly to me, does that count as discussion that requires public hearing or is that okay for work that would be done prior to submitting the letter on the 19th to the full Committee?

Dr. Daniels: I think if there is likely to be a lot of significant concerns and so forth raised, that that would really need to be happening on a public phone call. If you think that we could do it as a simple yes/no vote after you have made the changes that you think need to be made, I think that would be fine. But it seems a little bit up in the air as to whether the Subcommittee could get to the point of being able to do just a yes/no, up/down vote.

Dr. Mandell: So, guys, in the interest of getting something to the full Committee and having this be timely – because if we wait even another month, I think it will be as if we did nothing. So, would people feel comfortable if I attempted to incorporate these changes, sent it out to you, and then, just have a yes/no vote withholding all comments, just saying yes or no? And what you would be approving is that the letter in its current form at that point go to the full Committee for a vote.

Dr. Batra: This is Anshu.

I would be in favor of that. Sitting here as a public member, I am feeling frustrated with the process, and that is where I feel that the general public feels the way the process for autism is going. So, I would be in favor of that.

Ms. Redwood: This is Lyn.

Me, too.

Ms. Abdull: This is Idil.

Me, too.

Ms. Crandy: This is Jan.

I support the letter as is. So, that will work for me, too.

Dr. Mandell: All right. So, can we –

Mr. Robertson: This is Scott.

That will work for me as well.

Dr. Mandell: All right. So, Susan, do we need to put this to an official vote or does this count as the official vote that we are having?

Dr. Daniels: So, no.

Dr. Dougherty: I have a question.

Dr. Daniels: So, you were agreeing that you would like to do a yes/no vote over email after you have seen the changes, but you cannot vote right now that you would potentially accept a letter with the types of changes that David is suggesting that it just go to the full Committee. And then, you would have an opportunity for discussion in full Committee.

Ms. Abdull: This is Idil again.

Dr. Daniels: You want to reserve the right to have further discussion within Subcommittee, is basically what you are saying.

Ms. Abdull: Hi. This is Idil.

I actually agree with Dr. Daniels because I think we agree. If all we are going to say is yes/no, couldn't we just say that yes/no because we know what the four changes are? And then, not waste any more time and just go to the full Committee?

Dr. Daniels: Yes. So, Idil, thanks, that is exactly what I am trying to say. If you think that you can handle having David just make those changes, and then, even if you don't completely agree with the changes, allowing the next discussion to happen on

March 19th, then you could vote now and have the Subcommittee accept it with the discussed changes as being the Subcommittee's draft that will go to full Committee. And then, anybody that has significant concerns can raise them on that call. And I can look into trying to lengthen the call, if we think that we are going to need to have a lot of discussion.

Ms. Redwood: I think that is a great idea.

Ms. Abdull: I favor that one.

Female Participant: I support that.

Dr. Daniels: Okay. Then, David, can you take it to a vote, please?

Dr. Mandell: Sure. So, I will call for a vote, then, on that plan, which is for me to make changes to the letter that people discussed, and that, with those changes, that letter will go to the full Committee for discussion and vote.

Ms. Abdull: So moved.

Dr. Mandell: Susan, do you want to call the roll for the vote?

Dr. Daniels: Okay. All in favor?

(Chorus of ayes.)

Any opposed?

(No response.)

Any abstaining?

Mr. O'Brien: Susan, this is John O'Brien. I am going to have to abstain.

Dr. Daniels: Okay. John O'Brien abstaining.

Actually, just to be clear, let me make sure that I have a list of who has voted aye.

So, with that, Denise? Or let me just go down the list and make sure that I have an accurate count of the vote.

Denise, what is your vote?

Dr. Dougherty: Aye.

Dr. Daniels: Okay. How about Idil Abdull?

Ms. Abdull: Aye.

Dr. Daniels: In favor.

Okay. Jim Ball, are you on?

(No response.)

No.

Anshu?

Dr. Batra: Aye.

Dr. Daniels: Jose?

Dr. Cordero: Aye.

Dr. Daniels: Jan?

Ms. Crandy: Aye.

Dr. Daniels: David?

Dr. Mandell: Aye.

Dr. Daniels: Laura?

Ms. Kavanagh: Aye.

Dr. Daniels: John O'Brien is abstaining.

Lyn Redwood?

Ms. Redwood: Yes.

Dr. Daniels: Cathy Rice?

Dr. Rice: Yes.

Dr. Daniels: Scott?

Mr. Robertson: Aye.

Dr. Daniels: And Alison did not join, I don't believe.

Okay. So, then, we have not quite a unanimous, but a vote of most of the Committee is in favor and we have one abstaining. So, we will record that vote.

So, then, this letter, once David makes

the amendments, will be distributed to you as an FYI of what has been done. And, in fact, the way we are doing this, we are copying the entire Committee on these Subcommittee emails because there were so many non-Subcommittee members who were interested in the proceedings. And then, this amended letter will go to the full Committee for discussion and vote on March 19th.

Dr. Mandell: All right.

Dr. Daniels: Thank you.

Dr. Mandell: So, that concludes our first agenda item.

(Laughter)

Ms. Crandy: So, do we schedule a meeting for our next agenda item?

Ms. Abdull: No, we only have half an hour, I think.

Mr. Robertson: Well, in the process of discussion, David, before we got to this, we actually had some things that were brought up related to some things on services, supports, and more emphasis on adults, et cetera. So, some of that could be I think possible points for things to be considered for what we are going to focus on in the next several months.

Dr. Mandell: Yes. So, one of the things that – I hope that this process has not burned anyone out too much. But we did talk about other issues that we would address in a similar fashion, with the next one being the needs of adults with autism. And so, I would put that out there as one of the activities that we could engage in.

Ms. Abdull: I think that is a good idea. I was just wondering if we could say adolescents and adults with ASD because Scott is right, that we focus so much on younger kids that we forget that they get teenagers and then into adulthood.

Dr. Mandell: I would be comfortable with that.

Dr. Batra: David, this is Anshu.

And I would like to add not only to place an emphasis on the adolescents and adults in terms of their functioning, in terms of their level of independent functioning, but also to emphasize the need to identify those individual endophenotypes that Cathy was alluding to and Scott was alluding to in terms of these individuals have different strengths and challenges.

And that is one of the reasons why I think we all basically are discussing the same issue, which is that this is such a heterogeneous disorder, and you can't compare one individual to another individual. I think that is one of the key issues we have to do, is start teasing out what the different profiles are, because that will then help us with, as Cathy mentioned, outcomes, outcome measures. And then, how do we best address those individual features of that group?

Dr. Mandell: That sounds like a Chapter 4 issue, though, the issue of –

Dr. Batra: We discussed that. We discussed that earlier in the week, but I think that it does carry over into the services arena as well.

Mr. Robertson: Well, this is Scott Robertson.

I think, if I hear what you are saying, partly it is what carries over is in the unmet needs.

Dr. Batra: Correct.

Mr. Robertson: What individual areas do individuals need? And this really fits into – and I hope that maybe for this plan we can even go further on this –in the last plan it mentioned parenthetically the possibility of a needs assessment around the unmet needs and support and service needs of autistic adults.

I wonder if there is a possibility to go a little bit further on that, on what this upcoming 2013 Strategic Plan has with its focus on autistic adults, and finding out, as was mentioned, you know, what individuals could be benefiting from supports and services, to be getting better independent living, higher quality of life, to be addressing things like getting folks into gainful employment, getting folks maybe the needed assistive technologies they could use so they may not have as much of a need for extensive staff during the day, and may not require as much supports and services if they can get assistive technology access, for instance.

I mean, those kinds of things I think fall into different kinds of areas of prioritization, I think, for adults, autistic adults' needs, and adolescents as well.

Dr. Batra: This is Anshu.

I would like to add – and again, you can tell me if this is more a question for or if this is more the services and policy end – but to see how interventions within communities, community-based interventions, how they affect, for example, in the adolescent population the rates of bullying and harassment in that population or –

Dr. Dougherty: This is Denise. Could I make a suggestion?

Maybe that we look at the four topics that folks said they wanted to work on at the last meeting we had, January 29th? And then, either say we don't want to work on those anymore or kind of prioritize those? I think maybe Susan wants to say something about prioritizing. And I am not sure that sequencing our work is the best way to prioritize as much as to try to figure out what each of these projects would mean for the Subcommittee, and how we would go about it, and what would constitute success at the end.

Some of these things sound to me like topics for a Strategic Plan for future research. So, I am sorry, but I am not exactly sure what each of these projects would mean.

So, should I just say what they are? They were in the email.

Dr. Daniels: Sure. You can go ahead and name those projects.

Dr. Dougherty: Okay.

Dr. Daniels: They were ones that were brought up in the last Committee meeting, although it sounds like right now the Subcommittee is focusing on wanting to do something around adults. And now, Anshu has brought up another project.

Dr. Dougherty: Right.

So, the first one was the project on ACA/Medicaid expansion and insurance exchanges, which we just talked about. So, that is almost done.

Then, the second one was a project to address lack of diagnosis, intervention services, for adults with ASD. And that just got modified to include adolescents.

The third one was a project on health disparities, including early diagnosis, access to healthcare and services, outreach to minority communities, and addressing cultural barriers.

And then, fourth was a discussion of how coordination between service agencies can be improved and recommendations for improving service provision and delivery.

Dr. Mandell: That actually gets at what Larry was talking about.

Dr. Dougherty: So, those are all really

good things, I think, though, as I said, I am not sure what a project is, being new to this Committee.

Dr. Daniels: Right. And, Denise, this is Susan.

Just in terms of prioritization, I was sort of talking about sequencing a little bit in some ways because the kind of discussion we had today, it would be pretty tough to have multiple parallel discussions going on many different topics at the same time. And the Subcommittee might be able to successfully complete projects more if they focus on one of those huge issues at a time. Even though I know that everything is urgent, we might be more likely to have success and impact if we kind of focus our efforts in one of those directions at a time.

Ms. Abdull: I like that idea. This is Idil.

We can maybe go in the order it is written. I like doing sequencing one at a time, and then, in the order they are written.

Dr. Dougherty: Well, I am afraid, though, that we are going to get to September 2014 and people are going to be very frustrated that we have only actually been fully able to address one topic.

Ms. Abdull: So, should we put a time for each topic? Like we should we put each topic –

Dr. Dougherty: I think the most important thing is to define what the topics are, what we would like to see at the end of them, and then, maybe different sub-subgroups could, if we decided to do them simultaneously, different sub-subgroups could work on them simultaneously.

Dr. Mandell: Yes.

Dr. Daniels: This is Susan.

One other thing I just want to bring up is that we do have another Subcommittee, the BTR Subcommittee, and they just proposed several projects the other day as well. So, there is a matter of coordinating multiple projects at the same time while there are other ongoing projects that are mandated by

Congress that we also have to do. So, we need to keep this a little bit manageable.

Dr. Dougherty: Right.

Dr. Daniels: So, that is why I would suggest sequencing rather than multiple in parallel.

Dr. Dougherty: That is really important to know that we can't rely on the OARC staff to do the work for us. It is all going to be volunteer.

Mr. Robertson: Denise, could I ask a question? On one of those projects, the one that was mentioned on intervention services for adults and adolescents, is that where – I just wondered, by the term services for that, it also includes what could be done in terms of getting more availability and innovation of assistive technologies and augmented communication technologies folks use?

Dr. Dougherty: I think any of these could mean whatever the Subcommittee wants it to mean. But I think it is important to kind of think through what it would be and what the product would look like at the end. Is it a letter to the Secretary? Is it a research agenda that gets published?

Mr. Robertson: I was assuming that some of this is in terms of focused around research in terms of informing, you know, helping to inform some of the things that go into the 2013 Strategic Plan.

Ms. Abdull: Right. That is what I thought, too. Is this not part of the plan for next year?

Dr. Dougherty: So, these could be things that are more in-depth looks at areas, so that we would wind up with a section in the Strategic Plan that would be more informed than we were able to do last year, though I must say it came out pretty well.

Dr. Insel: This is Tom.

Can I weigh-in for a second, based on what the other Committee decided this week, which was that they would like to see the 2013 update be much more an update about accountability, and rather than adding to the

78 objectives, looking at what had been accomplished, what objectives could be taken off the list.

And I am sort of curious, Denise, about your comment about not being able to rely on the OARC staff. I don't understand in what respect you mean that.

Dr. Dougherty: Well, I think Susan has laid out all the other projects that she has responsibility for. So, I think we need to be careful of what we ask the OARC staff to do.

Dr. Daniels: Right. Denise, this is Susan. Maybe I could clarify a little bit.

Dr. Dougherty: Maybe you could explain better.

Dr. Daniels: Yes. So, why I am talking about just being cautious about how many different things we have going on is, as much as it sounds like a wonderful idea for everything to happen through groups of volunteers, under FACA, we are required to follow certain rules, regulations, and policies. And it is the responsibility of the

OARC to be convening meetings, providing accurate documentation of what has happened at meetings, distributing things to the public, making sure that things are being announced properly to the public, et cetera.

So, there is a lot of administrative and policy work that goes on behind the scenes. And we can't just have groups of volunteers doing everything themselves without OARC being involved in those.

So, we can't really just have little groups of people going off in the corner and doing their own thing. We have to be operating in such a way that we are completely well-documented and that we are making everything accessible to the public.

And so, unfortunately, with those constraints, it does mean that we can't be running 25 different projects at the same time.

Ms. Redwood: Tom, this is Lyn.

I have a question, as sort of a follow-up on something I was going to bring up as well with regard to what the other Committee decided to do, the Basic and Translational Research Committee, in that we are looking very closely at each of the questions that we worked on the updates on and determining whether or not the objectives that we currently have in the plan have been met, what progress has been made to meet those objectives. And that was part of our updating process for 2013.

And it is going to be very fragmented if this Committee sort of doesn't do something similar or the Basic and Translational Research Committee would take over those chapters that the Services Research Committee did updates on.

So, I am wanting some clarification on that process because we can't update a plan unless we actually break the plan into two separate plans, one that is more based toward, you know, research and the other more toward services.

Ms. Crandy: This is Jan Crandy.

I think it is important that we do accountability for all the areas.

Dr. Insel: So, that would mean that this group would need to do this for Chapters 5 and 6 and to go through that same process.

Ms. Crandy: Exactly.

Mr. Robertson: So, Tom, this is Scott Robertson.

Ms. Redwood: And that will help you be able to identify some of these other areas here that you have that should go into the plan by doing that update process.

Dr. Insel: Right.

Mr. Robertson: So, Tom, this is Scott Robertson.

The one concern, while I think accountability is a fruitful route, the one concern I have is that it kind of conflicts with the ability to say we should be doing some things to find out things, take like, say, the needs assessments and it focuses on autistic adults, et cetera. Because we already kind of know from the literature, as was mentioned on the previous IACC meeting, that really the accountability is that things really haven't been done that well. Nothing has been done mostly.

In the vocational area, we don't really have much evidence, et cetera. I mean, the literature reviews already show there is not much out there.

So, if the focus is completely on only continuing to say this has been what is done, you know, it is not that great, rather than saying these are the things that should be done, then it worries me a little bit because I think that there is so much need, specifically on the area of adults, to have an emphasis on things that could be happening in that area, rather than focusing singularly on the fact of things that have already happened, which is not much because there is not much work in the area around adults.

Dr. Batra: This is Anshu.

I would have to second that, Scott. I think in our January meeting, I mean, David's study pretty much highlights the disparity and the need. And I think that we really owe it to the public to really highlight what the gaps are, what the needs are, so that that pushes us forward to do something about it.

I think the Basic Research Committee, I think that is a different – we are looking at something different. We have research in certain areas of diagnosis and treatment. We have to develop a thermometer in terms of where we are headed.

But here, we know. We know there is a disparity. And again, I would be concerned to go through this whole process and, then, come back to the same place where we are 14 months later; to say, "Yes, there is a need. There is a gap. We need to do something about it."

Ms. Redwood: This is Lyn.

I would like to respond to that. Because the other thing that this Committee could do would be to have a workshop specifically on that particular topic and use that information to inform the Strategic Plan.

But there are things in here. Back like a year or 2 ago, there was much more of a focus on adults. Just for example, one of the short-term objectives in Chapter 6 is to launch two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of service delivery. And it has in here safety, integrated employment, post-secondary educational opportunities, community inclusions, self-determination, relationships, access to health services.

So, we don't know if that has been funded. We don't know if we have research currently underway to help provide some of that information. So, we don't have it now, but we don't know what is in the pipeline.

Dr. Koroshetz: This is Walter.

The other Committee, Lyn, we had a very similar discussion on the other Committee call. I thought the conclusion was that we were going to do a pilot on just Question 1 and try to see exactly what we could accomplish, what kind of resource it would take.

Ms. Redwood: We are but for this Committee I didn’t know if they’re going to do the same thing with their chapters.

Dr. Insel: You know, my thought about this for the services group here is I wouldn't constrain yourself to the Research Plan. That is something that we need to do by statute. But what I would like to challenge you to think about is what you want to do as a group that is maybe not related to research, but it is more relevant to policy or to some other issue that you think is more urgent.

By nature, the Research Plan is a long-term endeavor. And yet, what we hear at every meeting is the urgency of addressing some of the services needs.

So, I would like you to think about what you might do that may be independent of the whole process we go through with updating the plan, and that you shouldn't feel limited by that, as if that is the full extent of what you can do here.

Ms. Abdull: Hi. This is Idil.

So, I agree with that, and I agree with Anshu that we don't want to go through this whole process and, then, say, "Oops, yes, there is a need."

While the research is important and that we are mandated by Congress to do that, I think – and Alison is missing here; she always says it better, eloquently – but the services delivery part, we have to really concentrate on that. So that people are not just saying – we don't have 5-10 years to wait for this research or that research – "Where do I take my kid now? Where can I go as an adult now to get services?"

I think we should concentrate on the services delivery and services policy that will make people see benefits in a relatively short time.

Ms. Redwood: So, that is Item No. 4. Then, are you recommending prioritizing toward that?

Ms. Abdull: I like the ones that we have now. If we can go in the order that they are there – we have done No. 1 –if we could do the other three, in addition to updating the two chapters and doing the accountability, I think we need to take that upon ourselves with the help of OARC and do those things. So, yes, I do agree with that.

And do it in a sequence, like not doing it simultaneously. Just doing it one project at a time. Because, otherwise, if we are concentrating on too many things, the message might get lost in the middle. But if we do it in sequences, and maybe have a timeframe for it, so we will do the project, the adults and adolescents project for this time, updating this time, and then, the disparities, and then, the coordination.

That is even like one of our topics, the coordination of services. It just seems like a lot of agencies within HHS are not coordinated in order for people to really see the benefits of the autism services and resources. And we need to have a guide for families, and we need to have a guide for professionals even.

Dr. Batra: Idil, this is Anshu.

That is very well-said, and that is exactly, again, as a parent and as a pediatrician that deals with and manages and guides families every day, that is exactly the biggest problem that I face and we face. It is, okay, you have delivered this news to me. What do I do about it? How do I get the services? Where do I go? Who pays for it? And it is the right hand doesn't know where the left hand is.

And that is what I do. I spend countless, countless hours of my time to help navigate through it and, then, help families navigate through it.

And so, absolutely, I think that is a focus we need to emphasize.

Ms. Crandy: So, this is Jan Crandy.

I do think that maybe we need some Federal guidelines, and maybe that is a letter that we ask to try to get states more consistent, so that all states at least have some roadmap of what they should be doing for individuals with autism.

Dr. Batra: And, Jan, this is Anshu.

You know, I wish Geri was on the line. They have a toolkit for diagnosis, the first 100 days after diagnosis. They have a toolkit for –

Ms. Crandy: Right.

Dr. Batra: – allied health providers. They have a toolkit for schools. They have a toolkit as you are aging into adulthood.

And so, how can we provide a toolkit that goes across, whether you are in California or Minnesota or on the East Coast? Or can we do that? Is that something that is doable?

Ms. Crandy: And I think for professionals, the American Academy of Pediatrics has come out with a toolkit per se for the medical evaluations.

Dr. Batra: Yes, but the problem is, you know, you have got the AAP, but, then, you have got the American Academy of Neurology coming out with guidelines soon, which, again, I am serving as a panel member there. And then, you have got the DSM-5 being revised by another committee.

But there is no –

Ms. Abdull: There is no roadmap. We need a roadmap. And I think –

Dr. Batra: No, everyone is working discretely. I feel that is where I don't want this endeavor to, then, fall into another pile on my desk, you know, that I have to at some point go through to help navigate myself and my families through.

Ms. Crandy: But I would hate for us to make another set of guidelines. We don't need to be redoing things that are already done.

Mr. Robertson: So, this is Scott Robertson.

I had some comments. Definitely, some of this is questions of Dr. Daniels. Is there the ability to actually create, as was mentioned, toolkits or a guidebook or a roadmap, or whatever, in addition to what is actually required by statute, you know, things like the Strategic Plan. Can this Subcommittee help to develop the beginnings of, say, things around like autistic adults and recommendations for supports and services? Are we actually able to do that?

Dr. Daniels: Yes, you can decide, if the Subcommittee's priority is to develop some type of a document around services, you can decide that you are going to do that. You would need to decide what the focus is, and we could plan another call for you all to talk about this or an in-person meeting.

Dr. Rice: This is Cathy Rice.

One thing I would say is that there's a lot of great resources being developed by programs or within states or different Governors' councils. And there are some organizations that have tried to coordinate some of this.

So, for instance, AMCHP, the Association for Maternal and Child Health Programs, and AUCD, the Association for University Centers on Disabilities, have grants. They have had grants from CDC, from HRSA; I don't know if from NIH or other agencies as well.

And they have tried to compile some of this, but I would definitely say that we would want to, to start, maybe bring in some of those folks that have worked to pull across what other states are doing and supporting some of the state implementation plans that are happening right now, so we don't start from scratch.

And some of you remember that this Committee in an earlier iteration of it did come up with a roadmap, but it was much more of a what is needed for service in general, and it sounds like we are talking more about roadmaps more in the vein of like the 100-Day Toolkit or a transition guide, or things that are much more targeted.

Do I understand that right? Is that what people are really interested in doing?

Dr. Batra: Yes, and I think that is very well-said, Cathy. And again, you know, I am a parent and I am a pediatrician, and it wasn't until I became involved in Autism Speaks that I became aware of 100-Day Toolkits. And that is where, again, I think there is a lot out there, but I don't think it is being disseminated, I guess, as robustly or as efficiently as it needs to be. And I don't think it is being utilized.

Yes, I think that we, as the Committee that actually, again, serves a role to help bring things together and, then, guide our –

Ms. Redwood: One of the things we have been working on – and, Susan, it would be great to have an update – is "The State of the States".

Dr. Daniels: Yes. So, I don't know if John O'Brien is still on the call. But, in July, we are planning to get a read on "The State of the States". So, hopefully, CMS will be doing a presentation on –

Mr. O'Brien: Yes. No, Susan, I am still on. We are committed to doing that at the July meeting.

Dr. Batra: This is Anshu.

Can you elaborate? What do you mean "State of the States"?

Mr. O'Brien: So, we did a review of 50 states. We looked at a variety of areas. Specifically, we looked at what were they covering as part of their Medicaid program. We looked at what were some of the state statutes, very similar to what NCSL has done around ASD. We looked at a couple of other Federal programs that were being administered by the states to see if there were specific activities they were doing around service coverage for ASD across the spectrum, across the age range.

Dr. Batra: So, these are Federal agencies that you were looking at?

Mr. O'Brien: No, it wasn't Federal agencies. In some cases it was Federal dollars that were going to states. It was a state focus, both in terms of how the states used the money, but also if states had laws on the books that had nothing to do with Federal monies around ASD coverage, what did those laws say?

Mr. Robertson: So, this is Scott Robertson.

I had just a couple of comments on that. By "State of the States", I am guessing this is kind of similar in some ways to "The State of the States" that is done in the broader developmental disabilities world by some of the research at the University Centers for Developmental Disabilities. I believe that Dr. Braddock, I think, is one of the people who has been involved in that, where they went for each state individually in a large book every year that talks about how many people are receiving these community-based services and try to qualify and quantify what things look like across different states.

But what I wondered, two things related to that. There are some states that there may not be laws on the books, but there might be either Executive Orders or, for instance, in the case of Pennsylvania, we have a guiding document that is not a law per se or even an Executive Order, but it is an Autism Task Force Report that has been the blueprint for everything happening here.

And I did want to make a recommendation that, with any process to be looking at or to be thinking about how things could be innovated around a toolkit or otherwise for adults and adolescents, that I would highly recommend getting in contact with the Bureau of Autism Services we have here in Pennsylvania that has one of the more – I would say we have the most developed autism-specific state government agency in the U.S. right now.

They have been doing very, very extensive things around adults, and around trying to address unmet needs, through not just our service systems, but also the ASERT collaboratives which are university-based here in Pennsylvania that are funded partially by the state government to be doing innovations around employment and around higher education and around life-coaching, and around many, many other areas on enhancing quality of life and expanding access to services.

So, I would hope that they could be as experts, or otherwise, be able to assist this process of coming up with things to innovate what we think of when we are talking about services and policies around adults and adolescents.

Dr. Mandell: This is David.

I wonder if we are getting into the weeds a bit, especially given –

Ms. Abdull: Yes, I was going to say that.

Dr. Mandell: –especially given the time. I don't know what the requirement is for us to be done by 4:30, Susan, but we are clearly past that.

Dr. Daniels: The schedule is subject to change based on the needs of the Committee. So, if the quorum of the Subcommittee can stay and wants to stay to discuss further, they can. But if we lose our quorum, then we need to end.

Dr. Mandell: Okay. Well, I wonder if we could think in more broad strokes about the things that we want to take on.

I think the idea of a roadmap was actually, I think, one of the first service activities of the IACC a number of years ago, but did not end well because I think of a lack of specificity and direction. I wonder if we want, instead of thinking about – I like very much the idea of providing support for families and policymakers with regard to what already is out there, and how to access it, but I wonder if we need a little more specificity.

And I wonder if the four things that we originally came up with that Denise read to us at the beginning might offer us a framework for doing that. It sounds like people still think that they are very important. And maybe we should be thinking about a broader set of documentation around those issues that addresses this roadmap for that particular group as well.

Ms. Abdull: I agree, David. I think the four things that Denise and you have read earlier, it is a good idea but then the roadmap is sort of just a broad sense for it. So, a roadmap for the adults, for the disparities, for the coordination. And then, the roadmap, ultimately, is to help the family, the person who is autistic, and also the professionals, the provider, and within those four items that we have.

And one we already took care of, the letter. And so, the other three, right?

So, I wonder if, in the interest of time, if we can have some sort of either consensus or vote. Do we agree that that is what, in addition to updating the questions for the Services Policy Committee, in addition to that, for the research portion, if we can have this as a services delivery, sort of what Alison has been saying consistently ever since I have known her, that we need a services delivery for the people that are being affected by autism, which is some of these things that we talked about.

Can we sort of agree on that? Or can you, David and Denise, guide us in how to wrap that package?

Dr. Mandell: So, I think that service delivery for people with autism is way too big a package. I think that is where we get ourselves into trouble.

And the reason I like the four things we talked about is because it provides a lot more specificity and implicit direction for the people working on that. And I would rather –

Ms. Abdull: Sorry. Yes. So, no, I meant services delivery within those four things. Okay? Not the whole services of the whole –

Dr. Mandell: Okay.

Ms. Abdull: Yes, yes. Sorry. It is too late in the day.

Mr. Robertson: David, the four things, are they now becoming these things like potential subsections or something of a roadmap kind of document that has specificity in it?

Dr. Mandell: That we might work on one at a time, so that they could stand alone, but that they would form a coherent whole together.

Mr. Robertson: Oh, okay.

Dr. Mandell: Yes. And, you know, Tom has encouraged us to think broadly outside of, you know, not constrict ourselves to the Research Plan. While I think accountability is a critical component of what we do, we don't have that much time. And so, in some ways, we need to think about what we want the legacy of the work we do to be.

And so, having documents that provide a map for people for what needs to be done in the future with regard to services and policy, and what people should be doing now, seems like a very good place to start.

And starting with some of the highest needs or least researched populations makes a lot of sense. So, to that extent, I think the focus on adults and adolescents is critical. I think Idil's call for us to focus on disparities, which we have now mentioned in both our plan and the update, but have not discussed concretely how to address, would be another critical issue that we could address.

Ms. Abdull: I agree. So, what do we do now? Do we all agree or –

Dr. Dougherty: It sounds good. Is somebody going to write that up?

(Laughter)

Mr. Robertson: David, I thought you were going to take your magic wand or something and have that document appear or something.

Dr. Dougherty: Oh, no, I am not talking about a document. I am talking about notes that we can know how to proceed.

Mr. Robertson: Oh, okay.

Dr. Dougherty: Gosh.

Mr. Robertson: I was just making a joke; that's all.

(Laughter)

Ms. Redwood: This is Lyn, and I support that. The only question that is nagging me is, when the other Subcommittee does the updates to the Plan, what will happen to those other two chapters that are in the plan now that are currently part of the Services Subcommittee?

Dr. Daniels: Lyn, this is Susan.

Maybe I would like to speak a little bit about what happened with the BTR Subcommittee the other day, the Basic and Translational Research Subcommittee.

So, as Tom described, they decided that they wanted to do an accountability exercise around the entire plan, but they first are going to start with a pilot of Question 1 on diagnosis and screening and come up with a plan for doing this accountability review.

And one suggestion that didn't come up in the BTR Subcommittee, although my sense is that they would be open to this, is that perhaps in developing that model, we might want to have one or two people from this Subcommittee participate. Because whatever model is used might be the same type of model that you would use to update Chapters 5 and 6.

And so, given that the topic is diagnosis and screening, I don't know if there is anyone here that would be interested.

Now Coleen Boyle is already leading that effort. So, Cathy wouldn't be able to participate. But if there might be one or two people from this Subcommittee who would volunteer to help them out in drafting the plan for that, it might help, so that you could bring that information back to this Subcommittee.

Ms. Redwood: Well, I'm on both.

Dr. Batra: Yeah, I’m on both.

Ms. Redwood: So is Alison. And I think Alison also volunteered to help with that process, Susan.

Dr. Daniels: Right, she did. So, do you feel that that is sufficient, then, to bring that information back to this Subcommittee?

Ms. Abdull: There is Anshu and Lyn and Alison. I think that is more than enough. We don't want to overrun or take over the place.

Dr. Daniels: I don't think Anshu is in that planning group, though. Alison and Lyn are. So, then, they would be the representatives back to this Subcommittee to talk about that. So, that is fine. We can leave it that way.

And then, something else that I can bring up offline with folks later, but I wanted to mention on this phone call, in case there are people listening to this phone call that weren't on the other phone call the other day, is that there is a subgroup that is going to be looking, a planning group looking at DSM-5. And on that call, they mentioned specifically that there were several members of this Subcommittee that they would like to have participated in that. And I don't have the list in front of me, but I believe Laura Kavanagh and John O'Brien's names came up, and there may be some others.

And so, I can do that offline and just see if there are at least a few members from this Subcommittee that want to serve on that planning group. So, just be aware that there are multiple projects that different people might want to be involved in across the two different Subcommittees.

Mr. Robertson: Susan, I also had participated in that call of the other Subcommittee and had mentioned interest in the DSM-5 group.

Dr. Daniels: Yes, you probably are on that list. Like I said, I don't have the list in front of me. I was just trying to bring it up –

Mr. Robertson: Okay.

Dr. Daniels: –especially for the benefit of those who weren't on that call, and I know there were some folks on this call that were not on the other call.

Ms. Redwood: Thank you, Susan.

Dr. Daniels: Sure.

Dr. Mandell: All right. So, it sounds like we could potentially participate with or at least listen-in on the process that they are going through for –

Dr. Daniels: Yes.

Dr. Mandell: – for that kind of

accountability exercise. And since they are only doing it for one question and not for all of them, so it won't be that our chapters are conspicuously missing that kind of accountability report.

Dr. Daniels: No. So, they are going to develop the model using Question 1 as a test case. And then, once that model comes to the full Committee and is voted upon, then the two Subcommittees can take on their respective chapters and work on the actual accountability exercise.

Dr. Mandell: Great. That takes us back, then, to the four areas that we outlined and whether we want to prioritize any. I had put on the table the idea of prioritizing adolescents and adults with autism and addressing issues of disparities in care.

I would open it up to discussion from other folks about whether those are the right two or whether there are other things we ought to be considering. But I would urge us to sort of keep it at that broader level.

Ms. Abdull: I agree, we should keep them at that broader level, and then in that order. I think we should focus first on the adults and then on the disparities.

Dr. Mandell: So, any other thoughts about that? Agreement? Disagreement?

Mr. Robertson: Yes, it seems reasonable to me.

Dr. Mandell: Now we already have a chapter on adults in the Strategic Plan. So, what is it that we would be doing now that would build on that and be different from that in what we present on adults? Are we thinking about a similar type of letter or document that could be used by advocates that comes from the IACC? Or are we thinking about developing something that is more of a specific manual, if you will, about service access for adults with autism?

Ms. Abdull: I think what we have for – and, hopefully, we are going to add adolescents, right?

This is Idil.

Dr. Mandell: Yes.

Ms. Abdull: So, adolescents and adults, the chapter that we have basically just says there is nothing. So, if you are going into the teens or you are an adult, there really just isn't any research.

So, maybe what we should come up with is what exactly do we know, even if it is very limited. So that at least people who are now teenagers and adults can have some sort of guidance of what to get, whether it is housing or whether it is assistive technology or whether it is social skills support. So, what is available now, just to give them some guidance. That is what I would be thinking.

But, of course, Scott and the other two guys might be better at this than I am.

Mr. Robertson: Yes, to dovetail a little bit on this – this is Scott – when I said in terms of what do we know, that should also encompass not just in the research literature, because the research literature needs a lot more work, but what do we also know from broader resources out there. What do we know from things in government, from things in practice? You know, what other areas can we pull from as far as knowledge other than just the peer-reviewed literature?

Dr. Mandell: Okay, but the general idea, we are in agreement about?

Dr. Rice: Can you restate what you mean by the general idea? Sorry.

Dr. Mandell: The general idea of developing a services roadmap, drawing on extant literature, for adults with autism.

Ms. Crandy: This is Jan Crandy.

Would we do that through a workshop? Would we bring in experts?

Dr. Dougherty: This is Denise.

I wouldn't rely just on the literature, but maybe other ways to identify best practices, and then, be clear about which ones have been researched.

Ms. Crandy: Right. This is Jan Crandy again.

I look at like Ohio. They have put out a whole series on transition, adolescence, adulthood, employment. I wouldn't want us to reinvent the wheel when all these other states have done such a great job. It would be better to bring them into a workshop and share with us.

Ms. Abdull: Yes. And, Jan, I think what you are saying is do a workshop, and then, sort of get ideas of what other states are doing, and make a generalized idea for the whole country. Yes?

Ms. Kavanagh: The UCEDDs, funded through ADD, should be part of that as well. They have developed a lot of different resources as well.

Dr. Mandell: We can probably make a lot of decisions about those specifics. I like that idea of pulling on expert knowledge to do that. We can probably make a lot of decisions about who should be involved, but maybe we want to set the general idea of what we want to do first, and then we can talk about the details.

Ms. Abdull: Right. As long as you said adolescents and adults, I think that would be good.

Dr. Batra: This is Anshu. I agree.

Ms. Kavanagh: So, if we are speaking to different activities, are we saying that each one will take about 6 months? Or what is the timeframe for each of the two activities as well?

Ms. Abdull: Please God, don't say 6 months.

Ms. Kavanagh: Well, we have two activities that we want to complete. I mean, what is realistic?

Ms. Abdull: Well, if we look at the way we did it last time, it was somewhat similar. Maybe 3 months, 4 months?

Dr. Daniels: Sorry. This is Susan.

I didn't hear the beginning of the question. So, the timeline for this activity to have a workshop on adults or –

Ms. Kavanagh: I think we are talking about both a workshop and some sort of a services roadmap that would include both literature – I mean, I am hearing two things, is that correct?

This is Laura.

Dr. Daniels: So, you are talking about a timeline to complete a document as well as hold a workshop?

Ms. Kavanagh: Right.

Dr. Dougherty: Three to four months is way too short for that kind of thing.

Dr. Daniels: And remember that you will be engaged in the update to the Strategic Plan at some point as well. So, if you are working on drafting this document, many of you will also be involved in working on updating the Strategic Plan in the next few months.

Dr. Dougherty: So, I think it will take until February to get the roadmap together.

Dr. Daniels: Sorry. What was that? I think things are cutting in and out.

Dr. Dougherty: Yes. This is Denise.

I said I thought it would take us until next February to complete a roadmap that we are all happy with.

Ms. Abdull: Hi. This is Idil.

So, Denise, would that be for both questions? So, 6 months for each one or is that what you are saying?

Dr. Dougherty: I was just talking about the adult services roadmap. So, what is the other one, the disparities?

Ms. Abdull: Right.

Dr. Dougherty: Disparities? Well, that is why I think dividing up into groups, and the disparities one could be done on the same kind of timeline.

That is a harder question to develop a roadmap for.

Dr. Batra: Yes, I agree.

Dr. Dougherty: So, maybe that would take until next April.

Ms. Crandy: So optimistic. It only took us – what? – 2 hours to agree on that letter.

(Laughter)

Dr. Dougherty: Believe me, that is top of mind in thinking about the timeline.

Ms. Abdull: I think if we divided into – we have until September of next year – so if we divided in half for each one, or at least do the adults in, say, 6-7 months, and then, keep in mind that it will take equally the same amount of time of the other one. I don't know if doing them simultaneously is a good idea. I think doing them, concentrating on one area, because we also have to update the plan and the other two questions. So, doing them one at a time might be better because, then, we can concentrate more on that particular project.

Ms. Kavanagh: I agree with you, Idil.

This is Laura.

Dr. Dougherty: This is Denise.

I don't agree.

Ms. Kavanagh: You don't agree? You think we can do all three?

Dr. Dougherty: I think we have to do both simultaneously or the second one won't get done; the disparities won't get done. I mean, maybe start with the adult, and then, phase it so that we don't start on the disparities for another couple of months, but --

Ms. Abdull: What do others think?

Dr. Mandell: I apologize, but I am going to have to get off the phone.

Dr. Batra: Yes, I’ve had a patient waiting for the last 30 minutes, so –

Dr. Daniels: We need to, then, adjourn the call. So, can we defer further business to another call?

Dr. Mandell: That would be great.

Dr. Batra: Can we discuss this on the 19th, by chance? It is something that we –

Dr. Daniels: That is a full Committee call. So, that is not a place for the Subcommittee to have discussions of their internal business.

So, we can try to set up another call. In the meantime, there might be some minor things, planning things, that can be worked out on email that aren't major decisions that would require a call. So, we can try to do some of that in between, but, then, we will need to set up another call. I don't know that we would necessarily be able to have another call before the next full Committee in-person meeting on April 9th, just because right now the BTR Subcommittee has two calls, and there is a call for the full Committee, and then the full Committee meeting. And so, we have got four meetings coming up in the next few weeks. So, this would probably have to happen toward mid-April.

Ms. Redwood: Susan, this is Lyn.

Do we have time on the agenda? I mean, I am just wondering. It seems like we always run out of time at our full Committee in-person meetings. How much time do we have on the agenda to do work as a Committee together?

Dr. Daniels: It is not planned yet, but we have already lengthened the time of the full Committee meeting from 9:00 in the morning until 5:30. We could even make it go until 6:00 to try to give extra time. But one of the issues is that more and more presentations are proposed. And so, we will have to balance it to try to leave more time for discussion, but that means we will have to give up some presentations in order to have more time for discussion.

Ms. Redwood: Can the Committee be involved in setting the agenda for the meeting?

Dr. Daniels: According to FACA, the Committee agenda is set by the DFO and the Chair. So, we can take suggestions, but, ultimately, the Chair is able to make the final decision on the agenda. And we always do take feedback from the Committee, and you have all proposed many, many ideas for what could possibly be on that agenda. And we are going to try to work it out.

We always attempt to find some balance between the different priorities and wanting to have some services issues, some research issues, et cetera, on the agenda. But, unfortunately, the problem we always run into is you can't really do everything that is needed for autism in one meeting. So, we will have to prioritize some things.

Ms. Redwood: I am just worried we don't have enough time set aside for the important things to discuss as a Committee during the meetings because they are so packed with presentations.

Dr. Daniels: Right, and we have heard that feedback from you all, and we are going to try to set aside more time for discussion. But the tradeoff will be that we might not be able to have quite as many presentations, although we are trying to add some time onto the meeting to accommodate additional presentations. So, we will do our best.

Ms. Crandy: This is Jan Crandy.

We couldn't make it 2 days for the in-person meeting since we are traveling there already?

Dr. Daniels: We can't do that at this time. It has already been scheduled, and we can't just add an extra day at the last minute. If we are going to plan additional days, they have to be done pretty far in advance. Most people on the Committee have pretty packed schedules, and it is pretty tough to even get them for a single day.

Ms. Redwood: Yes. I noticed for one of the Committees, Susan, it was meeting, like they started their meeting maybe at 1:00 or 2:00 in the afternoon the day before. So, they just flew in in the morning. So, there wasn't an additional cost for a hotel or a flight or anything. So, maybe in the future we could do something like that or at least part of the Committee could do that.

Dr. Daniels: But we can't meet with part of the Committee. We need to have at least a quorum. And if you even have only 51 percent of the Committee or whatever would constitute a quorum, that is not really acceptable because we really need to have almost all of the Committee members participating for it to be effective.

Ms. Redwood: What about having a Subcommittee meeting the day before, if there were members of the Subcommittee? Because we have had separate in-person Subcommittee meetings before. Could we maybe do that?

Dr. Daniels: It is pretty difficult on an administrative level for the office to handle all of the materials and announcements and all of the things that go into planning a meeting and to have them back-to-back like that. It is not something that is very feasible. So, we probably would have to plan it separately.

But we are perfectly willing to do in-person meetings where it is possible for us to do them, and if the Subcommittee wants to have an in-person meeting in April, we can do that.

Dr. Mandell: Guys, I am really sorry. I really do have to go.

Dr. Batra: This is Anshu. I really have to go. Thank you so much.

Dr. Daniels: So, this meeting is adjourned.

Thank you.

(Whereupon, at 5:05 p.m., the conference call of the SRP Subcommittee was adjourned.)