U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR PLANNING THE ANNUAL STRATEGIC PLAN UPDATING PROCESS

FRIDAY, DECEMBER 3, 2010

The Subcommittee convened, at the Bethesda Marriott, 5151 Pooks Hill Road, Bethesda, Maryland, at 10:00 a.m., Thomas Insel, *IACC* Chair, presiding.

PARTICIPANTS:

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

DELLA HANN, Ph.D., *Executive Secretary,* Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

ELLEN BLACKWELL, M.S.W., Centers for Medicare & Medicaid Services (CMS) (attended by phone)

COLEEN BOYLE, Ph.D., Centers for Disease Control and Prevention (CDC) (attended by phone)

PARTICIPANTS (continued):

GERALDINE DAWSON, Ph.D., Autism Speaks

LEE GROSSMAN, Autism Society

JENNIFER JOHNSON, Ed.D., Administration for Children and Families (ACF)(representing Sharon Lewis)

ARI NE'EMAN, Autistic Self-Advocacy Network (ASAN)

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds (attended by phone)

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF)

MARJORIE SOLOMON, Ph.D., M.B.A., University of California, Davis and M.I.N.D. Institute

TABLE OF CONTENTS

PROCEEDINGS

10:04 a.m.

Dr. Insel: Thank you, and good morning.

Welcome to another meeting of the Subcommittee for Planning the Annual Update of the Autism Research Strategic Plan.

There are a few of us gathered here in Bethesda around the table and some on the phone. So, I think what we will do is go through a quick roll call, so the Committee members will know who's here, and those listening in from elsewhere can also know who is participating.

I want to encourage you to use your name to identify yourself, especially towards the beginning of the meeting, so that everyone will know who is speaking.

This is Tom Insel, and I will be chairing the meeting from now until a little bit before two o'clock, when I have to leave for another commitment that couldn't be moved.

And at that point, Della Hann will sit in to help guide us through the last part of this Subcommittee meeting.

So, let's do a very quick roll call, and let me know who is present on the phone and who is here in the room.

Ellen Blackwell?

Ms. Blackwell: Here.

Dr. Insel: Coleen Boyle?

Dr. Boyle: I'm here.

Dr. Insel: Geri Dawson?

Dr. Dawson: Yes, I'm here.

Dr. Insel: And Geri's here in the room.

Lee Grossman?

(No response.)

Jennifer Johnson?

(No response.)

Walter Koroshetz?

(No response.)

Walter will not be joining, is that right?

Ari Ne'eman?

Mr. Ne'eman: Here, apparently just in time.

Dr. Insel: Yes, Ari has just arrived here in the room.

Lyn Redwood?

Ms. Redwood: Here.

Dr. Insel: On the phone. Okay.

Stephen Shore is not going to be joining us today.

Alison Singer?

Ms. Singer: I'm here.

Dr. Insel: And Marjorie Solomon?

Dr. Solomon: I'm here.

Dr. Insel: Okay. Marjorie, who came all the way from California.

Well, thanks to all of you. This may be the hardest-working Subcommittee on the planet at this point.

(Laughter.)

So, I want to really express my gratitude for everybody being so engaged in this process. This is a little messy. It's a lot of work, but it is really important that we get this right. So, thanks to all of you who stayed the course and worked hard to try to make this the best plan we can have.

What we have in front of us to do today is a couple of things. Initially, we need to go back over the minutes of the previous meeting, which these were sent to you in the last couple of days from Della and Susan. We want to make sure that those reflect the things that you would like to have in the minutes, and that they are accurate and complete.

So, if you take a moment, let's see if there's any revisions, corrections, deletions, additions that need to go in.

(Pause.)

Welcome. Jennifer Johnson is just joining us.

Hi. We're just taking a look at the minutes from the last meeting. So, we're just getting started a few minutes late.

(Pause.)

And you may want to keep these minutes handy because, as we get later into the meeting and we'll start kind of revisiting some of the changes that were made, it might be good to have those as a reference point to make sure the changes in front of you are the ones that we discussed last time.

But, hearing no other comments or suggestions, I am going to assume the minutes are accepted as written, and we will go ahead and start the discussion, which is the next item on the agenda.

There are two questions in the plan that we have not yet visited, which would be Questions 5 and 6. So, let's go ahead and we'll focus on Question 5 initially.

And let me ask, who wants to take us through this?

Ms. Blackwell: I guess it would be me, Tom. This is Ellen.

Dr. Insel: Ellen, okay. Thank you. Do you want to just quickly run through each of the sections here? And we will solicit some suggestions and comments from your colleagues on the Subcommittee.

Ms. Blackwell: Sure. I guess we will start with 5 because chronologically it's first. But I do have to say that, in drafting the language for these chapters, I know that at times we have put 5 and 6 together, but I would have to say that there is definitely overlap between these chapters. It was helpful to me in reviewing information for 5 and 6 to try to segregate what went into 5 and what I thought was more appropriate for 6. So, that is kind of the approach that I took.

Because we had so many changes in the law surrounding health and services that were put in place through the Affordable Care Act, I thought it would be good to start with a paragraph talking about recent legislative initiatives. So, that's what you see here.

And then, the second note refers to the MHPAEA, the mental health parity law. In fact, I did find an article that talked a little bit about mental health services for people with intellectual and developmental disabilities.

There were several articles on services related to dentistry, which is actually getting some attention in the research literature these days. I hope that that continues because it is a serious challenge for many people with intellectual and developmental disabilities, including autism. As states are beginning to retract these optional dental services, remove them from their Medicaid state plans, it emphasizes the need for access to dental care.

And then, there were several articles that came out in 2010 and late 2009 about family support. I thought it was important to acknowledge those because Jennifer certainly has always stressed, and

Alison, too, has stressed, the importance of family support. These came up in the context of both people with ID/DD and autism.

So, it looked to me that the gap areas sort of centered around oral health, which is not a surprise, and then, also, access to mental health.

So, my take on this was to go back and look at the 2010 plan, which we revised significantly in terms of Chapter 5, and see if there was a way to fit this focus into the plan. So, that was the approach that I took here. I think it is important to look at what is already on the table and how any new opportunities and research objectives can fit into what we already have.

In fact, because we were somewhat open-ended, and I think that we did that on purpose, waiting to see where the focus would be, that definitely family function fits into short-term objective A. The new focus on behavioral health services sort of to me said we really need to look at new objective C and maybe focus on mental health services, in particular, as a coordination piece that we should be looking at.

Then, as far as the dental health services, that seemed to me to fit into A and B 2010 long-term objectives. And my suggestion would be that we tweak the objectives to include two specific objectives on oral health. One on the cost/benefit of providing comprehensive dental services versus no dental services or emergency treatment only.

There are actually at least two states that have even removed emergency dental treatment from their Medicaid state plans. And the result is that people end up accessing services through the emergency room, which can be quite costly. So, I think that that would be a valuable piece of the research.

And then, two, to look at how to provide better dental services to children with autism. I think that that might support, in fact, the adult piece because some of the evidence that was published last year shows that children who are able to access dental services early on are much more compliant throughout life, probably not surprising.

So, that is kind of where I went with this draft of Chapter 5.

Dr. Insel: Thank you, Ellen.

Comments? Ari?

Mr. Ne'eman: Well, first, before I get into any substantive comment, I just want to thank Ellen for taking the leadership on this. I had initially volunteered to be lead on 5 and 6. And shortly after that, I fell ill, and Ellen -- what's it called? -- stepped up and really took charge of both. So, I am very grateful to her.

Substantively, I wanted to call attention to one of the things that was mentioned in regards to new legislative initiatives. In particular, the expansion of

Medicaid options to provide HCBS and the one related to targeting for people who do not meet traditional institutional level-of-care program requirements. It is the 1959 Medicaid option, which I think is exceedingly promising for individuals on the spectrum who do not meet institutional level of care.

And one of the challenges that may arise for states looking to take advantage of this new opportunity on their Medicaid is to figure out precisely what kinds of services are going to be necessary and what kinds of provider networks are going to be needed to cultivate in the event the state does decide to create, as one hopes, although one never knows with the budget situation that states are facing now, targeted benefitted for adults on the spectrum who do not meet institutional level of care.

So, I could see it is as valuable for us to include an objective looking specifically at that, at research that would evaluate program models or develop program models to serve that population which currently is in a gap in which they really don't have access to any significant service provision.

Ms. Blackwell: Ari, this is Ellen.

CMS is presently in the process of working on a task order that looks at the development of models for services that would be aimed at children, youth, and adults for autism. So, we could certainly add that over here to that project.

I'm not sure if it's totally appropriate for this plan. I would have to think about it a little more. But it would be an instant fix in that project that we have and are working on now.

Mr. Ne'eman: See, I could see it as valuable here, mainly because I think there is a need to essentially see a role for research from the private sector around this in the sense that, obviously, CMS evaluating the existing program models is going to be very necessary. But when we look at the ways in which this may interact with services that are not Medicaid-funded, such as, for example, vocational rehabilitation services or independent living centers, it is possible that, clearly, there are some areas in which this is CMS expertise that is needed. But there may be other areas in which the broader research community could be very valuable.

Dr. Insel: Ari, could we get you to look at the current objectives in the 2010 plan that would be short-term C and long-term A, and even long-term B, to see whether that meets what it is you're asking for? It doesn't specify 1959, but I wonder if it captures in terms of what the research need would be.

Mr. Ne'eman: So, what I would suggest is that, if we were wanting to incorporate it into an existing objective, which I am not adverse to, what we could do here is to do something very similar to what we did with short-term objective C, which is call out one particular underserved population in long-term objective C. So, we could say with at least one project aimed at the needs of adults on the spectrum who do not meet an institutional level of care. I think that would address the concern rather neatly.

Ms. Blackwell: Ari, this is Ellen.

I think maybe we could work together to draft something, but it might be better placed in Chapter 6, not Chapter 5.

Mr. Ne'eman: Well, I actually think, and I misspoke, I think it could be applied for both children and adults. But, I mean, if it's in 5 or 6 I suppose is an open question.

Ms. Blackwell: Okay. All right. Well, what if we work --

Mr. Ne'eman: The reason I raised

it here is because we had the mention of 1959. So, it seemed to --

Ms. Blackwell: What if we work together to try to review the goals and then maybe draft something? Then we could say that that's tied to the new changes in the Affordable Care Act. Would that be okay?

Mr. Ne'eman: Yes, sure.

Ms. Blackwell: Is the Subcommittee okay with that?

Dr. Insel: What do other people think? I see heads nodding in the room. Anyone on the phone who has concerns, speak now.

Dr. Hann: Ellen, this is Della.

I just want to make sure I'm following it. So, what you and Ari are discussing is modifying the current long-term objective C?

Ms. Blackwell: I think, Della, I would actually want to go back and look at 5 and 6 and see where this perhaps fits.

Dr. Hann: Okay.

Ms. Blackwell: But I understand, Ari. You know, I don't disagree with Ari that this could cross the child, youth, and adult group. So, I just want to go back and look at both.

Dr. Insel: Right. But just as a point of reference, if we are thinking about children as well here, which it sounds like we are, it probably belongs here, not in Chapter 6.

Ms. Blackwell: Okay. Sure.

Dr. Insel: And one other thing that I think would be helpful for those of us who aren't deep into this is to use references like the 1959 item. It really helps us to anchor to whatever the legislation is.

Ms. Blackwell: Yes.

Dr. Insel: Because, often, those other terms just don't mean very much.

Ms. Blackwell: No.

Dr. Insel: And that provides the

readers with something to go back to. That is a great idea.

Ms. Blackwell: Yes, I didn't get too deep in the weeds with the specifics of Section 1959 of the Social Security Act, but we can do that as well.

Dr. Insel: Yes, I just mention it, Ellen, just because there's so much in these acts that it is difficult for us to be able to find the signal with all of the background. So, it is helpful, as Ari has mentioned, to sort of reference that.

With respect to that, there were two other pieces. I just wanted to check with you and the Subcommittee about this.

The Affordable Care Act includes the Cures Acceleration Network and PCORI, both of which have big research implications. Now the Cures Acceleration Network, actually, both of them are maybe more appropriate for Chapter 4, but is there any reason to do them here? Or should we just leave that in Chapter 4? I think we have already put a tag in that chapter about the Affordable Care Act and its implications for interventions. Do we want to leave it the way it is? So, we don't need to refer to it here.

And the second question I had was on mental health parity. I wasn't exactly sure what it -- I mean I think it is important to reference it since, even though it is a 2008 piece of legislation, it really did not get implemented. It doesn't kick in or it didn't kick in until January of 2010. So, it actually was within this past year.

In the way that this is described, I am just thinking about the language that we use. I wonder if there's -- I am not sure that the two articles you referenced are that helpful. It seems to me that what may be more useful to refer to is the continuing need for research to inform the way in which this is implemented, particularly research on autism, but in other areas as well.

I think about this because I was in a meeting yesterday with a group that is responsible for implementing much of the parity law. And they were still complaining that there are big areas of research that need to be filled in here. There are still some gaps in understanding how to do this.

So, I'm not sure that the bullet you have here fully captures that. And if you wouldn't mind, I would like to just take a swing at providing a little bit different language to suggest how this is relevant to research.

Ms. Blackwell: Sure. That would actually be really helpful, Tom. I was cautious about this because, frankly, CMS is fully engaged in the process of understanding the implications for the Medicare and Medicaid program. And as you mentioned, most of the law was effective January 1st. There are some other pieces that are open at different times.

So, I was very well aware of the

changes that we think that perhaps MHPAEA may bring, but I was not thinking specifically about the need for services research related to the changes that may come about because of MHPAEA. So, I do agree that that is a very important piece. And if you could kind of take a stab at that, maybe we could work together to make it fit.

Dr. Insel: Will do. So, we will follow up and provide something. Again, I don't think that necessarily dictates an objective, but I think it is in terms of trying to identify for people who read this what has happened in the past year. This is still an ongoing and really important issue that should be somewhere in this report.

The last thing for me was the final two bullets in this what's new in this research area; what have we learned this past year, so the first part of this.

I think we can consolidate this a little bit better. I'm not sure that we need to mention every article in the way that we have done here, but simply to note that there are these emerging issues. And certainly the dental issue was not one that was in the focus prior to 2010, at least in the strategic plan. So, I appreciate having that brought forward.

And, then, the issues around family support as well, I think if you are okay with this, I would like to simply do some wordsmithing around this to consolidate these two items and clarify where the specific research opportunities might be.

Ms. Blackwell: That would be great.

Dr. Insel: And finally, we heard a lot in public comment about elopement at the various meetings. That would be a service issue.

I guess there was a comment from the Safety Subcommittee. Alison or Lyn, do you want to speak to this? Because that would be another addition to think about in here.

Ms. Singer: I'll do it.

The Safety Subcommittee had its first meeting earlier this week. And that was as a result of the Safety Subcommittee having been commissioned by the full IACC at the last IACC meeting.

We specifically focused on the issues of wandering and elopement as our first topic. One of the things we did was to draft for consideration by this Committee some additional objectives that spoke directly to research that could help us to tackle the issue of wandering.

So, one of them focuses -- and you have them in your packet. The one that is specific for Question 5, "Where can I turn for services?", is to develop and test the effectiveness of at least two prevention programs.

The three key areas that the Safety Committee is targeting is, first, data collection because we certainly need to have more data on the magnitude of the problem.

And the second one really focuses on prevention. So, this is the one that we are talking about in Question 5, which is to develop and test the effectiveness of at least two prevention programs, such as first responder training, parent training, and training of individuals with ASD, to reduce the occurrence of wandering-related safety incidents by 50 percent.

There are some good piloted projects for first responder training, parent training, and individual training, but none of them really have any evidence behind them. They are all anecdotally-based. So, that was the purpose of this objective.

Ms. Blackwell: Alison, this is Ellen.

I think it would be good if maybe we could sort of integrate part of this into maybe one of these introductory paragraphs in terms of under "What is new?" and "What have we learned this past year?"

And then, maybe if I could wordsmith this suggested goal a little bit? Because I think one of the missing groups is providers.

Then I would have no objection to adding it to Chapter 5.

Ms. Singer: I can provide you with an introductory paragraph to include --

Ms. Blackwell: That would be great.

Ms. Singer: -- in your section "What is new?" The only concern I have is what we know is not necessarily research-based. It is anecdotally-based because we don't have data. So, I think if we just spell that out, we could still put it in that section, although it is not necessarily data gleaned from research.

Dr. Insel: So, let me just jump in here. This is Tom.

There is a bullet in the

introduction of Chapter 6, which we haven't gotten to yet, which might be relevant. It is from this Swedish study that was published this year.

And this is part of this long-term follow-up of a large population from 1962 looking at mortality. This is the Chris Gillberg data.

I think it probably could go in here in terms of the concerns about service needs and elopement and wandering. The paper is kind of extraordinary, though. There are only 120 kids with autism that were followed through this period. They have a 5.6-fold higher mortality rate than the rest of the population. So, that is a pretty profound number. It's, I think, the best data we have. Maybe Geri would know more.

So, you could put that in here as the bullet point --

Ms. Singer: Okay.

Dr. Insel: -- that would serve as

your anchor. Then I think, also, talk about what we have heard in meetings, you know, the sort of concerns. There are recent numbers that were shared with us in meetings as well. They were somewhat anecdotal, but, still, I mean very powerful.

So, I think that could all go in here, and then that would tie to this new objective.

Certainly, if you ask what has emerged in the past year for the Committee, this is one of the most profound new topics. I think this would be the place to put it rather than under adults.

Ms. Blackwell: I think that's excellent, Tom.

Ms. Singer: Right. We don't -- I'm sorry, did you want to say something? We don't have a proposal for Chapter 6. You know, I think the members of the Subcommittee were clear that we wanted to make sure that this was not interfering with any issues regarding self-determination, but that this was an issue about a subpopulation of children who are prone to wandering whose parents were deeply concerned about their safety. So, we tried to make it clear in all of our materials that this was focused on children.

We do have two additional, we actually have three additional objectives, two for Chapter 7 that focus on data collection.

Dr. Insel: We'll get to those later.

Ms. Singer: We'll get to them later? Okay.

Dr. Insel: Yes.

Ms. Blackwell: This is Ellen.

I would just interject and say that I think it actually fits better in Chapter 5 because this is an issue that crosses all ages of people with autism. So, I think it is a great idea to move the Swedish study over here and kind of hang our hat on that.

Yes, absolutely. I think, Alison, we can work together to come up with some language that will make this just fit perfectly.

Mr. Ne'eman: This is Ari.

I would like to just sort of actually express my appreciation for the consideration of the self-determination issues and rights protection in this context. I am looking forward to joining future meetings of the Safety Subcommittee, but I guess my hope is that we can sort of use this as an opportunity to show the broader community that we can collaborate on these kinds of issues.

I was wondering, actually, in that spirit, if we can add just some brief mention in the objective being proposed for Question 5, which I said I do support, acknowledging something to the effect of, you know, while acknowledging or while protecting the rights of individuals with ASD to self-determination and freedom of mobility, or potentially the rights of adults on the autism spectrum, if we want to call out that population specifically. So, I am very comfortable with the language you put forward, but I think with that addition it would be even better.

Dr. Insel: I'm sorry, Ari. I don't see where that would go. So, could you just walk us through that again? Which part of the Chapter 5 objectives?

Mr. Ne'eman: Well, I'm referring to the proposed new objective under safety, that the Safety Subcommittee put forward.

Dr. Insel: Okay. Got it. So, this is the one that is a separate piece.

Ms. Singer: But I'm still not certain where it would go in this new objective from the Safety Committee.

Mr. Ne'eman: I could see two areas. Let's see. Well, actually, the main area I think would just be at the very end, to just place it, "To reduce the occurrence of wandering-related safety incidents in people with ASD by 50 percent by 2014, without adversely affecting the rights of adults on the autism spectrum to self-determination or freedom of mobility."

Dr. Insel: Comments about that from anyone? Alison is frantically writing. Okay, Geri?

Dr. Dawson: So, just two quick comments. One, when you were talking about prevention, so this is kind of a wordsmith thing. But you could consider prevention of wandering or you could consider prevention of the consequences, negative consequences, of wandering. So, if you are focusing on the first responders, it would be more the latter, and if you are talking about children and parents, it might be the former. So, just to maybe add that in as a nuance.

The other thing is just bringing up the issue of mortality, although I don't want to like open up a whole new area of potential objectives. I think we should keep in mind that, when we think about a risk related to the higher level of mortality with autism, it does bring up broader issues around prevention than just wandering. Wandering is a significant part, but, actually, in the Gillberg paper I think the most common cause of death was sudden, unexplained death due to epilepsy. And they mention in there about how, if there were better awareness and understanding of epilepsy, that these probably could be prevented in some cases.

When we talk about mortality, there is a range of issues that could be considered under the area of prevention and trying to reduce mortality. Another one is heart-related disease, which is what is actually turning out to be most prevalent in Marsha Seltzer's longitudinal work, which we don't know whether that is an inherent part of autism, which probably it isn't, but we don't know, or whether this is secondary to a lack of exercise, or even the side effects of certain psychoactive medication.

So, these all kind of fall under this area of mortality and thinking about risk.

Ms. Blackwell: Geri, this is Ellen.

I really like your idea. I kind of want to play with this a little bit because I think there is a way to phrase it a little bit more positively. Maybe the objectives should be more focused on how to increase community health and safety, and then cite wandering. Because I am well aware of the issues related to concurrent epilepsy.

So, if we could, Alison, maybe you and I can work together a little bit to try to enlarge this a little bit. I think that is really important, and it also fits in with the mortality study a little bit better.

Ms. Redwood: This is Lyn.

I concur and would be willing to

help with that, too.

Ms. Blackwell: Thank you, Lyn. That's great.

Ms. Redwood: It would be an important addition.

Ms. Blackwell: That's great.

I just need to think about it a little bit more, but these are great ideas.

Dr. Dawson: So, we may want to keep this in mind if we get to talking about -- is it Question 3? I can't remember which question. Four. Thank you. Where we have struggled with whether to add an objective around kind of health promotion because this starts to interact somewhat with that. So, there may be a way of folding that into this rather than having a separate -- but that is another discussion, but just we will keep it in mind.

Dr. Boyle: Yes, Geri, this is Coleen. That is exactly what I was thinking as well.

Dr. Insel: Ari?

Mr. Ne'eman: So, first, I just want to mention I hope that restraint and seclusion and, also, just other areas in which there is violence against people with disabilities is included in this broader discussion around mortality. And obviously, we have a plenty of a hook on the restraint and seclusion side with the recent hearings and the bill that passed the House, and with other issues around violence.

I might also consider including mention of the fact that disability is newly included this past year in the federal hate crime laws. So, that is another area that is potentially useful.

Ms. Blackwell: Ari, this is Ellen.

I think if we sort of refocused this on community health and safety, that seclusion and restraint could also be an example that we cite.

Mr. Ne'eman: Certainly. Certainly.

Have we covered -- because I have another potential objective under 5, but I don't want to move on to it if we are not done with this conversation.

Dr. Insel: Well, let's see if there are any other comments before we get to anything else under 5 because we are really now looking specifically at the objectives.

One comment or one question I had, Ellen, was whether the focus on dental services, which, again, is an emerging area, whether that really needs to be a completely separate objective or whether that is something to roll into the issues that we have dealt with before around co-morbid issues.

I mean, in some sense, while this may have been more overlooked, it is not that different than the concerns we have had about GI and various other health issues related to autism.

Does it require a separate calling out as an independent objective or would it be best to wrap it into what we have talked about elsewhere in terms of overall healthcare and a more holistic approach?

Ms. Blackwell: I guess I was sort of driven by the fact that there were all these new objectives popping up, and I was trying to fit it into something that was already there.

But I will tell you that this is a very large issue. Dental services are optional in Medicaid. Many people with autism are served by the Medicaid program. It can be quite difficult, even for children served in Medicaid and CHIP, to access dental services, even if they are entitled to them.

So, it is certainly a much larger problem for adults, but certainly, as the economy has contracted, this has been one service that has been almost universally -- it has universally for the most part disappeared from Medicaid. So, it is extremely important. And as I am sure our Chief Dentist here, Conan Davis, would attest, there have been hearings in the Congress about dental services.

Does this Subcommittee want to single it out as a special objective? And if so, would we put it in Chapter 4, intervention?

Dr. Insel: Or maybe the other satellite question that goes with this is, what is the specific research question here that you would want science to focus on?

Ms. Blackwell: I think it's Nos. 1 and 2 above the word "references". "Support at least one study on the cost/benefit and support at least one study focusing on the provision of" --

Mr. Ne'eman: I don't know if cost/benefit is the best approach. Maybe the better approach is to talk about effective, promising practices or program models.

Ms. Blackwell: Well, I actually

would support cost/benefit, Ari, because the states, I mean some people believe that it is cheaper to remove the service from the plan. And there is some evidence that costs, in fact, increase when dental services are removed from the plan because people still need them, and they access them through more costly mechanisms, emergency rooms, and other places.

So, I do think that if we could show through research that it is more cost-effective to provide dental services than not to provide them, that would be important research.

Dr. Johnson: This is Jennifer.

I don't know if looking at the DD community would be helpful in this regard because this is a prevalent issue in the DD community, and we have a number of our programs that are working on dental service issues in terms of model demonstration, but, also, in terms of training. So, I don't know if there is something that we can look at there to help better refine how this might be incorporated into the plan.

Dr. Insel: Again, this is Tom.

I stand corrected. Because, as I read this more carefully, what you are suggesting here is that this is really incorporated into the current objectives. Essentially, this isn't a new objective, but it is one that you wanted to have wrapped into long-term A and B from the 2010 plan. Is that right?

Ms. Blackwell: Yes. Because if you go back and look at those objectives, they are very open-ended. So, I thought this would be a way for us to say, okay, here are some services and supports that could be identified as specific targets for study.

Dr. Insel: Right. So, I mean, just to get very concrete about this, if long-term objective A originally said, "Test four methods to improve dissemination, implementation," et cetera, what you are arguing here is that one of those four should include a focus on dental care?

Ms. Blackwell: Yes.

Dr. Insel: Okay.

Ms. Blackwell: And then, Jennifer, as I look at No. 2, I think maybe you and I could work together to focus this a little bit more on what exactly it is that we want specific to ASD and how that fits in with what you guys are doing. Does that sound sensible?

Dr. Johnson: Yes, and I would actually suggest adding to objective C mention of dental services in terms of dental providers.

Ms. Blackwell: In terms of training?

Dr. Johnson: Training. I'm sorry. Yes, training.

Ms. Blackwell: Yes, excellent.

Dr. Johnson: Yes.

Ms. Blackwell: Yes, that is a great idea.

Mr. Ne'eman: Should we say mental and dental? Because I don't think it is limited to the dental community.

Dr. Johnson: I would agree that medical would be good to include.

Dr. Insel: But, then, at that point, it seems to me you are back to one of the earlier chapters which talks about the need for comprehensive medical care. I thought that this point of this, and maybe I misunderstood, Ellen, but I thought the point was that you saw this as a new or it is a gap that was newly-identified this year. So, you wanted to specifically call out the need for a focus on dental services?

Mr. Ne'eman: I mean that is a fair point. I guess I can see Ellen's point there in the sense that, not so much that we didn't know that autistic adults and other adults with developmental disabilities needed dental services before, but in line with state budget cutbacks, this is perhaps a more pressing concern. So, I could see that.

Ms. Blackwell: Well, and also, in terms of the research that was published in 2010.

Dr. Insel: Okay. And the last thing before we get to Ari's addition, the first two objectives are basically just kind of highlighting objectives that are already there saying don't forget about this.

Do we actually need this or are these things that would fall below the bar that was set about adding new objectives?

Ms. Blackwell: I'm sorry, Tom. This is Ellen.

Could you explain that again? Maybe I just didn't --

Dr. Insel: So, I mean, what you are basically doing in the first two objectives is specifying that short-term objective A and new objective C that are in the current plan are really important --

Ms. Blackwell: Yes.

Dr. Insel: -- and we want to make sure that they really get done. And I think that is great, but I don't know that we actually need to say that because we don't want to imply that other ones in this plan are any less important or a lower priority.

So, my only question was, since we have tried to set a pretty high bar for making revisions to the plan, and that the update really only represents new, emerging science or new, emerging opportunities, are these really, do they go over that bar? Or is this a place where we could contract a little bit? I'm really just asking, is this essential or not?

Ms. Blackwell: These were just, basically, as you have said, observations. But with the second one, what I was trying to specify here is that mental health, you know, when you look at new objective, let's see, C, which talks about coordination between state and local agencies, I think with a focus on mental health that has been brought to us through MHPAEA and also other avenues, that what I was trying to suggest here is that one of these projects actually looks at coordination in the mental health community specifically. Because this objective mentions two models of practice and policy-level coordination, but doesn't specify what agencies or what services.

Dr. Insel: A good point. Okay.

Ms. Blackwell: So, maybe I didn't stress that enough in this second paragraph, but that's what I was trying to say, that we need to say that one of those two models should be aimed at mental health.

Mr. Ne'eman: So, then, we could probably, I mean we already call out one in particular, with at least one project aimed at the needs of transitioning adult use by 2015. We could add to that by saying "and at least one project aimed at coordinating among states and local mental health agencies." We might want to increase the number of projects, though, if we are specifically naming two.

Dr. Insel: Well, I withdraw my question. I think you have explained why you see this as an important issue.

Anything else? Do you want to go ahead and talk, suggest an additional objective here?

Mr. Ne'eman: Well, there were two things. And the first, actually, was brought to mind when you brought up some of the other aspects of the Affordable Care Act. So, one of the other things the Affordable Care Act did with regards to comparative effectiveness research was create the Patient-Centered Research Outcomes Institute. One of the ideas behind that, and this obviously did not apply to NIH, but it was specifically called out in regards to this new, independent entity to do comparative effectiveness research, was to ensure that when cost-effectiveness research was being done, it was done in the appropriate way, which was to assess, for example, like what Ellen was saying. How, if we don't fund a service or a type of care in one context, we may pay for it or have increased cost in another context.

The Patient-Centered Research Outcomes Institute included specific protections to ensure that what cost-effectiveness research did not mean would be something akin to the disability-adjusted life-year system used by the World Health Organization, in which people with different disabilities had their quality of life assessed, and depending on what disability you had, your life could be considered to be worth more or less, and adding years of your life could be considered more or less, depending on your level of disability.

So, I think it would be valuable to include similar language to avoid that here; namely, that when we talk about cost-effectiveness research, we are not endorsing, and we are not intending to support, anything that would incorporate a quality-adjusted life-year system, simply because that language was included by the Congress in regards to the Patient-Centered Research Outcomes Institute.

And then, the other area in which I wanted to raise a concern was we heard I think some very significant comments around peer support with regards to the services workshop. I could see it as very valuable to add an objective focusing around peer support, either to Question 5 or to Question 6.

I think this is something that is certainly relevant in the adult context. So, I would have no objection putting it there, but I thought I would bring it up now.

Ms. Blackwell: Ari, this is Ellen.

I think we should hold off on that until we get to Chapter 6, if you don't mind.

Mr. Ne'eman: It could just as easily belong in Chapter 5.

Ms. Singer: Yes, I don't think peer support is limited to adults. I think we have seen good research over the last year about peer-mediated and peer-supported interventions in middle schools and in high schools, but I think we need to expand on it.

And those are great studies because, you know, you take those to your school district and you say, look, here's the data.

Dr. Insel: Aren't those interventions? Wouldn't that be considered an intervention like in Chapter 4?

Mr. Ne'eman: Not necessarily. I mean I think this is something that really falls more easily into the context of service provision models. For example, SAMHSA -- I wish Larke was here -- funds a considerable amount of peer supports for adults that I don't think could reasonably be called interventions, but are more oriented around improving quality of life and other such things within a service provision or a human service context.

I would be glad to work with Alison to take some of those studies and some of the SAMHSA information and put together a draft objective incorporating both children and adult issues on this.

Ms. Blackwell: This is Ellen. Here's my concern: our specific task here was to look at research that had been published since we last reviewed the plan. And I looked very carefully for research papers that were published in 2009 and 2010, and there were a few things that I did put in the update to Chapter 6. But I am not sure that we can just pick up a topic that we like and put it in here. That would be inconsistent with what we have done in other places.

So, we are working on a peer support recommendation that will come to the full Committee as the result of our Services Subcommittee meeting on November 8th. So, not to say that peer support here isn't important, but I just want to make sure that we keep it in context.

So, the research that I found related to -- there really was little research that was published in the journals, if any, on peer support in 2010.

Ms. Singer: Geri, maybe you can correct me, I think Connie Kasari published in 2010 on peer support.

Dr. Dawson: Well, first of all, I was going to say I think we have to sort of talk about the difference between interventions that utilize peers, which, by the way, have been around since the LEAP model of Phil Strain in the 1980s, right? So, there's just a ton of research on that, and it continues.

And, yes, Connie's paper was published this year that used peer-mediated intervention strategies. So, there's that, and some of it has been published this year.

And then, there may be something different that you are talking about. I don't know; I think it is a little bit semantics of whether you call it intervention or support in this case, because you still have to do something that improves the lives of people with autism, whether it is to increase their ability to engage and interact and communicate with others or improve their quality of life, which you would hope would be related.

Mr. Ne'eman: Well, and I think Erik Carter may have come out with some new research recently as well, but I would have to check the date on that.

The reason I think this belongs more in services than interventions is I think, particularly when we get to -- and we want a broad definition of peer support, so we can be looking at any of the different, very different kinds of models we heard about in the workshop. But, particularly when we get to peer support provided by people with disabilities to people with similar disabilities, that is something that has really almost always been in the human services context. So, I wouldn't want to place this in a context that would make it difficult for research of that nature to be included.

Ms. Singer: I think another area of delineation is interventions for which you would apply for insurance coverage versus those for which you would not. And peer interventions I would say would fall outside the realm of insurance coverage.

Dr. Dawson: I think that a good applied behavior analysis program at some point is going to involve peers in the process. That would be not a best practices program.

Ms. Singer: But would you be able to apply for coverage of those hours that are not being delivered by --

Dr. Dawson: Yes, you should. Yes, absolutely. And we've actually done it at the Center and had it paid for. So, I don't know.

Ms. Singer: That's promising. That's great.

Dr. Insel: So, there a couple of items on the table I just want to get clarity on.

One question is, does this belong in the plan at all? I am seeing mostly enthusiasm for the idea that there is both a research area that can be talked about, that is, there's something new in 2010 that we could point to.

Connie's paper I think actually hasn't gotten much attention in this draft, and it probably should. It is a very interesting insight into the effect size here.

So, heads are nodding that this should be in, both because there's something new in 2010 and that there could be in the new objective.

The second question is, if it is going to be in this document, does it live here or does it live somewhere else? And what I am hearing from this conversation, if I hear it right, is that this really is a services issue more than seen as a kind of efficacy interventions kind of issue, which would be more a Chapter 4 question. Is that fair to say?

Ms. Blackwell: Geri, maybe you and I could work together to try to fit, you and Ari and I could work together to try to fit it into Chapter 5.

Dr. Dawson: Sure, but I guess I would disagree. It definitely is an intervention.

Ms. Blackwell: Yes, I know.

Dr. Dawson: And it's talked about. I think it is used in both contexts is I think what we are struggling with.

Ms. Blackwell: I know.

Dr. Dawson: So, I think you could see it in a service context. I think you could see it definitely in an intervention context.

But Connie's work is in intervention, and Phil's is in intervention, and that has randomized control trials with outcomes and specific objectives for outcomes.

Mr. Ne'eman: Well, we may be referring to different things.

Dr. Dawson: Yes, that's what I'm saying.

Mr. Ne'eman: I mean that's the challenge.

Dr. Dawson: I think we are talking about two different things here.

Mr. Ne'eman: So, conceivably, what we may need, not to overdo it on the objectives or anything, but we may need an objective or incorporating it into an existing objective in Chapter 4. And we may need one, because I think it doesn't fit into any of the Chapter 5 objectives that exist, a new objective looking at the human services implications in Chapter 5.

Dr. Insel: So, yes, I hear that there are complications here, but I think we can draft language. I should be careful how I use the word "we", but someone could draft language that addresses this and says, while this could be understood as an intervention and we could refer to it in Chapter 4, that there is need here to take a broader look.

So, do we have a mini-group that will work on this and bring us back some language that we can use, then take to the full Committee? Ari, Alison, and Ellen. And I should also add that --

Ms. Blackwell: I think maybe Geri can help us as well.

Dr. Dawson: I'm happy to do that or I can tweak the Chapter 4 part of it, or make sure that it is incorporated into that part, and then you guys can do the service. That might be --

Dr. Insel: Yes.

Ms. Blackwell: That would be perfect, Geri.

Dr. Insel: So, we will defer to this to an email conversation and hope that you will be able to bring something together.

I should also mention Lee Grossman has joined us. So, we will start volunteering him for all kinds of things as well as we go forward.

Mr. Ne'eman: I thought we volunteered people when they didn't come.

(Laughter.)

Dr. Insel: Okay. Anything else for Chapter 5?

Ms. Singer: Yes. Just before we leave Chapter 5, the Swedish study that you mentioned that I was to cite in the paragraph introducing the safety issue, I don't see it on the references for Chapter 5. So, can someone send that to me?

Dr. Insel: It's not. It's in Chapter 6. It is the one that --

Ms. Singer: It's in Chapter 6? Okay.

Dr. Insel: Yes. It is Gillberg, et al., March 2010 in JAD.

Ms. Singer: Okay, the bottom of page 3?

Dr. Insel: The bottom of page 3, Chapter 6.

Ms. Singer: Okay.

Dr. Insel: And we can also send you the reference, if you need it.

Ms. Singer: Now JAD I can get. So, that's good.

Dr. Insel: Okay. Della?

Dr. Hann: Okay. So, here's what I'm hearing for changes for 5. Okay? This is Della. The first is that Ari and Ellen will look at Chapter 5 with regard to the legislative issues that we talked about for

Section 1959, the Social Security Act, et cetera; that that needs to be included in the first part of Chapter 5 update, which is "What's new?"

Then, we got into a discussion with regard to including the mental health parity information. And, Tom, you agreed to help with the wording of that section, as well as the next two sections in the chapter under "What's new in research?", in terms of tightening them up.

Dr. Insel: Right. I'll consolidate.

Dr. Hann: Let's see, we talked about, then, the issue with regard to wandering and elopement, and the need to include that issue in the "What is new?" And that is where we were just talking about the Gillberg article. And Alison has agreed to work on that, right?

As well as, then, that will lead to an objective, development of a new objective. And Alison, Ellen, and Lyn have agreed to work on the wording of the objective.

Mr. Ne'eman: I have a quick question. We had mentioned a particular objective we were going to incorporate the 1959 stuff into. And I can't, for the life of me, remember which one it was. Could you jog my memory?

Dr. Hann: Here it is. I think it is long-term C potentially.

Mr. Ne'eman: Do you think it belongs there most appropriately? I could see it in a few of the --

Dr. Hann: Wherever you want it.

Mr. Ne'eman: Well, we'll talk about it all.

Dr. Insel: We will get to the objectives in a moment.

Mr. Ne'eman: Okay.

Dr. Hann: All right. Then, so we are moving now into the objectives. Long-term

A, B --

Dr. Insel: Actually, before we get there --

Dr. Hann: Yes.

Dr. Insel: -- we didn't talk about the gap areas that have emerged since last year. Do we have references? Because there's some comments made about access and about, well, mostly access, even the statement that access to psychiatric expertise in state mental health systems is poor. That may be true, but do we have a way of supporting that with a reference? Or can we provide numbers?

Ms. Blackwell: Yes. No, actually, there is a reference, Tom, and I apologize. I drummed this up pretty quickly. It's --

Dr. Insel: So, if Ellen or anybody else can add it --

Ms. Blackwell: Yes.

Dr. Insel: I think especially when we make these sort of judgment comments, we need to be able to support them with data.

Ms. Blackwell: Yes, that's actually straight out of the article. So, I will cite the article there.

Dr. Insel: Terrific. Okay.

Ms. Blackwell: Okay?

Mr. Grossman: Is that relating strictly to seclusion or restraint issues?

Ms. Blackwell: No.

Mr. Grossman: Okay.

Ms. Blackwell: Lee, it was actually all of these.

Mr. Grossman: Okay.

Dr. Hann: Okay?

Dr. Insel: Moving on, okay.

Dr. Hann: Okay. So, Ellen will work, then, on the citations for the gap areas.

Dr. Insel: Right.

Dr. Hann: Okay. Objectives. Looking at the writeup for the update, what I heard was that there was agreement that the first area that is listed under "What's new?" research opportunities and objectives, that that won't be dropped because it is just sort of emphasizing the need for an existing objective.

The second one, though, on the focus on behavioral health needs to be wrapped into short-term C.

Dr. Insel: Right, which it is.

Dr. Hann: And Ellen and Ari, you all, I believe, were going to sort of look to see if that language needed to be modified.

Mr. Ne'eman: I think Jennifer was also expressing an interest. I had mentioned, and I think Jennifer looked like she agreed, that if we are calling out two examples on an objective that is only talking about two studies, we might want to increase the total number of studies.

Dr. Hann: Okay. Long-term A, B, and C all need to be modified to include issues of dental health. And, Ellen, I believe you were going to work on that.

The issues around peer support, which were just discussed fairly recently in the conversation, some of that work needs to be cited in the "What's new?" section. Then, an objective needs to be created with regard to peer support. And I have Ellen, Ari, and Alison, and that Geri will, then, look at some of the language in Chapter 4 with regard to potential for peer support.

Dr. Dawson: I think the "What's new?" pertained to Connie Kasari's study. So, does that belong in the services section? That doesn't seem -- yes, it's an intervention.

Mr. Ne'eman: Well, I think that was an area we were sort of arguing a little bit about. I think that might be something we may want to try and resolve over email, because I still do think -- and I think Alison had expressed a similar opinion, but correct me if I'm misstating that, Alison -- but I still do think there is a role for this in both Chapters 4 and 5.

Ms. Blackwell: One thing -- this is Ellen -- we might want to do is, Geri, I am kind of leaning, actually, towards saying that, because the research is specific to an intervention, putting it in 4, but maybe making a nod to the services arena.

Dr. Dawson: Sure.

Ms. Blackwell: Because in this exercise, again, we are looking at what came out last year. But when we work on the plan next year, well, if we work on the plan next year, there would be further support based on the work of the Services Subcommittee and possibly research and other venues to support peer support.

Mr. Ne'eman: See, I don't know that I entirely -- I mean I guess my big concern there is we really are talking about very different types of things when we're talking about this in the context of intervention and when we are talking about this in the context of human services. I think it is something we should probably discuss in more detail.

Dr. Insel: So, just to wrap this up, what I am hearing, then, is that there will be something in Chapter 4. I think everybody agrees there's a need to do that there. And that, for this chapter, there needs to be a specific callout to peer support among some of these objectives that we have here already.

What I think that means is that, for the update, we are going to need to add a bullet in here that says that, in short-term or long-term, you take your pick about which ones would be best, to consider how to include this particular, whether you want to call it intervention or service, as an area of study. Is that okay? And that way, it does end up in both places. It is not an area that we have really referred to much, as far as I can recall.

Lee?

Mr. Grossman: Yes, I can help with some of the wording on this for Chapter 5 because, I mean, from our perspective, we see peer support as being an ongoing service that is provided in preschool, regular school, and on the adult level.

I guess my struggle here is trying to see how it fits into the research realm versus then applying that service aspect to it. I am having a hard time wrapping my mind around that.

So, I see it as a long-term service, an ongoing service.

Dr. Insel: Yes. So, I think what we are hearing, though, is that both things are true; that there is a need for the science of this to look at its evidence base and to look at how to optimize it, which is really a Chapter 4 question.

But, as you read these Chapter 5

objectives, "Implement and evaluate two models of policy and practice-level coordination," I mean you can see how peer support could end up in one of these more, we'll call them, services research agendas as well.

So, can we look to the group? And I'm not sure who has now volunteered to do this, but someone to wrap this into the Chapter 5 objectives and identify where this could be inserted as an additional bullet, or not a bullet, but as an additional example of the kinds of programs that would be implemented?

Mr. Ne'eman: See, I could see this as more easily inserted as an example in Chapter 4 than in Chapter 5. But I think we are in agreement that we should be looking at options for both.

Dr. Insel: Jennifer?

Dr. Johnson: I was just going to say, not to further complicate things, but I would be happy to volunteer to help start this out, because I think it does get into interventions as well as services and informal support. So, it just crosses a continuum.

Dr. Insel: So, that's great. Why don't we draft a little bit of language that reflects this conversation, saying that this is neither fish nor fowl? And make sure that we don't lose it out of this.

I am just wanting to, because there is interest from the Subcommittee in this, I think we need to tell the full Committee that in some part of these objectives for Chapter 5 we want to include this as an example of a practice that we would like to see implemented.

Is there anything else from Chapter 5?

Dr. Solomon: Well, just sort of in closing, to get a little bit out of the weeds, I mean I think it really raises a larger issue of services, the relationship between services and interventions. It is something we maybe want to consider next year, as we have a symposium on services, and perhaps sort of edge more into the area of interventions as well at that time.

Dr. Daniels: I have one other -- this is Susan Daniels -- item in my notes. I don't know if you still wanted to do this.

You mentioned adding medical and dental providers to objective long-term C?

Ms. Blackwell: Yes, Susan, this is Ellen. I have that.

Dr. Daniels: Okay.

Dr. Insel: I think we are going to just call out the dental.

Dr. Daniels: The dental?

Dr. Insel: Yes.

Della, was there anything else? No other items? Okay.

Thanks. This was actually very helpful. I think it was an interesting conversation. Della?

Dr. Hann: Just one more procedural piece. In terms of the work that we are doing here today, and it's great everybody is working together and it's wonderful, but this will probably all need to come together over the next week. Because the final output from you all needs to go to the full Committee meeting on the 14th of December. So, next week is really your opportunity to do all of this and get it pretty much wrapped up. Because by the end of Friday next week, we really need to have them so that we can prepare them for full Committee.

Ms. Singer: Given that we are all here now, is it possible to take some of the time today and break into small groups and bang out the language?

Dr. Insel: Yes, I was going to say, you know, for those pieces that I need to rewrite in the introduction, I will do that over the lunch hour and bring it back to you.

Ms. Singer: I would like to get it done.

Dr. Insel: Yes, I think we can quickly roll this over and get language that is a lot closer.

Ms. Blackwell: And this is Ellen.

I can also try to take all these comments when we take a break and see if I can start us over again with another -- you know what I mean? -- with a clean slate to look at that incorporates a lot of our discussion today.

Dr. Insel: Great. So, let's do that. Let's run through Chapter 6, and then we can take some time and do some homework right here, and bring it back to class.

Ms. Blackwell: Okay.

Dr. Insel: So, we can get this thing finished.

Chapter 6. Ellen, I think you might be on again.

Ms. Blackwell: I know. I'm so

sorry. Everyone is going to get really bored and tired of listening to me talk.

Yes, Chapter 6, as I said, it is sort of the same chain of chapters, 4, 5, and 6, that are all related to each other. So, there wasn't much that came up in Chapter 6, but there were some things. And I listed those at the top of this draft. You know, parenting behaviors, people with high-functioning autism.

I also wanted to take a look at some of the DD literature, Jennifer, because, again, I think this is an umbrella issue. A lot of these things touch people with developmental disabilities as an entire group.

So, this is what I saw. And obviously, we need to remove mortality because we are going to be moving that to Chapter 5.

You know, I listed a couple of studies here that talked about family stress and mothering, in particular.

There were quite a few studies

that looked at behavior in adults and youth, which I thought was great. I think in the past -- I mean, anything is better than nothing.

There were several articles that looked at higher-functioning of people with autism. Again, that is something that I am not sure that we have seen in the past. So, I thought that was notable.

There was one article on recreational services that I included here because this is an area that we have talked about in the Services Subcommittee, and it is really an under-discussed area. So, I definitely wanted to include it.

There was a study about medication use in children and adults. And I struggled in putting this here, Tom, because I wasn't sure if it belonged maybe in 3. So, we might want to talk about that.

But, also, because this study focused on medication in youth and adults, I wavered and ended up putting it in this draft for 6.

And then, there was another study that talked about under-diagnosis in the adult population, which is another topic that we have talked about in the Committee quite a bit.

And then, I also added a published scan that CMS sponsored, in part, with our NIH partners that was published this year that looked at the strength of the evidence behind a variety of services for people with autism and, in fact, pointed out some places where there is absolutely no research.

So, what gap areas have emerged? Again, Tom, I am sure, will go back to discussing it. I mean there are basically comments, but there still isn't a lot of research.

I put in a paragraph here that talked about the fact that the landscape of the fiscal situation in the states is definitely having an impact on children, youth, and adults with autism, many of whom are served through CMS programs, including Medicare.

I couldn't find any papers on older adults with autism. You know, I think that is kind of an ongoing issue that we probably need to talk about. There just isn't anything. If there's very little on adults, there's nothing on older adults with autism.

And one of the areas, this last one on page 2, Jennifer, I would kind of like to hear your thoughts, but when we engaged in our environmental scan at CMS, I specifically asked for information about the efficacy of day habilitation, day services known by different names.

These are programs where a lot of people with autism who have completed the school venue end up going in many cases because they can't get jobs or because training and support for jobs isn't available to them. They are very similar to what you might see in the older adult world, you know, day programs for adults.

But there is no research on the efficacy of day programs. So, I identified that as an area where it would be very helpful to have scientific information to support or refute the efficacy of this service because Medicaid in states and I believe, also, families are paying for these sorts of services. We just don't know anything. So, that is why you see this bullet at the bottom of page 2.

And then, on page 3, as Ari has consistently pointed out, there's very little, although there was some research published last year on high-functioning adults on the spectrum, I wanted to acknowledge that more is needed, and that there should, in fact, be greater participation in research efforts by people, by this group; that their contribution was important and necessary. So, that's kind of where I went with that.

And then, in terms of the new research objective, I identified day programs for people with autism as a priority that should be targeted specifically through objective B, and that we should modify the research opportunities section to acknowledge the importance of including input from people with autism throughout the research process.

So, that is what I did with Chapter 6.

Dr. Insel: Thank you, Ellen. Let's open this up for discussion.

Dr. Solomon: Hi, Ellen. This is Marjorie. And I want to thank you. You did an amazing job.

I just wanted to add, and I have already drafted some language for you on the second bullet point. I am remembering about the several recent studies that looked at behaviors in adults with autism. I am remembering a really interesting symposium I went to last year at NFAR, done by Marsha Seltzer's group out of Waisman, that called out the fact that individuals transitioning from high school with high-functioning autism were actually at greater risk than some of their lower-function peers because they stopped receiving services. And I wanted to make sure that we noted that. So, I have written a piece for you to put at the end of that bullet.

Ms. Blackwell: Great. That's wonderful. Thank you so much, Marjorie.

Dr. Insel: Geri?

Dr. Dawson: So, on the issue of elderly persons with autism spectrum disorder and aging, there was a conference held in 2010 that was cosponsored by the NIH and a private donor, held at the University of North Carolina, where people in the area of Alzheimer's and aging and services for individuals as they age were brought in, as well as people with expertise in autism. And we spent two days talking about what's known and what the field needs. So, that probably should be noted as an activity that occurred that was significant.

I am aware, mainly because I just sent it to Joe Piven, who has a strong interest in this area, that just within the last month or so there has been one paper published on challenges and diagnosis in the elderly with autism.

Dr. Insel: Geri, was there a report from the North Carolina meeting?

Dr. Dawson: What there has been, it is actually a paper that has been submitted for publication that summarizes the whole conference. So, that is available, I'm sure.

Dr. Insel: But there's nothing on the web, for instance, or nothing we can access?

Dr. Dawson: You know, I think there might be. I honestly cannot tell you whether there is or not.

Dr. Insel: Okay. Maybe we could check and see if there is a way to cite that.

Other comments? Jennifer?

Dr. Johnson: Just to add to the conversation about the aging issue and research that is out there, there is more and more research, and research that is being conducted in the developmental disabilities population on aging issues. We might be able to glean something from that literature.

But the other associated issue with aging is not only understanding how people with developmental disabilities are aging and how aging-related disabilities or disorders or diseases, how they come out on that, but, also, the issue of aging caregivers is a related issue. A lot of times, people aren't prepared for end-of-life issues and how to transition an adult with disabilities into independent living because they have been living with their parents. So, I think the aging issue is a bit twofold in that regard.

Ms. Blackwell: Jennifer, this is Ellen.

That actually came out a little bit in the 2010 study that I cited in the first dash, that these were mothers of youth and adults, and some of the adults were older. I mean the parents were older adults, and the adults were my age. I wasn't able to call it out, but maybe this is a place to sort of tie that in as well.

And the other comment that I wanted to add here is that the Department has been working very hard on an initiative that looks at individuals with multiple chronic conditions. I have been involved in that and have written some language over the past couple of days that acknowledges, again, changes made through the Affordable Care Act to look specifically at people who are dually-eligible for Medicare and Medicaid.

When I worked with my colleague, Melanie Bella, yesterday to develop this language, it occurred to me that there might also be a way to acknowledge that initiative or that change to the law that could also have an impact. Because my guess, although I don't know this, is that there are, indeed, some people with autism who are also older adults who are going to benefit from the changes that have been made to our organizational structure and the work that will be done through it.

Does that sound like something that would be appropriate?

Dr. Johnson: Yes, I think so. I mean I think part of the issue, too, though, is this whole notion of transitioning adults with autism or other developmental disabilities as their parents age. And we don't, I think, have a lot of evidence. We have a lot of anecdotal, not research, evidence on what's going on out there.

We hear a lot of stories of families in crisis or people, adults with developmental disabilities showing up for services because their parents are no longer available to provide that support or issues within families in terms of transitioning caregiving activities to siblings, if they are available to provide that kind of support.

So, I think it is a real emerging area and turning into a crisis area for many families.

Ms. Blackwell: But we can integrate all of this into this bullet, which it sounds like the group agrees that this is a really important area.

Dr. Insel: Just as a logic question, what we are really talking about here is not adults with autism, but the services provided by people who take care of them. So, isn't this really a Chapter 5 bullet?

Mr. Ne'eman: Well, not exclusively. I mean, as I understood the conversation, we were talking about both.

Dr. Johnson: Yes.

Mr. Ne'eman: I mean we are talking about the issues associated with aging, and we are also talking about aging caregivers, and those are distinct issues that I think both need to be addressed.

Dr. Insel: So, the bullet that we have now is about aging caregivers. The bullet that has been introduced is about the transition in the way that both Jennifer and Marjorie have described it. So, that is a different topic.

Ms. Blackwell: Well, I really didn't put, under new research opportunities and objectives, I didn't add a bullet here specifically targeting research on either the situational issues related to older adults and the issues related to older adult caregiving.

So, is that something that we think that we need to add this year? Because, I mean, there is no research. That is part of the problem.

Mr. Ne'eman: Well, but there is

an expansion in the aging infrastructure that we can tie it to in regards to the policy component. This past year was the Year of Community Living. There has been a substantial investment in aging and disability resource centers.

Ms. Blackwell: Well, I did mention some of those things, Ari. So, I mean, I think there is a way, if the Subcommittee wants to do this, to call out a new research opportunity and objective.

Dr. Insel: Geri?

Dr. Dawson: So, yes, I would strongly encourage us to include an objective on better, actually, understanding elderly and adults and the aging process, and autism as part of this.

Certainly, it was very clear from this workshop that we know almost nothing about the aging process in autism and what kinds of services are going to be unique to autism as compared to other individuals with disabilities.

And by the way, the issues that you brought up, Jennifer, about caregivers and transitioning, those were actually a very strong focus of the conference. We had people from the Sibling Network, which is a very active kind of advocacy group around families that support people with autism as they are growing older. They were there, and they talked a lot about it in relationship to other disabilities.

Ms. Blackwell: What if I draft an objective here, and then, after lunch we can kick it around? Does that sound reasonable?

Dr. Insel: Yes. So, I am going to be a little disruptive here. My sense was that the message that you wanted to convey about what's new in this research area is mostly a message of need.

What you have here, you have several bullets, actually, more than we have in most other chapters, that would suggest that there has been a lot of work in this area. And yet, the conversation is mostly that there has been almost no work.

Many of the bullets that you have here, frankly, are just really weak in terms of the quality of the science and the impact it would have. These are not game-changers, which is kind of what we were looking for in terms of new research areas.

So, what I was wondering is whether we should draft something that sounds more like what Geri just described, what came out of the single conference and anything that we have heard in the past year that calls forth a new research agenda.

I really thought that the second, third, and fourth bullets here probably, there are no game-changers in this. There's nothing here that would merit, to me, a real change in direction. So, I would have probably deleted those.

The fifth one, which is the

Swedish study, we have already moved.

The psychotropics, arguably, could go into, as well as the very last one, could go into Chapter 4 because they deal with interventions.

And the last one on the first page, the one on prevalence, is really a Chapter 1 consideration, which is, how do we identify, how do we detect this, and pointing out that 50 percent may be missed in adults. That is a really big issue for Chapter 1.

So, I am not sure any of these actually, other than maybe the first one and possibly the last one, really fit into what we are asking, which is, what have we learned in the last year that would cause us to change direction, except the observation from what we have just heard that there's been so little work in this area. And it is an area that needs new attention, especially these issues around transition.

And some of what is coming out, as

Marjorie mentioned, is actually counterintuitive. It is not what you might expect from just thinking about this without having the data in front of you.

Ms. Blackwell: Tom, this is Ellen.

When I looked at this charge, the first one, I mean, to me, I just read it as what came out over the past year.

Dr. Insel: Yes, I know, but we have tried to set a very high bar for that throughout this update. There are hundreds and hundreds of papers across all these different seven questions, I think, actually, maybe now thousands of papers. Unless something really merits, I think, an action item, I would hate to see us just clutter this report with every paper that we can find out of PubMed. It just doesn't do justice to this being a strategic plan document.

Ms. Blackwell: Okay. It was harder for this chapter, frankly, because there was so little.

Dr. Insel: Yes. So, that may be the only bullet to make.

Ms. Blackwell: Yes.

Dr. Insel: Just to say, you know, in reviewing the literature, this is just an unacceptable gap. And that's fair to say, if that is the main observation. But that is not what one would take from reading what we have here.

Ms. Blackwell: Okay. All right. Well, we can shift this around, and maybe that paragraph that starts the second page, "The continuing dearth of...," et cetera, should be the beginning of "What is new?"

Dr. Insel: Oh, that's a great idea, yes.

Ms. Blackwell: You know?

Dr. Insel: Yes.

Ms. Blackwell: That's what I'm hearing. Then, I also am hearing, you know, Marjorie wants to add something to that second bullet about behaviors. So, maybe we could just sort of consolidate that second one, Marjorie?

Dr. Solomon: Sure, that would be fine.

Ms. Blackwell: And then, we are going to move -- I just want to make sure I understand -- we are going to move Iceland to Chapter 1, psychotropic to Chapter 4, which I agree with.

Let's talk for a second about recreational activities. I threw that in, Jennifer, because it is a really important area, and I struggled with whether or not the Subcommittee would want to make a recommendation about research on recreation for people with autism. But, Jennifer, you might be better prepared to say whether or not this is the time or there is more research coming down the pike. This particular article was specific to recreation and people with autism.

Dr. Johnson: Well, again, I think the research that I am going to be familiar with in this area is going to be developmental disability research as it relates to recreational activities.

And again, not a lot is known there, though. There is not a significant amount of research going on there. Obviously, there's anecdotal evidence of the benefits of recreational activities and the importance of. And I think this gets a little bit into the notion of peer support because some recreational activities can engage peers in more social settings.

So, you know, I don't know if I have much more that I can really offer to that discussion.

Ms. Blackwell: Would it be worth calling out the lack of data again on recreational activities, as we did with day habilitation, as another area of focus?

Dr. Insel: Geri?

Dr. Dawson: I am wondering whether this could be added on page 35 of the current strategic plan under Question 6. There's the "Develop at least two individualized community-based interventions to improve quality of life or health outcomes." We could say, "including programs that focus on recreation as a method of improving quality of life and improving health outcomes".

Dr. Insel: Does it need to be? I guess that's the question. I am trying to get a sense of the Subcommittee's sense of priority. Is this something that really rides to the top?

Ari?

Mr. Ne'eman: I just want us to take a step back here and ask sort of a process question that we should really consider here.

When we are talking about adding new things to the plan, my understanding was, or modifying existing things, that we are not incorporating only new journal articles over the course of the last year in our considerations, but, also, new developments in the context of the service provision system.

I have some thoughts on the discussions that we have been having, but I just want to seek clarification on that. Because it seems to me that right now we may be leaning a little bit heavily on the journal article side, but not considering some fairly significant new policy developments.

Dr. Insel: Well, the way I understand what the update is doing, and this is kind of the format that we followed, is, essentially, we're asking what's happened in the past year that would -- and I'll use the word very literally -- mandate an update, mandate something new in the plan. That is, taking something that is in the plan and removing it or adding something that is not there because it is a new opportunity.

That could be a new discovery, and that is most of what we have been looking at. I mean, how has the science moved to open up a new opportunity? So, stem cells has been a new opportunity that wasn't there when the 2009 plan was drafted. There have been a number of things like that.

Policy could come in, but I think it is only going to come in when it dictates new research, new science. And sometimes it does because it is a policy that is in need of evidence, and that is the case, for instance, with mental health parity and with some of the other areas we talked about. Sometimes it's more about providing services and not so much doing a new set of research studies.

But this is -- I just want to underline -- this is a research strategic plan. It is not about the need for services, the need for providing them, except to the extent that it may test out whether current services have an evidence base or not.

Mr. Ne'eman: And I think we all understand that. I would like to just highlight a few policy developments that have immediate implications that I think require research with some of the things we are discussing.

For one thing, in the last year, and this was included in the health reform bill, but there have also been a number of steps taken out of Health and Human Services as part of the Year of Community Living. There has been a substantial investment in the aging and disability resource center infrastructure.

And one of the challenges that has come out of that is these programs are charged with serving both elderly individuals and people with disabilities and elderly individuals with disabilities. And in regards to the latter two groups, they don't have a great deal of knowledge or expertise as to how to do so. So, that would seem to call out specifically this discussion around the need for more research in regards to the needs of older adults on the autism spectrum, given that we are seeing the investment in the service provision infrastructure that really only understands traditional aging needs. And there has to be the research that is going to inform a needed expansion of expertise.

But I have others.

Dr. Insel: Yes. So, that may be a terrific addition here because, just as we have done for some of the other chapters, when there have been major policy shifts in a given year that call out a need for new science, I think it is important to reflect that.

I would be interested in how the rest of the Subcommittee feels about this. Because it seems to me that you could easily draft a bullet here that tries to summarize what has happened in 2010 in the world of policy that is important for a research strategic plan. So, a lot of heads are nodding.

Ari, I think you just volunteered yourself.

Mr. Ne'eman: I will do it over the lunch.

(Laughter.)

Or try.

Ms. Blackwell: Well, this is Ellen.

If we are going to talk about the grant expansions between AOA and SAMHSA, and the OARCs, then, as I said, I drafted some language for something else yesterday. Then, I think we have to also start looking at maybe the health home provision, which applies to people with multiple chronic conditions.

So, I would also like to also think about how we could, if we are going to do that, there are some other pieces that might fit into that.

Mr. Ne'eman: Well, I mean, I think we could certainly discuss other areas in which there have been needed policy developments. I couldn't speak to the health home stuff as well as you could, Ellen, but I would love to hear more about that.

The one additional area I did want to highlight in regards to where there has been a new policy development is, only a few months ago, the President signed an Executive Order essentially instructing renewed effort across government to hire people with disabilities of all types, including people with developmental disabilities and the autism spectrum.

This has resulted in a substantial amount of systems change, including revision of the definition of targeted disabilities to include a broader scope of individuals than it has in the past. This is going to require, I think, a more developed knowledge of employment support. So, I would highlight that as another area in which we have seen a policy development that is going to require potentially calling out employment as a further example for additional investment under these objectives.

Dr. Insel: So, do you think you could do this as a bullet? I mean I guess this is beginning to sound expansive, but, clearly, the Subcommittee is interested in seeing this. But I think if it drowns out the rest of the update, it might not provide the balance we want.

Mr. Ne'eman: No, no.

Dr. Insel: So, if there's a way to do it concisely, that would be great.

Mr. Ne'eman: So, you are essentially requesting two bullets outlining the new policy developments over the course of the last year, and then, whatever implications that should have on objectives?

Dr. Insel: No. So, let me clarify. I think, for this chapter what we're asking is, any new policy developments in the past year that will be important for research on adults on the spectrum. So, the ones that you mentioned early on I think are particularly relevant, and employment is particularly relevant.

Now I am not sure that we need a full explication, but certainly a citation of what are the important new developments in the policy arena that should raise questions for the research community that they can help to contribute to.

Anything else here in this introductory section?

Della, I have no idea how you are going to summarize this, but I will leave it to you to figure that out.

(Laughter.)

Dr. Hann: Thank you.

Dr. Insel: Shall we move on to the gap areas? Comments or questions about what we have here?

Mr. Grossman: This is Lee.

As was mentioned in the research,

and I think that it is picked up pretty well in the first bullet, in the gap area about the dearth research, we just need to expand it probably in the third bullet to include the caregiver and the transition from the end-of-life issues that the caregivers are facing and putting the adults, transitioning them into a new situation.

Dr. Insel: Ellen, is that feasible?

Ms. Blackwell: Sure.

Dr. Insel: I had a couple of other thoughts about this first bullet. They are sort of wordsmithing, but one of them is more substantive.

One is I would include -- you say, "the continuing dearth of research and the portfolio analysis". I would also include public comment as another source because we also heard in public comment through the year about the urgent need for additional research specific to this group.

Ms. Blackwell: Yes, that is good.

Dr. Insel: And this is just syntax, but the way it is written, it might imply that we are talking about research on youth and adults with autism and without autism. What you really mean, I think, is research on youth and adults with ASD, and then, in parentheses, I would say, "(diagnosed and not diagnosed)".

Ms. Blackwell: Okay, very good.

Dr. Insel: So it's clear that this is adults with autism, but not all of them necessarily carry a diagnosis.

Ms. Blackwell: Thank you. Thank you.

Dr. Insel: And then, the last thing, in the last sentence, "In 2010, advocacy groups, including ASA and Autism Speaks, devoted resources to initiatives." I wasn't clear whether those were research initiatives or just initiatives on service provision.

Ms. Blackwell: I believe they were general initiatives. I mean I can strike this sentence, if you like.

Dr. Insel: The first bullet, the last --

Mr. Ne'eman: Yes, I don't know that that belongs there.

Ms. Redwood: It also doesn't seem to be a gap.

Ms. Blackwell: Okay, I'm happy to strike that.

Dr. Insel: So, maybe we could just take out that sentence.

Ms. Blackwell: Geri had added some language in 4, and I'm not sure what happened to it. So, I thought this might be a good place to put it. But, no, let's take it out.

Dr. Insel: Okay.

Ms. Blackwell: I was trying to be, you know -- so that's fine. We'll just strike it.

Dr. Insel: I'm all for striking here, to the extent that --

Ms. Blackwell: Brevity. Brevity, right.

Dr. Insel: -- I want this to be short and sweet, when we can.

The next bullet, I think the word "mediated" should be "mitigated" in that first line.

Ms. Blackwell: Okay. Thank you.

Dr. Insel: And a question I had is whether we actually have the evidence for the claims that are in here, if there's any place we can --

Ms. Blackwell: Yes. There are lots of places.

Dr. Insel: Okay.

Ms. Blackwell: The State Budget Directors, the State Medicaid Directors, all sorts of research entities are publishing papers practically on a weekly basis at this point. So, I would be happy to cite some support for that.

Is that what you want, Tom?

Dr. Insel: Yes. I just think, again, whenever we make a statement about a particular need, or this is rather sweeping, I just think it is important to back it up with a citation that comes from a very reputable place.

Ms. Blackwell: Yes.

Dr. Insel: Other comments about this, what gaps have emerged?

Dr. Johnson: This is Jennifer with just a couple of questions and comments.

I guess I have a general question about what we know, again, from the developmental disabilities community in terms of transitioning from pediatric care to adult healthcare systems. And basically, most adults with developmental disabilities continue in pediatric care because of a lack of available medical professionals who have the expertise to provide medical care to adults with developmental disabilities.

I don't know the extent to which it is happening in the community of adults with autism spectrum disorders, but I just raise that. I am not sure if it is in here or if it needs to be in here. Maybe related to the aging issue? So, I just wanted to ask that of the group.

And then, in the last bullet on page 2, in terms of the scientific research regarding services for adults with developmental disabilities, again, we have some research that is going on in the DD community related to this. I don't know if we want to look at that at all to maybe glean some information for this chapter. But there are needs that are reflected in this paragraph that are also in the DD community. So, I think they are fairly consistent.

Dr. Insel: Jennifer, do you want to add language to that effect? Or how do you want to change this?

Dr. Johnson: In terms of the last bullet?

Dr. Insel: Yes.

Dr. Johnson: I guess, you know, in looking at it, I would want to take a closer look at our literature to know if there would be anything to add. When I look at it now, I don't think so. But, again, I would probably want to take a bit of a closer look at that, if I could.

Dr. Insel: So, is the point that there is a literature on this for developmental disabilities, but it is not specific to ASD? Is that the point to make?

Dr. Johnson: I think that is one thing I would want to look at, is whether there is anything specific to ASD or to other disabilities.

Again, we tend to talk about and conduct research on intellectual and developmental disability populations. So, whether our research is identifying specific disabilities within that, I would like to take another look at that to know.

Dr. Insel: So, I am not sure I know what you are recommending. Do you want to take a pass at it? Because we are trying to wrap this thing up pretty quickly. So, do you want to do this? I mean after the meeting I assume you will take a look, and then if you think this needs to be altered in some way, you will let us know?

Dr. Johnson: I think that is my recommendation, yes.

Dr. Insel: Okay.

Dr. Johnson: Thank you.

Dr. Insel: Geri?

Dr. Dawson: So, I was just going to recommend maybe some wordsmithing on the very last point under the gaps where it says, "Although some research is focused on high-functioning adults, more is needed, including greater participation in research by this group."

And I only bring this up because, of course, we have gotten the other comment, right, that, in fact, most of the research is on high-functioning adults because they are the ones that can participate in the scanners, et cetera, and that we haven't actually studied lower-functioning individuals.

So, maybe what we need to say is that, as we research this area, it is important to consider and include the full spectrum of individuals with adults.

Ms. Blackwell: Yes, Geri --

Dr. Dawson: Because I think we will get some --

Ms. Blackwell: Excellent. I just changed the word in here. That's a great suggestion.

Dr. Insel: Ari?

Mr. Ne'eman: I hate to break the spirit of agreement we seem to have so far, but I just want to bring up an issue around wording.

I think we all acknowledge that there is a tremendous amount of diversity in regards to the autism spectrum, a tremendous amount of different strengths, challenges, functional needs, and legitimately impairments.

I guess I have never seen the value of the terms "high- or low-functioning", only simply because (a) I think they rank people in an inappropriate way, but (b) because I don't think they're actually very descriptive. They don't tell us if somebody has an intellectual disability, the degree to which somebody can or can't talk, their self-care, independent living skills.

I would actually move that we really avoid using those terms throughout the plan and replace with something that would be more useful.

Ms. Blackwell: Ari, this is Ellen.

I agree with you. The only

obstacle I found was that those were the terms that were being used in the research literatures. So, if this Committee could come up with some other language, maybe we could lead the way here.

Dr. Insel: So, it is a great opportunity to lead instead of follow, isn't it?

Mr. Ne'eman: Absolutely.

Dr. Insel: So, what about if we change this bullet altogether and just say something around greater participation is needed by people on the spectrum?

Ms. Blackwell: Yes. When I rewrote this, I said, "Although some research is focused on high-functioning adults on the ASD spectrum, more is needed, including greater participation in research by the full spectrum of people with ASD."

But maybe that's still --

Dr. Insel: No, no, no. You got it. Stop right there. Everybody's head is nodding. Okay.

Ms. Blackwell: Sorry.

Dr. Insel: So, we're on to the objectives now. And you have got two bullets for the objectives?

Ms. Blackwell: Yes, two bullets for the objectives. One, I think I said this already, was to prioritize day programs. And, Jennifer, you may have some thoughts on that.

And the second was I didn't discuss high- or low-functioning people with ASD in the second recommendation, but that some acknowledgment be made in the research opportunities section of Chapter 6.

Dr. Insel: So, if I can make an editorial comment, Ellen, I think the wording that you put in here about prioritizing these as targets is really great. And it is something that I hope we will do more often, as we do this update.

I think what the scientific community is looking to often is not just more and more objectives, but how to prioritize what it is that this Committee is recommending. So, by calling out this particular area and saying, if you're going to be doing CER, think about this one, it's very, very helpful in helping to guide the research plan.

Ms. Blackwell: That was actually my intent, also, in focusing on dental in 5, to try to get the flashlight to shine on exactly what you said, Tom.

Dr. Insel: Terrific.

Ms. Blackwell: What exactly should they be looking at?

Dr. Insel: That's great.

Comments here?

Ms. Redwood: I have a comment about the second bullet point for research opportunities. Would it be possible to also add the importance of including direct input from people with ASD along with their families? Because some individuals with ASD may not be able to provide direct input, but their families can be a proxy for their voice. So, I think it is very important to include families as well in this.

Mr. Ne'eman: See, I think that it is important to include families. But what I would say is families represent a distinct and wholly different stakeholder group. So, I would seek some acknowledgment of that in this.

I guess the other thing I would say is we had had discussions, and I haven't been able to find it elsewhere after the update, so it may have been taken out. But we had had earlier discussions around the use of participatory action research models in order to specifically ensure that we were funding research that included the community of adults on the autism spectrum to a greater degree. And if we can potentially consider incorporating some mention of that here, I think that would be valuable.

Dr. Johnson: I agree. I was going to make that recommendation, not only that we add families as another stakeholder group, and potentially even practitioners, depending on how this is conceptualized, but, also, the idea of conducting participatory action research.

And I did, just on a side note, provide Coleen with some information about that for Chapter 7. It is just a notion of broadly thinking about the research that is supported or promoted through this plan, that it is also engage or utilize that method.

Mr. Ne'eman: So, are we talking about creating an objective around participatory action research? And if so, would it best belong in Chapter 6 or Chapter 7?

Dr. Johnson: Again, I would conceptualize it as something that could be applied in any of the chapters, depending on how the research would be conducted. So, I think, generally, it is a method that should be considered.

But depending on the chapter, it may be more relevant to utilize it as a method, Chapter 6 being an example. It might be more relevant to use it as a method in this chapter because it is addressing adult issues.

Dr. Insel: So, let me summarize what I am hearing. So, Lyn's suggestion is that we add the phrase, where it says, "from people with ASD", you would add, "and their families"? It wouldn't be "or their families"? So, the idea is that both would be important stakeholders throughout the scientific research program?

Ms. Blackwell: Tom?

Mr. Ne'eman: But I would say --

Ms. Blackwell: Tom, this is Ellen.

I was listening to what Lyn said, and I have been thinking about it. Because it is more than families. It could be a guardian or people who are significant in that person's life. So, it is a big corral. I would hate to just say families because it is more than that. It could be a guardian. In fact, in terms of adults, it may not be a family member. It could be a sibling.

So, I was sort of toying with the idea --

Dr. Insel: Well, a sibling would still be part of the family. But the word "caretaker", would that be helpful?

Ms. Blackwell: No, not caretaker. How about significant others? Jennifer, do you have a suggestion here?

Dr. Johnson: Well, generally, we define families very broadly, so that we can capture the multiple types of people who might interact and be a part of the lives of people with developmental disabilities. So, we, again, conceptualize the concept very broadly to deal with that issue.

Ms. Blackwell: Okay. Okay. All

right. I'm okay with that then.

Mr. Ne'eman: I want to acknowledge some language we have in Chapter 1, Question 1, that might be useful in regards to ethical, legal, and social implications. We deal with this issue of individuals and family members by including the language, "ensure the inclusion of both individuals on the autism spectrum and family members as distinct stakeholder groups". I think that that communicates that we are not talking about family members, you know, participating in the same way that individuals would be participating. But if one is studying the attitudes of family members, then, clearly, it is necessary to include them as well.

Dr. Insel: So, I don't hear an argument against what Lyn is recommending. It sounds like people still want to have families added into this, but to not say "or" but "and"? Is that --

Mr. Ne'eman: Well, "and", but

also acknowledging that these are distinct and different stakeholder groups. So, I think that is an important acknowledgment.

Ms. Singer: But I think you have pointed out that we have acknowledged that already elsewhere in the plan.

Mr. Ne'eman: Well, it's specifically in regards --

Ms. Singer: So, I like Lyn's language. I thought it was --

Mr. Ne'eman: -- to ethical, legal, and social implications.

Ms. Blackwell: Yes, I'm also okay with people with ASD and their families.

Mr. Ne'eman: I guess I would see it as valuable to just add the language "as distinct and different stakeholder groups" after "individuals on the autism spectrum and their families".

Dr. Insel: I'm not sure you're getting a lot of support from your colleagues here.

Mr. Ne'eman: May I ask what the harm to that is? Clearly, we do it elsewhere.

Ms. Singer: So, then, why do we need to do it again, I guess is my --

Mr. Ne'eman: Because it would seem that we are doing it as part of a specific objective in Question 1, and now we are using similar language in Question 5. And in the interest of consistency; also, I think this language is really only modifying that objective in Question 1. If we're raising the issue again, we should be modifying the objective in Question 5, too.

Dr. Insel: Geri?

Dr. Dawson: So, I don't think there is a need for necessarily raising it again, but there perhaps is a difference between a family member who is talking about their own needs in relationship to this person with autism versus someone who is trying to represent a person with autism because they can't speak about their own needs or communicate about their own needs on the level that is required for the decision that is being made.

Dr. Insel: So, I'm not sure what you're recommending then. Do you want to include the additional language or not?

Dr. Dawson: No, I don't think it's necessary to provide it again. I think it is mentioned once, and I think that is all that is needed.

Mr. Ne'eman: I mean I think, if that is the case, my concern would be I would have concerns about bringing -- so, I think we want to bring up participatory action research, but I do not think it is legitimately participatory action research when you have family members speaking on behalf of individuals as opposed to on behalf of family members. Clearly, there is context in which family members do need to speak on behalf of individuals, but I worry about a dilution of the value of a very specific model of research, if we are introducing that element here.

Dr. Insel: Marjorie?

Ms. Blackwell: Ari, this is Ellen.

I understand your concern, but I am okay with the language here. And I think that maybe this discussion might be more appropriate in terms of discussing, especially for adults, the role of guardians in the lives of people with autism who have guardians. I think you are getting way too deep in the weeds here as far as this particular, you know, modification.

Mr. Ne'eman: Well, but not if we are talking about a specific research model that really depends on the definition of the core constituency. I mean I think this is very relevant.

Dr. Insel: Marjorie?

Dr. Solomon: I think we could handle it -- I'm not in favor of putting it in again. I think it is kind of inelegant and we would have to kind of go back and look at the whole document then.

But I think if we took a look at the introduction under "consumer-focused" as one of the core values, we might be able to, you and I, draft a little language over lunch that would make it more inclusive for the whole document.

Dr. Insel: Does that satisfy you, Ari?

Mr. Ne'eman: We're going to have to be doing a lot of work over lunch. I don't know that all of it is going to get done today.

Dr. Solomon: So, we can do it over the phone. It's okay. Or, you know --

Mr. Ne'eman: But, yes, I would be comfortable working with you around that. I'm not going to say I'm satisfied, but let me see the language that ends up coming out of this, and then we can discuss what modifications are necessary.

Dr. Insel: We need to talk about the objectives before we get to lunch. So, tell me where you are in terms of these two bullets.

Mr. Grossman: I wanted to ask Ellen a question about the first one. Ellen, would you have any objections in there about adding "and housing" in there to the day programs? Because I think that is certainly a priority as well, and the two go hand-in-hand?

Ms. Blackwell: Yes, I hear you.

Jennifer, I didn't do any particular looking for research on housing, but it has come up repeatedly as an issue in many realms of service provision. It is a big hole, just like day programs.

And in fact, I could actually probably tie it to our evidence-based services scan because I did ask the contractor again to look for something on housing, and there wasn't anything really particular to people with autism.

But, Jennifer, how do you feel about that?

Dr. Johnson: Well, I think the challenge is, when we start identifying specific areas to research, then how do you stop at one? Because I think we could continue to add to the possible areas for research, not that I don't see the value in identifying the housing or day services, but, again, the challenge is, where do you end, then? Because, then, we can just carry on and --

Mr. Grossman: To me, this objective is referring directly to CER. And employment is going to be a hard, I believe, looking at it from a research objective, it is going to be hard to really determine or to draw up a protocol that you can examine that is going to properly evaluate employment.

I think, for the most part, looking at that, you are going to say that most people, if they are employed, are going to benefit from it.

Dr. Insel: We've done that. So, we have a huge literature on supported employment.

Mr. Grossman: Well, right. Or you may or may not. But I think with housing and with the day programs, that you can really design various models that, looking at it from a CER perspective, should be able to provide us with some good data in terms of what is truly working out there.

Dr. Johnson: So, as an example of what else might be included, post-secondary education. I think you could do some comparative effectiveness research and cost analysis of looking at outcomes in terms of people who have access to post-secondary education opportunities.

Peer support might be another one that could be added here. How does that affect a person's life outcomes?

So, again, it is just, where do you end the list?

Dr. Insel: So, I need some help here because this bullet basically says, of all the things that we could do, what we want to prioritize is research on day programs. And as written, that is what we will be taking to the full Committee. And maybe we don't agree.

Mr. Ne'eman: Yes, I don't know that I would agree with that. I mean, for one thing, I don't know that there has been any new research or policy developments on day programs over the course of the last year. Clearly, it is a gap area, but if we are talking about areas in which there have been new developments, employment and housing and post-secondary education, when we include the new grant programs in the Higher Ed Act and some of the recent legal decisions, are probably all more immediate.

And then, we also have so many

questions that are coming up around prioritizing what in some contexts is a fairly restrictive service provision setting.

Dr. Johnson: Yes, I would be concerned with that, too, that we would be suggesting research on day programs. I would want to, I think, change the wording there.

Dr. Insel: Well, so we are going to need to take a closer look at this. Because, in the introductory section, in terms of gaps, we pulled that out as the key gap is that we don't have information on day programs. And there is a whole paragraph in here saying this is the thing we need to do. So, if this little Subcommittee doesn't think that is the thing to do, we have got to get clear about that before we bring this closure.

Mr. Ne'eman: Yes.

Dr. Johnson: I guess the question is not whether the research should be done. I think it is just how are we conceptualizing this in a way that promotes systems integration, promotes community living, inclusion, independence, those kinds of things?

And I think that is where we might be in some of this, and prioritizing, then, topic that contribute to those outcomes.

Ms. Blackwell: So, this is Ellen.

Are we trying to say here that there are -- I'm hearing several areas, employment, housing, day programs, but maybe this might be better described as several areas where there is no research or a little research?

Dr. Insel: Alison?

Ms. Singer: Well, I thought the point that Ellen was making earlier with regard to the day programs is that they are a practice in wide use right now, but that there is no research. And so, we were looking at it almost the way we were looking at some of the interventions that we talked about in Chapter 4, where we talk about interventions widely used where there is no evidence base. I think this is how we want to look at day programs, not necessarily -- I understand the point you are making. We don't want to recommend sort of research for improvement of day programs, but it would be interesting to see if there was any evidence of value of any day programs. And there's no research there at all, to my knowledge.

Mr. Ne'eman: So, we could make a very similar argument around post-secondary education, given the proliferation of programs around that, some that have been made, they have proliferated as a result of public policy decisions; others that are private pay programs that are pretty expensive for families.

We could probably also make a very similar argument -- or I'm not saying we shouldn't say day habilitation. Just, if we are, we should include these other things, too.

Mr. Grossman: Yes, I think the point here, the way that I framed here and my understanding of this first bullet, is that everything is put in the context of CER. And that is how I was framing it in my response of why I felt that the day programs could perhaps fit into that type of research modality, but there were others as well that were important.

If we took that CER out and went with what is evidence-based, yes, that opens up everything. So, I think that we would have to really have a better understanding of what type of service modality would best be, what I would think that we would get the biggest bang for our buck looking at it from a comparative effectiveness research methodology.

Dr. Insel: But, you know, what I think was so important, as I said at the beginning, was that Ellen put her foot in the water here and said this is the priority; this is the thing we need to do.

But this is a suggestion. If the

Subcommittee doesn't think they can identify one or two high-priority areas within CER, we need to let everyone know that. Or, if you think that this is the right one, that would be extremely helpful.

Geri?

Ms. Blackwell: Let me just say for one -- this is Ellen -- that one of the reasons I focused on this is because, very typically, when people are transitioned out of school, they are put into these day programs. That is the substitution for 21 years of schooling.

And there's enormous amounts of funding, both by families and the federal government, to pay for these programs that there's no research on.

You know, I mean we have lots of research on housing, and we have lots of research on employment, but we have nothing on day habilitation.

Dr. Insel: You make a good

argument.

I think Geri, then Marjorie, then Alison. Or, I'm sorry, then Ari.

Dr. Dawson: So, I was just going to make the point that I do think that, for all those other areas that we have discussed, including employment and housing and post-secondary education, that one can have comparative effectiveness research. So, that I don't think is necessarily an issue.

I am wondering in terms of the day programs whether the issue that would be a broader umbrella issue is that transition from the school-age or the school system into adulthood, and for the need to conduct comparative effectiveness research that looks at the effectiveness of different strategies for promoting best outcomes.

Because I think the day program is one aspect of that transition that we are saying, is this really the best way in which people should be served at this point?

Perhaps not.

But there are so many other issues that surround that transition into adulthood that I wonder whether that is what we are more concerned about.

Dr. Insel: To just paraphrase, Geri, what you want to see is language that is really focused on the outcome, not on the technique or not on the specific.

Marjorie?

Dr. Solomon: I'm looking back here at the new objectives we suggested last year, new objective C, which was a comparative effectiveness objective. And perhaps we could sort of roll some of the more specificity, so that the kinds of things we might be looking at, other than just services and supports, we could talk about including employment-related services, housing-related service, post-secondary education, and transition-related services and day care services, and roll that all in there, and also include the outcomes focus that Geri mentioned.

I do very much support including all those types of research. I just wouldn't want to focus on daycare as one.

Dr. Johnson: I like the suggestion to focus on transition and identify certain areas. I kind of agree that I don't know whether it's important, or to me it's not important to suggest investing in research on day programs when we are investing in research to look at more effective ways of providing supports and services to adults with autism spectrum disorders and other types of disabilities. And I question whether we suggest investing in research and looking at the effectiveness of day programs.

Mr. Ne'eman: And I would strongly agree. I think Geri and Marjorie read my mind because I was just thinking that this entire issue around day programs versus post-secondary Ed. versus employment, versus what have you, could all simply be encompassed with an investment in post-secondary outcomes and comparative effectiveness research or post-secondary service provision models and comparative effectiveness research, focusing on that.

I would also echo Jennifer's concerns about calling out day habilitations specifically, as it does not seem to me that that would be the service provision model we wish to be investing in in the future.

Dr. Hann: So, it sounds, based off of this recent discussion, it sounds like potentially a new objective that is focusing on the transition to adulthood.

Dr. Insel: No. I think what they are saying is the last sentence in that first bullet, where it says, "Day programs should be prioritized," we want to take that, what I'm hearing is the group wants to take that out, and they want to make this objective, which is basically just informing objective C --

Dr. Hann: Yes.

Dr. Insel: -- to prioritize research on the transition to successful adulthood, or something like that.

Dr. Hann: So, just take the existing C and modify the language to focus on the transition?

Mr. Ne'eman: The one thing I would add to that is, again, I think you're right, but when we are talking -- the language of C, apparently, is "to improve health outcomes and quality of life for adults on the ASD spectrum." I think quality of life encompasses a lot of what we're talking about here, but my concern is, since we are specifically calling out health outcomes, that may not -- I mean there's stuff relating to healthcare transition that's one very small part of a much broader scope of things we're prioritizing. Or quality-of-life outcomes, yes. Exactly.

Mr. Grossman: When I think of transition, a transition, although we are transitioning into post-secondary, it is a result of everything that has been happening since the child has been diagnosed. So, how broad do we want to make that?

And what we are trying to do is address quality-of-life issues. I think that would be consistent with what is said in the first part of the bullet, that any aspect of quality-of-life programs should be prioritized in objective C because we are not doing that now.

Ms. Blackwell: This is Ellen.

My thought was that, as you said earlier, Tom, maybe the point of this is to sort of flag for researchers what areas we are interested in. I was hearing that maybe the idea is to say what areas should be prioritized; for example, employment, housing, post-secondary education, transition. Maybe those are the priority areas that we could identify for researchers here.

Dr. Insel: Is there anything you

would leave out? I mean I think the problem we have here, and this is really kind of a major issue, I think, for the strategic plan, is the extent to which this Subcommittee wants to use the plan to put a stake in the ground or, as you said, to shine a light on a particular area.

What I am hearing is, the more we discuss this, everybody wants to include everything in here, almost everything they can think of. And then, just to leave it to the research community to set the priorities, that is one way to do this, but that is not usually what you think of with a strategic plan.

Geri?

Dr. Dawson: So, I would like to make an argument for having the callout focus on that transition to post-secondary activities and quality of life because I really think that, if one were testing a program, that you wouldn't want to say, okay, now I'm going to look at how I do this for health and that's going to be separate from how I look at it for employment.

I do think that one could start thinking about programs that are really going to be comprehensive, right, in terms of what strategies do we use to make sure that that transition is successful. And I wouldn't way necessarily to say I want to see one on this and another on this, because I think probably the most successful programs are looking at it in a more integrated way.

Dr. Insel: Alison?

Ms. Singer: Can I just ask maybe for a point of order? I don't have the portfolio analysis in front of me, but can we look at what studies were done against this objective? So, when we are talking about let the research community decide, can we see what those decisions were? Oh, she has it.

Mr. Ne'eman: And let me just speak to one other case, just simply talking about post-secondary models, broadly defined.

We may wish to compare between different means of post-secondary service provision. For example, I would be interested in seeing the difference in types of outcomes between different types of supported employment, but, also, between supported employment versus day habilitation or some of the new post-secondary programs for students with intellectual and developmental disabilities.

So, by not calling out one in particular, we may open up lines of research that we otherwise would not have had available to us.

Dr. Insel: Okay.

Ms. Singer: Well, what the data show are that, by not calling out anything in particular, we had no studies against this objective. So, we might be more successful if we called out one or two.

Mr. Ne'eman: But aren't we getting more specific than we have in the past by calling out post-secondary service provision in general?

Dr. Insel: So, I'm going to suggest somebody draft the language for this particular one to reflect this discussion. I think it is clear enough that nobody wants to, maybe with a couple of us as exceptions, to focus specifically in the way that we have on day programs. But there is a real interest in focusing on transition. So, if somebody could give us that language? Marjorie?

Dr. Solomon: I'll take that on, yes.

Dr. Insel: Okay. And we can do that very quickly in the next half-hour or so.

So, Della, we're ready now to take a look at where we are with Chapter 6.

Dr. Hann: Okay.

Mr. Ne'eman: Sorry. Wasn't there one objective underneath the first one in regards to that? The research opportunities section?

Dr. Insel: I think we did that.

You'll hear that in a moment, I think, as we go through the summary.

Mr. Ne'eman: Okay.

Dr. Insel: But you know what? You will probably have yet another opportunity to talk about it because, as we go through this, we want to make sure we've got the full discussion reflected in these comments.

So, Della, let's start from the top.

Dr. Hann: Okay. So, going back to the beginning to "What is new?", this section sounds like it has basically a complete overhaul from the discussion today.

And, Ellen, I believe you have agreed to sort of take it on in terms of doing the overhaul. Are you still there, Ellen?

(Laughter.)

We lost her. Anyway, I thought she did.

(Laughter.)

Dr. Insel: She left town.

(Laughter.)

Dr. Hann: That much of it, bullets 2, 3, and 4 are gone, although elements of 2 now are going to be consolidated with the first part.

The fifth one on the Swedish study is being moved to Chapter 5.

Information that is on the psychotropic medication in youth is being moved to Chapter 4.

The 2012 article with regard to Iceland is being moved to Chapter 1.

And then, I think the rest of it is staying. The environmental scan part was going to stay.

And then, there needed to be information about the elderly and the aging process. However, that actually sounded much more like a gap in the discussion as opposed to what we know.

Dr. Insel: So, Geri was going to add a paragraph based on the meeting in North

Carolina.

Dr. Hann: Okay.

Dr. Insel: Even though we don't yet have a report, just something that will reflect that. And by the time this comes out in January, it may be that we have that citation.

Mr. Ne'eman: And I was going to add mention of the new policy developments.

Dr. Hann: Right.

Dr. Insel: Right, a whole section on policy, which may be the lead bullet on this because that is how we have handled those in the previous chapters.

Mr. Ne'eman: And I was mentioning that incorporated aging.

Dr. Insel: Geri?

Dr. Dawson: And my quick question is, the study that says that study over time of psychotropic medication showed an increasingly high likelihood of staying medicated across a life course, I think that is a very important study. My question is, is that a game-changer in terms of what we want to include?

I do think there have been quite a few studies of this phenomenon, and it is an incredibly important one. I don't know if it course-changing in terms of the strategic plan, but maybe it is. Maybe it wasn't emphasized enough before.

I mean I'm happy to include it, but --

Ms. Blackwell: Yes, Geri, I would really support that. We have brought this up in our discussions when we revised the strategic plan last year.

If you look at the plan, I think we actually called it out as a specific goal or objective somewhere. I have to look at the plan for a second. But, yes, I think it is really important.

Dr. Insel: Okay, moving on.

Ms. Blackwell: Go ahead. Della,

were you done? I still have a question about how we are going to change that last draft on new objective C.

Dr. Insel: We haven't gotten there yet.

Ms. Blackwell: Okay. Thank you.

Dr. Insel: So, we're still doing the gaps.

Ms. Blackwell: Go ahead.

Dr. Hann: Right. So, we were going to move now to gaps. I heard some discussion that the first bullet under gap was to be moved to the front section, to the first section, and that we are going to drop the last sentence of that bullet.

The second bullet on state budget cuts has references to be added. The word "mediated" should be changed to "mitigated".

The third bullet needs to be expanded, particularly with regard to some of the issues we talked about in terms of the transition for elderly and end-of-life issues for caregivers.

Let's see. Then, we've got Jennifer is going to review the fourth bullet, which is kind of long, and see how that stacks up with regard to the DD literature.

The final bullet Ellen has rewritten, based off of the discussion already. So, she will provide that information.

And that's what I have for gaps.

Dr. Insel: Did we get that right or is there something missing?

Ms. Blackwell: This is Ellen.

We had a lot of discussion about that final bullet. So, I will try to draft something over our break, and then maybe we can -- could we revisit it?

Dr. Insel: Yes, I think we are going to revisit everything eventually, but we are getting closer.

Ms. Blackwell: Okay.

Dr. Insel: Jennifer?

Dr. Johnson: I just had one question about -- and actually, I think this goes, I'm sorry, back to the research, the last bullet on page 1 about the Iceland study as it relates to new objective C under Chapter 6, which talks about diagnosis. I don't know if that research is relevant to that objective. It just substantiates it, I guess. So, I just wonder if it needs to stay in Chapter 6 for that reason.

Ms. Blackwell: I thought we were moving it to Chapter 1, Jennifer?

Dr. Johnson: Yes, that's why I was just raising it as a question.

Ms. Blackwell: Oh, oh.

Dr. Johnson: Because we do have new short-term objective C.

Dr. Insel: Great point. Why don't we leave it where it is?

Ms. Blackwell: Okay.

Dr. Insel: So, we won't make that change because it links right in there.

Ms. Blackwell: Okay.

Dr. Insel: All right. Are we ready to, I was going to say, take a break for lunch? But, actually, this is a working lunch. So, I won't say "take a break", but why don't we plan -- it's now 12:20 --

Ms. Blackwell: Can I make a suggestion? Could we possibly expand lunch a little bit because it is a working lunch?

Dr. Insel: Well, you know what? I have just been told we haven't even gotten there yet. So, we'll finish the job and then we will figure out what we are going to do next.

So, what about research opportunities and objectives?

Dr. Hann: Okay. What I have, there was a great deal of discussion with regard to the first one, but I think it was left that Marjorie was going to take a look at that particular new objective C. I think it's long-term objective C on comparative effectiveness, to see if she can craft some language based off of the discussion.

Then, in terms of the opportunities that -- let's see, who was working on that one? There was a great deal of discussion about that with regard to -- this one I found a little bit confusing, I will be very honest, because there seemed to be a couple of different things intertwined.

There was mention of a particular methodology in terms of participatory action research, but, then, sort of like a break, and then there was also a discussion with regard to what's currently written here about direct input from people with ASD and their families throughout the research/scientific, through the process.

And it was not clear to me if the methodology that was discussed was necessarily linked to this particular element.

Mr. Ne'eman: I guess not to complicate things further, but I guess the one thing I would add was my impression of that discussion was that it was not about that particular line, but was about the somewhat similar line at the top of the page, which was still under the section of gap areas.

So, I guess we could talk about whether we want the discussion we had there to apply here as well, but --

Dr. Hann: So, then, there was also a discussion, Ari, that you and Marjorie would work on potential language to add to the introduction.

Mr. Ne'eman: All right. Well, then, related to this issue? Okay, Marjorie and I will work during lunch around that.

Dr. Insel: Okay. Anything else on this?

Ms. Redwood: Hey, Della, this is Lyn.

If you look in the introduction, there is already language in there that includes community-based participatory research. So, if you could look over that and see if it needs to be touched up more, but --

Dr. Insel: Where?

Dr. Solomon: Where is that, Lyn? Is that in the aspirational core values?

Ms. Redwood: It's the introduction.

Dr. Solomon: Which section of the introduction?

Ms. Redwood: Hold on. Let me go look it up real quick.

Dr. Solomon: Core values has a consumer focus.

Ms. Redwood: Cross-cutting themes, community engagement and ASD research.

Dr. Solomon: Okay, great. Thank you.

Ms. Redwood: Yes.

Dr. Dawson: Della, did you also -- and I might have missed it, and I apologize if I did, but the issue of phrasing the need for participation broadly across the spectrum, was that mentioned?

Dr. Hann: That, I believe was part of the rewrite to be in the gap area.

Dr. Dawson: Okay.

Mr. Ne'eman: All right, Lyn, I am looking at that section right now. I don't see participatory action research mentioned. Are you referring to the last paragraph on page 7 of the introduction?

Dr. Insel: Page 6. Oh, I'm sorry, Ari, it's in the actual document.

Mr. Ne'eman: Okay.

Dr. Insel: I can read it out, for those who don't have it in front of them. "Community engagement in ASD research: people with ASD, their families, their educators, their caregivers, and advocacy organizations have vital roles to play in shaping, participating in, and disseminating research. Their insights and perspectives are needed in order for interventions and services to be developed that will have maximal impact and have the strongest evidence and means for real-world uptake and utilization. Strategies are needed to gain and use the firsthand experience of people with ASD, their families, and caregivers."

Mr. Ne'eman: So, I think that's very good. The issue is that participatory action research, as well as similar community-based participatory research, refers to a specific methodology of accomplishing these things that is used a considerable amount in, for example, minority and low-income communities. And there are researchers with particular expertise and best practices around that methodology.

So, I think it makes sense for us to call it out specifically and by name.

Dr. Insel: Yes, and just to clarify, I am amazed the depth of your knowledge about these things. So, in the NIH vernacular, this area has been featured as one of the missions of the CTSAs, the Clinical

Translational Science Awards, that needs specific push.

So, we can argue about the actual phrasing of this, but it was felt there that it needed to be featured or it would be neglected.

It is very much in the spirit of what we are saying here. And because it is now somewhat of a term of art for the research community, there is probably real value in saying, when we talk about being inclusive, what we are talking about is what you have heard elsewhere as community participatory research, which is, as I say, an area of great interest right now for NIH funding, especially within the CER context.

So, Ari, if you want to put in a sentence, we can come back to it and look at that as part of that same bullet that says this is what we mean when we talk about inclusion.

Dr. Hann: For where? Where are

we?

Dr. Insel: This is the second bullet under objectives. This is sort of a modifier to the current objectives. It says just remember what we're talking about is including input, and input is aligned with this community participatory agenda.

Mr. Ne'eman: I'm sorry. The second bullet under objectives in Chapter 6 or --

Dr. Insel: In Chapter 6.

Dr. Hann: In Chapter 6, which actually will become a research opportunity. It's not an objective.

Dr. Insel: Okay. Anything else before we bring this one to a close?

(No response.)

All right. It's now 12:30, and we should discuss how you want to proceed because we have all taken on some of the tasks here. We are going to take a break for refueling, but at the same time some people are going to take a swing at trying to give us some new language.

We also have all the revisions that have already been done in previous meetings that we want to run through very quickly, so you can see those before we break today.

The goal is to end the day with something that we are ready, or pretty close to ready, to take to the full Committee.

So, given that, how do you want to proceed? Should we take 30 minutes and grab something to eat and use some of that time as well to try to reword some of what we have talked about? Do you want more time to do that? What's your sense?

Dr. Dawson: So, I'm wondering whether, given all the things that we have to discuss, whether we want to just have a working lunch and actually have these small sections done by email. It seems like those are smaller groups. And yet, having the broader discussion is the unique thing that we have here today.

So, even though I thought it was a great idea to begin with, when I think about you leaving it to 1:30 -- yes, so I don't know how important it is to have Tom in the discussion of the other pieces. I'm willing to go either way. I'm just raising that as a question of whether it would be better just to have a working lunch and then these small sections just work out over email.

Dr. Insel: How does the group want to proceed? Marjorie?

Dr. Solomon: I would agree with Geri. I think that is a good idea. It is good to get your input.

Ms. Redwood: Yes, the same here.

Dr. Insel: All right. So, what I'm hearing is we need to refuel very quickly, but we can come back here. And then, you want to start with the other parts of the plan and look at what we have done so far?

I think that may go much more quickly because we have already been through this a couple of times. I think people have worked really hard to give us comments back. We could actually even just start at the introduction and run very quickly through. And if there is anything there to flag, do it in that way.

Marjorie?

Dr. Solomon: Is it possible to bring in the lunch, give them an order or something?

Dr. Hann: We're looking into it. That was not the original arrangement.

Dr. Insel: It may be. Is there a way to do this quickly? Susan, Della, do you know if we can just --

Dr. Daniels: So the arrangement that was made was that there was a lunch table reserved for you in the restaurant, and there is an express lunch menu, and they were told to serve the IACC members first.

However, I am not aware of whether the restaurant would allow you to bring food in the room. I doubt it. I think that you usually have to eat in the restaurant when you get restaurant food.

Dr. Insel: That's not a good solution.

Dr. Daniels: So, they're going to ask whether we would be allowed to bring food, but usually they want to do a plate at lunch, and if you're eating in the conference rooms --

Dr. Hann: Well, there's another option, if we can do it biologically. There is fruit and muffins out there. If you want to have that as a snack right now, so we can continue to work, and then you can have your lunch at 1:30.

Dr. Insel: I vote for that. How does the rest of the group feel? Can you go another hour? Because I think we can get a lot done in this hour. Especially if you're hungry, you can even do more.

(Laughter.)

Dr. Solomon: And then we can work over lunch.

Dr. Insel: Yes. Okay. So, let's grab whatever is on the cart.

And those who are on the phone, stay with us and we'll work for another hour and try to get now other parts of the plan that we have already gone through and made revisions, we'll start taking them on just to look at the new language.

There are not nearly as many changes. So, I think we can do this, I hope, a little bit more quickly.

Della, shall we just start at the beginning? Do you have an order you want to follow?

Dr. Hann: Actually, I would suggest that you start with No. 7. Because, of all the chapters, that one has sustained the most change.

Dr. Boyle: Yes, and this is Coleen.

I'm going to run to the restroom. So, I'll be back in like two minutes.

Dr. Dawson: It's not allowed, Coleen.

(Laughter.)

Dr. Insel: So, we'll take two minutes and then we'll start again.

(Whereupon, the Subcommittee took a brief break at 12:35 p.m. and reconvened at 12:41 p.m.)

Dr. Insel: Coleen, do you want to take us through the changes to 7?

Dr. Boyle: Sure. I would be happy to.

So, there was substantial suggestions in terms of additions to the first section in terms of what research areas, what we have learned in the past year.

So, with regard to data-sharing, I added a couple of sentences on the recent released information available through NDAR.

Then, under biobanking, this is an area that I found it a little bit challenging because I don't know as much as others around the table, but --

Dr. Insel: So, just before you go on, Coleen, the numbers there for NDAR, this is from the press release from last week?

Dr. Boyle: Yes.

Dr. Insel: Perfect. Okay.

Dr. Boyle: And that is all that was in the press release, nothing more specific than that.

Dr. Insel: Yes. I just wanted to make sure it was up-to-date.

Dr. Boyle: Yes, that's it.

Dr. Insel: Great. All right.

Dr. Boyle: And I added information under biobanking from the Simons Simplex Collection. That is also from their online -- and I will add a reference to that -- their online article from, I think, last week as well in terms of the number of families that are enrolled, and the expectation that they are going to be completing enrollment in the summer of 2011.

And then, Claire and Andy from Autism Speaks provided me more detailed information on both the biosamples available in the Autism Genome Project and the AGRE data repository. And I think I got the numbers right there in terms of the overlap between those.

Then, I know there is additional information that needs to still be added to this section in terms of the NIH intramural biobanks. So, I think we still need to add some information. I know Susan and Della were going to try to help me with that.

Dr. Insel: Yes. We can get that very quickly. You have to be a little bit careful here that you don't report the same samples twice.

Dr. Boyle: Yes, yes.

Dr. Insel: That is the whole idea of the GUID.

Dr. Boyle: Claire did a nice job trying to outline that for me. So, I think Della and Susan had received that as well.

Dr. Insel: Okay. Well, we can run this past the people who run the NIMH repository and just make sure.

Dr. Boyle: Okay.

Dr. Insel: Because I think that is the final common resting place for almost all of these samples. Just make sure that all the numbers sort out correctly. But these look pretty good.

Dr. Boyle: Okay.

Dr. Insel: These look like numbers I've seen.

Dr. Boyle: Okay. That's fine.

So, added just a little bit of changes to the surveillance and, then, on the information and communication dissemination pieces, more of that in what the particular gaps are.

So, going to the next page, under data-sharing, under the gaps, and I don't know if this belongs in opportunities or gaps here, but, obviously, the Affordable Care Act calls for the unprecedented transition in terms of hard copies to electronic records systems. This will really works both from the surveillance aspects as well as the data-sharing aspects, the ability to share data more quickly and explicitly. So, I just tried to capture those sentiments under the data-sharing aspects.

Lyn Redwood had made a number of excellent suggestions in terms of some of, I guess, the challenges to our surveillance capacity. So, we tried to incorporate those as well under the surveillance piece.

The communication and dissemination, tried to reflect Ellen's concerns about the fact that we were being a little bit too targeted in terms of what was out there, in terms of the opportunities for communication and information dissemination.

Jennifer suggested, and, actually, I just shortened what she provided for us under the communication, information, dissemination piece that came out from the Services Subcommittee Workshop, which called for research that is meaningful for teachers and family members. And that is also conducted in non-clinical settings.

And then, there was also -- and, Jennifer, you can speak to this probably better than I can, but I guess what I'm understanding from what you provided to me, and did a little work myself and was trying to understand this, is there is really a whole body of work that the Agency for Healthcare Research and Quality is involved in which may be very applicable to what we are trying to do here in the context of the discussion under Questions 5 and 6, and other questions as well.

This is the whole knowledge transfer capacity and the body of research evidence that they are putting into place in terms of formulating models for that.

And I thought Jennifer's idea was great in terms of trying to highlight this as a very useful framework to try to guide autism research translation efforts.

And then, the last part, which was the research or course development, we talked last time about I guess the growth of autism research within the context of private industry, and mostly the pharmaceutical industry.

Then, Claire also provided me with some information on which pharmaceutical companies were actively engaged. I didn't use the actual names of the companies, but what was actually going on there.

And I see there is a note whether or not this should be moved somewhere else, which I'm fine to do.

Dr. Insel: Yes, I think the idea was this was more progress rather than a gap.

Dr. Boyle: Okay. That's fine. No problem.

Dr. Insel: So, it looks like there's a place to move that in the first section.

Dr. Boyle: That's fine.

And then, in terms of revisions, we went through the revisions last time. I did add, based on, I think it was your suggestion, Tom, that we add a specific objective about conducting a meeting that would establish standards for data collection on phenotyping and imaging protocols. And I don't know if there are other aspects that are not already contained within the existing objectives.

Then, there was one last objective, too, that, again, we talked about on our phone call last time. And I think this is a retooling of one that we had in there that Ellen was feeling uncomfortable about. That was to create information resources for providers, researchers, families, and individuals with autism spectrum disorders which could serve as a portal to obtain the most recent evidence-based reviews and plans.

So, again, I think last time we had talked about it being a web portal, but I still feel like there is this need for a to-go place where people can actually trust the source, where people can go to obtain information that is going through the translation process.

So, that was it.

Dr. Insel: Thanks, Coleen.

Questions or comments? Ari?

Mr. Ne'eman: So, just very briefly, I see from the notes that we had talked, if memory serves, we had talked, and it may be here and I didn't see it, about including mention of diversifying the research workforce. In particular, also, diversifying it to see more researchers with disabilities, including the autism spectrum.

Is that represented anywhere in the add-ins?

Dr. Insel: Yes, apparently, do you see that piece where it says, "OARC to provide information" at the bottom of page 2?

Mr. Ne'eman: Hold on one second.

"OARC to provide information, opportunity" --

Dr. Boyle: Yes, I missed that. Sorry. That was the impact of the Recovery Act, but that was also to be added.

Mr. Ne'eman: Yes, I mean we can include, if we can ensure that's included there as well, just as sort of a broader cross-cutting theme when we are talking about workforce.

I notice we have research workforce development as a section in gap areas as well. So, I mean, insofar as we can incorporate that, not just as sort of a discussion around the stimulus. I think I brought it up because there was an NIH Directors' initiative around research workforce diversity, but, also, wherever we are talking about the research workforce, I think that would be very positive.

Dr. Boyle: So, Ari, just a clarification and I can add something into the gap part. So, you are talking about including people with autism spectrum disorders and their families in the context of research as researchers?

Mr. Ne'eman: Well, I'm talking about the fact that, just as it has been stated in NIH that it is a priority that we have a diverse research workforce, you know, representing the diversity of the country in the context of race and gender and religion, and so on, that we also include disability within that --

Dr. Boyle: Okay.

Mr. Ne'eman: -- because of our

focus, you know, the autism spectrum, as one example, in particular.

So, this is different from our discussion in Chapter 6 about the inclusion of the organized self-advocate community. Here we are simply talking about ensuring diversity in the research workforce and disability being included within that.

Dr. Daniels: This is Susan.

This was a part of what OARC still owes for this section.

Dr. Boyle: Okay.

Dr. Daniels: So, we'll be handling that.

Dr. Boyle: Okay.

Dr. Daniels: We just haven't gotten a chance to do it yet.

Dr. Boyle: That's great, Susan.

Mr. Ne'eman: Incorporate it, not just on page 2, where you have that called out, but, also, in the page 4 section on research workforce development. That would be very positive.

Dr. Insel: Yes. So, I guess the rule is OARC gets to hand in their work later. So, they are still on target with this.

I had one maybe unnecessary suggestion. Let me just throw it out there and see what the group thinks.

On page 3, the piece of the electronic health record I think is useful to add in here because it is such a priority of the Affordable Care Act.

There is another sort of implicit part to that, which might be useful to mention. And that is the need for quality metrics that can be built into health IT because that will be the basis on which, probably the basis on which there will be reimbursements made in the future.

It might be worth putting in just a simple parenthetical note saying that, in that new part on page 3, something like, "The development of EHRs provides an opportunity to consider the use for data collection and for the development of quality metrics related to the service needs." Because it is coming, and it will be a really important thing.

Dr. Boyle: Yes.

Dr. Insel: And you want to be ready when it comes because this is one of those cases where, if it is not ready, there will be other quality metrics for diabetes and for heart disease that will be picked up instead. So, it is probably worth building it into the language here ahead of time.

Dr. Boyle: Yes, yes. I don't know if there is represented anywhere else in the plan, but it may be worthwhile even considering an objective related to that. I think that is very important.

I mean this is the opportunity now, and I know that is the work we are doing within the context of my Center, is making sure that those metrics for those conditions we represent are represented both within the child and adult EHR record.

Dr. Insel: Okay.

Dr. Boyle: Is anyone looking out for that?

Dr. Insel: Geri?

Dr. Dawson: So, I'm wondering, do we have a place in the plan where we talk about the development of outcome measures? Because this may be a place where we could fold that in and say something, not only for use in research, but also in the context of --

Dr. Insel: Yes, I think there are a couple of places where we have talked about making sure we've got the outcomes developed.

I mean, to be frank here, I don't think this is going to wait for research. The request is going to come, and either you're ready or you're not.

The first request came through about a month ago. We weren't ready. So, just as I predicted, we are not on the list.

So, it will come again, as

healthcare reform continues to evolve, and we are going to have to do this. It is probably not going to wait for this strategic plan to have it done.

So, I am not sure whether it even needs to be an objective because it has to be done, but it wouldn't hurt to put it into this, just as a kind of placeholder, so that we know that we are thinking about it, even in 2010. It is probably one of the things that will have to be accomplished in FY2011, and we've already got a task force that is hard at work at this. So, it will happen. But I didn't want to leave it off altogether.

Alison?

Ms. Singer: The Safety Subcommittee had two proposed objectives for Section 7. I'm not sure they fit in Section 7, but we weren't sure where to put them. They focus on the need to collect data with regard to the wandering issue, given that there is an absence of data on that issue.

So, the material that we handed in calls for one objective that says, "Conduct analyses using existing datasets to determine the occurrence of injuries and death for people with ASD compared to people with other developmental disabilities in the general population by 2011."

So, you know, I'm not sure where that goes. It's an objective using a dataset. I think other objectives throughout the plan use datasets. So, maybe it fits better in Chapter 5, where there will be introductory language about the issue of wandering.

The second objective talks about "supplementing national surveys to collect data on the occurrence, types, circumstances, reasons, and outcomes of wandering-related incidents". Again, I'm not where to put that objective, but it is clearly data we need to collect. We thought surveillance, but I'm open to --

Dr. Insel: Ari?

Mr. Ne'eman: So, I support both of those objectives. The only thing I would say is, in regards to the second one, when we are talking about supplementing national surveys, I don't think that should be limited to wandering. I mean there are critical components around health disparities, for example, that I think would be very valuable. And depending on the survey, there are other areas in regards to both safety and quality of life that could be important.

So, I encourage us to think creatively about how we could broaden that and call wandering out as perhaps a particular priority.

Dr. Insel: What does the group think about whether this goes into this part of the plan? It looks like there's support for the inclusion of this someplace. It's just a question of where and how.

Dr. Boyle: Yes. I mean I could see it going in Chapter 5 or going here, either way.

Ms. Singer: I think one thing we talked about, or one way to accomplish the first objective under 7, was through the IAN database. The Committee had talked a little bit about approaching the IAN group, and we have actually gone ahead and done that. But I think that was one of the things.

I know IAN is mentioned in the introductory comments for Section 7. So, that may be a reason to keep it in 7.

Again, there are other objectives elsewhere in the plan that could use the IAN database as well.

Dr. Insel: So, let me take the Chair's prerogative and suggest that we keep it here. We can bring it to the full Committee, and if they are uncomfortable with it and want to move it, we can deal with it then.

But I think, since people want it included, I'm less concerned about which chapter it ends up. It looks like this is capturing something that the Subcommittee wants.

Is there anything else for feedback to Coleen or anything for the group as we look at this?

Coleen, you have done a great job here. This really captures so much of what we talked about. And as Della said, this was probably the chapter that had the most reworking.

Dr. Boyle: Well, thanks. I appreciate it. I will make those couple of changes and get it back to you, Della, in a few minutes.

Dr. Insel: Ari?

Mr. Ne'eman: I'm sorry. I just had one additional area, and I don't know if this appropriately falls under 6 or 7.

But I thought we might have discussed this, but perhaps we didn't. And I think, now that I think about it, a conversation may have occurred outside the IACC context.

So, there has been a growing effort to try to determine the correct incidence of ASD, not just amongst children, but also amongst adults. And obviously, this has significant implications, both in respect to service provision and in respect to other relevant questions around the autism spectrum.

Insofar as we can incorporate that here, I think that would be very valuable as a new objective.

Ms. Blackwell: Ari, this is Ellen.

We actually did have this Iceland study that we talked about in 6. Are you suggesting that maybe that information be moved to 7?

Mr. Ne'eman: I mean, the Iceland study is not really what I'm talking about, because that was -- and I remember that study. I think I suggested it for the portfolio or the list of new advances.

But that study was looking very specifically at, I think, a particular setting, institutional setting. What I am thinking of is more something akin to the kind of broad-based health surveillance, broad-based surveillance that CDC does for, I think, for 8-year-olds.

I think there was a very limited effort to do something of this nature in the United Kingdom with regards to the National Health Service. But what we really need is a broad-based population-able surveillance effort to determine the incidence of ASD amongst the adult population in the United States.

Dr. Insel: So, Della points out that there is an objective in the plan on page 35 already. It is a new one from 2010.

"Develop one method to identify adults across the ASD spectrum who may not be diagnosed or are misdiagnosed to support service linkage, better understand prevalence, track outcomes, with consideration of ethical issues, insurance, employment, stigma, by 2015."

Mr. Ne'eman: That strikes me as speaking more to diagnostic tools at an individual level. I think what we are talking about here more falls into the category of surveillance.

Well, I mean the initial example, and again, I think the study was really just to start, was what recently occurred in the United Kingdom.

Dr. Boyle: I feel like we could modify one of these to perhaps include that. So, maybe I can -- and I feel like I can't put my hand right on the objective now, Ari, but --

Dr. Insel: Okay. Let's make sure we capture that someplace in here.

Dr. Boyle: Okay.

Dr. Insel: I seem to remember we

had this conversation and this is in here. I just can't find it right now.

Dr. Boyle: No. Me, too.

Dr. Insel: But I know we talked about this at a previous meeting because of the frustration of not having information about adults.

As Ari says, to simply focus on 8-year-olds is giving you just a single cross-section.

So, Coleen, you'll look through, and if it's not there, we'll add it in?

Dr. Boyle: I agree with Ari; I think it should be in here.

Dr. Insel: Okay.

Dr. Boyle: I feel like it is in here somewhere.

Dr. Insel: I remember seeing it, but I can't find it. So, if you can take a look through --

Dr. Boyle: Okay.

Dr. Insel: -- and if it isn't

there, let's make sure we get it in someplace before we take this to the full Committee.

Dr. Boyle: Okay.

Dr. Insel: Okay. Anything else on Chapter 7?

(No response.)

We are ready, if people are comfortable with that one addition and a couple of other minor modifications, to send this forward. Okay? It's a wrap.

Dr. Boyle: Okay.

Dr. Insel: Della, where do we go from here? Intro?

Dr. Hann: Okay. I would recommend going to the introduction next.

Dr. Insel: Introduction. I think, Lyn, you drafted that? Are you still with us?

Ms. Redwood: Yes, I'm sorry. Can you hear me now?

Dr. Insel: Great. We can hear you.

Ms. Redwood: I had it on mute. There's a lot of background noise. Hold on just a minute. Let me get it out. Does everybody have the introduction in front of them?

Dr. Insel: Right. We're good to go, and it's also up on the screen.

Ms. Redwood: Okay, great.

You can see where I added in a comment regarding President Obama's speech that was suggested. I don't know if anybody has any questions or comments about that.

Also, the changes that we discussed were made. The only one that I was really unclear on that I was having a difficult time with is down in that last paragraph with regards to identification of mechanisms of injury.

The suggestion was made to take out the word "injury" and just have "identification of mechanisms", but that really seemed incomplete. So, I was wondering if the Committee would have other language they would want to insert there, because it just seems like it is less hanging when it just says, "identification of mechanisms".

Mr. Ne'eman: So, I mean, I would probably be one of the people who would object to the term "injury". I wonder if "identification of mechanisms of action" or "identification of mechanisms of causation" might be a more appropriate role.

I would also add I believe there are some things that we did decide at the last meeting we are going to need to take to the full Committee around this.

Ms. Redwood: So, is this one of the things we want to take to the full Committee in terms of whether or not we leave the word "injury" in there? I think "causation" would work, too, Ari, but we have "causation" right before that.

Dr. Insel: Yes. We talked about this last time, and I thought that the

Subcommittee said they wanted to drop the term "injury". Does anybody want to reconsider that?

Ms. Redwood: Well, my point is, Tom, when you drop the word "injury" and it just says "mechanisms", it doesn't really, to me, it's not specific enough in terms of what we are meaning when you read the sentence without the mechanisms of something. That was my point.

If the Committee finds that it can just say "mechanisms" and they think that's clear enough, then --

Dr. Insel: Marjorie?

Dr. Solomon: You could insert the word "biological mechanisms"?

Ms. Redwood: How does the Committee feel about that?

Dr. Insel: Geri?

Dr. Dawson: Another possibility would be, so the sentence currently says, we need research that deepens our understanding of ASD, including "the complex genetic and environmental factors that play a role in its causation". We could say "including their mechanisms of action", right?

So, in other words, we are interested in, if it is an environmental factor, what is the mechanism of action? Or even "including their underlying mechanisms", right?

So, you're basically referring back to genetic and environmental factors and trying to understand what their mechanisms or their mechanisms of actions.

Dr. Insel: Could you collapse those, Geri, and just say "including the mechanisms by which complex genetic and environmental factors play a role in its causation"?

Dr. Dawson: Yes. That would be another way.

Dr. Insel: And then, you could leave out that whole clause.

Ms. Redwood: I think that works.

Dr. Insel: Okay. Moving on?

Ms. Redwood: Since I can't change on the CD, did OARC capture that?

Dr. Insel: We've got it.

Ms. Redwood: Okay.

Dr. Insel: Let's move on.

Ms. Redwood: Right. The next change was the progress toward accomplishing research objectives. I think that was accepted last time. That wasn't anything new.

The part that we need to discuss goes down under heterogeneity. There was much discussion about using the proxy "24-hour care and supervision" for the term "nonverbal".

OARC staff has drafted a second option version, too. "This section includes people with ASD with significant disabilities who need a great deal of assistance, including healthcare community-based supports and services, to live in preferred community-based settings, and others who, with minimal or no services or with appropriate services as set forth, are able to support themselves and live independently in their community."

So, the Committee will need to decide which of those two they would prefer.

Mr. Ne'eman: I feel pretty comfortable with the latter.

Dr. Insel: I think we decided this is one that we were just going to take for a vote to the full Committee because we don't want to rehash it here. Is that okay? So, we're going to punt on this, and both versions will go, and they will decide.

Let's move on.

Ms. Redwood: Co-occurring conditions, Tom, I included the language that you had suggested. If everybody wants to take an opportunity to read over that, or I can just keep moving on?

Dr. Hann: Folks are reading it right now, Lyn.

Ms. Redwood: Okay, great.

(Pause.)

Dr. Insel: Any issues with the language here? Lee?

Mr. Grossman: In the middle it says, "and too often these conditions may not be treated", and then it has "either". That kind of gives you just, it makes it sound that these are the only two circumstances. So, it could say, "For example, because...."

Dr. Insel: Okay.

Mr. Grossman: Change that.

Dr. Insel: Good. All right. So get rid of it, right. Right.

Mr. Grossman: Yes, and "For example,...."

Dr. Insel: Yes.

Ms. Singer: On line 2, where it says, "medical symptoms occur in autism", right now it says, "may be a major source of disability". I would say, "an additional source of disability" because we want to leave in that the behavioral issues themselves are a source of a disability.

Dr. Insel: Thank you. Okay.

Okay, anything else?

Mr. Ne'eman: Well, I would only add that where we say, "These conditions, if not treated, can limit a person's ability to benefit fully from educational and behavioral interventions," I would say, in addition to that, "and fully participate in community life".

Dr. Insel: Okay. That's a good addition. Heads are nodding here.

I think we're ready to move on. Thanks, Lyn. Let's go on.

Ms. Redwood: Okay. The next section that I thought was somewhat controversial that still needs some work is the very last paragraph on community-based engagement.

There was concern before about the human dimension of the disorder. And I apologize. I was thinking OARC staff was changing that, and we had discussed "including personal experience of individuals with ASD and their families is reflected" instead of dementia.

Dr. Insel: Yes, I think that's right. I think we had some other language in there, which I think you just captured it.

Ms. Redwood: Yes. Do you want me to read it again?

Dr. Insel: So, can you read that again, if you have it in front of you? And we'll make sure it gets in.

Ms. Redwood: Okay. So, "essential to ensure that the personal experiences of individuals with ASD and their families is reflected in scientific considerations, investment strategy, and research focus".

If you want to also specifically put "and community-based participatory research" here, "the strategies are needed to increase community engagement. For example, community-based research, participatory research", that would be the place to put it.

Mr. Ne'eman: I would be glad to write up, in addition to what I'm writing for Question 6 on that, I would be glad to write up a sentence for the introduction on that.

Dr. Insel: Okay. We will insert that, unless there is any concern about that. I think it is good to put in these terms of art when they show up like this.

Okay. Anything else on the intro? Jennifer?

Dr. Johnson: Yes, just one other comment on the community engagement and ASD research paragraph. In that first sentence where it says, "People with ASD, their families, and their educators", I'm just wondering if we might change "educators" to "practitioners" because not only educators would be involved with research, but other types of practitioners that work with people with autism spectrum disorders and their family members. So, instead of identifying a specific type of practitioner, I would like to suggest that we just generally refer to practitioners in that paragraph.

Dr. Insel: Ari?

Mr. Ne'eman: So I would --

Ms. Redwood: Would "caregivers" not fall under practitioners?

Mr. Ne'eman: I don't like the term "caregivers". I think there is a lot it doesn't encompass.

Dr. Johnson: To me, practitioners would include medical practitioners, dental practitioners, educators, social workers. So, again, the term, to me, encompasses a variety of types of professionals who work with people with ASD and their family members.

Dr. Insel: Alison, your light is on. Did you have a comment. No?

Ari?

Mr. Ne'eman: I had a separate concern that I had thought I had raised earlier, but I may have not done so.

And that's on page 1, in the fourth paragraph, we have "The cost to society to ASD is currently estimated to be $35 to $90 billion annually." You know, frankly, and I think I have expressed this before, I think there are significant ethical concerns that defining individuals on the autism spectrum as burdens on society, you know, I think there is a long history of such language being used in policy and legal settings to devalue people with disabilities and to make it more difficult for people to have access to the services and supports necessary for community integration.

So, I personally feel that we should strike that. I don't think, actually, in much of the development disability world outside of the autism context language like this would likely to be utilized.

Dr. Insel: I think this is one of those places where the perspective of thinking of this as a disorder is very different than thinking of it as a disability. So, in the realm of research funding, if you couldn't express the cost of what we are now facing in economic terms, I don't think you have a seat at the table in terms of expecting to get funding for research.

I suspect that that is part of what drove the inclusion of this language in the first version and the second version of the plan.

Mr. Ne'eman: Perhaps we could get a perspective from the DD community on this.

Dr. Johnson: On identifying the cost? Well, you know, I understand your concerns, and I think, to a certain extent, we would share the concerns that identifying people with disabilities is a burden to society. It is not the way we would want to conceptualize disability in general. In other words, developmental disability or other types of disability.

But, at the same time, you know, the cost is a real factor. I guess I look at it in some ways as perhaps these costs can be reduced by conducting research to look at different areas, to look at interventions and the efficacy of those interventions and cost-effectiveness of different types of interventions, as an example of how to reduce the costs associated with disabilities.

So, maybe it is just a matter of how it is conceptualized in this introduction. Maybe the cost is higher than it has to be.

Mr. Ne'eman: Well, but, if that's the case, then we're not --

Ms. Redwood: That could be added in the next sentence.

Mr. Ne'eman: Well, if that's the case, then we're not talking about the cost to society of ASD. We're talking about the cost to society of the lack of the appropriate services, supports, and education. And currently, I don't think that that's adequately reflected.

Dr. Insel: Lyn, did you have a comment?

Ms. Redwood: Yes, I was just going to respond that we could actually put that in the following sentence that says, "Although research on ASD has expanded in the past decade, there remains an urgent, unmet", "an urgent need for increased research support", and we could say something there to try to reduce the burden of disease and the cost.

But, Tom, I agree with you that this is a research document, and that it is important to reflect what the cost of the disorder is to society.

Dr. Insel: Well, why don't we do this, because there's, obviously, some disagreement? Why don't we use this as another area that we flag and ask the full Committee to weigh-in on. If there also is significant discomfort from the full

Committee, we'll take it out.

But, Geri, and then Lee.

Dr. Dawson: So, just a couple of points. One is that it may be, I think, more sensitive to these issues that are being raised, which I understand, if we were to say, instead of "the cost of ASD", would be to say, "the cost of providing services", right?

Mr. Ne'eman: That may not accurately be reflecting what --

Dr. Insel: Yes, I don't think it is just the cost of providing services. Yes, this is looking at a whole series of issues around opportunity loss.

Dr. Dawson: Okay. So, actually, are you sure in the Ganz study? I don't think they did look at opportunity losses.

Dr. Insel: Yes.

Dr. Dawson: This is services and education actually.

Dr. Insel: Right, but that is not the 90, is it? I think that's the 30 number.

That's the lower number, right?

Dr. Dawson: No, $35 billion is -- I don't know about the 90, but my understanding is that it was services and education and care.

But, in any case, what I was going to say is, if we do leave it in, it should be the incremental cost. So, I think a lot of people don't understand that this is the cost above and beyond typical cost. So, it's not the total cost. It's the incremental cost, and he makes a big point of that in the article, and I think a lot of people don't really understand that.

The other point is that I think it should say, "conservatively estimated", if we keep it in, because that is based on the old prevalence figures.

Mr. Ne'eman: See, once again, this brings us back to -- and I understand we'll take this to the full Committee. Fine, but I think this brings us back to the underlying problem with this kind of language and this kind of thinking, which is essentially, as you described, this is about identifying precisely how much more expensive and how much more burdensome the population this Committee is designed to serve is as compared to the general population.

And if that's how we're defining our mission, I have to say, you know, I don't actually think it is a very good rationale for arguing for service provision. It speaks not to the potential of what service provision can accomplish, but to really a very limited vision of our mission.

Ms. Blackwell: And this is Ellen.

I would add that, generally, in terms of serving of people, we look at an individual's needs, not their diagnosis. So, that also is inconsistent with how we look at service provision for the most part.

Dr. Insel: Lee?

Mr. Grossman: Yes, in 2002, I was

part of a small group that pulled the $60 to $90 billion figure together, and I will be happy to provide the reference sources to that.

It was never meant as -- it's quite a large range, obviously, and was meant to be exactly that, because we don't have the exact figures on what the costs are. And what these costs are, and what we explained, these are the costs of service provision. It is not the cost to society. It is the cost of service provision, and we were pretty accurate upon that, and for reasons. Because we felt that there needed to be an understanding of what it costs now to treat the entire population, as it would be with any health condition, of any disability.

And part of that, also, was reflected in Michael Ganz's study, and he and I have had numerous discussions about this, is that he could only identify approximately about $30 to $35 billion of cost.

So, when we look at the total cost of provision, most of these costs are coming out of families' pockets or are not reported. So, the figures are there as a wide range, but mainly to give the breadth of the rationale of why this needs to be addressed as a societal problem.

I think that it is fine the way it is if we add -- and I can understand Ari's concern about the cost to society because the connotation of that is that this is a terrible burden. I think if we put, as it was meant to be in its original context, the cost of service provision, I think that that, at least in my mind, would address it.

Dr. Johnson: I think if the costs are referencing service provision, that does speak to some of the policy issues related to how services are determined in states, and how that can be driven by values in the state, which can lead to more costly services.

So, if it based on service

provision data, then I think we do need to somehow address this in a way that acknowledges some of the issues that Ari is raising, because, again, those costs are driven by values, and not necessarily cost-effectiveness.

Mr. Ne'eman: For example, the State of Oregon most likely has a much lower per-person cost for community-based services because they are not using costly and, frankly, ineffective and bad-for-people ICF/MR services. They have moved entirely to a community-driven system. Whereas, my home State of New Jersey uses a lot of very expensive services that people would probably be best serviced if they were replaced with something that was more integrated.

Ms. Blackwell: And this is Ellen.

And it gets back to the study itself, which the bulk of these costs are related to something that Dr. Ganz defines as, quote, "adult care", unquote. But I have never been clear on exactly what he used to calculate that figure.

So, I would just advise stepping carefully in this area, as we are.

Mr. Ne'eman: So, we don't know what this includes. We don't know for sure what we mean by it, and we seem to strongly disagree as to how to frame it.

I'm fine taking this argument to the Committee, but it seems to me that I don't know that any side is very well-served with keeping this in as it stands.

Dr. Insel: So, I will make the counterargument.

Oh, go ahead, Geri.

Dr. Dawson: I just want to say, you know, representing an advocacy organization, that these kinds of figures are very compelling, right. I don't think they necessarily, and I think we could add language around it to make sure that the intent isn't to devalue people with autism. I mean you could say, what is the cost of educating people in America, right? Or what is the cost of whatever it happens to be that you are interested in helping around, right? People want to know about that because they want to know, what is the scope of the issue here?

A lot of people think about autism as being a rare condition still, right? They don't understand that really the scope of what we are trying to really provide services for here is large.

So, I think from an advocacy point of view, and getting people's attention, that we want to have the appropriate services in place, that's what this is all about. It is not in any way meant to devalue people with autism. In fact, it is absolutely the opposite. It is to advocate for people with autism.

Mr. Ne'eman: So, speaking from the perspective of an advocacy organization run by autistic people, you know, I don't think anybody is proposing not paying for the cost of public education in the United States at large. But, you know, there are any number of individuals who are proposing that, as a means of not having to shoulder the costs associated with autistic people across the lifespan, that we move towards a day and age where we do not have such people in our society.

So, I think that reflects perhaps why we who are being referred to here perhaps are more concerned than one might have with simply a cost estimate of providing service provision to the general population. So, this may perhaps speak to the different kinds of values that exist between our two organizations, Geri, and perhaps the different kinds of objectives.

Dr. Insel: Well, we've got already one sort of line in the sand here about another issue in this same chapter. What I think might be best, and this is a very compelling discussion to have with the full Committee, if we could look to the two of you to represent the two sides of this? And I am sure other people will want to weigh-in as well.

But, Ari, I think you make a great case, and it is something that I think the entire Committee ought to hear about. And, then, let's get feedback about what they want to do.

Remembering, this was language that is already in there that they put in in 2009, and put in again in 2010. But if sensitivities are such that it is time to make a change, this will be the chance to do it.

Is there anything else from this introductory chapter that we want to revisit or that we need to give Lyn feedback about?

(No response.)

Okay. Lyn, thanks very much. This is a great improvement.

And I think we are ready to move

along and will do Chapter 1.

Dr. Boyle: Okay, that is me again, Coleen.

So, I was just looking over this. There were not a lot of changes, at least in the content of the new research and the gap. So, I don't know if anyone had any problems with it, but I wasn't going to go over it again, unless there were.

So, do you want to just turn to the second-to-last page, which was the research opportunities and research objectives that emerged? And we also talked about these as well.

So, there were two new objectives that were added, which we discussed the last time we met, one on furthering sort of the translational aspects of the work that was identified by Miller on the G-band karyotyping.

And then, the second one was one that I thought was a great addition, provided by Ari, his suggestions in terms of examining the ELSI issues related to issues around genetic testing and counseling.

And then, we had revisions, a revision to short-term objective C, which was to better define the screening and referral system and targeted disabilities. Again, we talked about this last time. So, this isn't anything new.

And that was really to incorporate the issue of expand that objective to include the implementation of an, and access to, screening, diagnosis, and referral. And we also added, I think, the gender of the child to that one. We also added gender as a population qualifier, and then resources for international settings to objective B. I guess I could reverse the order there.

Then, I think this is the only new addition from the ones that you have seen previously. That was to revise long-term objective A, and this is really to reflect the issue of evaluating risk markers or risk profiles that can improve the early identification through heightened developmental monitoring and screening. So, that was just sort of tweaking objective A to include that there.

So, other than that, this is one that you had already seen previously, except for that minor change to objective A.

Dr. Insel: Thank you, Coleen.

Comments? Questions?

(No response.)

I had one quick question.

Dr. Boyle: Okay.

Dr. Insel: On the second bullet on conduct at least five studies on the ELSI part --

Dr. Boyle: Yes?

Dr. Insel: -- is that five completely new, independent studies or is the idea to include ELSI as a component in the studies on genetics?

Dr. Boyle: I mean, Ari, you can speak to it, but I guess my instinct would be that it would be a component.

Dr. Dawson: Actually, I was the one that added that objective.

Dr. Boyle: Okay. I apologize.

Dr. Dawson: Yes. And so, yes, I was seeing it as that they could either be done in conjunction with or could be separate studies. I don't think that these would be --

Dr. Insel: Would it help to clarify that? Because it sounds like we are adding five new. What we really want, I think, is to make sure that this perspective and the research around this is informing what is being done for many of the studies in question.

Mr. Ne'eman: And I think that language came from an earlier objective that we had proposed. My impression was that we wanted both the possibility of independent studies and, frankly, what I think should be the requirement of incorporating it across the scope of genetic studies that are being conducted.

So, I mean, I am open to clarifying it to reflect that. I guess the only thing I would say is that, if we are talking about the broad scope of studies, it shouldn't be limited to just five. I think every time genetic research and other research with ethical, legal, and social implications is undertaken --

Dr. Insel: So, that is an interesting point. I mean maybe we want to take a number out of this and just to talk about the inclusion of this component.

Geri, I don't know. You were the one that worked on this. What's your sense about how to do this? Because we do this in other areas, but it hasn't happened as much in ASD. But it is not like we want to build a separate industry for ELSI studies.

Dr. Dawson: Right. I think

that's fine to integrate that; that would be fine, or separate. Because I can imagine people putting in a study where they just want to look at these issues that have to do -- I mean there's a lot here, clinical utility, genetic counseling, the ethical, legal, social issues.

So, to say that you only do it, that may be a whole broad area of research unto itself. So, I wonder whether it should be called out for that reason. And that is not to rule out -- and, in fact, I think it should be encouraged, as Ari is saying, that anytime that we are looking at the issue of genetic testing, that we should consider these other issues as well and use it as an opportunity to perhaps gather data on that.

But, yes.

Mr. Ne'eman: So, let me make a suggestion here. Why don't we keep this as it is, with the idea that these at least five are going to be looking at, you know, independent studies for a field that is vastly in need of investment, really has not, as you said, Tom, has not really done so in the context of ASD?

And then, let's add a cross-cutting theme to the introduction to look at ethical, legal, and social implications and to establish the intent of the IACC that, frankly, everything we fund that has ethical, legal, and social implications, that should be incorporated within. Thoughts?

Dr. Insel: The spirit of the group? We've got a suggestion on the table. Is there interest in this?

I don't hear a lot of enthusiasm. But, on this particular bullet, Geri, can we get you to massage the language in such a way that it is clear what it is we're asking for, which is the inclusion, as well as potentially new studies.

But I think what we want to avoid is separating this out from the science itself, so that this becomes sort of an academic exercise that is not informing the actual studies that are being funded.

Dr. Dawson: So, I guess the question I have is I am thinking about studies that are actually going on right now, right? So, I know that there are -- and you are funding a lot of them -- the studies going on right now that are doing sequencing, and so forth, that don't necessarily have a whole component on the ethics, those folks, right?

But, at the same time, there are people who are devoting their whole career -- well, Holly Tabor and others -- to looking at the ethical issues. So, each of those is talking with each other and informing each other, but we don't necessarily have, you know, every project has both components.

So, the question is, do we want to require that or not?

Dr. Insel: Oh, I can't imagine that you would want to require this.

Dr. Dawson: Oh, okay.

Dr. Insel: But it seems to me that you have just defined the problem. And we have this in a lot of areas where you have the development of neuroethics which is separate from neuroscience. So, it becomes an entity unto itself. It has no practical impact on the research that you want it to have an impact on.

Dr. Dawson: Right.

Dr. Insel: Now it is an academic exercise.

What I thought the Committee wanted was to bring ELSI into the genetic studies that are being done in autism in a way that ensures that there is real interaction between these two communities.

There are a few people who are interested in ELSI issues and genetics of autism, but they are not doing the genetic studies. So, the point would be to link these two and to find a way to foster the inclusion of this in ongoing studies or in studies that start to be launched.

I can't imagine that you are going to stop everything you are doing until it includes this because this is a very fast-moving train with lots of implications. But we want to make sure that we bring this piece of it in, so that it informs a lot of what we are doing.

Mr. Ne'eman: So, I guess the one concern that I would have there, and I would be glad to work with you in massaging the language, but it strikes me, I want to know what's going to be counted as fulfilling this objective. Because I wouldn't want to see, for example, a study that is really near exclusively simply about identifying genetic markers, and what have you, and includes a paragraph saying there are some fascinating ethical, legal, and social implications of this that need to be discussed further by policymakers, et cetera, as really having fulfilled our intent here.

So, I guess that sort of instructs my feeling that, yes, it does need to be cross-cutting throughout, but, at the same time, we also need to be giving some support to what needs to be a dedicated and emerging conversation that will, hopefully, significantly influence autism research.

Dr. Insel: Can I just weigh-in here one last time? There is somebody on the full Committee, Alan Guttmacher, who is really one of the nation's experts on this question. Maybe we can turn to him, when the time comes, to try to figure out the best way to address this.

I am going to have to depart at this point in time. Before I do, I just want, again, to thank all of you who have really been so committed to this process.

And as you can see, as we go back through it, I think it really does get refined and gets better. I don't know that we will get it all done before four o'clock, but I am sure you will make great progress. And then, what remains to be done thereafter, we can do electronically.

So, when we meet again later in December, there will be a chance, I think, to get all of this in the form that we are happy with to the full Committee.

So, thanks. I'm sorry I have to leave. It is only because of something that I really have to attend that I couldn't change.

Dr. Hann: Okay.

Dr. Insel: Della is driving.

(Laughter.)

Dr. Hann: Well, I think the first order of business, actually, is your lunch.

Dr. Boyle: Della, before we leave, can I just make a suggestion on that one right there? And I just changed the wording slightly to say, "Conduct at least five studies of the ethical, legal, and social implications of autism research, including this perspective within newly-funded or to-be-funded studies," something like that. Then, we would at least have that thought put in there.

Mr. Ne'eman: See, and that's precisely what we are trying to determine right now. You know, I think we need a little bit more time and thought --

Dr. Boyle: Okay.

Mr. Ne'eman: -- and probably Alan's advice to figure out the best way of phrasing that.

Dr. Boyle: Okay. That's fine.

Dr. Hann: I will throw out a suggestion for you all to consider in rewording this. The word that came to my mind, or the phrase, was "ancillary studies". Because if you've got ongoing genetic work, and then you want to have this become a bona fide component of that, that implies the linkage, in my mind.

Ms. Blackwell: I like that, Della. This is Ellen. I vote for that.

Dr. Hann: And then it also will allow us to count it.

Mr. Ne'eman: So long as we are talking both about ancillary and dedicated studies.

Dr. Hann: Absolutely. I didn't mean to have one be supplanted by the other, but that might be the phrasing that might be helpful.

Dr. Daniels: So, you could have both dedicated studies as well as ancillary studies.

Ms. Singer: I have a non-controversial change.

Dr. Hann: Ha, ha, ha, ha.

(Laughter.)

Really? What makes you so sure?

Ms. Singer: All right. Well, we can vote on whether it is non-controversial.

(Laughter.)

The King study and the list of references is out of alphabetical order.

(Laughter.)

Dr. Hann: Very good.

Ms. Singer: It should be -- well, we know where it goes.

Dr. Hann: Yes.

Ms. Singer: Anybody have any concerns about putting it in alphabetical? Okay. Good.

(Laughter.)

Overly detailed-focused, in the weeds.

Dr. Hann: Okay. So, I know we prevented you from having a dedicated lunch before. So, I think, you know, we had all agreed that this would be the moment in time for you to actually to get something substantive to eat.

I am very confident, actually, that we are going to go through the other three chapters this afternoon and, actually, potentially even have time for you all to have your discussions with regard to some of the other changes, and so forth, like that. I'm very confident.

So, Susan, is there any additional information we need to provide with regard to lunch? It's after 1:30.

Dr. Daniels: So, it should be ready.

Dr. Hann: It should be ready.

All right. So, let's take a break, and you all come back. Then, we will get going again.

Dr. Boyle: And, Della, for those of us on the phone, when shall we fall back in?

Dr. Hann: Let's see. I have that it is about 1:40 right now. So, let's say like about 2:10.

Dr. Boyle: 2:10, okay. And just I'm leaving at 3:00. So, I'll be here until then.

Dr. Hann: Okay.

Dr. Boyle: Okay?

Dr. Hann: Great. Thank you, Coleen.

(Whereupon, the Subcommittee recessed for lunch at 1:42 p.m. and resumed at 2:16 p.m.)

AFTERNOON SESSION

2:16 p.m.

Dr. Hann: Okay. I think we can go ahead and get going.

I realize a few of our folks, I think, are still taking care of some issues. Marjorie and Ari are here still with their heads together on additional language.

Coleen, are you on the phone?

Dr. Boyle: Yes, I am.

Dr. Hann: Oh, wonderful. All right. We need Marjorie because she was the author for 2, Chapter 2.

Ms. Redwood: Hey, Della, this is Lyn, and I'm on the phone, too.

Dr. Hann: Oh, good. Okay.

Ms. Redwood: Hey, Della?

Dr. Hann: Yes?

Ms. Redwood: This is Lyn again.

Just as a heads-up, I am going to be traveling, so I will have it on mute quite a bit, and then I may miss the last few minutes of the call before 4:00.

Dr. Hann: Okay. Thank you for letting us know, Lyn.

Ms. Redwood: Okay. Thank you.

Dr. Boyle: I'm leaving at 3:00, Della.

Dr. Hann: Okay. So, we are going to try to go through this as expeditiously as we possibly can.

Dr. Boyle: Wonderful.

Dr. Hann: Marjorie?

Dr. Solomon: Okay. I'm back at the other side of the table now.

Basically, what we did in the preamble here, as I said on the last call, is reviewed for 2010 studies in a list of about 10 high-impact journals in both the psychology literature, psychiatry, and cognitive science, and then just provided three bullet points here to summarize some of the findings that would fall under Question 2. That's what you see.

We have structural imaging studies, just structural imaging studies, then studies of different brain structures, and then, finally, neurocircuit-based studies.

Since we wrote this, I would like to propose adding a bullet under the structural imaging studies for a recent postmortem study in The Journal of Neuroscience that detailed some white matter abnormalities. And I can take care of that.

Then, under the third bullet point, I wanted to add in a new paper that came out by Kevin Pelphrey, who addressed the Committee about a meeting or two ago. That was in Proceedings of the National Academy of Sciences. That was about a neuroendophenotype, based on some of the biological motion work that he presented to us.

So, that is pretty much what we had for "What is new?"

Dr. Hann: Does anyone have any comments on the "What is new?" section?

(No response.)

Dr. Solomon: Okay. Oh, and then, that was just really amended onto a summary of what this Committee has looked at as promising developments, and those were written up as well. So, we did sort of an independent literature review, but, then, also used what the Committee has put under advances.

Oh, then, well, a couple of us also had a couple of ideas. Lyn recommended more focus on metabolic and immune system interactions, and we added that in.

Then there's been some interesting studies on mouse models of autism. I think some animal models do show up in the strategic plan, but we made a mention to those, as there were a couple of good papers this year.

And then, I think that is pretty much it.

Dr. Hann: Geri?

Dr. Dawson: I am wondering about, and I have been trying to look, did you include anywhere the Persico postmortem study that had to do with the virus findings?

Dr. Solomon: I'm pretty sure we did. Persico, yes, 2010.

Dr. Dawson: But that's a different study, isn't it, or is that that one?

Dr. Solomon: No, you're right, that's a different one.

Dr. Dawson: Yes.

Dr. Solomon: It was the metabolic deficit one.

Dr. Dawson: That's different.

Dr. Solomon: I didn't review 2009. Maybe it was in 2009?

Dr. Dawson: No, no, it is a 2010 paper.

Dr. Solomon: Okay. Can you tell me where it is, and I will include it?

Dr. Dawson: I will send it to

you.

Dr. Solomon: Okay. Or, I mean, I could easily find it, too.

Ms. Redwood: Hey, Marjorie, this is Lyn.

Dr. Solomon: Hi, Lyn.

Ms. Redwood: Do you guys hear an echo when I talk or is it just me?

Dr. Solomon: No, I'm sorry, it's just you. We hear you fine.

Ms. Redwood: Okay. I'm hearing myself twice every time I speak.

We had discussed on the Safety Committee call adding or making a little bit of a tweak to one of the objectives that is currently there in the plan.

Dr. Hann: We haven't gotten to the objectives. Lyn, wait a second. We haven't gotten to the objectives yet.

Ms. Redwood: Okay. Never mind then .

Dr. Hann: Okay.

Ms. Redwood: I'm rushing.

Dr. Hann: Hearing no more discussion on what is new, can folks take a look -- Marjorie, do you want to walk us through gaps?

Dr. Solomon: Yes. Gaps. Again, Lyn make an excellent suggestion of, and Walter concurred, adding of metabolomics and genotype/phenotype relationships.

We also talked about the concept of becoming more cognizant of endophenotypes in autism, and those are sort of partial constituent phenotypes based on work in family members that are more proximal to the genes than necessarily behaviors. So, we talked about mentioning that.

There is a lot of talk in research about using those in the search for genes. So, we wanted to raise awareness about endophenotypes.

We incorporated public comments related to the need for the study of regressive autism, which actually is covered already under the strategic plan; girls with autism, and then there are new concerns that were raised about epilepsy, liver, and other diseases and inflammation.

Also, implementation issues that came up in our group included the need to include a lot of new rapid findings into existing database and to phenotype the autisms. And finally, that we have to emphasize the translation of our findings to clinical practice.

Mr. Ne'eman: So, you said you made mention of women and girls on the autism spectrum. I am having trouble finding that. Could you just point --

Dr. Hann: Go to page 2 of the update.

Dr. Solomon: It's page 2 of the update, right, and it is, "What gap areas have emerged?", paragraph 2. And it says, "Public comment points to the need for continued study of regressive autism and females with ASD."

Mr. Ne'eman: So, you mention that regressive autism is already covered by the strategic plan. Is there an objective in the existing Question 2 that calls out --

Dr. Solomon: Yes, there is a definite callout. And I don't believe this is the only place in the strategic plan that there is a callout.

Mr. Ne'eman: So, there is a definite callout for regressive. Is there one for women and girls?

Dr. Solomon: Yes.

Ms. Singer: Short-time B, Chapter 2.

Mr. Ne'eman: Okay, yes. Thank you.

Dr. Solomon: But I wanted to note it again because it is public comment.

Mr. Ne'eman: Yes. Okay.

Dr. Hann: Okay. Any additional questions or comments with regard to gaps?

(No response.)

Okay. Research opportunities. And, Marjorie, if you would just overview it, and then I know, Lyn, you want to raise a point.

Dr. Solomon: So, we had three new opportunities. Again, one on metabolomics, one on children who regress during fever, and metabolic pathway perturbations. And these were Lyn's additions.

Ms. Redwood: Actually, it was regress or improve during fever.

Dr. Solomon: I'm sorry. Yes. "Research on children who either regress or improve during episodes of fever." Is that okay?

Ms. Redwood: Yes.

Dr. Solomon: Great.

Dr. Hann: Could I ask about that one? I mean there is a research opportunity now on regression. It is the very last research opportunity in Chapter 2, right before you get into objectives. It has, "Prospective research on children with language regression, both with and without autistic regression, including potential underlying genetic and other risk factors, including seizures and epilepsy."

Dr. Solomon: That's okay, yes.

Ms. Redwood: It is more than just language regression.

Dr. Hann: Pardon me? I'm sorry, Lyn, I really didn't hear you. I'm sorry.

Ms. Redwood: I'm sorry. My phone is acting up.

The only thing with that is I think it is more than just language regression. It is regression in behavioral skills. Some children stop eating. They stop interacting.

Dr. Dawson: So maybe we just take out the word "language".

Dr. Solomon: Yes, let's take out the word "language".

Dr. Dawson: And then add "fever" to the end.

Dr. Solomon: Yes.

Dr. Hann: Does anyone have any alternative language to that?

(No response.)

So, we are going to take out -- so it would be, "Prospective research on children with autistic regression, including potential underlying genetic factors, other risk factors, including seizures, epilepsy, and fever."

Ms. Redwood: The only thing that that won't capture is the children who actually have autism and improve with fever.

Dr. Dawson: Is there one on immune that we could add that to?

Dr. Hann: Yes, there is. There is short-term A concerns immune. So, short-term A currently reads, "Support at least four research projects to identify mechanisms of metabolic and/or immune system interactions with the central nervous system that may underlie the development of ASD during the prenatal/postnatal life."

Dr. Dawson: So you could add "including studies of alterations in behavior related to fever".

Ms. Singer: Have we now -- oh, I see. That is not an objective. Okay. Forget it.

(Laughter.)

Dr. Hann: Okay. So, we have --

Ms. Redwood: I think that would work.

Dr. Hann: Okay. So, we have the idea of adding "fever" --

Dr. Solomon: "Fever" to short-term A.

Dr. Hann: Right. And modifying the language to the last --

Dr. Solomon: Taking out "language"; just talk about regression.

Dr. Hann: Yes.

Dr. Solomon: And I believe there are multiple studies underway of that.

Dr. Hann: Okay. Go ahead, Marjorie.

Dr. Solomon: Okay. And then, for short-term objectives, I think we actually decided that there weren't really any new ones to be added because, Lyn, that will take care of, we already have the regression point. So, I hope you are okay with that.

Then, my big concern was that we had a lot of studies in our portfolio that were unclassified. But working with the Committee and with the Office, we decided that probably it is not a big issue this year, but in the coming years we will work together to find a way to classify the 40 to 50 percent of studies that don't really fit neatly into a category. We didn't just want to go ahead and put in a bullet point, an extra bullet point, when we are already meeting the objectives of studying those things.

So, we will work on that next year, and that will solve the concern.

Dr. Hann: Yes?

Mr. Ne'eman: I am not proposing any new objectives for the short-term objectives section, but I notice the new objectives from last year, D and G, they both relate to genetic research. Well, more G really, honestly, more G than D.

And in light of the conversation we had earlier today about the importance of including ethical, legal, and social implications in the context of existing genetic research studies, I wonder if we might modify objective G to mention, also, including consideration of the ethical, legal, and social implications of these genotype studies.

Dr. Solomon: You know, after the conversation we had at lunch, it is sort of occurred to me that the idea we came up with for the family issue, where we had the self-determination, we wanted to include families, but we didn't want to eliminate an individual's right for self determination, maybe we should include the ethical and legal point upfront as either a cross-cutting theme or as a core value.

Mr. Ne'eman: So, I'm very comfortable with that, except I proposed it before lunch, and I think people weren't so comfortable with it. But if we are comfortable with it now, I mean --

Dr. Solomon: Well, it's a work-in-progress.

Mr. Ne'eman: Yes.

Dr. Solomon: I think it works.

Mr. Ne'eman: Okay. I guess we were just hungry before.

Dr. Solomon: Yes.

(Laughter.)

Dr. Hann: Everybody needs a little sugar in their systems.

Mr. Ne'eman: I will write something up for a cross-cutting theme around that and send it --

Dr. Hann: So, the question I have for you, I don't mean us to necessarily go back into the introduction at all, but truly do you think it is a cross-cutting theme or do you think it is a core value?

Mr. Ne'eman: I have to look it over --

Dr. Hann: Okay.

Mr. Ne'eman: -- and think about that.

Dr. Hann: Because the core values are written very succinct, and then there's usually several sentences to go with cross-cutting.

Mr. Ne'eman: I think it's a cross-cutting.

Dr. Hann: Okay.

Dr. Solomon: Okay. And then, is that okay with everyone? Okay.

So, we didn't add any objectives. Yay!

As exemplified, you know, in looking at the portfolio analysis, it really looks like autism research is proceeding at a very brisk pace in our Question 2. There's a lot of promising studies. We just also wanted to call out the fact that there's a lot of new investigators from other fields entering autism, and young investigators entering our field, I think largely due to the wonderful mentorship and training programs that all the funders are underwriting these days.

Ms. Singer: Lyn, do you want to talk about the Safety Committee's objective? I'm actually looking at short-term objective E. And I am wondering if, rather than add a new objective -- the objective that the Committee wanted us to bring to this Committee was a new objective about the underlying biology of wandering, especially in nonverbal individuals and those with cognitive impairments.

I am thinking maybe it fits in

objective E. "Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures, sleep disorder...." Can we add "wandering" to that list?

Lyn, do you think that would reflect the decision of the Subcommittee?

Ms. Redwood: Well, actually, I had looked at adding it over under G, when it had "behavioral and medical phenotype", and as an example, "nonverbal individuals with ASD, those with cognitive impairments, and wandering behaviors".

Ms. Singer: But that's talking about associating genotype and phenotype. It is not really getting at underlying biological mechanism.

Ms. Redwood: I guess I was thinking that, if they identified structural abnormalities, it would help to identify underlying mechanisms. But I'm fine with it in either place.

Ms. Singer: So, I think it goes more with E.

Dr. Hann: Yes. I think, given what you described, too, Lyn, I would see that more falling with E.

Ms. Redwood: Okay. That is fine.

Ms. Singer: Because I don't know how we would genotype.

Ms. Redwood: How do you genotype wandering?

Ms. Singer: Well, possibly through fMRI. I mean if there's some way to put, I'm hoping like Jamie McPartland will do the cap and we will find some sort of structural --

Dr. Solomon: Yes, impulse control.

Dr. Hann: Okay. So, we could add wandering to the current short-term objective E as another group.

The other one, you all may have talked about it, and I may have sort of spaced out for a moment, and I apologize. On the update on the last, the very last, little bullet on page 2, "Studies to investigate metabolic pathway `pertur'" -- I'm not going to be able to say that right. But, anyway, "that affect immune function methylation and redox homeostasis".

Dr. Solomon: Can you tell me which line?

Dr. Hann: Oh, it's the very last bullet, there under "research opportunities".

Ms. Redwood: Yes.

Dr. Hann: So, you wanted to add that as a research opportunity?

Ms. Redwood: Yes.

Dr. Hann: Because I was wondering the relationship between that and short-term A.

Dr. Solomon: Yes, actually, it's probably already in A.

Ms. Redwood: Yes. The only thing that wouldn't be captured there --

Dr. Solomon: Metabolomics and microbiomics are not in there, and we could add that potentially to short-term A.

Ms. Redwood: Also, methylation and redox homeostasis isn't in there, either, which are two new real important areas of research.

Dr. Daniels: This is Susan.

With methylation, you might be wanting to talk more about epigenetics in general, not just methylation, because there are many other types of marks.

Dr. Solomon: That is a really good point. Epigenetics would be an excellent thing to put in there, something related to that.

Yes, it is actually in the text. That's right, it's in Chapter 3. It's in Chapter 3, yes. Yes, definitely, that is right, yes.

Ms. Singer: But it's a research opportunity, though. I don't think it's instructive, is it?

Dr. Hann: No, I think it is instructive. Wait.

Dr. Solomon: Yes, it is right here.

Dr. Hann: You found it?

Dr. Solomon: I found the objective.

Dr. Hann: What page?

Dr. Solomon: On page 20. That's the opportunity.

Dr. Hann: I could have sworn we added it last year.

So, that probably should be in Chapter 3, don't you think?

Dr. Solomon: Yes.

Dr. Hann: Yes. Okay. So, let's hold that. Let's put that in the Chapter 3 parking lot right now.

Dr. Solomon: Okay.

Dr. Hann: Epigenetics, we will take that back up.

So, the question remains, do we want to include this last bullet as a new research opportunity for Chapter 2?

Dr. Dawson: We did add that in 3, and when we get to it --

Dr. Hann: It will be there?

Dr. Dawson: Yes, we added it.

Dr. Hann: Oh, okay. It is starting to sound familiar.

Ms. Redwood: Can you use the microphone? I can't hear.

Dr. Dawson: Lyn, I was just looking ahead at Question 3, and we did add that as an objective. I mean we may want to talk a little bit more about your focus in it, but we have a bullet on epigenetics and methylation, et cetera, in Question 3.

So, why don't we, when we get to that, look at whether that could be tweaked to incorporate the issues that you are raising?

Ms. Redwood: That sounds perfect.

Dr. Hann: Okay. So, then, we are

not adding it as anything for this chapter. Okay.

Ms. Singer: Are they adding any of those others?

Dr. Hann: I'm hearing no.

Dr. Solomon: Those were the two that we said no to, I think.

Dr. Hann: Correct.

Dr. Solomon: Short-term objectives, no.

Dr. Hann: Right. Okay. So, just to summarize, if I have got it, there's a paper that will be added.

Dr. Solomon: I'm going to add the Persico paper on postmortem study.

Dr. Hann: Right.

Dr. Solomon: Thank you.

Dr. Hann: Then, folks were going to reword research opportunity 7 to have a focus just on regressive autism, not language pieces of it.

We are also going to be modifying

short-term A to include the concept of fever.

Then, we are also going to be modifying short-term E to include the concept of wandering as a group that could be studied.

Is there anything I'm missing?

Dr. Solomon: I think you did a wonderful job.

Dr. Hann: You deserve the credit, not me.

Okay. Wonderful. Let's move to 3, since we seem to be begging Chapter 3. Geri?

Dr. Dawson: Okay. So, Question 3, which has to do with what caused this to happen and how can it be prevented.

So, there was actually quite a bit in terms of new research in the last year. This pertained to both genetic and environmental findings, which are outlined in the first paragraph.

The second paragraph discusses the new data that was presented at the IACC meeting from the Autism Treatment Network on medical conditions, and, also, talked about a finding or a point that came out of the workshop that we had on environmental factors within NIEHS, and where some of the medical conditions like GI conditions appear in Parkinson's to be precursors of the onset of disease and that that may be important.

And then, we provided a brief description of the recommendations that came out of the meeting that the NIEHS and Autism Speaks cosponsored on environmental risk factors.

And then, we also talked about some of the new technologies such as pluripotent stem cells and other new technologies that may accelerate the discovery of environmental risk factors and their interaction with genetics.

And then, we included the findings of the report from the National Vaccine Advisory Committee, which it was a report that was requested by the IACC. So, we summarized the recommendations that came out of that NVAC Committee.

And we summarized the disparity between the focus on genetic research and environmental research that was evident from the portfolio analysis, with maybe too strong of an emphasis -- not enough environmental research as compared to the genetics.

So, that was the new. Anything that we are missing or comments?

Mr. Ne'eman: So, I suspect this perhaps should go last in this discussion of 3, but since nobody else raised their hand, I will put it forward.

You know, I respect that there are a great deal of differences of opinion on this point. But, in keeping with that, I would like us to try to maintain as neutral language as possible.

As a result, I think it is important to bring up that not everybody on this Committee or Subcommittee is of the opinion that autism should be prevented. As a result of that, I would suggest that we change the title of Question 3 to read solely, "What caused this to happen?"

Dr. Hann: Comments from the Subcommittee?

Ms. Redwood: I think that that type of question should go to the full Committee.

Ms. Blackwell: Yes. This is Ellen. I agree.

Dr. Hann: All right, we can do that.

Mr. Ne'eman: No objection here.

Dr. Dawson: Any other points with regard to the new research or findings?

Ms. Singer: I'm wondering if it would be worthwhile to send this paragraph about the NVAC finding to the NVAC to just confirm that it reflects its point of view accurately. Can we do that? Can we send it over and make sure that they feel comfortable --

Ms. Redwood: Alison, it is taken verbatim from their report.

Dr. Dawson: Yes, I took it verbatim from the report.

Ms. Singer: From their report?

Dr. Dawson: It is literally a quote from the report. I didn't paraphrase it in any way.

Mr. Ne'eman: You could put it in quotes.

Dr. Dawson: So, moving on, what gap areas have emerged? And some of these were identified through the NIEHS Autism Speaks workshop, which was the need for suitable model systems to study environmental risk factors and their interaction with genetic susceptibility.

The need for expansion and integration of epidemiological studies that combine data on both genetics and environment and include standardized protocols for the collection of data. And there is a need for greater collaboration between genetic and environmental science investigators, and there is a need for focused work on the role of epigenetics, including sensitive assays to measure things like DNA methylation and histone modification and epigenetic marks.

We underscored the fact that the lack of adequate postmortem brain tissue continues to be a major barrier in progress to understanding the neurobiolology of autism, and then there is a need to increase the analytic capacity in core facilities to study some of these complex interactions that require large datasets.

So, anything there in terms of feedback from the Subcommittee?

(No response.)

Dr. Hann: Okay. Hearing none, let's move on to the research opportunities and objectives.

Dr. Dawson: Okay. So, the new research opportunities and objectives, the first is to -- and what I did here is actually to pull together and combine several that were fleshed out as several bullets before. But these are at least three epidemiological studies that take advantage of special populations or expand on existing databases to understand environmental risk factors for ASD in pregnancy and during the early postnatal period.

Then, we go on to call out different populations that would be of interest, which you can read there. There's many of them.

This is Walter's addition here. The influence of environmental factors on the prenatal and early postnatal period is of particularly high priority.

And then, the second is to support a workshop that explores the usefulness of bioinformatic approaches to identify environmental risks.

Dr. Hann: I have a question, actually. Let me, if I could, go back to the first one that you just mentioned?

Dr. Dawson: Sure.

Dr. Hann: The last sentence, and this is on environmental factors that influence prenatal and early postnatal developments, particularly of high priority. Is that only in -- because then it goes, "with special attention to racially- and ethnically-diverse populations". So, you only want to do it in ethically-diverse --

Dr. Dawson: Yes, I was thinking about that myself.

(Laughter.)

Yes, I think it might need to be two sentences.

Dr. Hann: Yes, exactly.

Dr. Dawson: So, then, we have a workshop, which I have already mentioned. Then, let's see, where am I here? Okay.

Then, let's see, "Support at least two studies that examine the potential differences in the microbiome of individuals with ASD versus comparison groups."

And perhaps I should add here that Linda Birnbaum wrote in a comment that she felt that this was premature. I do remember Tom going "Yay!" when we added it before. So, obviously, there's a difference of opinion there.

So, I think both feel it is important. I think the question is, are we ready to do it? She thought it would be better to have a workshop on it.

So, I don't know if you want to discuss that now among the Committee before we go to the next.

Dr. Hann: Well, I think it would be worthwhile to see if the Committee has any thoughts about that in terms of, since Linda weighed-in on it, and that is one of her areas of expertise.

Ms. Redwood: The only comment I have is that I would hate to slow down researchers who are already working in this field. When we say we are going to have a conference on something, typically, they don't happen when you look back. Last year, we identified several conferences, and they weren't funded. So, I think that may have the potential of slowing down that research if we identify having a conference instead. It might be good to bring it up at the full Committee and leave it there for now, when Linda can explain why she thinks that it is not ready for primetime yet.

Dr. Dawson: Yes, I think we could certainly have Linda be able to represent herself and certainly, since this is her area of expertise, she, I'm sure, has some very important comments.

I think the reason why we put this in as a study is kind of twofold. One is that there has been already some meetings on GI, and they have included extensive discussion/workshops on the microbiome. So, I don't know if that would be repeating that.

And, you know, I think it is one of those things where if you just study it -- I am not sure what a whole workshop, what you could discuss, you know, because there's no data. So, I am not sure exactly what the discussion of the workshop would be, but Linda may have very specific and good thoughts on that.

Okay. Now we get to the new bullet on epigenetics, including studies that have assays to measure DNA methylation and histone modifications and those that explore how exposures may act on maternal and paternal genomes, the epigenetic mechanisms to alter gene expression.

So, Lyn, do you feel that -- that doesn't exactly address, I think, what you were interested in, but is there some way to fold what you are wanting to put in into this?

Ms. Redwood: Hold on. I'm going back to look at the other one.

Is there a way that we could include something on redox homeostasis and oxidative stress? Or do we already have specific objectives in here that deal with oxidative stress? I guess that would be my only suggestion there, is if we could expand it to include those two areas.

Dr. Dawson: I think if we want to focus on oxidative stress, we may want to -- isn't there a place where we talk about mitochondrial disorder?

Dr. Hann: That's in 2.

Dr. Dawson: It's in 2? Yes, I wonder whether this really does fit under 2. Now that I am reading this one, I actually am now thinking that maybe it fits better under 2 in terms of the underlying biology. Because we don't know if these things are a cause or a consequence. So, I don't think we're ready to put it into what caused autism, but we need to understand it, obviously, as a major underlying biology.

Dr. Solomon: Perhaps under short-term objective A, mechanisms of metabolic and immune system interactions and oxidative stress?

Are you okay with that? I think there's no objection here.

Dr. Hann: Okay.

Ms. Redwood: If you could put in redox homeostasis, too, and oxidative stress because they both go together.

Dr. Solomon: Lyn, I'm sorry to be ignorant about this, but could you explain a little bit more about what that is?

Ms. Redwood: A lot of the work of Jill James has found that children with autism have a lot of markers where they are much more oxidized. Their glutathione is oxidized.

Dr. Solomon: Right. I'm sorry. Yes, I remember.

Ms. Redwood: Coming out of the

work of Jill James.

Dr. Solomon: Yes.

Ms. Redwood: Also, some of the work of Mark Noble with redox homeostasis imbalances. That is the literature that I am citing.

Dr. Solomon: Yes.

Ms. Redwood: And then there is also, I think, in the -- hold on a second. Let me grab the one that I wrote initially for, I think, Chapter 3. Because when I first started the update before we were instructed to just do the bookends, I had citations in there for it.

Dr. Solomon: Yes. No, I know Jill James' work. I'm sorry, it is not my area of expertise.

Is it really a form or related to oxidative stress? So, could it be incorporated under the term "oxidative stress"?

Ms. Redwood: I think that would

cover it --

Dr. Solomon: Okay.

Ms. Redwood: -- because they both go together. Your redox homeostasis is what determines whether or not you are under oxidative stress.

Dr. Solomon: Perfect. Okay. So, then, we all agree, I think, that it belongs in 2 in that way.

Dr. Hann: Okay. So, we will add the concept of oxidative stress --

Dr. Solomon: To short-term objective 2A.

Dr. Hann: Right. And that is the one that we are also putting fever in, too?

Dr. Solomon: Yes.

Dr. Hann: Okay. Okay, good.

Dr. Dawson: Okay. So, the last one is to support studies and workshops that facilitate the development of vertebrate and invertebrate systems for exploration of environmental risks and their interaction with gender and genetic susceptibilities for ASD.

Dr. Hann: Any additional comments on these new objectives?

(No response.)

So, we have one, two, three, four, five, right? Great.

Geri, you're still on.

Dr. Dawson: Okay. So, moving ahead to Chapter 4, which treatments and interventions will help?

Dr. Boyle: Geri, may I just interrupt? This is Coleen, and I apologize.

I'm going to have to leave the call. So, I enjoy working with all of you, and I will see you on the 14th.

Dr. Dawson: Okay. Bye, Coleen.

Dr. Hann: Thanks, Coleen.

Ms. Blackwell: Yes, thank you, Coleen.

Dr. Dawson: Okay. So, Question 4, which treatments and interventions will help?

We started by noting a number of studies that had been published in 2010, which you can all read there. I will be adding the Connie Kasari study that we are moving to Chapter 4.

Then, in terms of gap areas, so we highlighted the fact that the research in the area of genetics is moving ahead very quickly. So, this really points to the urgency to translate these findings into identifying subgroups of individuals with autism who may be more responsive to specific medication or intervention approaches; to inform signaling pathways that may be affected in autism for the development of animal models and for the discovery of targets for developing therapeutics.

We talked about the continuing need for autism intervention networks, and we also again included the information that was presented to the IACC. And I guess there is this question of whether we need to have that in both places.

But, in this particular one, we also refer to the consensus statements that were published in 2010 on the assessment and treatment of GI conditions.

And then, we also reviewed the findings and recommendations of an NIH-sponsored workshop on children who have not developed functional language.

And we also included a need to focus on addressing the health disparities for people with autism.

And that's it for the gap areas.

Then, finally, for the new objectives, five community-based studies that assess the effectiveness of interventions and services in the broader community, including studies of widely-used community interventions for which there are not a lot of data for their empirical effectiveness.

And then, to support five studies on interventions for nonverbal individuals with autism. We describe in detail the types of studies that would be helpful.

And then, third is two studies that focus on research on health promotion and the prevention of secondary conditions in people with autism, including overweight and obesity, injury and co-occurring, psychiatric and medical conditions.

I will say, in terms of comments from Tom, he has felt that perhaps although this is a laudable objective, that in the spirit of focused priorities, that this one may not be needed. And others of us on the Committee advocated that actually we think this is quite important. So, there was quite a bit of back-and-forth in terms of the working group on this.

I think some people felt like this was kind of part and parcel of the treatment of co-occurring conditions which is addressed earlier. But I think Coleen and I both felt fairly strongly that this is really different than that because we are talking about prevention of secondary conditions rather than treatment of them.

So, this may be something we want to bring to the whole Committee.

Ms. Singer: So, on objective 1, are you talking about studies that look at interventions that are delivered in community settings or are you looking at conducting the research in community settings? I'm not sure what that clause is modifying or if it is intended to modify both.

Dr. Dawson: I think this would be both. Yes. So, the idea is that most of these studies thus far have really been conducted in university laboratory settings and that we are now ready to assess them in community settings. That could be either interventions that have already been assessed in smaller settings, moving them out, or it could be the interventions that are already being used in the community, but have not really been studied for their effectiveness.

Dr. Hann: Is this the objective that you were thinking of having the peer support?

Ms. Singer: I mean Connie's study would fit in this. She studied a community-based intervention in a community setting. A school is a community setting, and the intervention is delivered in a school, and she studied it in a school.

Dr. Dawson: Right. So, that's the kind of study that we are encouraging.

Dr. Solomon: So that would fit in here? Okay.

Dr. Dawson: I guess my question about the peer interventions, now peer support may be something different. But, as far as peer interventions, I mean that is not anything new. I don't know why we would call that out. I can think off the top of my head of a dozen peer-mediated interventions that have been going on since, I mean, really the very first studies of early intervention of autism were peer-mediated. So, this is not --

Dr. Solomon: There is not anything novel.

Dr. Dawson: What is novel about that one is that it is a community setting really.

Dr. Solomon: Yes, but all of these would be novel in a community setting, right?

Dr. Dawson: Right.

Dr. Solomon: That's what I mean. So, I don't know why we would call out peer interventions.

Dr. Dawson: No, I know. No, I'm just saying --

Dr. Solomon: Well, I think it also stemmed some from the Services Subcommittee meeting where peer intervention for adults was discussed.

Dr. Dawson: Yes, that may be more novel.

Dr. Solomon: Yes, that may be how we think of it differently.

Mr. Ne'eman: I think my microphone, oh, now it's kind of working, half of it. I don't know.

No, just to explain, I think the issue was initially raised in the context of human services settings where it is more novel, particularly in the autism field. So, I think that was, to some degree, what we were responding to.

Ms. Blackwell: And, Geri, this is Ellen.

I'm looking at Connie's paper, which several others brought up earlier. You know, it looks like the only thing -- again, in the context of what is new in 2010, I don't know if this is new, but if you were going to bring it up, I guess you could bring it up in terms of the conclusion drawn by this paper and maybe any other papers that came out this year.

Which is to say that promoting children with ASD skills to share with peers earlier on may be a key preventive intervention to protect social relationships in later grades.

Dr. Dawson: I'm happy to include it. It's a great study, and I couldn't agree more about the importance of peer, you know, whether it is inclusion and with interacting. I mean, for example, Cathy Lord's longitudinal study where they looked at the predictors of best outcomes and the opportunities to interact with typically developing peers was cited as one of the most important early predictors of positive outcome.

And honestly, there are just a lot of peer-focused interventions, and they have empirical support, and they have even been done in RCTs.

But we could include Connie's. It's a beautiful study, and it's great. It is just not like changing the course of what we're doing in intervention.

Ms. Blackwell: Yes, I understand.

Ms. Singer: I disagree. I look at that study, and I say maybe we have to create a new category for it. Because it is an example of taking research, picking up the paper that was published, going to your Director of Special Education in your school district and your Board of Education and saying, "This is an intervention we have been talking about for years. Now there's data. Here's the research."

It's a cost-effective solution, and what that study has done, it has allowed a lot of parent groups at school districts to bring this now evidence-based research. And if it has been evidence-based for a while, so be it. But now that we have this paper particularly, we are able to get it into schools.

So, maybe what we have to cite it as is an example of how we bring research into the community or how we can disseminate that research to affect positive change, real change for real people.

Dr. Dawson: I'm happy --

Ms. Singer: But it has been a game-changer.

Dr. Dawson: Yes.

Ms. Singer: That piece of research has been a game-changer.

Dr. Dawson: Well, I'm happy to include it, and I love the paper. Like I say, it is a beautifully-executed study.

I will say that I have brought in other empirical studies of peer to my own school districts and advocated effectively. Because, I mean, really, this has been around for a long time. If this is more ammunition for people to do that, that's great. But there are other studies out there, which just shows that it is effective.

Mr. Ne'eman: I have an issue, actually, to raise in terms of something that

I think should be added to the "What's new in this research area?"

You know, we have discussed in the past both including new research and new policy and new conference proceedings, and this may fall into a little bit of all three.

In August, the Institute for Education Sciences conducted, as part of their "What works?" clearinghouse, conducted a review of the Lovaas model of applied behavioral analysis and came to a number of conclusions as to the quality of the evidence base that is often utilized to support it.

I would like to suggest that we include mention of their report and some of their findings.

Ms. Singer: What were their findings?

Mr. Ne'eman: Well, I could send you a copy of the report. That the model, according to the "What works?" clearinghouse criteria, the Lovaas model has potentially positive effects on cognitive development, no discernible effects on communication/language competencies, no discernible effects on social/emotional development and behavior, and no discernible effects on functional abilities.

The Institute for Education Sciences is the research arm of the Department of Education.

Dr. Solomon: And they are doing wonderful education research, and I think that Connie's study, one of the wonderful aspects of Connie's study is that it does help researchers to see how you can implement.

In intervention research, I think we go to do a manual, and take your manual and test it in an RCT. In the school setting, that's often less feasible.

So, what Connie's study is very novel in is that it is a large-scale, good implementation in a school system of an evidence-based treatment. And I think that across the country -- and this is some of my own sort of thinking that I have been doing here on the line between services and interventions -- is now that there's a couple of groups in the country trying to develop evidence-based practices for schools. There's the National Professional Development Group with Sam Odom. There's David Mandell's group. So, I think there's a lot of groups kind of looking to provide an evidence base.

IES has put out RFAs that are aimed at helping cognitive scientists, behavioral scientists come up with evidence-based practices that can be put into schools. And it is difficult in a school to really implement a manual that an experimental psychologist would want to use for an RCT because often the fidelity to the implementation of a manual is very challenging.

Mr. Ne'eman: And I think this speaks to the fact that we want to be encouraging this kind of research. As a result, when reviews of evidence-based do come out, particularly from, you know, a major research arm of the federal government, it is incumbent upon us to incorporate them in our strategic plan.

Dr. Dawson: So, first of all, I like that idea in terms of framing Connie's study. I think we should mention the peer part of it, but I think the real novel game-changer part of it is the implementation aspect of it. So, I do think if we put in there, that will strengthen that bullet.

And, yes, I mean I'm happy to include that. There have also been, then, some other reviews and things that have been published this year, too. We will need to kind of include that whole -- there's been a lot of meta-analyses and things. So, if we want to include a whole section on what has come out in 2010, and the evidence for early intervention, we certainly could do that.

Dr. Solomon: Also, I would just say there is going to be a special interest group at this year's MFAR on school-based interventions. And the group, it is a very mixed group, consisting of individuals who are more university-based researchers, but are trying to move their interventions into the community. So, I encourage you all to attend the school-age intervention SIG at MFAR.

Dr. Hann: Any other comments with regard to Chapter 4?

(No response.)

Okay. Hearing none, let me see if I can capture what it is we have just discussed.

It sounds like the "What is new?" section will be expanded to include the Kasari study as well as some other work. Ari brought up the Institute for Educational Services work and others, in terms of developing the evidence base for early interventions. Right? Good.

And that was primarily it.

Mr. Ne'eman: One more thing.

Dr. Hann: Okay.

Mr. Ne'eman: Yes, in what gap areas have emerged since last year, we mentioned at the end a 2010 congressional briefing held as part of the Advancing Futures for Adults with Autism Initiative.

My impression is that the purpose of congressional briefings is, in fact, to present information that already exists, not to determine new information or to discuss and come up with new ideas or program models. I guess I have some question. I guess I would question the degree to which this belongs in the strategic plan.

Dr. Hann: Comments?

Ms. Blackwell: Well, this is Ellen.

You guys told me earlier to take it out, take mention of ASA and Autism Speaks' efforts out of the other chapters. So, it seems like that would be concurrent with that other request.

Ms. Singer: Yes, I agree.

Dr. Dawson: I'm fine with that. I guess, you know, it is an important, I think, new development that there is an initiative on advancing futures of adults with autism that represents a large coalition, and that they were able to hold a congressional briefing on that.

But if people feel like that's not relevant to what happened in 2010, you know, a major part of that was recommendations around services research that was needed to the Congress. So, that seems kind of relevant, but I think we could take it to the full Committee.

Mr. Ne'eman: I mean I guess my question would be, and if you want to take it to the full Committee, I'm sure we can, but my question would be there are many congressional briefings; there are many agendas that are taken to Congress. You know, none of that represents either research done or legislative or policy initiatives undertaken.

So, I guess I find it difficult to imagine how this could be presented as something new to 2010.

Dr. Hann: Thoughts from the group?

Ms. Blackwell: This is Ellen.

I actually think, if you want to leave it in, you should restore the language, take it out of 4. And I had one sentence alluding in Chapter 6 which pertains to adults. It was that, "In 2010, advocacy groups, including the Autism Society of America and Autism Speaks, devoted resources to initiatives on adult services and supports."

But, again, I was told to strike that earlier. So, I think you either need to leave that one sentence in 6 and take this out of 4 or take them both out. That's my feeling about it.

Dr. Dawson: I think we should take this to the whole Committee because I think we are making sort of a policy decision about the strategic plan of whether we include congressional briefings about autism that occurred that year that made from the community recommendations for research. And if we decide not to, then I think that is fine.

Ms. Singer: But that wasn't Congress, a congressional committee called for testimony. This was just a presentation. I mean I think it is exactly similar, exactly what Ellen is saying. It is exactly the same as the one we took out from the other chapter, where it's advocacy groups did this; they talked about -- I mean it was a great presentation, but it wasn't really, it didn't create a research agenda. New research wasn't discussed. It was just a presentation.

So, I think we have to either

leave them both in or take them both out.

Dr. Dawson: Actually, it did develop a research agenda.

Mr. Ne'eman: Well, let's just be clear as to what a congressional --

Dr. Dawson: But it came from the community rather than science -- actually, it did create a research agenda very specifically with numbers of dollars requested, with gaps in the research that existed. And I think it is the voice of the community, you know, at least a part of the community. I think that is important to represent in our strategic plan because why are we doing this if we are not trying to address the gaps that the community has identified.

I think we could decide as a larger group that we don't want to include congressional briefings. I think I would certainly stand with whatever the vote of the full Committee goes on that. But I think it is not a Subcommittee decision to strike that kind of information from the strategic plan.

Mr. Ne'eman: So, I mean I just want to be very clear, in case anybody is unfamiliar, as to what a congressional briefing is. Like Alison said, it is not a hearing. Essentially, what a congressional briefing is one rents a side room in a congressional building or in a building nearby, and one invites as many Members of congressional offices as one can convince to come. So, it's not something that actually holds any kind of official status.

By way of example, in the past year, there has also been very relevant congressional briefing from TASH, a social justice organization, for people with disabilities, on restraint and seclusion, and another one on inclusive education. I think some of the other organizations and the IACC have also presented congressional briefings.

I think between the 20-some-odd people who are represented on the IACC, we could probably come up with a good dozen congressional briefings that occurred in 2009 and 2010.

So, I mean, I find it very difficult to understand, even if we were to decide that congressional briefings should be included here, and I can't imagine why we would, why we should be highlighting this one in particular.

Ms. Blackwell: This is Ellen.

I have to say that I agree in Ari. In some ways, I don't think it is really equitable to mention one group and not all the others and the work that they do.

And then, I also have an issue with putting an item about adults in Chapter 4 when the appropriate place, if this were even included, and we took it out earlier already, was in Chapter 6.

Mr. Ne'eman: Anybody outside of Geri feel this should be included?

Mr. Grossman: I agree with Ari.

I mean there is a significant group out there that Ari's group has been involved with, the Coalition for Promotion of Self-Determination, that has been working on adult services across multiple disability groups and puts on numerous congressional briefings per year. It has introduced legislation. It has talked about research.

So, there are a number of these initiatives that are currently going on. Yes, I don't know why it would appear in a research strategic plan.

I, myself, have participated in at least four congressional briefings in the last year, and probably do that on an annual basis for like the last five or six years.

The relevance and importance generally are not that great because we are the ones hosting and sponsoring it and putting it forward. It is what you do afterwards that goes head in, and it is entirely public policy. It's not research necessarily.

Dr. Hann: Okay. I'm seeing a lot of nodding of heads at the table.

So, there were two, actually, three, but given the nods of the heads, there are sort of two ideas on the table. One is to strike it at the Subcommittee level. The other is to allow it to go forward for discussion at the full Committee.

Those in favor of striking now?

(Show of hands.)

One, two, three, four. Four in the room.

Anyone on the phone?

Ms. Blackwell: Strike. Ellen.

Dr. Hann: Five to strike now.

Those opposed?

(Show of hands.)

Two in the room.

Anyone on the phone?

Ms. Redwood: I sort of agree it should go to the full Committee for a decision. This is Lyn.

Dr. Hann: Okay. So, we had five to strike and three to take it --

Dr. Dawson: And I would just like to clarify that I think it is not so much this specific one. What I feel is important to reflect in the strategic plan is the voice of the community. And I know there's many voices, and I think all of those voices should be represented.

And if we had, just like we have paragraphs on workshops, right, which don't have any teeth in terms of what they mandate, but it does represent real commitment and people pulling together to try to move the field forward.

And if there were paragraphs that summarized, you know, we have five congressional briefings this year, right, that reflected issues around the urgency for needs on these issues, to me, I think that is important. But I, obviously, will concede to the vote of the Committee.

But I do think those are very important to reflect somewhere because we don't have that many opportunities to reflect the larger voices out there that I think care about the strategic plan.

Mr. Ne'eman: I just want to mention a little bit about the variety of different coalitions that exist out there, because I think Geri is right; there is a wide variety of different groups in the community, all of which I think have done congressional briefings or are planning congressional briefings, and have done substantive work on behalf of the autism and disability community.

I mean, just off the top of my head, Lee mentioned the Collaboration for the Promotion of Self-Determination. There's a Consortium on Citizens with Disabilities, a Justice for All Action Network, the Alliance for the Prevention of Restraint, Aversive Interventions and Seclusion, Community Access Now, the Coalition of Organizations for

Accessible Technology, Alliance for Full Participation --

Dr. Dawson: Excuse me. I'm not saying that we should include a listing of every --

Mr. Ne'eman: I could go on.

Dr. Dawson: -- advocacy group. I'm saying, if there are things that occurred that year that are congressional briefings around specific topics where people have organized themselves to express --

Mr. Ne'eman: There are dozens.

Dr. Dawson: Right. So, I think they should be captured is what I am saying because I think it is a voice of the community. So, that's all I'm saying.

I'm not trying to say this specific one is more important than any other one. I'm trying to say that I think those kinds of activities, like we are, for example, including some mention of people who are writing in to make a public comment on our plan. And yet, if people go through the effort of organizing major briefings where people have a lot of passion about this, it may be worth putting in the plan.

But, like I say, I mean, obviously, I concede to the vote of the Subcommittee.

Dr. Hann: Marjorie?

Dr. Solomon: And I agree with Geri that it is really kind of a policy issue. You know, what can get into the plan? And I think that it might spark a deeper discussion of that.

I mean, for instance, we put in the plan in Chapter 3 a meeting, a random meeting that occurred about aging.

Dr. Dawson: Yes.

Dr. Solomon: So, what are the standards by which something rises to the level of making it into the plan or not being okay for the plan? Just in the name of sort of fairness of what gets in, I think it is a reasonable discussion for us to have.

Mr. Ne'eman: So, I just want to clarify here. It is not simply that I think that the Subcommittee seems to feel that congressional briefings are not appropriate as a medium to put in the plan. It is also that we have no means of determining which of the dozens of congressional briefings from considerable numbers of different coalitions which represent the autism and disability community should be included.

I think the meeting you were referring to on aging, I think the reason it is in there is, at least to some degree, it was unique. And if we are not talking about calling out this specific one, I am not exactly sure what you are proposing, Geri, that we should have a sentence that says, "There were some congressional briefings that occurred this year on autism and related issues." I don't know how that is novel or useful.

Ms. Blackwell: Well, this is Ellen.

That is the sentence that I put in Chapter 6, and maybe the Subcommittee is interested in revisiting writing just sort of a broad-based statement that could be in Chapter 6 related to adults, which is what this targets.

Mr. Ne'eman: I mean I think our critical component here is that we should not be privileging any particular coalition or group, given the wide number and variety that are out there.

Dr. Hann: Ellen, can you help us with Chapter 6? Where was that originally?

Ms. Blackwell: Hold on just one second here. Of course, I am sure all of you are surrounded in papers.

Under page 2, gaps, I put in a sentence that said, "In 2010, advocacy groups" -- and I limited it to groups that participate on the IACC -- "including the

Autism Society and Autism Speaks, devoted resources to initiatives on adult services and supports."

I thought that sort of took the place of that previous sentence and it acknowledged that others were also, you know, others that belonged to the Committee were also looking at adult issues.

Mr. Ne'eman: So, I mean, I think there are certainly more groups than that that devoted resources to initiatives on adult services and supports.

Ms. Blackwell: Well, I just said "including", Ari. I didn't say --

Mr. Ne'eman: Well, no, I realize that, but I think this goes back to our initial point. If we are going to call out any groups, we need to call out all groups.

Now I know ASAN is on that list. I imagine, Lyn, SafeMinds may have done something. Alison, have you guys done anything related to adults?

Dr. Hann: So, I would like to sort of move this along a little bit. It sounds like we have a larger discussion to convene with the Committee, more so than just the inclusion of one sentence.

It sounds like what I am hearing people say is, I think Marjorie said it last, which was, what is it that makes it into the plan? And are advocacy meetings, particularly congressional briefing advocacy meetings, something that belong in the plan?

And I believe that is a different discussion, and I don't believe we are going to get resolution today. So, what I would like to suggest is that we bring that to the Committee. Because I think, too, in the interest of fairness, if there is a decision by the full Committee to include those types of things, we have to do a wider canvass to find out what all of them are. Because right now what we have is sort of sparse, based on our individual histories, but there would probably need to be a little bit more systematic attempt to sort of figure out what those are, if, indeed, those kinds of things are to be included into the plan.

Mr. Ne'eman: I think that makes a lot of sense, Della. I guess just the two things I would say is I would extend the question to not just address what congressional briefings, whether or not congressional briefings should be included, but I would also extend the question to ask whether or not and, if so, under what conditions we should call out initiatives belonging to particular groups or factions. I think that is also a relevant question.

I would also ask, if we can, when we present this to the Committee, or if we can reflect in the notes, the substance of the vote we did take on this.

Dr. Hann: Yes, absolutely.

Okay. So, for now, this sentence will go away, and this discussion will occur.

Does that sound -- okay, I'm seeing a lot of nods.

Anybody on the phone disagree with that idea?

(No response.)

Okay. So, we have worked through all the chapters. Congratulations, everyone.

Everyone has homework assignments, it sounds like, to be busy working on. I am not going to run through them all right now.

But it sounds like, in terms of this particular chapter, I didn't do my due diligence with this particular chapter. The major change is in the beginning with regard to the Kasari, the intervention studies, Connie's studies, and framing it in terms of the evidence base for early intervention. That was the major thing that I heard in terms of an addition to this particular chapter.

Mr. Ne'eman: And the IES.

Dr. Hann: Yes, that's part of it. That's part of that, yes.

What's the matter, Marjorie?

Dr. Solomon: I'm just wondering, there's a couple of things I think we maybe could clean up even before we went away. I'm trying to think. I was just wondering if I should bring that up.

Dr. Hann: Yes.

Dr. Solomon: Ari and I wrote an objective that we would need a little approval on. So, just to get it off our plates.

Dr. Hann: That would be fine. Which chapter are you --

Dr. Solomon: And I think you were saying Alison has one as well.

This was in the adult Chapter 6.

Dr. Hann: Okay.

Dr. Solomon: And we were grappling with the issue of transition, as you remember.

Dr. Hann: Yes.

Dr. Solomon: So, I was to redraft an objective that represented sort of a compilation of what was already in the plan about comparative cost-effectiveness, comparative effectiveness, I mean. That was going to dovetail with new objective C, which is on page 36.

And so, new objective C, which is on 36, currently reads, "To conduct comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services, and supports, to improve health outcomes and quality of life for adults on the spectrum over age 21 by 2018."

And working together, we changed it to be, "Conduct comparative effectiveness research with a cost-effectiveness component to examine community-based interventions, services, and supports, to improve quality of life with a focus on the transition from secondary education."

Ms. Blackwell: Marjorie, this is Ellen.

Could you read that slowly one more time?

Dr. Solomon: I'm sorry, Ellen.

Ms. Blackwell: Okay.

Dr. Solomon: This is hard, I know.

So, we are going to redo new objective C to say, "Conduct comparative effectiveness research with a cost-effectiveness component to examine community-based interventions, services, and supports, to improve quality-of-life outcomes with a focus on the transition from secondary education."

So, essentially, we just added, basically, just added onto the end of the current bullet. We changed -- we had "health and life satisfaction and quality-of-life outcomes". We just collapsed that based on the discussion to "quality-of-life outcomes", and we put "with a focus on the transition from secondary education".

Dr. Hann: Okay, folks feeling comfortable with that change?

Ms. Singer: Read it one more time.

Dr. Solomon: I'm really sorry.

It is very much the same as the current bullet that is there.

"Conduct comparative effectiveness research with a cost-effectiveness component to examine community-based interventions, services, and supports, to improve quality-of-life outcomes with a focus on the transition from secondary education."

Somebody on the phone has a lot of stuff going on in the background. Thank you.

Mr. Grossman: Do you want to use that word "with a focus" or do you want to set it as a priority?

Mr. Ne'eman: "Prioritizing the transition from secondary education"?

Mr. Grossman: Or "with a priority on".

Dr. Solomon: I like that, "with a priority on". That sounds good. I think Ari agrees.

Dr. Hann: All right. Anyone on the phone have any comments or objections to that revised wording?

(No response.)

Okay. We got that one done.

Alison, go for it.

Ms. Singer: Okay.

Dr. Hann: Which chapter are you in?

Ms. Singer: I was charged with changing, taking the information about the Swedish study on risk factors out of Section 6, moving it to Section 5, as one of "What have we learned?", and using that as a way to introduce the new objective on wandering.

So, what I wrote is, "A 2010 Swedish study" -- I mean this comes from Chapter 6 -- "A 2010 Swedish study examining risk factors and causes of death indicated death rates are high for children with ASD and called associated medical disorders like SUDEP and accidents as a cause of death. In addition, information about children with autism suffering fatal accidents and death following wandering was presented to the IACC. In response, the IACC formed a Subcommittee and called for the need to gather data about the scope of this issue and to test preventative practices."

Ms. Blackwell: Alison, this is Ellen.

I looked at that study, and I thought it focused on causes of death, is what I had here before, in young adulthood.

Ms. Singer: I'm looking at the study now, which I want to thank Lena for pulling very quickly for me. And it looks like -- well, I mean we can go through it. I can find the age.

It said the follow-up was at -- I mean we can correct that. We can just say "individuals", and then we can cite the study.

Are you looking at it, Ellen? Because I actually --

Ms. Blackwell: I have to find it in my 2-foot pile of studies, unfortunately, which might take a few minutes.

(Laughter.)

But I can dig it out, too, while we're talking.

Dr. Hann: Okay. But it sounds like the wording that you had, once we get the age range taken care of, is setting it up, is setting up the reason for looking at it.

Ms. Singer: Right. And then, the objective itself is the objective that we turned in, adding at the end -- so it reads, "Develop and test the effectiveness of at least two programs to prevent wandering and to prevent negative consequences of wandering, such as first responder training, parent training, and individual training, to reduce the occurrence of wandering-related safety incidents in people with ASD by 50 percent by 2014, without adversely affecting the rights of adults on the autism spectrum to self-determination or freedom of mobility."

Dr. Hann: Comments?

Ms. Blackwell: Alison, I'm sorry, could you read that one more time?

Ms. Singer: "Develop and test the effectiveness of at least two programs to prevent wandering and to prevent the negative consequences of wandering, such as first responder training, parent training, and individual training, to reduce the occurrence of wandering-related safety incidents in people with ASD by 50 percent by 2014, without adversely affecting the rights of adults on the autism spectrum to self-determination or freedom of mobility."

Ms. Blackwell: I'm sorry, I had myself on mute.

When I was looking at this before -- is Jennifer still with us?

Dr. Hann: Yes, she is.

Ms. Blackwell: Jennifer?

Dr. Johnson: Yes.

Ms. Blackwell: Yes, I just like the idea of talking about increasing community health and safety. "For example, develop and test the effectiveness" -- or, instead of suggesting programs that increase overall community health and safety, and then citing some examples, including wandering, epilepsy, and then talking about interventions that you mentioned, first responder training. I had parent and caregiver training, provider training, training for people with autism.

I just was a little bit concerned about the entire focus on wandering, and I think we talked about that earlier when we had the discussion about other health and safety issues like epilepsy, which came up in the mortality report.

Mr. Ne'eman: So, weren't we talking about --

Ms. Blackwell: And also, restraint and seclusion.

Mr. Ne'eman: So, weren't we talking about broadening the national surveys, but where we were talking specifically -- I think we were talking about addressing that in the context of their proposed objective for Question 7, not in the context of Question 5.

Dr. Hann: That was my remembrance as well, that 5 was still pretty much focused on the wandering issue, but that the surveillance issues might be broader.

Mr. Ne'eman: Alison, how would you feel about altering the language of Question 5 to say, "To reduce the occurrence of" -- see, the problem, if we just say all threats to health and safety, is I have no idea how we would measure that.

Ellen, what are you proposing?

Ms. Blackwell: I don't know. I would like to think about it a little bit more. Because I think if we just focus on wandering, and we lose this emphasis on other causes of death that seem to be incidental to people with autism, like epilepsy, wandering, and restraint seclusion --

Ms. Singer: I think there's a long list of issues, but I think this is the one that came to the IACC's attention. This is the one that the IACC at its previous meeting decided to focus on. This is the issue with which the Committee was charged, the Subcommittee was charged, by the overall Committee. So, this is the issue that we focused on.

And I think to not include this one because we're not including all of them, I mean we can certainly add more next year as we take on more, but this is a real egregious issue from which children are dying. I think it is incumbent upon us to take action where we can.

Mr. Ne'eman: Well, but they are also dying from restraint and seclusion.

Ms. Singer: But I think you're saying that we don't include all of them, we shouldn't include any of them.

Mr. Ne'eman: No, I'm not saying that.

Ms. Singer: And I'm saying that --

Mr. Ne'eman: I'm saying we should find a way to be more inclusive.

Mr. Grossman: My understanding was this is the Safety Subcommittee, and wandering is an important issue, but there are so many other issues that are affecting the safety and health and well-being of people on the spectrum. And to limit it just to one, I think is really we're losing an opportunity.

I would like to see all aspects, if we are looking at this as a research mode, not only wandering, but how can we reduce incarceration? How can we reduce restraint and seclusion? How can we reduce caregiver abuse and victimization and bullying, and everything else that applies here for the safety of our community?

The other question I had was in the wording that you have, why are we limiting self-determination to adults?

Ms. Singer: Okay, we can take out the word "adults".

Dr. Johnson: My microphone doesn't seem to be working.

But I did want to -- oh, is that the problem. Oh, you've got us all controlled over here. Okay.

(Laughter.)

But I just wanted to make a somewhat related comment in terms of the training of first responders. We have done, our grantees have done some work in this area, not specific to the wandering issue, I don't think; I can check into that. But we do have a lot of resources and training on just how do first responders deal with the needs of people with disabilities, including people on the autism spectrum disorder. So, it would contribute to this overall idea of a broader focus on safety concerns.

Dr. Hann: So, here's what I'm hearing, though: it sounds like there's still -- people are sort of like still sinking this in and trying to determine it.

What if, Alison, if you would send us your suggested language, and make any changes that you just heard that you think would be appropriate? And then others, via email, take it into consideration and think about if there is additional wording that they would suggest. Okay?

Did anybody else do any homework over the course of the day? Ari?

Mr. Ne'eman: I have a considerable amount of homework I did over lunch, not all of which, in the interest of ending on time, I think I should read right now.

(Laughter.)

I have found it is a very

dangerous thing to keep people past the appointed hour, and I don't wish to risk my skin in that respect at least. But let me speak to just a little bit of this.

So, I was asked to come up for Question 6 with an update on policy developments. I think I will probably communicate that via email.

But another thing that we were discussing around Question 6 was this issue -- and Marjorie helped out -- there were two issues. One around CBPR, and Tom suggested we specifically call it out the CBPR model, and then the other around more broadly including both families and individuals on the spectrum in the research process.

So, first to address the CBPR model, if we can scroll up a little bit? Right there.

"Although some research is focused on...," I think the Committee decided to delete the word "high-functioning". And we had, "Although some research is focused on adults on the ASD spectrum, or as needed, including greater participation in research by adults across the full autism spectrum". I added after that, "The use of community-based participatory models represents a very promising avenue towards accomplishing those ends."

In addition to that, in order to address this question of including both individuals and families in the modifications to the research opportunities section, the way Marjorie and I decided to ensure that the inclusion of families would not adversely impact the self-determination rights of individuals on the spectrum was to add a cross-cutting theme around self-determination, similar to what we had discussed with regards to ethical, legal, and social implications. And then to place in the research opportunities section "inclusion of people on the autism spectrum and family members in study design across the research process". The only thing I added to that after Marjorie left for her side of the table again is I'm inclined to think that should go in 5 rather than 6.

"Inclusion of people on the autism spectrum and family members in study design and other steps across the research process", and, then, also adding a cross-cutting theme, which we can write later, around self-determination.

Ms. Singer: The one thing that I would suggest we think about is, if self-determination is going to be a cross-cutting theme, we should just indicate where applicable or where possible, so that we don't discount the results of individuals on the autism spectrum who don't rise to the level of self-determination. It is not a failure if you don't, if your cognitive level is not such that you can be self-determining.

Ms. Blackwell: But, Alison, this

is Ellen.

I mean I have to say I absolutely believe that everyone with any disability can lead a self-determined life, and it may be with the assistance of people who support them, but I would not take self-determination off the table for any human being with any disability or without any disability.

I think it's that important to acknowledge that people can lead self-determined lives, no matter what.

Dr. Johnson: We have a project that we are funding right now on self-determination. We have a research article that was produced through that project that defines self-determination. So, it might be useful in this discussion to have that definition, and also it is focusing on youth with autism spectrum disorders and how they are using self-determination in their lives, which kind of goes. So, Ari's point about, why focusing just on adults with regards to self-determination.

So, I would be happy to provide that to the Committee.

Mr. Ne'eman: I think that would be great.

And I guess just the one thing I would add, Alison, is I understand and I respect the concern that you are raising. I mean I think it is one that comes up a lot. Whenever we talk about rights protection, we do not wish to be blocking off areas for family involvement.

And I think, you know, you understand how the term "self-determination" is intended and how it has been utilized in the intellectual disability context and other aspects of very significant developmental disabilities.

You know, I don't think it is intended to mean in every single instance being on a committee or a public policy session or doing everything for yourself without help. I don't know anybody who does everything for themselves without help.

I think it is intended to mean more broadly being supported to make your own decisions to the maximum extent that it is possible to do so, and to also be supported to still have the chance in areas where there are more challenges to express preference.

So, I don't know it would be appropriate to qualify self-determination when we consider it through that meaning.

Mr. Grossman: I mean self-determination has to be a cross-cutting theme. If it's not, then I can't be on this Committee. It is that fundamental of a right that everybody deserves and should have.

And I think it also would violate federal policy if we didn't assume that everybody's right to self-determination is going to be maximized because I think that is the statute that currently exists and certainly the stance that the federal government has taken.

Dr. Solomon: I just also wanted to say that I hear Alison's concern that whatever we write needs to be really thoughtful. So, I am really looking forward to the study that Jennifer is going to provide us with because I think we just need to do what makes sense.

Dr. Hann: Yes, it sounds like if in your paper, Jennifer, that there is a good definition essentially of what this is, that might actually be quite helpful. Because I have a feeling that, without that, we are not going to be able to come to some closure on the value of this.

Dr. Johnson: There is a good definition, and it is theoretically- and research- based.

Mr. Ne'eman: If it would make Alison more comfortable, I would be glad, if she is willing, to have Jennifer be the one who writes the draft of that cross-cutting theme.

Dr. Johnson: And anybody else who wants to --

(Laughter.)

Ms. Singer: I'll help, too.

Dr. Hann: Okay. So, we have a number of homework assignments that have emitted from here today. And let's talk a little bit about timeline kinds of issues.

Dr. Johnson: Della, I'm sorry to interrupt. I just wanted to mention, before we move on, in regards to the suggestions around additions to language to include the participatory action research, I don't know if it is worthwhile to mention, but we have done work in this area as well, and we have some resources on it.

So, if that would be helpful in any way to include in the strategic plan, I would be happy to provide that.

Mr. Ne'eman: If you could send that to me --

Dr. Johnson: Yes.

Mr. Ne'eman: -- we can work together to put some language in.

Dr. Hann: Are we ready for wrapup? It looks like it. Okay.

So, we have the full Committee on the 14th. Today is the 3rd. In fairness to our colleagues, to your colleagues on the full Committee, you all have been entrenched in this, are incredibly familiar now with every living word that has been used; they are not.

So, I think we have to be mindful of that and provide them some sufficient time to be able to read the beautiful prose that you all are working on. So, I would like to suggest that people do their homework and work with each other as you have been, please, copying Susan and myself because of FACA. We're fine. We have big email boxes. We just store it away. And to basically get this wrapped up by Wednesday, because we need to, then, convert them into format and get them out. And we need at least a good day, day and a half, to be able to do that.

And oftentimes, too, when we are in the process of doing that, we have questions back to whoever the leads are, and so forth, like that, to make sure that we have got it right. So, we have to go build in that little bit of a buffer.

I don't know what day that is. Is Wednesday the 8th? Yes. So, by the 8th.

I will work with Erin and try to make a to-do list. I think it is going to be really long, but I will do my best to get a to-do list out to you, probably not tonight, but I will get it out to you certainly by Monday morning.

But I think many of you know the different areas that you are supposed to be working on. So, please don't wait for my list to begin your work.

Ellen, I am still assuming that you are the primary drafter for 5 and for 6.

Ms. Blackwell: Okay. So, then, people need to send me the language. Because you know what? I kind of threw up my pen a while ago and went, "Help."

So, I actually work much better when I can see things. So, maybe if people could send me what their pieces are, I can try to integrate it into the document that we looked at for 5 and 6 today.

And this was very helpful, this discussion. I think it was really I was just sort of taking a flyer to get something on the page for 5 and 6. We didn't have the opportunity to do that before. So, I am glad that we got this far with them today and look forward to finishing them soon.

Dr. Hann: So, OARC, today I will send out the Word versions. All you have are PDFs right now, unless you were working on one in particular. We will send out the Word versions of each of the pieces that were given to you today, so that you can start changing and modifying and doing what you need to do.

The leads for each chapter, though, I am still looking for to be the leads. So, if there's going to be modifications, bits and pieces that other people might be working on, they need to go to the leads, so that that they can incorporate it into the chapter. Okay? The easiest thing is just to "reply all" with whatever you are providing.

All right.

Ms. Redwood: Question?

Dr. Hann: Yes, Lyn?

Ms. Redwood: Yes, I have a quick question. Can you also send us your notes from today?

Dr. Hann: I don't have anything prepared to send at this moment. Erin has been over there busily typing away all day long. They would be very rough. We can send you the rough notes.

Ms. Redwood: That would be great.

Dr. Hann: They will have errors in them. I mean they are going to have typos and everything else, but they will be rough notes that you could have.

Ms. Blackwell: And can we acknowledge for a moment Erin's wonderful contribution to just taking such beautiful notes on our meetings and the minutes, because she does a marvelous job?

Dr. Hann: Congratulations, Erin.

Lyn, you were trying to say something as well?

Ms. Redwood: No, that was it, just having the notes when we go back to make the edits will be really helpful.

Dr. Hann: Yes. We can do that.

All right. I want to thank you all for a very productive meeting. I appreciate the time and the effort that all of you are devoting to this, and I think it will be well worth it. Enjoy, and I will see you on the 14th.

(Whereupon, at 3:56 p.m., the Subcommittee adjourned.)