U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR SERVICES RESEARCH AND POLICY

CONFERENCE CALL AND WEBINAR

WEDNESDAY, SEPTEMBER 19, 2012

The Subcommittee convened via teleconference and webinar at 10:00 a.m., Denise Dougherty and David S. Mandell, Co-Chairs, presiding.

PRESENT:

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

DAVID S. MANDELL, Sc.D., Co-Chair, University of Pennsylvania

JAMES BALL, Ph.D., BCBA-D, JB Autism Consulting

LAURA KAVANAGH, M.P.P., Children with Special Healthcare Needs Programs

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

CATHY RICE, Ph.D., National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)

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

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

PRESENT (continued):

JAN M. CRANDY, Nevada Commission on Autism Spectrum Disorders

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

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

IDIL ABDULL, Somali American Autism Foundation

ANSHU BATRA, M.D., Our Special Kids

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation

TEMPORARY DESIGNATED FEDERAL OFFICIAL:

GEMMA WEIBLINGER (filling in for Dr. Susan Daniels)

STAFF:

ELIZABETH M. BADEN, Ph.D., Policy Analyst, Office of Autism Research Coordination (OARC), NIH

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(10:00 a.m.)

Ms. Weiblinger: My name is Gemma Weiblinger, as the operator said, and I'm temporarily acting as the Designated Federal Official for Dr. Susan Daniels, who I think most of you know is currently out on maternity leave.

Welcome to the public webinar meeting of the Services Research and Policy Subcommittee of the Interagency Autism Coordinating Committee.

I will be taking the roll of subcommittee members, and then I'll turn the meeting over to the subcommittee chairs, Dr. David Mandell and Dr. Denise Dougherty, who will lead the discussion about the updates of the IACC strategic planning with respect to Services Research and Policy.

But before I take the roll, I would like to encourage everyone to remember to identify yourselves when you speak, so that all of our listeners will know who it is that is speaking.

So I'll start with the two co-chairs, Denise Dougherty?

Dr. Dougherty: Sorry, I was on mute. Hi.

Ms. Weiblinger: David Mandell?

Dr. Mandell: Good morning.

Ms. Weiblinger: Laura Kavanagh?

Ms. Kavanagh: Present.

Ms. Weiblinger: John O'Brien. We know John will be about 15 minutes late.

Mr. O'Brien: No, I'm actually on.

Ms. Weiblinger: Okay, great.

Cathy Rice?

Dr. Rice: Yes, I'm here.

Ms. Weiblinger: Idil Abdull?

(No response.)

Ms. Weiblinger: James Ball?

Dr. Ball: Here.

Ms. Weiblinger: Anshu Batra?

(No response)

Sally Burton-Hoyle?

Dr. Burton-Hoyle: Here.

Ms. Weiblinger: Jose Cordero?

Dr. Cordero: Here.

Ms. Weiblinger: Jan Crandy?

Ms. Crandy: Here.

Ms. Weiblinger: Lyn Redwood?

Ms. Redwood: Here.

Ms. Weiblinger: Scott Robertson?

Mr. Robertson: Here.

Ms. Weiblinger: Alison Singer?

Alison?

(No response)

Ms. Weiblinger: Okay, one more time. Idil Abdull?

(No response.)

Ms. Weiblinger: Okay, and Anshu Batra?

(No response.)

Ms. Weiblinger: Okay. Well, with that I will turn the meeting over to our subcommittee co-chairs.

Dr. Mandell: Good morning. This is David Mandell, and we have a lot of work to do today in order to meet our responsibilities of the Subcommittee for Services Research and Policy.

So briefly, I'm hoping that we can talk about what we need to do in order to update the Strategic Plan including what are our charges from Dr. Insel. Denise, Gemma, Elizabeth and I have been talking a lot about the best ways to rewrite the What We Know and What We Need To Know sections of our chapters, Chapters 5 and 6, which is our most pressing objective, and we want to propose a plan to you all that we hope you'll find acceptable. And then we need to determine which experts we will ask to participate in this process when we meet on October 19th, and also which members of the subcommittee will take the lead in helping to put together the sections of the chapters that need to be put together.

We have slotted from now until 2:00 p.m. to accomplish these tasks, or really to figure out what's going to happen between now and October 19th. My understanding from the other subcommittee is it doesn't necessarily take that long, depending on how much consensus we have. But we can certainly use as much of that time as we need.

And I also want to thank everyone who both volunteered to assist in writing with the chapters and who sent in potential experts for us to invite to the meeting. Thanks very much. That was very helpful, and you'll see that there was often a lot of overlap.

Ms. Weiblinger: The only thing I would say, David, is that the workshop is on October 29th, not the 19th.

Dr. Mandell: Oh, excuse me, October 29th. Today is the 19th, right.

Ms. Weiblinger: Right. Yes.

Mr. Robertson: David, just to say quickly, my recommendations had gone to Denise Dougherty when I just found the email message from it.

Ms. Weiblinger: Could you please identify yourself when you speak?

Mr. Robertson: Yes, sorry. This is Scott Robertson.

Dr. Mandell: So Denise, Scott is saying that he sent you his list of experts instead of to OARC, and that some of them did not make it onto the list. But Scott, hopefully you can bring them up today when we're looking over the list of experts.

Mr. Robertson: Okay, thanks.

Dr. Mandell: And so are there any questions about the process, or what we need to accomplish today on this call?

Then maybe we could go to the charge. So I just want to read the charge so we can all, and I know you have it in front of you, but so that we can be very clear, because this is a slightly different charge than has been in past years.

"That the Services Research and Policy Subcommittee of the Interagency Autism Coordinating Committee will assist the IACC with its responsibility to provide advice to the Secretary of Health and Human Services on changing needs related to research and policy about the organization, financing, and delivery of services for individuals with autism. These services include but are not limited to those that address identification and treatment needs, housing, employment, safety, and social inclusion.

The Subcommittee's immediate task will be the update of the Research Strategic Plan by December 1st, 2012. The Subcommittee will provide to the full IACC, a draft update of the sections entitled "What Do We Know?" and "What Do We Need To Know?" for Chapters 5 and 6 of the 2011 version of the Plan.

For the purposes of the Research Strategic Plan, the Subcommittee will address what is known and needed in the area of services research. In addition to this initial task, this Subcommittee will support IACC roles and responsibilities related to services research and policy including assistance with the annual update of the Research Strategic Plan beyond 2012."

So as I said, our immediate task is to update those sections, and I think our hope is that we will have a bulleted draft of that by the October 29th meeting.

Denise, Elizabeth, Gemma, is that correct?

Dr. Baden: This is Elizabeth. Yes, I think that's what we had discussed.

Dr. Mandell: Okay.

Ms. Weiblinger: And we have a timeline near the end of the slide presentation, so we'll go over the timeline.

Dr. Mandell: Right. Okay, good.

And so if we could go to the next slide. One of the things that as Elizabeth, Gemma, Denise and I discussed the two chapters, there's clearly a lot of overlap. And in some ways it's certainly not an arbitrary distinction, but there are a lot of ways you could divide up the different components of those chapters.

And one of the thoughts that we had had was that because there's so much overlap between the chapters that it might make sense to break them into smaller areas that involve our experts and our subcommittee members, and have in each of those areas people cover issues related to the entire lifespan, and that they would be divided into, and those issues pertaining specifically to adults would then be in Chapter 6, but the people covering those broad topic areas would cover them for the whole lifespan. And you'll see in a minute what we're proposing as those topic areas.

We can invite external experts to work with us to produce a draft, and that's why we asked you to send in the list of experts who may help us with that. We need to invite those experts very quickly. We really have not given them a lot of time to rearrange their lives to participate and to come on the 29th, so one of the most important tasks we have for this call is to decide who those experts are going to be and to invite them within the next few days.

And then during the workshop on the 29th, we'll have breakout groups to discuss different aspects of the draft and then report back to the full group with feedback and recommendations about how we should proceed to put together those chapters. Denise, did you want to add anything to that?

Dr. Dougherty: No, not at all.

Dr. Mandell: Okay, or any questions from any of the subcommittee members?

Mr. O'Brien: So David, hi. This is very helpful. It's John O'Brien.

Dr. Mandell: Hi, John.

Mr. O'Brien: Can you talk a little bit about who's going to be part of the breakout groups? Is that folks from the committee and the experts, or is it larger than that?

Dr. Mandell: It would be folks from the subcommittee and the experts that we invited and were able to make it to the meeting on the 29th.

Mr. O'Brien: Great, that's helpful. Thanks.

Dr. Rice: David, this is Cathy Rice. Do we have like an idea of how many folks we're trying to invite from the outside?

Dr. Mandell: Well, I think we've gone back and forth on that. Denise, Elizabeth, and Gemma?

Dr. Dougherty: I think what we're going to try to do is, when we get to the lists of experts that we derived from the recommendations that people sent in, nominations of people sent in, try to prioritize those. And then given the timeline that we have, kind of just go down the prioritized list and see who we can get.

And it's kind of a hard question to answer because each person brings something different, so we may need more in certain areas than in others, and we have certainly more nominated than in other areas.

So OARC has not given us a specific number. The other committee, I think, is going with three experts per question. Is that right, Gemma?

Ms. Weiblinger: That's right.

Dr. Mandell: And they have more questions than, there are really three questions per chapter, right? Two or three experts per chapter or is it --

Ms. Weiblinger: Yes. Three experts per question and they have five questions.

Dr. Mandell: Right. So --

Dr. Dougherty: Five questions or four questions. I thought it was Chapters 1 through 4.

Ms. Singer: And Question 7.

Dr. Dougherty: And 7, okay. So we have five topics. So maybe we should go on to the topics and things will become a little clearer. But the question of how many is still relevant.

Dr. Mandell: So I think it would be helpful to look to the deliverables, right. So just so that you have a sense of the timeline that we've been asked to adhere to, we're trying to work very quickly. So the goal would be to have a bulleted draft of the report or those sections of the report by October 15th, so really in the next four weeks. And then for Denise and I to take on the job of synthesizing that draft into one document in those two chapters very quickly.

We will send it out to the subcommittee members for your feedback, but we'll need to get that very soon in order to give OARC a week before the workshop to process that.

We then will have the opportunity to present and discuss it at the workshop on the 29th, and incorporate feedback from the workshop so that we can have the completed draft done by -- now, is it December 1st that it goes to Congress, or December 1st that we need to have a completed draft of those two chapters?

Dr. Baden:: This is Elizabeth. The completed draft actually, and again we'll go over this more thoroughly when we get to the timeline towards the end.

There will need to be a completed draft approved by the subcommittee, and that will be either the last week of November or the first week of December, and then it will go forward to the full subcommittee probably later in December, and then to Congress by, literally, the end of the year. So does that help?

Dr. Mandell: Yes, thank you.

Dr. Baden:: Yes.

Dr. Mandell: But in either case the timeline is pretty compressed.

So if we go to the next slide, we have a relatively limited window in which we need to focus. So when we're addressing the questions of "What Do We Know?" and "What Do We Need?", it's really with a focus on the past 18 months since the 2011 Strategic Plan was released. And this is separate from the analysis of what grants have been funded.

It's really about the knowledge base as opposed to what research is ongoing. Although that Portfolio Analysis Report can help as we, and a Summary of Advances can help when we're putting together the answers to the questions but we're certainly not limited to them.

And we're really looking for ultimately a relatively brief document, so two to four pages for each chapter, well, for each section of each chapter.

Dr. Dougherty: Or is it two to four pages for each of our topics, our five topics?

Dr. Mandell: No, I think it's for the, well, Elizabeth and Gemma, I'd welcome your feedback, but I think it's for the chapters since the topics are really our invention.

Ms. Weiblinger: Right.

Dr. Baden:: Yes. I think the guideline for the other subcommittee was two to four pages per question. But I think especially given the different approach that you're proposing there's some flexibility there. The overall idea is so just to be fairly brief and keep things fairly high level.

Dr. Dougherty: So this is Denise. So I have a question. Is this an appropriate time?

Dr. Baden: Sure.

Dr. Mandell: Sure.

Dr. Dougherty: When this says, "Include funded and unfunded gaps," I wonder if you could explain that a little bit. So if there's something we still need to know but it's been funded, it seems like it would be a good idea to point that out at some point so that we don't duplicate funding for that need.

Dr. Baden:: Yes, this is Elizabeth. I think the intent of including that was exactly as you said. If there is an area that's been identified previously as a gap in the Strategic Plan, for example, but you know that research is ongoing but that hasn't produced results yet, it would be good to include that and to mention that, that yes, this is a gap but it is in the process of being addressed. Does that make sense?

Dr. Dougherty: Yes. But you said, if we know that. So we don't have to do a thorough environmental scan of everything that's been funded --

Dr. Baden: Right.

Dr. Dougherty: -- by either the government or all these external groups.

Dr. Baden: Right. It's just to the best of your knowledge. You know, some of the federal members of the committee might know of some grants that have been awarded that are in process, so they might be able to include that information.

Some of the experts, you know, their own grants or their colleagues' grants might be addressing some of these areas that they might know about. So it's really just gathering, you know, from everyone's collective knowledge base without, as you said, doing an exhaustive environmental scan to try to find all of the information.

Dr. Dougherty: Great. That's helpful, thanks.

Ms. Singer: So this is Alison. I just wanted to respond to the last comment about the five topic areas being whittled down into the two questions.

Even though there's a short time frame for updating these two chapters, we can still use all of the information and all of the expertise gleaned at this workshop for writing the 2013 Strategic Plan, which will actually get underway as soon as we hand in the 2012 Strategic Plan.

So it's not like all of this expertise and all of this work that's going to get done is going to be for naught. It will all go into what will be a much larger rewrite of the plan starting in January.

Dr. Mandell: That's a really helpful point. And so, well, and I guess it remains to be seen the extent to which we could suggest changes to the structure for the 2013 plan.

So other questions or comments? Well, why don't we look at the topic areas then and see if there's some general consensus that these are reasonable topic areas and ways to divide up. And Denise, thank you for really taking the lead in putting together these topic areas.

So the way that we had been thinking about it is that in each chapter there are issues related to Access and Coverage, Quality of Care, Education and Workforce issues, Family Support and Comparative Effectiveness. And that when we thought about all of the topics that were covered in each of the chapters that the topics all seemed to fall under one of these five headings.

But that the issues, you can draw a line at 18 or 21, but the reality is that the issues are often very similar across the lifespan and so there would be less duplication of efforts and more potential synergy if we thought about these as lifespan issues rather than separately for children and for adults.

And so we wanted to put these topics out there as the possible way to structure our activities between now and December, and we welcome any feedback on whether you think these are appropriate, whether there's anything missing, whether we need a new framework all together.

Mr. O'Brien: So David, hi. This is John O'Brien. For the topic areas, whether it's these five or some other five, what I'm hearing you say for Question 5, we're looking at this across the lifespan. And then for Question 6, would we have the same topic areas, and if so, I'm assuming then we're really focusing on adults.

Dr. Mandell: Yes. So instead of dividing into two groups, one on services and a second on adults, we would divide into five groups each of which would be tasked with thinking about these issues for both for children and adults.

And when coming back with their ideas and their feedback, to really say here's how we thought about this for children and here's how we thought about this for adults, these are the issues that are the same, these are the issues that are different, and so then it would be incumbent on Denise and me then to begin to separate them out into the separate chapters and to synthesize what people had sent back within the subheadings of Chapter 5 and Chapter 6, and then to send it out for the committee to review and approve.

Dr. Dougherty: And also the other cross cutting item is to identify for each of these topics, identify any disparities work that you're aware of. Disparities, you know, what we know about disparities and what we need to know about disparities.

Mr. Robertson: Hi, David. This is Scott. I had one question on the topic areas. How does, with myself having a background, in part, in technology, how does assistive technologies and other issues of technologies fit into these areas? Would that be split into one of these subbed out or would that be better off being a separate topic area?

Dr. Mandell: So and I would welcome other peoples' thoughts on this, I think of assistive technology as a tool to achieve a particular goal, and that goal could be to improve actually any of these bullets, right. So you could think of assistive technologies as a way of improving quality of care.

We actually have been thinking about assistive technologies and its integration with the workforce, and what kind of training you need related to that. They could be used for a family support. You could test the effectiveness of interventions using different assistive technologies or assistive technologies versus interventions without assistive technologies.

So I would see them as being integrated into potentially each of these bulleted areas.

Dr. Dougherty: This is Denise. I could see another way to do this, and I guess I'm thinking of assistive technologies more in a medical and health care sense. But that may not be right.

If you wanted to be in one of these topic areas, you know, implementation or spread of evidence based, you know, appropriate assistive technologies could be part of quality of care. But of course, what David said is right too.

(Crosstalk)

Dr. Cordero: Hi, this is Jose.

And I think that assistive technologies is one of the those that have a role in sort of the research and development part in terms of new technologies that may help families and so on.

But also, and there are some technologies that are ready and are available, and the question then more also is about access to those technologies and how it is integrated into the package of health services for individuals with autism.

Dr. Rice: And this is Cathy. I had a question about dissemination and where that would fit. Is that something that we see the issue of dissemination methods and strategies integrated into each one similar to as David said about assistive technology, or does that need to be called out somewhere in particular?

Dr. Dougherty: We put it under quality of care and with the subheading of implementation.

Dr. Rice: Okay.

Dr. Dougherty: But certainly dissemination goes under everything.

Dr. Rice: And one more point just to keep in mind when we were also talking about interventions is that Chapter 4 is about what treatments and interventions will help.

And so for us to think not overlap with what's going on in that chapter in terms of assessing and evaluating specific individual treatments, but as I understand Question 5, it's more about systems based access and implementation more, you know, in an efficacy type setting versus the actual evaluation of the specific interventions.

Does that seem to gel with others' understanding?

Dr. Mandell: I might just change that word efficacy, unless I --

Dr. Rice: Effectiveness.

Dr. Mandell: -- yes, understood

you. Yes, I think that I would like us as a subcommittee, and I'm open to others' thoughts on this, to take ownership of that idea of the concept of type 2 translational research. That the issue of what happens in real-world settings, how interventions fare when they're implemented in the community as opposed to university based lab setting, really belongs under the domain of services research. And clearly it's the bridge between Chapter 4 and Chapter 5.

I think it would make a lot of sense for us to be the ones talking about what we know, what we need to know and future research should look like in that particular area.

Dr. Batra: David, this is Anshu, and I have to echo that as a practitioner, private practice practitioner.

And I'm on the committee for research for Question 4, and Denise, that's exactly how I see the distinction in terms of, you know, what are the effective treatments out there in looking at the research and seeing what's been found. And then I really see that again as Question 5 being, okay, how is it implemented and how is it disseminated and what's the efficacy of it within --

Dr. Dougherty: And that's a research question too.

Dr. Batra: Correct, yes.

Ms. Crandy: This is Jan Crandy. And I would support that too as someone that is running a community based intervention for our state, and also looking at not just the child's outcome or the client's outcome, but the family's outcome and the parents' ability to implement what's been taught to them in the support and how their strain changes because of the support they receive.

Dr. Burton-Hoyle: This is Sally, and I support that because the family's support and how the family feels and how the family fares is directly related to the responsiveness of the system to A, understand autism, and B, provide what would be necessary for that person to have a self-determined life.

Dr. Mandell: Great. So it sounds like there's some general consensus. And so with that in mind, and harkening back to Cathy's point, does it make sense then to think about dissemination and implementation as its own bullets given that it may relate to these other areas?

Denise, what do you think?

Dr. Dougherty: I think it's, well, that's an interesting question, because there are certainly probably commonalities across different areas like education and healthcare in dissemination and implementation, but at the same time each one has its own literature.

So I guess I would put it as a

subhead, something to be thought about as a research question under each of these topics, because even access to health care coverage has a different stream of implementation than does health care quality typically or education. So that's my thinking.

Dr. Mandell: That's a good point that people will have to think about dissemination and implementation potentially in a different way for each of these topics.

Other thoughts about that from the subcommittee?

Dr. Dougherty: I think that makes sense.

Dr. Mandell: Okay. All right, so why don't we start talking then, if we're in agreement about that we can start talking about the workshop and preparing for the workshop.

So you all should have received a PDF file that listed the experts that people sent in with the exception of the ones that some of the ones that Scott sent in. Sorry about that, Scott.

Dr. Dougherty: Yes, sorry, Scott.

Dr. Mandell: Scott, do you want to take a minute and just say who the other experts were that you recommended?

Mr. Robertson: Yes. Well, one of the experts was already mentioned on there but I was echoing, had a second nomination for someone from the Bureau of Autism Services, for instance, their clinical director, Clair Choutka, because they've been involved really extensively with adult services innovation, and I think that would really fit nicely into the, especially around the lifespan. I guess that's either lifespan or services. I'm so confused in terms of how, what exactly fits into either.

The other nominations that I had were someone from the Academic Autism Spectrum Partnership in Research Education, AASPIRE, which is this community based research group, community based participatory research group, I should say, that's studying health and well being in autistic adults, and right now has a National Institute of Mental Health grant to develop a tool kit to help autistic adults with accessing health care services.

And then the couple others I had were Kelly Henderson at the National Association of State Directors of Special Education, had published about a year ago on autistic use, uses of the educational system.

And then the fourth one I had was just that it would be good to have someone, and I didn't specify someone in particular, but have someone potentially in the area of AAC, the Augmentative and Alternative Communication.

Dr. Mandell: Okay, thank you.

Mr. Robertson: You're welcome.

Dr. Mandell: So Denise --

Ms. Crandy: David?

Dr. Mandell: Yes.

Ms. Crandy: Sorry. This is Jan Crandy. I had also submitted one that I don't see on the list, was the Ohio Center for Autism, a representative from them, because they have done a lifespan transition documents. They also made the Autism Internet Modules, which is an online training across the lifespan.

Dr. Burton-Hoyle: Actually, this is Sally, and they're all evidence based practices of excellence.

Ms. Crandy: And their documents are amazing for transition, IEP support, everything.

Dr. Mandell: For those of you who have names that weren't included on this list, or organizations where you feel like there's someone who we should find, can you please send those to Elizabeth, so that they can be integrated with this list?

Ms. Crandy: Of course.

Dr. Mandell: Thank you. And so Denise has taken a first stab at organizing some of these experts by those five areas. And Denise, do you want to talk a little bit about how you did that or who these people are on the list versus those that are not?

Dr. Dougherty: Well, yes. But first I want to say that I'm glad we're having this call, because this certainly was not a perfect method. I just tried to figure out from the, you know, there were some description of people, and just tried to get from that who might be a good person to be in a particular group.

So definitely feel free to say, why did you put that person there, because, you know, that's not what I meant by nominating that person. So now that you have all the topics in mind, we can move people around.

And also this was done on the fly

as we're doing all of this work, so if there were a number of people named for a particular effort or kind of research, topic and category, but that was the seventh person named for that category, I just took the first ones.

So that's why we sent you this list, which we thought was complete, so that you can say, well, you know, the seventh person I listed for that category is actually better than the first six, something like that. So that's the kind of thing we want to hear as we go through this list. Right, David?

Dr. Mandell: Yes. And let me add two things. You'll notice at the bottom of the slide it says Group Leader, IACC Member, which we didn't discuss yet. And our thought was that, you know, obviously there's more than five subcommittee members, but that we towards the end of this call that we could ask for volunteers to lead the facilitation of each of the five groups.

And of course there will be other subcommittee members on that group as well, but that there would be one person who would really be made responsible for getting that document completed and to us in a timely manner.

And the second thing is that sort of, and we haven't really discussed it, but there are obviously experts here whose expertise overlaps multiple areas. And is there going to be a way for us to involve them in more than one of these subgroups?

Mr. O'Brien: So David, I don't know. This is John O'Brien. I'm not sure this will answer your question, but can we just sit back and maybe just say, or have us hear a little bit about the role of the external experts and what that looks like during the course of the meeting on the 29th? Because that might help me answer that question or give you a thought about that question.

Dr. Mandell: Sorry. So you're asking about the role of the experts?

Mr. O'Brien: Yes, so both the role of the experts and then kind of what do they do on the 29th that would either allow them to cross groups if they have, you know, kind of a broader expertise, or may actually limit their ability to be able to kind of cross groups based on what the day looks like.

Dr. Mandell: Right. So prior to the working group meeting, workgroup meeting on the 29th, I would see them as acting as workgroup members. So in those smaller groups specifically, providing expertise on putting together that bulleted list of “what do we know?” and “what do we still need to know?”, or related to that particular area.

On the 29th itself in the breakout groups, I would see them as helping us to refine that document and make it into a fuller, more nuanced report.

Dr. Dougherty: But we were also thinking, and I think this is what he's getting to, one of our last slides is kind of a draft agenda, very draft agenda for the workshop.

We were thinking of having, in the morning having breakout groups by topic then having a report back, and then using the entire group, the subcommittee members and the experts as a plenary group to revise what the breakout groups had done, to refine the bulleted list.

Ms. Singer: This is Alison. Just by way of comparison, this same issue came up on the basic and translational research subcommittee call. There were several scientists whose names were raised for more than one chapter.

And the way we resolved it was to appoint them to the workgroup on one chapter, but to let them know that they had been nominated for another chapter, and to encourage them to participate actively during the discussion on the day of the workshop in that chapter.

But we thought that to ask someone to serve on more than one of these workgroups in preparation for the October 29th and 30th meeting might be too much.

Dr. Mandell: I think that that's a good point. We don't want to drive our experts too hard. So yes, maybe we can even on the 29th, just to even get their feedback and comments on the work that the other subgroups have done in the larger meeting would be helpful.

Dr. Batra: David, this is Anshu. How many experts are we envisioning to invite for each question?

Dr. Mandell: Well, there's how many we invite and then there's how many come, right? So my understanding is that the other workgroup invited about 15 experts total. Maybe we could aim for about the same number.

Ms. Singer: So our invitations went out and we had many people who said they were interested in participating but were not available on that date mostly because of the short notice.

So when you're putting together your list of experts you might want to, what we did is we made a list in order of who we would invite so that if we got no's, the committee had already decided on who the next person was to be invited.

Dr. Dougherty: And that's what we want to do now with these suggested lists, kind of put them in priority order.

Ms. Singer: But you have expect that given that we're just about a month away, there are going to be people who you really want who unfortunately are not able to participate.

Dr. Dougherty: Absolutely. But

maybe they could participate ahead of time as part of the team as David was describing, the team led by the subcommittee member.

Dr. Mandell: Alison, did the other committees do that as well? Are they having some of the experts participate ahead of time?

Ms. Singer: We did not. But I think it's actually a very good idea. I wish that we had thought to do that. But we limited participation to people who said they could attend on the 29th and 30th.

Dr. Mandell: Okay.

Dr. Batra: That's actually a very good idea.

Ms. Singer: But it is a very good idea. I wish we had thought to do that.

Dr. Batra: Because we had some, you know, on our short list we had some people who just weren't available for that particular date.

Ms. Singer: Right.

Dr. Batra: Other people there that are also quite good, but not first choice.

Dr. Mandell: All right, so with that in mind, and certainly given the relative inexpense of involving those experts who are not coming to the meeting, should we look at the proposed list that Denise has put together, and people can comment on particular individuals or whether they feel like there's an area of expertise missing or someone who they had submitted who they thought would be very good for this particular area but is not on the list?

Mr. O'Brien: So David, this is John O'Brien. This conversation has been really helpful for me to think about who we might want to have as part of that access in coverage discussion.

I had made a nomination for Mark Schaefer, who is terrific, but he will only know issues as it relates to one state. I'm beginning to think that it might be helpful to have the contractor or the lead staff from our contractor that's working on the state of the state of autism, actually be on this expert panel, or external experts, because I think they will have a better sense of what's going on not only across states in Medicaid coverage but also to some extent about what we're seeing relative to insurance coverage.

Dr. Mandell: And who is that?

Mr. O'Brien: I'll have to find out who the lead staff person is from the contractor that we have doing that. But they're almost done with their report so I'll get you that name.

Dr. Mandell: That's not the impact state of the state report is it? Is that the one that impact with the contractor for?

Mr. O'Brien: Well, yes, and I think they subbed it out to someone else. I could be wrong, but that's who I was thinking of.

Dr. Mandell: They subbed it out to sub (phonetic), and I'm not sure that's the person you want. But I think that that's a good idea, maybe we could have a separate conversation about --

Mr. O'Brien: Yes, I mean whoever, but I think my thought is it would be helpful to have kind of a broader perspective than just one state.

Dr. Mandell: Oh, I completely agree. Yes. And given that is there anyone from CMS other than yourself that you would recommend?

Mr. O'Brien: Let me think about that. Because again, you know, I think, I mean if they answer the question yes, we can certainly have someone from CMS there, but I'm also wanting to look at it from the commercial market as well as an access and coverage issue. Because sometimes I think the commercial market is driving some of what we're seeing around access and coverage.

Dr. Mandell: Okay.

Dr. Dougherty: So do you think later on in the list we have representative from Aetna or OptumHealth?

Mr. O'Brien: Yes. Again I think maybe a longer offline discussion about, you know, if whether or not someone from CMS and those representatives kind of round out the package.

Dr. Dougherty: So would you take Mark Schaefer off the list then? Or sometimes it's helpful to have somebody from an actual state perspective as well as the broader --

Mr. O'Brien: No, I agree it's helpful, but again, you know, you're going to get it from just one state.

Ms. Abdull: Hi, this is Idil. I agree with John, because we talked a little bit about that's it really important to get a good state, you know, maybe Pennsylvania or what have you, but it's also better to get a broader vision of the benefits of coverage from CMS in terms of Medicaid just to know what the access to services are, what exactly CMS is able to do versus what it's not able to do. Because often we think of parents that CMS is unwilling.

But what John so eloquently explained to me is that a lot of times it's because they're not able to cover XYZ services. And so it might be a good idea to get someone from Medicaid, and I suggested you, John, but I think you sent me an email, you said you'll see if you can find somebody else from the Division of Benefits coverage.

But then I also agree with you that we need to get somebody from the private insurances, and then also even for that it's state-regulated private insurances versus self-funded private insurances or companies that have federally regulated private insurances, because those are also different.

And if we get somebody who's already only for the state regulated and they can tell us, well, you know, we have coverage for 30 city (phonetic) or 32 states, I want to just remind everybody that doesn't mean everybody who lives in that state that has private insurance has autism coverage. Most of the time it's about 30 to 40 percent of the market. So in order to cover the whole country it's good idea to get different kinds of private insurances as well as Medicaid.

Dr. Cordero: Hi, this is Jose Cordero. Just want to clarify that CMS do not regulate coverage on the Medicaid states, that that's something that's done state by state.

Ms. Abdull: Right.

Dr. Cordero: And it is different from Medicare where CMS has direct line on what are the benefits that are covered. And that's the reason why there is such a diversity of coverage in Medicaid then.

And something that I think it would be important is to look at what states actually have the better models of a Medicaid coverage for autism, and that actually both cover the medical aspects of autism but also the mental health aspects of autism, and that's really the challenge.

But I don't think that you will --

Ms. Abdull: Right, yes. It's voluntary. You're right. It's not mandatory like Medicare, it's voluntary. And so some states choose to do, most don't.

Dr. Cordero: No. Yes, but --

Ms. Crandy: This is Jan Crandy. Is there someone that we could talk to from Medicaid, from CMS about how we go about doing a federal policy to change this so it would address every state, especially for the ABA coverage?

Dr. Cordero: Yes. Well, I think

that the point is that would require changing the Medicaid law.

Ms. Crandy: Right.

Dr. Cordero: Because it is based on the relationship of states with the federal government in terms of Medicaid coverage. And I just wanted to clearly, it's based on sort of a state mandate of and determining what is that they're going to cover, and also the group of people that are covered.

Dr. Mandell: So that is a reason, actually, to consider some state-specific folks who have state models that may be worthy of emulation.

I think for a lot of states their reticence to include a particular service as covered in their state plan has to do with they don't know how to do it in a way that's comfortable for them where they feel like they can manage costs and also manage the quality of the care that's delivered.

And so if there are specific state models that have some evidence of effectiveness in increasing coverage and at some level of quality it's probably worth including them.

Ms. Abdull: I think it's probably a good idea to get states that have maybe -- oh, sorry. The states that have, you know, early intervention all the way through adulthood. Because what I've seen in some of the states is that they have mostly just early intervention but really nothing for when you get to be a teenager or an adult.

So if there are specific states that have lifetime access to services through Medicaid that is certainly a good idea to figure out what they're doing, how cost effective is it. Because from the state legislators we always hear that it's very expensive for Medicaid to match that from the state point of view and so they often don't do it.

So it would be good to know, not only is it working for these children and these adults and these families, but how cost effective is it and is it driving, you know, the state into bankruptcy or are they able to handle it.

Mr. O'Brien: Well, and Idil, this is John. Maybe I'd broaden that a little bit, because I think it would be really helpful to be able to find someone to talk about the adult coverage, because I think you're right.

You know, as I look at what we're covering in Medicaid, a lot of it is, and for good reason, children-specific, but I think it's really helpful to think about what's the coverage for adults and kind of what is the benefit package that states have been thinking about or have constructed. Whether or not they cover it under Medicaid, I think is important, but I'd still like to hear what they're thinking about good coverage for that group.

Dr. Cordero: This is Jose Cordero. I think that you could look at probably someone from the national association, it's called National Conference of State Legislators. They actually have done an analysis of the coverage for autism by state, and someone that actually has done that may be a good resource in terms of, on their website they have a very, very good detailed description of what's covered and goes beyond Medicaid just in terms of what is the law in terms of insurance coverage.

Dr. Rice: This is Cathy Rice. Another perspective that I think is missing is looking at some of these state service system coordination grants and opportunities that exist that go beyond medical coverage.

So for instance, and I don't know if Laura Kavanagh is on the phone or if someone from HRSA, speaking of their state implementation grants that are trying to reach across Medicaid as well as other service systems in an integrated fashion.

And several states have these implementation grants, and I don't know if there's one state that really has more of a lifespan model. I've heard that Washington state does at least going up through adolescence. But there may be others that having a representative from the state demonstration grants would be very helpful to just not think one specific funding stream, because we're pretty heavy on insurance and health access, but much of services and access to services really cuts across the basic medical model.

Ms. Kavanagh: Thanks, Cathy. This is Laura. We could offer some models. I had included Bonnie Strickland as a contact across the state demonstration grant programs at HRSA support, so we could certainly come up with a particular state if we wanted to.

Washington would be a good example.

Dr. Rice: Yes, either way, certainly Bonnie would know lots across, and yourself as input on the project as well. But I think the state perspective would be helpful.

Dr. Dougherty: So this is Denise. I'd like to go back to the person who suggested NCSL. Was that Jose?

Dr. Cordero: That was Jose, yes.

Dr. Dougherty: I wonder if you could get us the name of the person?

Dr. Cordero: I'd be happy to work on that.

Dr. Dougherty: Great, thank you.

Ms. Crandy: And what about looking at Wisconsin? I think it's Wisconsin that went from a Medicaid waiver for children with autism to a slot program.

Dr. Mandell: Actually Paul Shattuck is someone who assisted with the development of their waiver and also has studied some of the effects of what's happening with content.

And one of the things I've noticed for access and coverage is that we actually have no one that does research on these issues. And I think for each of these subgroups it would be important to have a mix of people who are on the ground trying to address some of these issues and people that are studying them given that that's part of our mandate as a subcommittee. So I wonder if we could think about also who the researcher would be who could be on that group.

Ms. Crandy: What about Coleen, and I know at, because I see Lorri on there for Autism Speaks. When they just did their law summit they had somebody from the behavior analyst, because they just completed a document for health insurance guidelines, maybe having her bring somebody from, with her.

Dr. Mandell: Or, you know, when I look at the transitions list, so someone like Susan Parish actually, so we're actually, between Paul Shattuck and Julie Taylor we're pretty strong in that area in terms of what the research has been around transition issues.

And Susan Parish has studied a wealth of issues to policy as it affects individual's developmental disabilities. Maybe she might be a good person to tap for the Access and Coverage group.

Ms. Abdull: I wonder, David, or Denise or anyone, what you guys think about research on which therapies. Because do we know? I mean if ABA is better than Floortime, as parents you just confused. You don't know where to take your kid.

And you always hear ABA, and I feel like they maybe have this bigger lobby or maybe more vocal parents, but I wonder if there is a way to find out in terms of research. What does it show that if Floortime or DIR are just helping children just as much as ABA and other therapy services?

If we can get somebody just to narrow down what research exactly says that's, because you hear the words evidence based and you always associate it with ABA, but is that because it has more research than the others or is it because it has been repeated and you hear it more often than the others?

Dr. Mandell: So I think that that's clearly a very critical question. And I think the relative efficacy of different interventions is really the domain of Chapter 4.

And I know just based on some of the issues that they've addressed and that you can see that what in their description of what the research priorities are that they clearly see that as an important issue.

But I think for us to the extent that that relates to our charge is really about effectiveness, implementation, sustainability and the extent to which in community settings one of those interventions can be more successful than the others.

But in terms of the horse race between the interventions under ideal circumstances, I think that belongs in Chapter 4.

Ms. Abdull: In Chapter 4, okay.

Dr. Dougherty: And I wonder if I could --

Ms. Abdull: Oh, David, also -- go ahead.

Dr. Dougherty: Could I just ask David, how you're thinking of a comparative effectiveness and patient-centered outcomes research? Because sometimes that kind of comparison of one type of treatment versus another is done under comparative effectiveness research.

Dr. Mandell: Well, my understanding is that when it falls under the rubric of comparative effectiveness is when you're making a comparison between two services or interventions in the way that they are implemented in the community.

So that is, you're not offering additional research support, for example, bring the practitioners who are delivering that intervention up to a certain level of fidelity. You're not necessarily offering them additional training.

And so, but it's just when they're used in the community do you see that one is associated with better outcomes than the other separate than what happens in the lab.

Dr. Dougherty: Right. So that's what I'm saying. Two different services are already out there. People are obtaining them, and there's, you know, data. There's records, registries or whatever about those services, and you use that information to compare which of the two services works better. It's an effectiveness question, but it's done comparatively rather than to a placebo as most RCTs are.

Dr. Mandell: Right.

Dr. Dougherty: And AHRQ has done a lot of that work, and did some on autism to look at what works best for different kinds of autism problems.

So I think it's probably there could be more of the kinds of Chapter 4 research on different treatments, but then sometimes it's kind of too late. The treatments are out there in the community already so you need to use the data that you have because nobody's going to do an RCT of the treatment. Anyway, so I just wouldn't just put it in Chapter 4.

Dr. Batra: This is Anshu Batra. I'm working on Question 4, and I think the question you raised in terms of comparing the different ABA interventions, Floortime, PRT, et cetera and ABA, I think that, we can put that under “what do we need?” in terms of the gaps. And you know, again I'll take that to the committee, the subcommittee and let them know that that's a concern.

Dr. Mandell: I'm worried that we've wandered a little bit from our mission right now, which is to identify the experts we want to include.

And so for Access it sounds like there's some interest in getting someone where there's a state that seems to be doing impressive work covering individuals with autism, that we need some private insurance representation as well, and also some sense of what states are doing through other mechanisms.

And Cathy and Laura had recommended Bonnie Strickland, and perhaps one state that's using that state grant to good effect for individuals with autism. And then I had suggested we ask Susan Parish given her research expertise and experience if she could be part of that group as well. Is that a reasonable summation of where we are with that group?

Dr. Dougherty: This is Denise. I'm wondering if we could just --

Ms. Abdull: Did you also say there's someone for CMS in terms of the whole country or did you say just one state who's doing impressive work with their services?

Dr. Mandell: Thank you. And also we talked about the idea of finding someone at CMS who could give us also a national picture.

Ms. Abdull: Right, okay.

Ms. Crandy: David, this is Jan --

Dr. Dougherty: Does that mean that we're not including these other people who are already on the list, or are you going to go back through those names?

Dr. Mandell: Well, I think, so why don't we go through those names that you put? So if we think about Mark Schaefer and the representative from Pennsylvania, and I would actually -- Scott, you mentioned Claire Choutka. She's now left the Bureau. But Pia Newman was the person who actually wrote the Adult Autism Waiver.

Mr. Robertson: Okay.

Dr. Mandell: And so I might suggest that we pick one of those state folks. I think with having a representative from OptumHealth given that they got the NIMH contract, you know, that they're using their data to look at health outcomes for individuals with autism and their families, they actually probably have some preliminary data that they could share with us.

Dr. Dougherty: Well, this is Denise. I'll tell you about the Aetna person --

Dr. Mandell: Okay.

Dr. Dougherty: -- that Coleen Boyle shared with me at another committee that we're on together. That she had folks from Aetna come to her and show her some data that demonstrates that when a private insurance company does cover autism services that the costs are not that great. So they also have some data. So we might put them on the list as a backup person.

Dr. Mandell: Okay.

Dr. Dougherty: Okay.

Ms. Crandy: This is Jan Crandy. I really do think that we need somebody that can give us a nationwide look at what's happening in every state's slot programs, early intervention or services.

Dr. Mandell: I agree.

Ms. Crandy: Is there somebody -- okay.

Dr. Mandell: Do you know who that person is?

Mr. O'Brien: Yes, this is John

O'Brien. That's a collection of about three or four people that would need to be there because of just the way that we've got, how our program works.

And, you know, again David, I'll trust your judgement on this, but part of what we were trying to do with the state of the states was actually try to get that information in order to be able to understand kind of what, by state and nationwide, we're seeing in terms of some trends.

So again, you know, I just think that we can have those people there. Some of it we're going to know, some of it, frankly, we're not going to know just because of the way some of the state programs operate.

Dr. Mandell: Right.

Ms. Abdull: So is there, John, like maybe one person who might have an overall idea of the whole nation?

Mr. O'Brien: Yes. Well, I think there's somebody who can really speak to, so for where we've got coverage under our different programs, kind of here's what we're seeing in terms of the coverage. Most of it again is going to be what we're seeing as it relates to the home community based services programs. When we start getting into the kind of screenings and assessments and maybe even the more specific state plan services it's just a little harder to tease out.

Ms. Abdull: Well, this is Idil, sorry. But the state plan implementations, which the one that Cathy suggested, there's only a few states. There's like a dozen states or so have it for the screening and giving parents the information, and even that overlaps with the block grants for child and maternal health, because many state health departments are charged with telling families what to do and where to get services if their child has a disability including autism.

So that might be a little bit different than the actual services that are available in that state for autism as opposed to the state planning grants, right, or am I confused?

Mr. O'Brien: Yes. No, when I'm talking about state plans it's different than the state planning grants.

There's the Medicaid state plan that states have as the basis for their general Medicaid program, and then there's the add-on home and community based services waivers that a number of different states have taken advantage of specifically to target individuals with autism, which are different than the state planning grants out of, I guess --

Ms. Abdull: Out of HRSA.

Mr. O'Brien: Yes.

Ms. Abdull: Okay.

Dr. Dougherty: And I think the thing to keep in mind is that we're looking for research questions to be addressed here, as opposed to just describing the services that are out there.

Ms. Abdull: So it might be just good to get one person who knows a lot from CMS.

Dr. Mandell: Well, and I think if we got one person from CMS, if we had someone like Bonnie Strickland, and the other person who's not, we haven't talked about at all is, and I don't know if it's relevant here, is someone from Education.

Ms. Abdull: Oh yes, and it's relevant because not everybody gets these services. Most kids get education through the special ed.

Dr. Dougherty: Well, we have a list of experts in Education and the Workforce, so what are you thinking, David? We could put under Education, the Workforce, just like we've put implementation, we could put Access and Coverage.

Dr. Mandell: Well, when you say Education and Workforce, are you, maybe we should clarify that. I thought you meant workforce development as in people who are working with individuals with autism, and that education pertains to them. But you were thinking about it as educational/vocational issues.

Dr. Dougherty: Right. So in order to make it both children and adults that's where I put Education/Workforce.

Dr. Mandell: So maybe we could change that so that Workforce term is maybe just loaded for me and maybe vocational or employment would be --

Dr. Dougherty: Okay, employment. That sounds good.

Dr. Rice: But then that does bring up the issue of the basic professional preparation, and is that again something that is combined into each topic or certainly, I mean maybe that's under Access and Coverage because --

Dr. Dougherty: I think it's

under quality actually.

Dr. Mandell: Well, maybe we ought to have a separate bullet under Quality of Care related to workforce development.

Ms. Abdull: So would education be its own bullet then?

Dr. Dougherty: Well, education is actually a separate topic and group of experts as we've kind of laid it out here.

Ms. Abdull: Okay.

Dr. Dougherty: So I think the thing, David, one thing you didn't mention was having somebody from NCSL who's done the analysis of the coverage of autism by the state, who could give a state overview.

Dr. Mandell: All right. So yes. Let's talk about this, but let's try and get some names here for -- and John, I know that you have, the idea is that you would find someone from CMS. But I think that, can we go through these names that we have for Access and Coverage, and can we agree that

Bonnie Strickland and Susan Parish would definitely would be two of the external experts for that group? That we would have someone from CMS.

So let me share some of my anxiety with the subcommittee, so it can be your anxiety too, which is we really have to have a list of names by the end of this meeting because we've got to start inviting people.

We just, you know, the other subcommittee met on September 7th, so almost two weeks before us, and a lot of their experts couldn't make it. And so we're really late in the game. And so I think we have to, again we really have to come up with some names.

So for instance, do you have a name for someone from Aetna, Denise?

Dr. Dougherty: Coleen Boyle has the contact information, and I will email her now.

Dr. Mandell: Okay.

Dr. Rice: And this is Cathy. I'm also looking up, I may have --

Dr. Dougherty: Oh, Cathy, yes.

Dr. Mandell: Okay. Because then I also do have someone from OptumHealth if we wanted to have a backup for that person who is Francisca Azocar.

Dr. Rice: This is Cathy. For Christine Hunter, I had recommended her because she was over a review that the Office of Personnel Management did in an effort to see if ABA services should be classified as medical services versus educational services.

And that ruling happened earlier this year, and that was actually a very big change in that health plans, providers that are proposing to cover federal employee health care can now propose to include behavioral services, and particularly ABA, as a medical service, where that wasn't allowed before. And although it's specific to federal health care plans it really sets the stage for other health care plans to follow suit. So she has a very good picture in terms of the general health care issues around the classification of ABA.

Ms. Crandy: This is Jan Crandy. I would support her coming too, because we do have to remove that barrier.

Also, you know, the person from Pennsylvania, because they also have a 1915(c) Medicaid Home and Community-Based Waiver for three years and older, so that person from Pennsylvania could address adults and children.

Dr. Mandell: That would be Pia Newman.

Dr. Ball: This is Jim Ball. Is there anybody reaching out to TRICARE who's already been doing this for a long time?

Dr. Mandell: We did not put anyone on the list.

Ms. Crandy: That's a great idea.

Dr. Mandell: Yes.

Dr. Ball: It is a great idea.

Dr. Dougherty: When I was Googling insurance coverage I found TRICARE, so let me try it again.

Dr. Batra: This is Anshu. Can someone fill me in? What is TRICARE?

Dr. Dougherty: It's the military family benefits program.

Dr. Mandell: It used to be CHAMPUS. Yes, it's the insurance program that covers everyone in the military --

Dr. Batra: Thank you.

Dr. Mandell: -- and their families. And they have a covered ABA benefit.

Ms. Crandy: They did a demonstration pilot for a long time before they instituted it in their coverage too, which is, so they have all that study.

Ms. Abdull: Hi, this is Idil. I just really emphasize that we get someone from other therapies as well, not just ABA but, you know, people who can talk about the others.

Dr. Mandell: I think the interesting thing here, Idil, is not the ABA itself, it's that they've figured out a way to have insurance pay for that therapy. And so I don't think --

Ms. Abdull: Right, so do we know others then, David, who, other states or other insurances who are covering or paying for other services outside of, you know, Floortime or RDI? We know that almost everybody pays for this, but do we know others, people, experts in those area that can tell us, if the Floortime folks or the RDI folks have figured out a way to get this paid?

Dr. Dougherty: Well, the TRICARE demonstration list says it covers, the demonstration covers educational intervention for autism services that implement ABA and target behaviors, focus on changing the child's behavior, use scientific behavioral data, gather behavioral data, incorporate parent training.

Does that help? I mean it doesn't say Floortime specifically.

Ms. Abdull: Right. Well, usually when it says behavior or targeted behavior it's usually applied behavior analysis which is under the ABA. But I can --

Dr. Rice: Idil, this is -- what I found is, again, I end up prescribing for quote unquote "behavioral therapy" and again it ends up being sort of a general term.

And then depending on which agency can then provide the specific aspects of behavioral intervention that I'm looking for the child whether it's strict ABA versus a modified form versus more of a Floortime based that's where I think again, you know, we tend to have a little flexibility. But the big umbrella is behavioral therapy that now insurance carriers are mandated to cover.

Dr. Mandell: So I'm going to make the suggestion that we have, that Idil, if you can find someone or I'm happy to talk with you later about trying to find someone where that's a specific issue they've attempted to address, but that we will make an effort to try and find someone that we can include in that group, and that we try and otherwise finalize the name of people in this group and move to the next group.

(Crosstalk)

Ms. Crandy: This is Jan Crandy. I would say a lot of state early intervention programs are covering that. So if there was somebody from early intervention that you could have come and talk to that. Because I know early intervention programs in a lot of states are doing Floortime and ABA.

Ms. Abdull: If you know the names maybe you could send it to Jan, to David. In Minnesota they don't, the

Floortime and RDI hardly, they don't get coverage, whereas ABA, if you call it different names it gets covered.

But that's why I've just been thinking, there's a lot of people who just do it out-of-pocket. They think this therapy works for their children and they have to pay for it out-of-pocket because their state doesn't cover and the insurance doesn't cover it.

(Crosstalk)

Ms. Crandy: This is Jan Crandy. I have one more comment. What about programs in states that are paying for stuff out of general funds so CMS wouldn't know about them when they're looking at state of the state address? How will we capture those states that are --

Dr. Dougherty: Would Bonnie Strickland know? Because she's in the, where they have the block grants for special needs kids. She's in the division of children with special needs.

Laura?

(Crosstalk)

Ms. Crandy: Is there somebody from a legislative bureau that has done that research from state to state to see? Because I know, for instance, in Nevada we're using general funds and money from the tobacco grant to pay for our autism slot program.

Dr. Burton-Hoyle: This is Sally Burton-Hoyle and in Michigan, if things meet the national standards, those therapies are approved through the new autism insurance, and other things besides ABA, because Idil has a really excellent point that that is not the only thing.

Dr. Mandell: So I think what this speaks to is that the idea that with regard to access and coverage, we don't have a single data set that provides a sense of how services are covered across states.

And I think that the state of the

states that Abt did for that impact report, John, I think it was only nine states. And so they tried to pick a representative sample of states, but it's not 50 plus D.C. plus Puerto Rico.

And so perhaps rather than try and find someone who knows this whole landscape, because I don't think there's anyone who does, or to try and figure out every pocket of funding that this might come from and find an expert in each of those pockets, because I think that also will be very challenging, it might be really important as part of what we know and what we need to know, to make it very clear that there is no single collection of how states are financing coverage for individuals with autism across the many pockets of money from which they can draw.

Dr. Rice: This is Cathy, David. I think that's an excellent point. And also the fact that we do need to focus on research, so as part of the state implementation grants may not cover, you know, birth to death, but there are efforts to integrate and presumably an evaluation component to it.

So it may be the first step in putting our toe in the water of seeing how cross system efforts to characterize that information, look at increased access and then evaluate it is actually happening in a more tangible way, and then painting the bigger picture that really has many missing components to it as to what we need to do in the future.

Dr. Mandell: Well said.

Ms. Abdull: I agree with you.

Dr. Mandell: All right. If we can revisit again the experts for this. So Elizabeth or Gemma, have you been keeping track of who we've been saying for the --

Ms. Weiblinger: This is Gemma. And we have been trying to keep track of the names but some of the areas don't have specific names. For example, the Aetna representative, I think Cathy was going to suggest somebody.

So it would be really helpful to us if we could just go through and name specific people for this Access and Coverage. What we have so far is Bonnie Strickland -- and Elizabeth will add to what I don't have.

But we have Bonnie Strickland, Susan Parish, as I said the Aetna representative Cathy will suggest, Christine --

Dr. Mandell: Mark Friedlander.

Dr. Dougherty: No, I have the Aetna representative. I just --

Ms. Weiblinger: Oh, you do.

Dr. Dougherty: I just got an email. This is Denise. And you're cc'd on it so you have it too.

Ms. Weiblinger: Okay, thank you.

Christine Hunter from OPM, Pia

Newman from Pennsylvania. And do you have the others?

(Crosstalk)

Ms. Crandy: You are putting Lorri on there, correct, from Autism Speaks?

Dr. Batra: Lorri Unumb.

Ms. Weiblinger: Lorri Unumb, okay.

Dr. Batra: And she actually, I think, you know, has a broader sort of knowledge base of state and federal and private insurance actually, might be a good expert to get some feedback on that.

Dr. Mandell: And I would put if she's not able to make it, Stuart Spielman --

Ms. Weiblinger: Oh, yes, Stuart, okay.

Dr. Mandell: -- is also at Autism Speaks. I certainly don't think we need both of them, but he would be also a good choice for that role.

And then who put William Johnson

on the list?

Dr. Dougherty: That was me. This is Denise. Because of that CHCS, Center for Health Care Services report that he did with some other consultants, I'm trying to find the name of it, that you said was useful. Systems of Care, A Survey of States. It wasn't autism specific, but it was for individuals with intellectual and developmental disorders.

Dr. Mandell: Okay. And certainly that relates to our discussion just now that there are so many pockets of money from which people are drawing to cover these services.

So I think that that's a good list. And Idil, I'm happy to talk with you afterwards and make sure that your concern is allayed regarding coverage of interventions that are promising but don't necessarily have the same evidence base, and make sure that that's covered as well.

Ms. Abdull: Okay.

Ms. Weiblinger: Okay, this is Gemma again. So on the list, are we adding Dr. Johnson?

Dr. Mandell: Yes.

Ms. Weiblinger: Okay. And I wonder if you could give us some idea about priorities in anticipation of some of these experts not being able to make it. And do we want to invite all seven of them? How many did you want?

Dr. Baden: Right, this is Elizabeth. If we could have a sense of how many you would like to end up with that would be really helpful for our office.

Dr. Mandell: I think we'd like to end up with about three per group.

Dr. Baden: Okay.

Ms. Weiblinger: Okay, great. Thank you.

Dr. Mandell: And then so if we could go to the next group. I notice Denise, actually I didn't realize this until just now but you put Transition separately.

Dr. Dougherty: I did.

Dr. Mandell: And I don't know what --

Dr. Dougherty: Well, I couldn't decide whether it was a Quality issue or an Access and Coverage issue. It's really --

Dr. Mandell: I think transition is something we're hoping will pervade all five groups, right?

Dr. Dougherty: Okay, great.

Ms. Crandy: This is Jan Crandy. I apologize. You know --

Dr. Mandell: Jan?

Dr. Dougherty: Hello? Did we lose her?

Dr. Mandell: I think we did. Jan, we can't hear you. It's like we're having a séance.

Female Participant: She was going to say something very good, I think. I don't know.

Dr. Mandell: She always does. So --

Ms. Abdull: So can I just ask -- hi, sorry. This is Idil. Those seven people are hopefully we're going to pick three and the other four is backup, or are we inviting all --

Dr. Mandell: Yes, Idil. I think the hope is that we, I mean I think that it may vary slightly by group, but our hope is that we would get three of those seven.

Dr. Dougherty: So what I would say, this is Denise, given our timeline that OARC invite all seven and then see who is able to come, because we know it's not going to be all seven.

Dr. Mandell: Right.

Dr. Dougherty: And then we'll see who that is and if we need to fill any gaps by going back to you for additional names.

Dr. Ball: Well, this is Jim Ball again. I think what we had talked about earlier is if you get the seven and they can at least get on calls or give us information, if they don't make it we can still incorporate it into what we do.

Dr. Dougherty: That's right, yes.

Dr. Mandell: Right.

Ms. Abdull: Yes, that's a good idea.

Dr. Mandell: All right, so let's try the next group, which would be the Quality of Care.

Dr. Dougherty: Okay. Well, we don't want to say anything about these Transition people and what topics they would go under?

Dr. Mandell: Well, why don't we, I think we have all their names, and I think that we should integrate them into the group as we discuss that group.

Dr. Dougherty: Okay, great.

Dr. Burton-Hoyle: And this is Sally. I had the question, is Education in its own thing, it's not considered under Transition then?

Dr. Mandell: Well --

Dr. Rice: This is Cathy. I was thinking that the Education/Employment group that we had talked about before might be a good place for that.

Dr. Burton-Hoyle: Okay.

Dr. Dougherty: Yes. So I think what David was saying, suggesting as a change is that we make transition a subcategory of all the large topics.

Dr. Mandell: So if we have one of those experts on each of the five groups then they can particularly address transition issues as it relates to that topic.

Dr. Dougherty: Okay. That's okay with people? So we'll go to Quality? So Aubyn or Aubryn?

Dr. Mandell: Aubyn.

Dr. Dougherty: Aubyn, okay, Stahmer is doing some, I think it's NIH-funded research on actual implementation of evidence based practices into, you know, regular front line every day practice. So is it a she or a he?

Dr. Mandell: She.

Dr. Dougherty: She has just published a research protocol for her study. So she seemed like a good person, and David, you know her, right?

Dr. Mandell: Yes. She and I collaborate. She would be great. She's funded by both the U.S. Department of Education and by NIH to do this kind of work.

She also has a colleague who I would put as a second choice, and may even be involved in some of the discussions even if she doesn't attend the meeting, is Laura Brookman-Frazee.

Dr. Dougherty: Right. Her name

came up a lot, yes.

Dr. Mandell: Right.

Dr. Dougherty: She seems to have a separate grant.

Dr. Mandell: Yes, she has her own grants, and she's particularly interested in implementation of evidence based practice for adolescents with autism and older children with autism in community mental health settings.

Dr. Dougherty: So we might want to invite her too just in case we can't get one of them?

Dr. Mandell: That would be my thought, yes. I mean they're both coming from the West Coast. I think the potential for either of them to make it may be slimmer.

Dr. Dougherty: Yes. And then Donna Noyes, I got her. Somebody else suggested Donna Noyes and Connie Kasari.

Cathy Rice, you suggested Connie Kasari. I'm trying to find Donna Noyes on the list.

Ms. Singer: Well, I can tell you, this is Alison. The good news is that Connie is already participating in Chapter 4, so she's already agreed to attend.

Dr. Dougherty: Oh, great.

Ms. Singer: So it's just a question of trying now to recruit her to this additional subgroup.

Dr. Dougherty: So we could ask her to be at the meeting?

Ms. Singer: Same with Dr. Perrin. Dr. Perrin was also, I believe, Gemma, correct me if I'm wrong, an alternate for Section 4, for Chapter 4? I don't know if he has been invited.

Dr. Baden: This is Elizabeth. And Dr. Perrin is not one of the invited experts. I think he was an alternate but we had enough other people accept.

Dr. Rice: Okay.

Dr. Baden: But he's not on the

list, so he might be good for this group to invite.

Female Participant: And also to have a physician perspective in terms of quality in medical care and coordination.

Dr. Dougherty: Oh, yes. And then Connie Kasari has the other autism research network on behavioral health. Jim has the physical health one, if I understand it. And Connie has the behavioral health one?

Dr. Mandell: Yes.

Dr. Dougherty: So they both seem worth inviting.

And then Scott, on the list you sent you suggested Nicolaidis?

Mr. Robertson: Yes. That would be particularly for navigating the care system for autistic adults for health care services. She's done a lot of extensive work into actual developmental disabilities broadly and then autistic adults specifically and has, as I mentioned earlier, they have NIMH funding for investigating how autistic adults can connect to health care services. So I think she'd be really good, particularly on how adults are getting connected to the system.

Dr. Dougherty: Great. And then you know what we didn't do, David, is get a group leader from the subcommittee.

Dr. Mandell: Yes, I guess I thought we'd go through the five and then --

Dr. Dougherty: Okay. Okay, fine.

Dr. Mandell: So they could see who they'd have to work with before they said yes.

Dr. Dougherty: All right. So we have one, two, three, four, five, six invitees for the Quality/Implementation, Coordination, Patient Navigation.

Ms. Abdull: Hi, this is Idil. Do we have anyone who's more of an expert in nonverbal, classic --

Dr. Burton-Hoyle: That was my question.

Ms. Abdull: -- in adults?

Dr. Mandell: So that's actually Connie's area of intervention interest --

Ms. Abdull: Okay.

Dr. Mandell: -- is working with older children who, or is one of her many intervention interests, who are nonverbal.

Another person possibly to put on this list would be Phil Strain or Sam Odom. I think we'd want at least one of them for education, but another one possibly here because of the work they're doing at looking at services as they're delivered in the community for people all over the spectrum.

Ms. Crandy: This is Jan Crandy. Can we also add Doreen Granpeesheh on there? She did, I would have nominated her. Lyn had nominated her.

Dr. Dougherty: Doreen --

Ms. Crandy: From Center for Autism and Related Disorders.

Dr. Dougherty: On the Quality topic?

Ms. Crandy: Yes, for evidence based practices.

Dr. Burton-Hoyle: And this is Sally. I just wanted to know if the overall emphasis when we're talking about those evidence based practices are going to ABA or can we have a broader look?

Dr. Dougherty: It's just whatever is evidence based. So you have an evidence based intervention, treatment intervention or screening or diagnostic, and then this is about the implementation piece into regular, every day practice.

Dr. Mandell: Another way to think about it would be that the evidence for what's effective for people with autism is going to change. That interventions will change, new interventions will come along for screening, for diagnosis, for early intervention, for providing ancillary support.

And a lot of, I think, focusing on the quality of care and how to implement what's known from science into community settings is about what's the infrastructure for doing that rather than, it's not so much about, for example, how do we get discrete trial training or pivotal response training or Floortime into communities as much as it is, how do we shorten the gap between what's known from research and what happens in practice.

Dr. Burton-Hoyle: Thank you.

Mr. Robertson: This is Scott Robertson. One thing that I also wanted to add is that in the event that Christina Nicolaidis couldn't make it, you know, an or you might want to put there is Catherine McDonald who's a researcher at Syracuse University who works with, she's one of the collaborating researchers with Christina on their NIMH grant for AASPIRE.

So she could be, you know, she could probably be a person who could come to fill in on autistic adults' health care access if Christina Nicolaidis can't make it.

Dr. Mandell: Sorry, were you thinking about that as for Access, Scott, or for the Quality?

Mr. Robertson: That was for Quality. Well, it's for Quality of Care for health care services.

Dr. Mandell: Okay, that sounds like a great person to ask.

Ms. Crandy: This is Jan Crandy. And the thing about CARD is they also have an online training that many states are implementing for their kids on their waiting list. So they have a lot of studies that they could talk about how they're reaching out to communities and getting services out there.

And I understand what you're saying. Their focus is ABA, but it's about getting that treatment out in different ways to the community.

Dr. Mandell: Right. And I think that that's the important issue here.

Dr. Batra: David, this is Anshu. And I was just thinking about what you said in terms of, you know, someone who will take the evidence based research and then apply it and implement in the patient population.

And a couple names came to my mind. I know James Perrin is someone on the list, but Sarah, oh my god, Spence is another thought in terms of an M.D. who does research but also sees a lot of patients.

And then another one sort of, I was just thinking a little bit more in terms of someone who just sees patients in the community setting is someone by the name of Audrey Griesbach who is a developmental and behavioral pediatrician in Los Angeles here.

And she's been practicing for 30 years and really sees children as well all the way up to adults, and really works and addresses, there's all these issues that are on her list, actually, in terms of early intervention, transition, housing and family support, et cetera, et cetera.

So a nice community perspective, which I think is important when we're talking about, you know, implementation and disseminating across the populations.

Dr. Mandell: So do you think that she, so you're saying essentially you know her as a community clinician who is --

Dr. Batra: Yes, I do. And again, I think that perspective is important, you know, someone who sees patients and families in the community, and really is then able to take what we have in terms of research based and then apply it, and how to navigate through the systems.

And really, you know, in minor

actions and my dealings with her, she covers, because of what's she's been doing for how long she's been doing it, I think she's just this wealth of knowledge, you know, that I just haven't found in other professionals just because of how long she's been doing it and the comprehensiveness in which she's been managing patients and families.

Dr. Mandell: More than you?

Dr. Batra: Well, I have been doing it for a couple minutes, and she's been doing it for, you know, maybe an hour. So I think I definitely turn to her for her wisdom and her experience, which I think is really what she could bring to us.

Dr. Mandell: Okay, great. Thank you.

Dr. Batra: I had put her name in for several of the questions for the other committee. And Gemma and Elizabeth, I don't know if you still have her information but I can forward that to you.

Ms. Weiblinger: Yes, that would be very helpful, and I think you had also mentioned Sarah Spence.

Dr. Batra: Yes.

Ms. Weiblinger: And we had invited Dr. Spence for the other subcommittee but she's not available for the workshop at all.

Dr. Batra: And I think again, I think it's so important again when I think about what families when they come to me and they ask me in terms of, you know, the issues, and clearly we have, you know, in terms of state and federal guidelines and insurance carriers and blah, blah, blah, I mean I think that's critical in terms of being able to access services and then be able to implement them.

But I think having someone who can really take, like what you were saying, David, if I understand it correctly, you know, taking the transitional information and then applying it to services. I mean that's really what I see, kind of what I do in my little corner of the world and that's what I would like to see. Someone who can give us some wisdom and expertise in how they've done that and, you know, what's a good model that they have used.

Dr. Mandell: Sure.

Ms. Crandy: This is Jan Crandy. Could we look at someone from that Ohio Center for Autism then, because they are addressing the lifespan, and all the guidelines and documents they've put out in the Autism Internet Modules?

Dr. Dougherty: Do you have a name?

Ms. Crandy: I don't have a name from there. I have their phone number.

Female Participant: That works.

Ms. Crandy: It's the Ohio Center for Autism, and they have a Lifespan Transition Center. Their phone number's 866-

886-2254.

Dr. Batra: So Elizabeth, I'll forward you the other names that I've mentioned.

Dr. Baden: Great. Thank you.

Ms. Redwood: This is Lyn, and I also wanted to put in a plug for Dr. Doreen Granpeesheh. I know she's also working internationally, and they fund a lot of research as well. I think she would be able to bring a lot to the table.

Dr. Mandell: Okay, thanks, Lyn.

So Elizabeth, can you tell us who's on this list now for Quality of Care?

Dr. Baden: I can try. And I very well may have missed someone, but I have Aubyn Stahmer with Laura Brickman-Frazee as a possible alternate or a pairing.

James Perrin, Connie Kasari, Christina Nicolaidis or Catherine McDowell (phonetic), Donna Noyes, Doreen Granpeesheh, Audrey Griesbach, and someone from the Ohio

Center for Autism.

Mr. Robertson: This is Scott. Just for a quick clarification, the last name is McDonald. Sorry, I slur my words a little. It's McDonald.

Dr. Baden: Appreciate that.

Dr. Mandell: Is there anyone else that we would -- oh, and the other name that I would put on is either Phil Strain or Sam Odom, and have one of them on Quality of Care and the other on Education.

Dr. Baden: Okay.

Dr. Ball: This is Jim Ball. We didn't use them in the one prior, but it might fit better here if you got somebody from TRICARE to talk about what they do internationally with their system, nationally and internationally.

Dr. Burton-Hoyle: I support that because there are so many families in the military that are struggling with, you know, overall quality of their services.

Ms. Crandy: This is Jan Crandy. Going back to that Access Coverage group, and I know we're just picking three for each one, but maybe in that group we do need all those people on the list, the seven that we talked about, because it addresses so many different areas.

Dr. Mandell: I think we're not going to, I mean we could invite them. I think we'll see who's available to participate.

(Crosstalk)

Ms. Crandy: I just think we shouldn't limit it to three for that group.

Dr. Dougherty: I think we're going to invite them, and then if they can't come to the meeting have them participate with the work that the subcommittee leads are going to do.

Dr. Mandell: Let's move on to the Education/Employment subgroup.

Dr. Dougherty: Okay. And this

is Denise. I'm in the health care field. I don't know any of these people, but David, you've already endorsed Philip Strain and Sam Odom.

Dr. Mandell: Yes, I think they're great. And one of the things I'm struggling with is there are a number of people, like Peter Gerhardt, for example, who got several votes, a lot of people were interested in him, and making sure that we probably want to include them even if it's not always clear exactly which of these five groups they'd be shoe-horned into.

Dr. Burton-Hoyle: This is Sally. This is a great slate. I am particularly interested in Weick. I nominated her because of her use of assistive technology and its limits, and a big grant that she's gotten that's, and she's gotten CD, Council Director in Minnesota.

Cathy Pratt is excellent. So a lot of them are good people are on there, but those two in particular would be great.

Dr. Mandell: Okay.

Dr. Rice: This is Cathy Rice. I think this would be a good place for Peter Gerhardt, in particular, with the adult workforce and transition issues.

Dr. Mandell: I think another person I might add here is Paul Shattuck, who I think has done some of the best research on transition to adulthood for people with autism.

Dr. Cordero: This is Jose. Paul would be terrific, and I'd just like to echo for what Cathy Pratt -

Dr. Mandell: Okay.

Dr. Ball: This is Jim Ball. I know Peter, I know Cathy, I know Valerie. Just excellent. And I think Paul would be totally beneficial to whatever we could get him to do because all of his research is really cutting edge. And had the opportunity recently to hear him speak again and sat on a panel with him, and he's just a phenomenal speaker too. So the information that he would be providing regardless of where you put him, I think we need engage him.

Dr. Mandell: Yes, I share your enthusiasm for him.

Mr. Robertson: This is Scott --

Dr. Batra: David, this is Anshu -- the heading of Education/Workforce. So I'm hearing a lot of the emphasis is really towards transitioning than into, you know, employment and work. So is the education a separate entity that we'll be discussing later?

Dr. Dougherty: No, this is meant to combine both education and employment.

Dr. Batra: Okay. So education for, you know, the younger set as well transitioning into, you know, education for skill sets for the workforce.

Dr. Dougherty: Right, and being employed, for the adults.

Dr. Mandell: So I noticed that we don't have, so that means that we also have to have early intervention.

Dr. Batra: Early intervention, yes. I was thinking of Tony Shamman. I don't know if --

Ms. Singer: What about someone from SARRC, either their director of research or Denise Resnik? They're actually doing research on best practices for employment and they also do early intervention.

Dr. Dougherty: Somebody recommended Denise Resnik.

Dr. Mandell: I think Denise is an excellent choice. Another person I might suggest is Zach Warren, who's at Vanderbilt, who took over for Wendy Stone when she went to Seattle. And they both have a very strong research agenda, but they also do a tremendous amount with the State of Tennessee in trying to improve educational services.

Dr. Dougherty: And then Scott

had suggested in his email somebody from the National Association of State Directors for Special Education. Do you have a name there, Scott?

Mr. Robertson: Yes, let me pull up my list here. The person who had written the journal article on accessing educational services was Kelly Henderson, is her name. The article is called Policies and Practices Used by States to Serve Children with Autism Spectrum Disorders.

Dr. Mandell: That sounds like a good person to have involved.

Ms. Abdull: Is it possible, this is Idil, to get someone from the special education at the Department of Education? Maybe Alexa Posny, is she still on the committee?

Dr. Dougherty: Or David Wexler.

Ms. Abdull: Yes, just to explain from, before we get to the employment, from preschool or kindergarten all the way to the end of the person's education system in the public, what is it that we're doing, and then into the employment, and kind of so it's a smooth transition from early intervention on.

Dr. Rice: This is Cathy. This would also be a good group to have an individual with autism.

Ms. Redwood: Actually Valerie Paradiz, who is the person that I recommended, this is Lyn Redwood, as an individual with autism and also has a son with autism. And she would be able to bring a lot to the table. She currently designs curriculum and educational programs for both children and adults with ASD.

Dr. Mandell: Great. So Elizabeth, who do we have on this list now?

Dr. Baden: Okay, we have Philip Strain and/or Sam Odom, Colleen Weick, Peter Gerhardt, Paul Shattuck, Cathy Pratt, Denise Resnik, Zach Warren, Kelly Henderson, someone from the Department of Education, and Valerie

Paradiz.

Dr. Mandell: That's a substantial list.

Dr. Baden: That's a very big list.

Dr. Mandell: Do we need to prioritize a little bit?

Dr. Baden: That would be really helpful.

Dr. Mandell: So if I were going to prioritize the researchers I think Sam Odom and Paul Shattuck would be the two that I would prioritize.

I don't know if others have people that they would push to the, I heard a lot of enthusiasm for Peter Gerhardt certainly. And I think Valerie Paradiz as someone who is both involved in designing curricula and as a person with autism would be important to include.

Dr. Burton-Hoyle: And this is Sally. And Colleen Weick's employment grant utilizing assistive technology, we're going to look at the outcome, we're going to look at what we can do across the lifespan, but then also specifically what can we do with the employment. It's all got to be connected.

Ms. Abdull: And you know, I really do emphasize someone from the Department of Education special ed department and particularly someone that can explain the idea of law and what's in place now, sort of like what we were asking for the CMS person to also know from the Department of Ed, from beginning all the way to the end of the education system.

Maybe the director, I can, you know, maybe a list that you could find out who is the director of the special ed is for the Department of Ed.

Dr. Baden: Hi, this is Elizabeth. We can certainly look into that and see if it's a possibility.

Ms. Abdull: Okay.

Dr. Mandell: So Elizabeth, is that a reasonably prioritized list or is that still too many people?

Ms. Weiblinger: It's a lot of people. I think we have some sense of the prioritization, and I think if everyone agrees that the priority order in which Elizabeth read the names is the correct priority, then we do have it.

Dr. Mandell: Okay. All right, let's look at the next group which is Family Support.

Dr. Dougherty: David, before we do this -- this is Denise. I was wondering if we could go back to the Ohio Center for Autism, because I found the advisory board member names, and maybe if I could read them out somebody could say which one, which name should be invited. Would that be okay?

Dr. Mandell: Sure.

Dr. Dougherty: So the chair of

the OCALI it's called, the Ohio Center for Autism and Low Incidence, is Barb, Y-A-Z-O-R-C-I-K, Yazorcik, from the Autism Society of Ohio.

Okay, I'll move on to board members. Bill Adams, he's an expert on -- what?

Dr. Mandell: I'm wondering if the board is not where we want to go. I would imagine that we'd want someone from executive leadership.

Dr. Dougherty: A director or, okay.

Dr. Mandell: Right, and that board is going to be a mix of people who are advocates and community members and aren't necessarily as familiar with the programmatic aspects of OCALI.

Dr. Dougherty: Okay, so Kevin Aldridge, I have the staff directory, is the program director for the Center for Systems Change, which is where the Autism Center comes under. And then the program director for the Autism Center is Amy Bixler Coffin.

Ms. Crandy: Let's talk to one of those two.

Female Participant: Yes.

Dr. Dougherty: Okay.

Dr. Cordero: This is Jose Cordero. The other person who comes to mind as we're talking about executive leadership during especially services involved, is Anna Hundley in Texas, the executive director of the Autism Treatment Centers, several of them throughout Texas.

Dr. Mandell: I don't know that person. And what committee were you suggesting them for, Jose?

Dr. Cordero: Dealing with the issues of services especially transition.

Ms. Weiblinger: We're having a hard time hearing you, Jose. Can you come closer to the phone?

Dr. Cordero: I'm pretty close to

the phone. I mean can you hear me better now?

Ms. Weiblinger: Yes, better.

Dr. Cordero: Okay. Anna Hundley has been very, and has some, and developed in Texas, I think, a very great model in terms of services especially dealing with the transition to adulthood. And if we're looking for someone that can speak to the area of services and transition, I think she can.

Dr. Mandell: Do you think she'd add something more than the people we currently have? And were you thinking about that within education or within --

Dr. Cordero: I was looking mainly in the education side.

Dr. Mandell: Do you think she'd add something more than the people who are currently on that list? Because remember, that was a very long list, and so we already had to cut it down and prioritize.

Dr. Cordero: I thought we were just talking about transition in general now. Did I miss something?

Dr. Mandell: So now we were going to turn to the, well, so just to refresh your memory, for each subgroup we were hoping to have at least one person whose work focused on transition, and to bring that expertise to that particular issue, which I think we have for the Education group.

And I think now we were going to turn to Family Support and who the people should be on for Family Support.

Ms. Abdull: I would say Autism Speaks, their director for family services or family support.

Dr. Cordero: Yes, I would agree, and someone at the national level of that, that would actually be fine.

Dr. Burton-Hoyle: And Ann Turnbull has had all kinds of family support grants, has worked specifically with the military in the area of family support, so she kind of represents that group that I'm sure we don't want to forget about, and that's the active.

Ms. Singer: So I'm going to throw out a name that might sound strange for family support, but I'm going to suggest Paul Law, because I think that the IAN database is this unbelievably rich source of information about what families are actually experiencing. And I think that could be extremely helpful as we're trying to identify gaps.

Dr. Rice: This is Cathy. I think that's a great suggestion.

Dr. Dougherty: What was the name again?

Ms. Singer: Paul Law.

Dr. Mandell: That's great. Thank you.

Mr. Robertson: This is Scott Robertson. A couple of comments. Someone maybe from the Autism Society of America, I think, would be good because they are the national association for parents and families, so that would seem to fit a lot on family support.

And then my other comment was, it seems a little out of place in terms of the suggestions around Temple Grandin and Eustacia Cutler, because Temple Grandin's day job is more around the animal science stuff.

I know she speaks and has written some things on autism, but like her primary background and a lot of her work is not focused around autism or family support. So I just don't see the fit on the last two people.

Dr. Burton-Hoyle: This is Sally. I nominated Eustacia Cutler. But Eustacia's concerned about the strength of the family and the support of the family and how we're doing things but we're not supporting the family.

Ms. Singer: But let me ask a question. Are we supposed to be thinking about this in terms of research with regard to family support or family support services in general?

Dr. Dougherty: Services, research and policy.

Ms. Singer: But for the purpose of the Strategic Plan, are we supposed to just focus on family support research?

Dr. Mandell: For the purposes of the Strategic Plan, thank you, Alison, we are supposed to focus on what is known and what we need to know from the research base.

Another person that I might suggest from that perspective would be Elisabeth Dykens at the Kennedy Center in Vanderbilt who has been doing some really interesting research on the mental health needs of parents of children with autism and the best ways to intervene to provide them support.

Dr. Ball: This is Jim Ball, and this would go along with the other comment made for somebody from the Autism Society of America. I would recommend V. Mark Durand from University of South Florida in St. Petersburg. He's on our special advisory board and he's done some really cutting edge research on optimistic parenting.

Dr. Burton-Hoyle: I support that. That's an excellent idea.

Dr. Mandell: Okay, thank you. So Scott, I definitely heard your comment about Temple Grandin and tend to share your thoughts about that. So that's someone we should take off the list?

Mr. Robertson: Yes, I mean I guess my concern is, I don't think we should have people just on the list because they have more of a personal experience on things. I mean I'd rather have people on here, on all the other lists it's because the people have kind of really in-depth professional qualifications on there and, you know, that's their day job, either because they work at organizations, you know, around that like ASA or whatever or, you know, for the government, or they have some kind of really extensive research background.

And I don't see that from, you know, I mean I realize that Temple Grandin has a PhD, et cetera, but again her work is in, you know, and animal science is what she does. And her mother speaks a lot about those things, but her mother's not working at an agency or conducting research on this area of family support, so doesn't really have this qualification.

That was more of my kind of concern, you know, on the area. I mean really, I suppose, to have kind of the background from experience kind of from personal experience from years of, you know, in the area of things, but I just don't think that they really fit into the model of kind of the professional experience in terms of targeting that area of family supports.

Dr. Mandell: Got you.

Dr. Dougherty: So this is Denise, just a little devil's advocate. Just the way for the Quality section we wanted to include the front line practitioners who are receiving the evidence based information on the receiving end, sometimes it's useful to have a family member or, you know, a person with autism to talk about what kinds of family support is needed.

But we have somebody like that in the Education group, right? Valerie Paradiz?

Ms. Singer: Well, Valerie is not only a person with autism, but she's a person who's dedicated her career to this, which I think is the point that Scott is making.

And particularly in the area of family experience, I think there will be many family members and individuals with autism who are members of the IACC, who are participating as experts who can also share their personal experience.

Dr. Dougherty: Great. I just wanted to be sure that we have that.

Mr. Robertson: This is Scott. My concern was that, I mean like I see it kind of differently as agreed with, you know, Valerie, where she has more, again, professional experience, qualifications, credentials. I think she's not just from the parent and/or autistic adult end is that she has the professional background and that's her job around these kinds of things, and I think that really fits well into the qualifications.

Especially, I guess my concern also on that was the, you know, just to briefly say that it's because we're only going to have limited people for each area, so we really want the best people who can really speak to this from the professional end, I think.

Dr. Dougherty: Okay, that's

fine. I didn't put them on the list so I have no attachment to them.

Dr. Mandell: All right, and I think, Alison, your point is very well taken about the number of family members and people with autism who will be part of the process already.

So Elizabeth, who do we have for this group? Because I am worried it's a little light though, so we don't have enough people.

Dr. Baden: Right. Although of course it all depends on who says yes.

Dr. Mandell: Right.

Dr. Baden: I might have missed a couple names from the beginning so please let me know if I did. But I have Ann Turnbull, Paul Law, Elisabeth Dykens, and Mark Durand.

Dr. Mandell: Okay, anybody that was missed or that other people would add to the list?

Dr. Dougherty: Did you say Mark

Woodsmall? Are we inviting him?

Dr. Baden: No one had really mentioned his name in the discussion, so I had not had him on the list at present but we can just include him if you'd like.

Dr. Batra: This is Anshu. I had nominated Mark Woodsmall as well as Areva Martin for both special needs and disability attorneys here in Los Angeles.

And Mark focuses not only accessing services and, you know, for special needs individuals, but also has a special niche or interest in trust planning, which again I think is an important aspect when we're talking about family support as our itty-bitty ones are transitioning into adults and what do we do with them after we're gone, and starting the dialogue and helping families plan for that.

And then Areva Martin is another person who's a disability attorney who not only works towards getting services from the school districts, et cetera, for individuals, but also has a non-profit called Special Needs Network. And it targets pretty much not only family support, education, services, et cetera, for a very underserved population here in Los Angeles, the Hispanic and African American population. So she again would be a wonderful resource.

Ms. Crandy: This is Jan Crandy --

Ms. Abdull: Did we say, I know that someone said that there's a lot of parents here that have children with autism that can speak from their experience, but does that mean we're not inviting people who do parent support or family support that also are parents?

Dr. Mandell: No, I think that's exactly what Scott's point was. That if there are people who are parents but also have developed those kinds of programs, have that kind of expertise or responsibilities then that's exactly who we would want to invite. Did you have someone in particular in mind?

Ms. Abdull: I have someone, Brad Trahan. He's the Minnesota state Autism Task Force, and he runs the organization. He doesn't do research, but he really does a lot of family support for rural areas.

So a lot of times support is concentrated in a metro or the cities, but he really makes it his way to go out and support families that live, you know, small-town Minnesota. And he does this all the time. Weekly he will, you know, figure out what the families need and try to connect them with services.

I would recommend him, and I don't know how many of the people we will invite will say yes or even if he'll be available.

Dr. Batra: David, I failed to mention both Mark Woodsmall and Areva Martin are parents as well of children with autism.

Dr. Mandell: So it sounds like we'll have very good representation.

Dr. Burton-Hoyle: The rural aspect, we really, that's a great thought.

Ms. Abdull: Yes, we have to concentrate a little bit on the rural area because they always get the short end of the stick. And his last name's T-R-A-H-A-N, and first name is Brad.

Ms. Crandy: This is Jan Crandy. And we did include somebody from Autism Speaks there because they give out those family, different grants.

Ms. Abdull: Yes.

Ms. Crandy: Okay.

Ms. Abdull: Yes, the director of family services hopefully is in there.

Dr. Batra: Is that Laurie Goring?

Ms. Abdull: Yes.

Ms. Crandy: Okay.

Dr. Batra: Lisa Goring, right? Is it Lisa Goring?

Dr. Mandell: Lisa.

Elizabeth, can you read out that list one more time?

Dr. Baden: Yes, but can you repeat the last name, someone from Autism Speaks? I missed that.

Dr. Mandell: Lisa Goring, G-O-R-I-N-G.

Dr. Baden: And that's from Autism Speaks?

Dr. Mandell: Yes.

Dr. Baden: Okay, Ann Turnbull, Paul Law, Elisabeth Dykens, Mark Durand, Mark Woodsmall, Areva Martin, Brad Trahan and Lisa Goring.

Dr. Mandell: Great.

Dr. Batra: And that's a good group.

Ms. Abdull: It sounds good.

Ms. Crandy: Sorry, I apologize.

Since we're having somebody from Autism Speaks, maybe somebody from TACA too so you have the --

Mr. Robertson: This is Scott Robertson. What also as they say about, you know, Autism Society, I mean it is the parent/family association, so I think someone like, you know, Mary Beth Collins or someone else from ASA would be good.

Ms. Abdull: They have a new director that replaced Lee Grossman, and he also has a child. He has an adult son with autism and -

Ms. Abdull: Yes, he would be very good. I think he would be very good.

Dr. Mandell: All right, thank you.

Dr. Baden: All right, this is Elizabeth. Could you give me that name as well, the one that Idil just mentioned, the person that Idil just mentioned?

Mr. Robertson: Yes, Scott

Badesch is his name.

Dr. Baden: Okay, thank you.

Dr. Mandell: So let's move on to the last working group which is Comparative Effectiveness and Patient-Centered Outcomes Research. So currently on the list are Anne Beal from PCORI, Lisa Simpson, Lisa Prosser and Kathleen Thomas.

Dr. Dougherty: So Lisa Simpson is on there because she was the only pediatrician on the IOM group committee that put together the priorities for Comparative Effectiveness, Patient-Centered Outcomes Research. So she probably would not be able to do it but she might have an idea.

Mr. Robertson: This is Scott. Can you change the slide on the webinar? Oh, thank you.

Dr. Mandell: So Anne Beal would be great to get. I think we may have the same issues that these are people certainly from autism is not their area of research, but are doing wonderful work in this more generally, and it would be great to at least have their expertise on the calls in starting to formulate those sections even if they can't come to the meeting.

Dr. Rice: This is Cathy. I would also recommend Kathleen Hebbeler. She's the director of the Early Childhood Outcomes Center that collects and analyzes a lot of data on outcome for people with disabilities, particularly from early childhood intervention.

Dr. Mandell: Okay, thanks. Is there any other names that people have?

So do you know, Elizabeth or Alison or Gemma, was Tris Smith invited for Chapter 4?

Dr. Baden: This is Elizabeth. He was not invited.

Ms. Crandy: I would like to add him to this list.

Dr. Mandell: He's one of the few

people who's doing comparative intervention work and he's doing it in schools also. And I wonder if he might be an autism specific person who would be great to have as an external expert for this chapter. And it's hard to think of others.

Ms. Crandy: Would Ron Leaf in here? Because he does do studies worldwide in different school settings. He does do some comparatives on models and on hours.

Dr. Mandell: Sure. I don't know him, but based on your description he might be a good fit too.

Ms. Crandy: I would definitely do Tris Smith first if we could get him.

Ms. Singer: Yes, so David, Tris Smith was nominated but didn't end up getting an invitation, but had many nominations.

Dr. Mandell: So well, it would be great to be able to include him this way.

All right, so I think we now have a list of invitees for each of the five groups.

I think our next step then is our hope is that there's one member of the subcommittee who will, that there will be one member of the subcommittee assigned to each of these groups and there will be others who would be involved obviously, but that one person would take the lead in saying which, you know, making sure that the group stayed on task and that there was a deliverable associated with the work of that group.

And so what I'd like to do is if we can decide on this call who those five people would be, one for each group, and then if other people on the subcommittee can email Elizabeth and Gemma and Denise and me about which of those subcommittees that you'd like to be part of, then we can make sure that there's an even distribution of subcommittee members across those five groups. Does that sound reasonable?

Ms. Crandy: This is Jan. Are

you going to pull Transition out or you're going to have it --

Dr. Mandell: Transition is going to be integrated with the other five groups. That was an accident that none of us caught on the slides.

Ms. Crandy: Okay.

Dr. Rice: A similar question about professional development. I feel like there's a gap a little bit about people that are out there actually doing the training for professionals. And that's something we said we wanted to integrate across, but I don't know that we have good representation of that.

Dr. Mandell: So actually, Aubyn and Sam Odom, Phil Strain and I, for all four of us that is an area of our research.

Dr. Rice: Yes, I would recommend an M.D. perspective as well, which is not usually what I say being a PhD. It's usually the opposite. But someone who's like a UCEDD or a LEND director. Catherine McClain from the University of New Mexico is somebody who fits that bill.

Dr. Mandell: So you'd put them on the Quality of Care group?

Female Participant: Yes, yes.

Dr. Mandell: Okay, that would be great.

Ms. Redwood: Also Doreen Granpeesheh through CARD offers continuing education for behavioral analysis training, so she may also be someone that would fit that bill.

Dr. Mandell: Good. Thank you, Lyn.

So I want to get back to this issue of getting a subcommittee member to take the lead in facilitating each of these groups.

Mr. Robertson: This is Scott. I'd like to, if possible, be a facilitator for the Education/Workforce group.

Dr. Mandell: You want to be the facilitator for that, Scott?

Mr. Robertson: Yes. I'm assuming that we're just going to jump in and, or are you assigning people just --

Dr. Mandell: No, jumping in is good. Jumping in was exactly what I was looking for.

Mr. Robertson: Okay.

Dr. Mandell: So are there other people who have interest in that or the other groups?

Dr. Burton-Hoyle: This is Sally, and I have a strong interest in the Family Support group.

Dr. Mandell: Great, thank you. And I'm assuming when people say strong interest that means that you're willing to take the lead and facilitate those.

Dr. Burton-Hoyle: Yes. Yes, sir.

Dr. Ball: This is Jim Ball.

I'll work with her on that.

Dr. Mandell: Okay, great. Thank you.

Ms. Crandy: This is Jan Crandy. I'm interested in the Access and the Comparative Effectiveness.

Dr. Mandell: Okay, do you want to pick one of those, Jan?

Ms. Crandy: I'd probably be better at Access.

Dr. Mandell: Okay, thanks.

Mr. O'Brien: And David, this is John O'Brien. I'd be willing to help Jan on the Access and Coverage.

Dr. Mandell: Wonderful. I appreciate that.

Ms. Abdull: I will also sign up for the Access.

Dr. Mandell: Is that Idil?

Ms. Abdull: Figure I'm the only one with an accent, so --

Dr. Mandell: Well, it's only an

accent depending on where you're from.

Ms. Abdull: Oh, yes, I suppose.

Dr. Mandell: If there aren't other people interested, I would be willing to do either Quality of Care or Comparative Effectiveness depending on what other peoples' interests are.

Dr. Batra: David, this is Anshu. I can help you with Quality of Care.

Dr. Mandell: Okay, thank you.

Ms. Crandy: So just so I understand this, you want somebody to be the moderator though of this --

Dr. Mandell: Yes. Someone to facilitate the work that would happen prior to that workgroup meeting on October 29th.

Ms. Redwood: Hey, David, this is Lyn. I have volunteered to lead the group for Question 3 for the other committee, so I'm sort of overwhelmed with it and I'm not going to take on any more work with this committee right now.

But I wanted to say that what we ended up doing was establishing a call once we had selected our external experts, to actually sort of make assignments to the different parts of the question and go ahead and set deadlines for when those writeups are due.

So just wanted to share that with the people who are leading this off. That they'll be responsible for sort of the overall coordination of writing the updates to the Strategic Plan.

Dr. Mandell: Yes. That would be the idea. And certainly, I think, Denise and I see in our role as co-chairs of the subcommittee as really assisting in that process as well and trying to, and because these five parts don't necessarily fall neatly into those chapters, to assist in helping put those chapters together as separate entities.

Dr. Batra: David, this is Anshu.

On listening what Lyn said, I'm actually helping quite a bit on Question 4, so I'm interested in Quality of Care, but again I too am swamped with the needs of that directive.

Dr. Mandell: I hear you. I will take Quality of Care and Comparative Effectiveness, hearing no other takers.

Ms. Crandy: This is Jan. I'll help you on Comparative Effectiveness too.

Dr. Mandell: Okay, I appreciate that Jan. Thank you.

Dr. Dougherty: And I will too. This is Denise.

Dr. Mandell: Oh, wonderful. Thank you. Okay, Denise, do you mind taking the lead on Comparative Effectiveness then, and I'll take the lead on Quality of Care knowing that I'll also provide support on Comparative Effectiveness?

Dr. Dougherty: No, I'll take the

lead on Comparative Effectiveness.

Dr. Mandell: That was a bait and switch on my part, right? Sorry about that.

Dr. Dougherty: Okay, great. Yes. Okay, great.

Ms. Abdull: I can support that Comparative Effectiveness on Denise or whoever is doing it.

Dr. Dougherty: Okay. Who was that? Sorry.

Ms. Abdull: Idil.

Ms. Kavanagh: And this is Laura. I can help with Quality of Care also, with you, David.

Dr. Mandell: Thank you. I appreciate that.

Ms. Singer: And this is Alison. I will help with Family Support, but like Lyn and Anshu, I am currently assigned to Chapters 2 and 7.

Dr. Mandell: All right. So now we have an invited list of experts. We have people who will lead each of those five groups in getting the work done.

So let's go to the next slide and talk a little bit about what exactly that work needs to look like.

Ms. Abdull: Can I, David, just interject one minute. And I know at the end it says that all of these experts will be asked about the disparity for each, but I just wonder on the Access group if it's possible to either get the person I recommended or anyone from the Office of Minority Health within HHS just to, because disparity is, I would have nominated you had you not been in this group.

But it's so prevalent and it's so persistent and it's only getting worse. And, you know, for someone to tell us, well, we know it exists, is sort of not good enough for me as a black minority person. I'd like to know what's the research saying? What is it that we need to fix? What are the gaps?

So that we're not asking the same question in another five years or two years down the road.

Dr. Dougherty: And that's what we're asking people to do, to come up with "What Do we Know Now?" and "What Do We Need To Know?"

Dr. Mandell: Right, so Idil that was an excellent segue.

Dr. Dougherty: Right.

Dr. Mandell: Because that's exactly what the responsibility is. It's to take that part from the 2011 Strategic Plan and use that as a guide to cover what we know and what we need to know.

And I think, Idil, you raise a very good point that, and as was put on one of the early slides, that we hope that people will use that disparities framework, ethnic, geographic, socioeconomic, to think about what we know and what we need to know.

Ms. Crandy: And this is Jan

Crandy. Going back, because I noticed on 2010's, and I see that we have the state of the state, but there was only one study to say, what is every state doing? That's such a big question. We do not know what every state is doing for autism. We have to know that.

Ms. Abdull: Right. I just wonder though, on the question of disparity, because disparity in terms of ethnicity especially and race, it's so different and it's so prevalent and it's just so persistent.

And it, you know, it's a big hurdle for the access services if you are a minority, if you are immigrant, the access to services for those children is far and few.

And I just wonder if it's possible to add, you know, anyone, the person I recommended, or anyone that you guys, or maybe David can recommend, just to tell us or even be part of the people that we talk to, maybe not invite, but we get their ideas on why is it happening. Because many, many, many states and many autism services are not following even the simple class standards 4 to 7, which are least mandatory. Almost none of them are following that. I mean I just wonder if we can bring that to the forefront of peoples' minds.

Ms. Crandy: Is Lyn looking at that? Because I know they're looking at that for identification.

Ms. Abdull: Right, but for services though, for services I wonder if for services. It's a problem.

Dr. Dougherty: But it's not only a problem for access, it's a problem for probably education, quality, family support and --

Ms. Abdull: Sometimes education not so much because everybody is able to go to the schools. But for services like the ABA and for other, speech, and things that are somewhat hidden. And how do you ask for something if you don't know it exists? It is more prevalent in private and other therapies as opposed to public education.

Dr. Mandell: Idil, the people I know who have done the most work in disparities, research in disparities, are Paul Shattuck, Susan Parish and me. And we're all --

Ms. Abdull: You, I know.

Dr. Mandell: Right. And so we're all going work on this, you know, hopefully all of us will be involved in putting this together. And believe me when I say this is an issue that's very important to me, and we'll make sure that it infuses those two chapters and that it's very much a strong theme that comes out.

Ms. Abdull: Okay, I will hold you to that, David.

Dr. Mandell: Please feel free to. You may just have to hold me back more than anything else.

Ms. Abdull: All right.

Dr. Mandell: All right, so for each of these five areas, our hope is to address the five questions that are on the bottom half of this slide.

So what are new key findings or discoveries and why are they important? What did we learn that was put in the 2011 addendum that is the summary of advances and the 2010 portfolio analysis? What's newly funded that's starting to address these gaps, and what gaps remain?

And then I think we can think of what are the needs of the community as what are the very practical issues that have to be addressed in order to improve care for people with autism in the communities where they live?

I want to turn to the next slide, which is the timeline.

Mr. O'Brien: David, before you

go, this is John O'Brien. Can you just say a little bit more about that second bullet in terms of the question, kind of what have we learned, and maybe just by example what that could like or what you're thinking about that?

Dr. Mandell: So I mean, and Elizabeth and Gemma, feel free to jump in here, but my feeling is that that summary of advances is, you know, it's a relatively brief description of what we know so far. It's not necessarily pegged specifically to the questions we're trying to answer. And so can we extract from that things that are relevant to the questions we've been asked to answer?

Dr. Baden: Yes, this is Elizabeth, and I think that's exactly right. It's not that we want you to specifically go through the Summary of Advances point by point and adjust things, or the Portfolio Analysis, but just to use them as tools to inform and see, you know, based on, for example, the 2010 Portfolio Analysis that has already perhaps identified some gap areas.

And so you could maybe use that to see if those are still the gap areas or if maybe there's something going on that has started to fill those gaps and things of those nature. So that one is more just to think about it and use those documents as tools to inform your process.

Ms. Crandy: This is Jan Crandy. Are we saying what policy we need too, to address these issues? Because we haven't mentioned anything about policy.

Dr. Mandell: Well, I think one hopes that the policy would be based on the evidence to support that particular policy, and that research can, in fact, very much inform policy and be about the policies themselves.

Dr. Dougherty: And sometimes we need policy research such as what is the impact on people with autism of the Affordable Care Act provisions that are mentioned in the 2011 Strategic Plan.

Dr. Rice: And this is Cathy. I mean as I understand it, this subcommittee really kind of has two different roles. And one is first task and the ongoing every year of updating the research based questions related to service and policy.

But then we may have a whole other variety of activities that we choose to come up with that are related more to actual service provision and policy and the things that support it but not necessarily the research base behind it. Is that an accurate understanding?

Ms. Crandy: Right, I would hope that we can try to drive some policy.

Ms. Singer: Well, again, this is what I was trying to get at before, which is I think we need to look at this workshop as really serving two purposes.

The immediate need is to update this section similar to the 2011 Addendum which is focusing on what have we learned and what do we need? So what do we know, what do we need? And I think for that the Summary of Advances is one of several potential useful sources.

But I think secondarily, this committee is going to have to make decisions in terms of updating the Plan for 2013 and 2014, and also may decide to look specifically at policy and services, provisions and recommendations that are outside of research and the Research Strategic Plan, and we should utilize this workshop for that purpose as well, but really separate those two outcomes.

Dr. Mandell: Yes.

Dr. Rice: I think it will just be important to be clear about the objective because of the day and that we do have to at least do the business of updating the Plan so we don't go too far afield in terms of very important but potentially tangential issues.

Ms. Singer: Absolutely.

Dr. Mandell: And I think one of the things to remember is that where the IACC, you know, where its mandate is, is into make recommendations regarding autism research. And that's where it has the potential to be very influential.

When we start to talk about broader policy recommendations or service recommendations, frankly, the IACC doesn't have the potential to be as influential. So to the extent that we can couch these as research issues, I think we have much more of an opportunity to drive change.

So John, did that answer your question?

Mr. O'Brien: It did, thank you.

Dr. Mandell: So are there other questions about that or is okay to turn to the timeline?

All right, hearing no other issues, so starting now the OARC staff are going to race to invite all the people that we just identified. And starting next week, we need to start work on our assigned topic areas with the goal of by the middle of October, October 15th, having two to four pages describing, you know, addressing the bullets that were on that previous slide.

Denise and I will then take that week to try and synthesize that into the two chapters and distribute it to the subcommittee members asking for very quick feedback, and then for distribution to all of the attendees at the IACC workshop.

We'll then have the workshop to continue to refine, add to, change what we've come up with, with the goal of having a near-final draft for review on November 15 for you, and then for you to return comments to us by that next week.

So it's a really tight timeline,

and I really appreciate your willingness to take this on. Our hope, Denise' and my hope is that by dividing it into these five areas the task will be a little more contained and manageable within the assigned amount of time. I feel like we need a team cheer now, or at least some kind of inspirational speech. So everyone go home and rent Remember the Titans.

Dr. Dougherty: And the Temple Grandin story, even though we're not inviting her.

Dr. Mandell: Right.

Dr. Dougherty: Impressive.

Mr. Robertson: Well, David, you're just as good on the leadership of this group as Vince Lombardi any day anyway.

Dr. Mandell: Thank you, I appreciate that. You've made my day, Scott.

Dr. Dougherty: Yes, you can go home now, David. Yes, thank you for doing this.

Dr. Mandell: So all right. So the next task is we'll invite the experts, we'll see who is willing to participate.

For those of you who agreed to lead one of these five groups, I will work Denise, Elizabeth and Gemma to contact you separately and make sure that you have the support you need to move this forward.

And thank you, everyone, very much for your participation and for working very hard on this important task.

Dr. Dougherty: Yes, thank you very much.

Male Participant: Thank you, David.

Ms. Abdull: Thank you, David, and bye.

Ms. Abdull: Thank you so much.

Dr. Mandell: Thank you all. We'll look forward to hearing from, you can look forward to hearing from us soon. Looking forward may be the wrong word, and we'll look forward to seeing you --

Ms. Abdull: We're excited. We're very excited. We're finally going to do something about Autism Services and Research Policy.

Dr. Mandell: That is my fervent wish. All right, take care everyone. Have a good day.

(Whereupon, the foregoing matter went off the record.)